Dementia – Caring, Ethics, Ethnical and Economical Aspects

A Systematic Review

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Dementia – Caring, Ethics, Ethnical and Economical Aspects

A Systematic Review

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30. Dementia – Economic Aspects

Questions of interest

The questions of interest concerning the economic aspects of dementia were formulated as follows:

- What is the cost of illness due to dementia in different countries? Are the costs comparable? What is the incremental cost of illness due to dementia compared to general aging?

- What is the cost of diagnosing dementia? What kinds of diagnostic procedures for specific types of dementia provide evidence of cost-effectiveness? What marginal cost-effectiveness does the addition of the following diagnostic procedures offer: imaging, neurochemical, neuropsychological, genetic, other?

- Is there any scientific evidence to support the cost-effectiveness of prophylactic interventions for dementia? How about the cost-effectiveness of drug treatment? What types of interventions involving the physical environment, organized living and caring programs show evidence of cost-effectiveness?

Summary of conclusions

The cost of illness due to dementia is growing in importance as the population aged 65 and up increases. However, comparing the cost of illness in different countries is difficult due to discrepancies in how resource utilization is specified and how resources are evaluated. The incremental cost of illness as compared to ordinary aging is an important factor in moderate and severe dementia.

Only model studies on the cost-effectiveness of various diagnostic procedures for dementia were identified. Although no conclusive evidence emerged, diagnosis clearly accounts for a small percentage of the total cost of illness.

No studies were found that dealt with the cost-effectiveness of prophylactic interventions.

Given that the clinical trials on the drug treatment of dementia were limited in number and low in quality from a health economic point of view, there is insufficient evidence of the method's cost-effectiveness. Model studies are considered inadequate to provide evidence of cost-effectiveness.

There is insufficient scientific evidence for the cost-effectiveness of dementia programs and environmental interventions, such as day care, caregiver support, case management and long-term care.

Background

The fact that dementia disorders include typical patterns similar to other chronic progressive incurable disorders has a number of implications for health economic analysis.

The period of illness is long (several years or decades). Due to the progressive and incurable nature of the various dementia diseases, stabilization or slowing down deterioration is a positive treatment effect even though improvement is rare. Furthermore, the nature of the diseases does not suggest prolonged survival as the preferred outcome in terms of cost-effectiveness. Nonetheless, survival is of critical importance given that it impacts long-term costs from a societal perspective. Finally, most costs are not associated with traditional medical care. Non-medical long-term care (such as nursing homes) and unpaid informal care account for most of the costs from a societal perspective. Thus, when evaluating interventions in dementia care, the impact on the natural course of the disorders must be considered. There may be transitions in terms of resource utilization, costs and effectiveness between different stages in the course of dementia, and among different payers (for instance, from formal long-term care to informal home care, or vice versa). Thus, defining the parameters of a health economic analysis is crucial. Based on these considerations, a societal point of view is clearly of interest [1]. Such an analysis may include the perspectives of various payers, such as county councils and municipalities.

The health economics of dementia have been the focus of several reviews [2–25], but few have proceeded from evidence-based medicine, ie, a systematic approach.

Types of studies

The studies in this presentation are broken down into two main categories: descriptive and evaluation (normative).

Descriptive studies

Descriptive studies are often referred to as "cost of illness" (COI) studies or examinations of a disease's economic burden on society and the distribution of costs among various payers. From an opportunity cost point of view, the question is what the value of these resources would have been, if not used for illness. Two approaches may be taken: one based on incidence, the other based on prevalence. The incidence approach estimates the annual and discounted future costs of new cases that arose during a particular period of time, such as one year. The prevalence approach estimates the costs of all existing cases during a particular period of time [26].

Data can be collected by means of either the top-down or bottom-up method. The top-down method distributes the resources consumed due to the disease throughout the healthcare system. The bottom-up method uses a representative subgroup of people with the disease and registers all costs related to it. The costs for the subpopulation are then extrapolated to the total group of people with the disease. Various kinds of cost studies with no outcome, no intervention and no comparison groups may also be regarded as descriptive. Such studies may describe the costs associated with unpaid informal care, different stages of dementia, etc.

Evaluation studies

Evaluation studies are normative, aiming to support health policy decisions and set priorities. A complete evaluation study is comparative, analyzing both costs and consequences (outcomes). This systematic review breaks evaluation studies down into three main categories: programs, pharmacological treatment and diagnostic procedures. Another option, as yet untried in the published literature, would be to combine the evaluation of programs and pharmacological treatments (perhaps including diagnostic procedures). The concept of program refers to a variety of interventions, including day care, caregiver support and counseling, long-term care (LTC), housing, etc.

Aims and limitations

This systematic review focuses on descriptive studies and economic evaluation studies of dementia, with the exception of those that deal with mild cognitive impairment (MCI). The evaluation studies are broken down into two categories: 1) incomplete evaluations with comparators but costs only (no outcome), cost analyses (CAs) and 2) complete evaluations, cost minimization analyses (CMAs), cost-effectiveness analyses (CEAs), including cost utility analyses (CUAs), and cost-benefit analyses (CBAs) [27]. The section entitled Resource Use looks at studies that presented resource utilization data (such as effects on institutionalization) without costing. Neither abstracts nor incomplete economic evaluations have been included [1,28].

Methods

Search strategies

The strategies for searching the literature were based on the questions of interest.

The search of published studies in English examined the PubMed, Ingenta, Cochrane Library, NHSEED/HTA, HEED, PsycInfo, ERIC, Societal services abstracts and Sociological abstracts. The search terms

(MeSH/Subheadings) were dementia/Alzheimer's disease/Alzheimer disease combined with costs, economics or cost-effectiveness. The search period was 1969 through July 30, 2004. A total of 4 234 abstracts were identified during the first round (duplicates were not excluded; most were found in the broad PubMed search on "dementia" and "economics": 1 116 hits). For the search results, see Appendix 30.1.

Systematic review of the literature

After the first round, the two reviewers included 168 articles regarding treatment or diagnostic procedures that were deemed to be relevant. Two people reviewed each abstract found in the database search. The studies to be included were broken down into three categories of study quality in accordance with a checklist: high, medium and low (but acceptable). Those with unacceptable quality were added to the list of excluded studies. Eighty studies with a cost of illness approach were identified but not classified in accordance with these criteria. Of these 22 were included in a background presentation.

A special reference list classified excluded studies on the basis of 11 different reasons (see Table 30.11 of excluded studies). The studies with the most obvious reasons for exclusion were assigned to classes 0 (not relevant to the question of interest) and 9 (no original data presented). For these reasons 93 articles were excluded.

Consistent with traditional evaluations in the area of evidence based medicine, empirical studies that included economic analyses were regarded as offering more reliable scientific evidence than model studies. But when empirical studies are lacking, only model studies can provide information about the expected costs and benefits of an intervention.

Of the 168 health economic studies assessed for quality 40 (5 regarding diagnostic procedures and 35 regarding interventions) were ultimately included. Table 30.11 lists the excluded articles.

A few remarks about model studies

For practical, financial and ethical reasons, intervention studies based on the best design (ie, RCTs) are difficult to conduct on people with dementia. Thus, models are regarded as "an unavoidable fact of life" [29] and may be used when limited clinical cost data are available, or when clinical trials and observational studies cannot answer questions – such as long-term cost effects – that are fundamental for decision makers. However, the models should not have time frames that are longer than those of their inputs. Nevertheless, one basic purpose of a model is to extrapolate a core of empirical data to a longer, albeit reasonable, period of time. The value of models is a current topic of debate [29,30]. While RCTs often have high internal validity, their external validity may be questionable in terms of generalizability to a real-life target population. A model may incorporate population data from many sources over a long period of time and thereby offer greater external validity. However, models are not empirical and its inputs are crucial. This systematic review regarded the inclusion of basic quality criteria for assessing model studies as essential [29,30]. The model's technique should be transparent, preferably based on established methods, such as Markov [31], decision tree [32] and survival [33]. The model should cover a time period that extends until the impact on costs and outcomes has stabilized. Because modeling results depend on several assumptions, a sensitivity analysis is also regarded as necessary. All models included in this report were assigned a study quality (high, medium, low, unacceptable), but only those with high quality could serve as the basis for – at best – limited scientific evidence in combination with empirical studies (Evidence Grade 3).

Costs

The costs identified by the included studies were converted to US dollars in 2003 for possible comparison. If the article did not present a cost year, the publication year was used. The conversions were based on purchase power parities (PPPs) (source: OECD, historical series, data on file – http://www.oecd.org for more details on PPPs) and the consumer price index (CPI) (source: OECD, data on file).

Results

Descriptive studies

Background

Given the growing percentage of retirees in the total population – the percentage of Scandinavians aged 65 years and over almost doubled during the second half of the 20th century (Statistics Sweden, data on file) – the prevalence of many chronic diseases has increased as well [34]. Because people with dementia require continued care (informal or community) for a period of several years, the social costs are high. This part of the systematic review presents some the descriptive studies that have focused on the economic burden of dementia care.

Cost of illness

One of the studies included in Table 30.1 is based on a random sample of individuals, 8 on survey data (published or independent), 4 on retrospective analyses of databases and 3 on models. Only the study by Kronborg Andersen et al was based on a large (more than 5 000 subjects, 2/3 participation) random sample of people aged 65–84 [35]. Apart from a model study by McNamee et al [36], Kronborg Andersen's was the only one with a follow-up period of several years. As mentioned above with respect to the methodological aspects of cost of illness studies, interpreting costs is difficult due to varying resource utilization specifications. However, the study by Kronborg Andersen et al clearly showed that costs were twice as high for mild dementia, five times as high for moderate dementia and nine times as high for severe dementia as for the age and gender average when no dementia disease was present (approximately DKR 25 000) (Table 30.1). This finding points to potential cost reductions for care if the progression of dementia can be slowed down.

Cost-of-illness models of dementia have the advantage of highlighting the utilization of resources that contribute most to overall costs. Wimo et al showed the importance of including informal care in the total cost (see discussion below) [37]. A model-based calculation by O'Shea et al pointed in the same direction [38]. Finally, McNamee et al presented a 37-year planning model that proceeded from a dementia care database for England and Wales [36]. Based on the expected growth in the number of very old inhabitants, the study predicted a net 50% increase in costs by 2031. Due to greater life expectancy, costs were five times as high for women as for men. The problem with cost-of-illness models (such as McNamee's) that have a very long planning horizon is that no improved functioning as the result of new drugs or other interventions can be included other than in terms of speculating about possible efficacies.

With respect to the other studies – ie retrospective studies based on different databases or cross-sectional data – included in Table 30.1, interpreting and comparing the findings for various countries is difficult. Wimo et al showed that, even when converted to the same currency and year with a correction for purchasing power, the differences among estimated annual costs per person with AD ranged with a ratio of 1:7 [37].

Informal care

Background

A large percentage of the societal costs of dementia stems from informal care. The figure has ranged from 35–85% in various published studies [39]. The variations are due mainly to the absence of standardized methods for measuring and evaluating the time required to provide informal care. The optimal measurement of that time would exclude normal household tasks. The inclusion of such tasks in cost-of-illness studies on dementia may be feasible when informal care totals more than 16 hours a day (such as Cavallo et al [40]) or is more a matter of supervision than assistance. Furthermore, the time evaluated is often that of retirees, whose views of the role of the informal caregiver may vary on the basis of satisfaction and other criteria.

Five different methods for evaluating informal care have been identified: opportunity cost, friction cost, replacement cost, time travel and willingness to pay (contingent valuation) [39]. Intangible costs due to depression or stress on the part of the caregiver should also be included in the valuation of informal care, but that has not been the case.

The methods employed to obtain information about the time spent on informal care also varies: direct interviews with caregivers, mailed questionnaires, phone surveys or combinations of the above. Sociological studies have shown that the various methods may lead to differing estimates [41].

In short, the valuation of informal care, as well as methods used to measure the time spent on it, have not been standardized. As a result, it is difficult to compare different studies.

Economic studies on informal care in dementia

As loss of ADL functions increased [42], more of the informal caregiver's time was needed (Table 30.2). Progression in the severity of dementia had a similar impact [43,44]. Based on market prices in the United States and a one-week cross-sectional survey, Langa et al estimated the annual informal care cost for mild dementia (8.5 hours a week) at $3 630, for moderately severe dementia (17.4 hours a week) at $7 420, and for severe dementia (41.5 hours a week) at $17 700 [45]. A six-month follow-up study in Israel, where informal care was evaluated on the basis of replacement costs, came up with an estimate of $10 420 [46]. A review by Wimo et al of published cost-of-illness studies concluded that, after conversion to the same year and currency and corrected for purchasing power, daily costs for the same severity of dementia ranged from $25 to $61 [37]. Informal caregiving at home gradually becomes more difficult for patients with the most severe dementia, so that they are likely to end up at nursing homes eventually.

Conclusions about descriptive studies

Because the cost-of-illness studies have a descriptive design, they are not normally considered when assessing evidence. Furthermore, there are no standardized methods for calculating the cost of illness of dementia or a valuation of informal care. As a result, the results of different studies are difficult to compare. The societal cost of dementia is clearly high, but it varies according to the measurement and resource valuation method employed, particularly when it comes to informal care. Very mild dementia is no more expensive than average care for corresponding age-groups, but the cost rises rapidly along with the severity of the disease.

Discussion

One important aspect of dementia care is that different payers are involved: municipalities, county councils, the national government, insurance companies, patients, families, etc. Switching interventions may not only impact total cost, but bring in new payers and new costs. If descriptive studies contain information about these issues, discussing interventions would be of value. However, there are many reasons that it is not easy to present cost data in a systematic way from that point of view. Even though a rough breakdown (direct medical costs, direct non-medical costs, indirect costs, including informal care) may be possible, differences among countries in terms of organizing and financing care make such presentations difficult to interpret.

Diagnostic procedures for dementia

Background

As discussed above, costs increase along with the progression of dementia. If the disease is discovered at an early stage, various interventions may slow down the progression. If the patient can stay at home longer, needs less care and enjoys a higher quality of life, the costs may be lower than if dementia progresses rapidly.

The primary aim of this assessment was to find evidence – primarily in published studies identified from the structured search of the literature – concerning the cost-effectiveness of different diagnostic procedures for dementia.

Results

The literature search did not identify any clinical studies of diagnostic procedures that included costs. However, there were five model studies: CT of reversible dementia, MR vs SPECT, SPECT plus drug intervention, PET and screening programs (Table 30.3).

The model study of CT – which was well-specified and transparent – focused on potentially reversible dementia, representing about 1% of all people with the disease [47]. Of diagnoses that included a risk for developing dementia, cost/utility was better for subdural hematoma (£14 171/QALY) than tumors (£117 901/QALY) or hydrocephalus (£762 605/QALY). The authors concluded that routine CT scans were inadvisable unless rapid deterioration had occurred after recent head injury.

A less well-specified model compared various MR strategies, including SPECT, for diagnosing dementia [48]. At $851 per accurate diagnosis, MRI plus contrast MRI was the most cost-effective strategy. The inclusion of SPECT increased the cost by almost 50%. The model that compared the cost-effectiveness of functional imaging tests (SPECT, MR) to standard examinations, all of which included drug intervention (Donepezil), concluded in favor of standard approaches [49]. The addition of functional imaging was less cost-effective.

Screening programs using MMSE tests to identify dementia among older drivers were compared to a possible increase in expected life-years [50]. However, the expected cost of $2 900 000 per life-year gained was far beyond the $50 000 per QALY gained considered reasonable by many studies.

A model study compared PET to MR for the detection of AD [51]. The PET strategy turned out to be the more cost-effective, reducing cost per accurate diagnosis by $1 138. The costs of MR were based on the procedure's relatively high price in the United States ($600–1 300).

Conclusions based on predictive studies

Only model studies on the economic aspects of diagnostic procedures were identified and included. Only one study was chosen for each procedure. Thus, no conclusions concerning cost-effectiveness could be drawn on the basis of published studies.

Intervention studies

Empirical studies on programs

Incomplete empirical, economic evaluations of programs

Seven studies that analyzed various kinds of programs for dementia care were included. All of them were assigned low study quality. Two studies were cost analyses and five were cost consequence analyses (Table 30.4). Two programs focused on long-term care (LTC) [52,53], one on day care (DC) [54], three on caregiver support (CGS) [44,55,56] and one on hospital care [57].

Engedal compared day care with nursing home care in an RCT from Norway [54]. Cost per day was lower in the day care group than in the home-based nursing group. Costs were based on the average price of acute care at hospitals and nursing homes. However, there was a lack of transparency in the calculation presented.

A small RCT by Rovner et al studied the Activities, Guidelines and Educational program (AGE) in the United States [53]. The costs were the same as the ordinary program, but there were fewer behavior disorders.

An RCT of an intensive 10-day residential training program for dementia caregivers (DCP) had lower costs than a Memory Retraining Program (MRP) and a Waiting List Group (WLG) [56]. Mortality at 30-month follow-up was lower in the WLG (10%) than the DCP (21%) and MRP (39%). The study lacked transparency and was based on a large number of assumptions.

A 6-month US follow-up study of the costs of formal and informal care based on diaries included 264 patients, of whom 141 remained for the entire time [44]. Of the total cost of $6 986, approximately 25% was for informal care. Patients with more severe symptoms of dementia, and families with higher income, reported significantly higher expenditures.

Complete empirical, economic evaluations of programs

Three studies with complete economic evaluations of programs based on empirical data were identified (Table 30.5). One open controlled study on day care found that the cost-effectiveness of the 2 alternatives was equal [58].

In a small RCT from Canada, Drummond did not find any significant change in terms of costs or the informal caregiver's quality of life when a supportive care program was adopted [59]. The dropout frequency in the caregiver support study was rather high, while the number of caregivers was low.

A cost-effectiveness analysis by Wimo et al compared costs and quality of life indices for patients in day care and ordinary care [58]. After 12 months, there was no significant difference in either total costs or the indices. In other words, day care did not turn out to be more cost-effective than ordinary care of people with dementia.

Conclusions about empirical studies on programs

The incomplete empirical, economic studies had several methodological problems, particularly a lack of transparency with respect to how the cost calculations were performed and low statistical power. No conclusions about the evidence for programs can be drawn from the complete economic studies, which were of limited quality and size. Thus, no conclusions about the evidence for the cost-effectiveness of programs are possible on the basis of these studies.

Empirical studies on pharmacological treatment

Four studies of at least acceptable quality that included empirical cost data were identified (Table 30.6). The resource utilization and cost data in RCTs were collected prospectively [60–62].

One empirical study of drug treatment with donepezil for mild to moderate AD was assigned low quality due to its high attrition rate [60]. The other empirical study on memantine was also assigned low quality [61]. The first study followed patients with mild to moderate AD who were taking donepezil for a period of 12 months and compared them with a placebo group [60]. The economic analysis was performed according to treatment per protocol. There was no significant difference in total costs between the two strategies. Thus, donepezil was not more cost-effective, as expected on the basis of some previously published model studies [63,64]. However, the experimental group had a significantly better outcome in terms of IADL and the Progressive Deterioration Scale. In that sense, the donepezil treatment strategy was more cost-effective than placebo.

The second study concerned a 28-week treatment with memantine for patients with moderate to severe AD [61]. The economic evaluation was performed according to treatment per protocol, with a last observation carried forward approach for an intention-to-treat analysis. Based on the treated per protocol patients, the total cost was lower in the experimental group than the control group. The calculations were based on high informal care utilization per 24 hours (average of 13.8 hours for the experimental group and 15.2 hours for the control group) as defined from structured interview questionnaires regarding the past month and a follow-up after 3 months. The cost per hour of informal care used the average incomes of corresponding age-groups and gender – as opposed to the shadow price of employees from the municipal home care service, which was lower. An effort to perform a retriever dropout analysis proved unsuccessful. These limitations on the design and implementation of the study reduced its quality.

The AD2000 study planned to include 3 000 patients, but only about 500 ultimately participated [62]. The study was based on a 3-years trial with respect to primary outcomes (institutionalization, ADL) and a 2-years trial regarding cognition, etc. For health economic outcomes, it had a 60-week horizon with pooled data. The study concluded that no significant cost savings had been achieved. From a health economic point of view, and although it is the largest RCT with prospectively collected cost data conducted so far, AD2000 suffers from the same limitation as the other empirical studies – insufficient statistical power. One of the endpoints was institutionalization, and it is unclear how costs were analyzed after that time. However, because AD2000 was an RCT with a rather long follow-up period, it meets the criteria for inclusion.

The study by Feldman et al [65] – which was conducted in Canada, Australia and France – used a similar approach as Wimo et al [60] but focused on patients with more severe dementia. The duration was a rather short 6 months. As in the other donepezil studies with empirical data, there was no significant cost difference between treated patients and controls from a societal point of view.

Conclusions about evidence in empirical studies on drug treatment of dementia

The three studies on donepezil, all of which were of low quality, offered no conclusive evidence. The only available empirical study on memantine was of low quality and thus not sufficient for a statement of evidence. Due to the absence of studies, no conclusions can be drawn regarding other drugs used in the treatment of dementia.

Model studies

Incomplete model-based, economic evaluations of programs

No study with at least low quality was identified.

Complete model-based, economic evaluations of programs

Three studies were identified that focused on programs and employed a complete health economic evaluation (Table 30.7).

The first study – which was a cost utility analysis with an 8-year Markov model of Group Living for dementia patients– was based on a 1-year empirical core study [66].

The second (willingness to pay – WTP) study was from Switzerland and based on hypothetical programs (given that the country has not adopted them yet) [67]. The study is based on interviews with a general population aged 18 and up, not specifically caregivers of dementia patients (although 17% had family members with AD). The assumption was that WTP was applicable to the entire Swiss population aged 18 and up and that a CBA approach would identify cost-effectiveness. The third study is a Markov model with Monte Carlo simulations of a program that included caregiver support and case management in Finland [68].

Conclusions about model studies of programs

Given that so few studies were identified, there is insufficient evidence for the cost-effectiveness of programs.

Model studies of pharmacological treatment

Incomplete economic evaluations of pharmacological treatment

Five studies – three on tacrine [69–71] and two on rivastigmine [33,72] – were identified that can be regarded as cost analysis models (Table 30.8). The tacrine studies were all based on the same clinical trial [73]. The rivastigmine models did not include the cost of the drug. One of the models included the cost of informal care. However, all of the studies employed a sensitivity analysis. The rivastigmine models presented only the difference among the groups, not the basic costs of each alternative. The period of the model varied from 2 to 9 years. Because these studies did not consider outcome, no conclusions about the evidence for cost-effectiveness can be drawn.

Complete economic evaluations of pharmacological treatment

Thirteen model studies were identified that had a complete health economic perspective: five on donepezil [63,64,74–76], one on rivastigmine [77], five on galantamine [78–82] and two on memantine [83,84] (Table 30.9). All donepezil studies are Markov models with severity of dementia or QALYs as the outcome. The rivastigmine study is based on a survival model of the number of QALYs needed to obtain cost neutrality, with the assumption that $20 000 (Canadian) per QALY is an acceptable cost. All galantamine studies were based on the AHEAD (Analysis of Health Economics on Alzheimer's disease) model as applied in various countries. All models except those applied in the UK indicate cost savings and a positive outcome when treatment lasts for two years or longer [74,82]. Even though the costing figures for the AHEAD models of galantamine are country-specific, the basic AHEAD model is derived from one study of 236 New York patients in the 1980s, making its use in several countries somewhat questionable [85]. All model studies use data on costs from sources other than the clinical trials from which the course of the dementia disease was extrapolated. The donepezil models are all based on cognition, while the galantamine models (AHEAD) use the broader full-time care (FTC) concept. A problem with the AHEAD studies is that the calculations are not fully transparent. The rivastigmine model uses a number needed to treat (NNT) approach instead of a C/E ratio. The reason for assigning two of the model studies high quality is that they were based on an established model technique, used robust sources for costing, adopted a societal perspective, included relevant outcomes and employed comprehensive sensitivity analyses [64,75]. Because the models are built on extrapolated efficacy data and assuming that there are no proven differences in terms of efficacy among the cholinesterase inhibitors, the only important factors that can generally influence cost-effectiveness in the models are the prices of the drugs, long-term compliance and survival. Possible differences among the drugs when it comes to cost-effectiveness may primarily reflect the type of model used.

The two Markov model studies on memantine had different time frames. The study based on UK data had a time frame of 2 years [83] and the study based on Finnish data had a time frame of 5 years [84]. Furthermore, the UK study proceeded from the perspective of the healthcare provider, while the Finnish study proceeded from that of society in general. Time to dependency was a primary outcome for both studies. Both studies reported that treatment with memantine provided cost savings due to expected increased time to dependency. The UK study also found that treatment was reasonably cost-effective. However, both studies assumed no dropouts and complete compliance, situations that rarely exist in practice – that probably favored the drug interventions.

No pharmacoeconomic evaluations were performed on the use of SSRIs, risperidone or other neuroleptics for dementia.

Conclusions about model studies of pharmacological treatment

There is insufficient evidence for the cost-effectiveness of pharmacological treatment.

Systematic reviews of drug interventions based on model studies

The systematic reviews conducted by CCOHTA [12], McGill University [13], NHS/HTA [86] and the NICE report [87] included model studies as specified in Table 30.10. The CCOHTA review [12] concluded that "donepezil and rivastigmine are associated with either a slight increase or a slight decrease in overall costs while producing a better clinical outcome for patients with mild-to-moderate AD. However, even in the most optimistic scenarios, the length of time gained in non-severe AD is very small. In addition, cost savings occur primarily due to a reduction in informal care costs and delays in institutionalization: the former is difficult to measure and there is no evidence yet that either donepezil or rivastigmine have significant impact on the latter. These studies are all based on modeling, are speculative, and are based on short-term data on efficacy, rather than effectiveness data".

The McGill study concludes that, "Patients receiving active treatment may have more favorable ADAS-cog scores for at least 6 months, after which scores of patients receiving active treatment and placebo will begin to converge [13]. Differences in methodology, types of direct and indirect costs included, and sources of cost data made it difficult to compare and synthesize the findings of available economic studies; therefore, the cost-effectiveness data are inconclusive".

The NHS/HTA review of 2001 concluded that, "It is difficult to quantify benefits from the evidence available in the literature [86]. Statistically significant improvements in tests such as ADAS-cog may not be reflected in changes in daily life. Economic implications of prescribing these drugs (ie donepezil and rivastigmine) are uncertain. The main issue is not drug costs per se, but the impact across different sectors".

The recent online NICE report, which was a preliminary version for purposes of discussion, questioned the cost-effectiveness of drugs used for dementia [87]. However, the report did not proceed from a societal perspective. Besides a review of the current literature, the report included a cost-effectiveness model based on the AHEAD framework. Applied to UK conditions, the model generated highs costs per QALY. The report found that the CEA calculations on drugs for mild to moderately severe AD are largely driven by the high costs of full-time, nursing home care. The report also indicated that drug treatment may delay the progression of AD and thereby reduce the costs associated with full-time care. The report concluded that the cost per QALY was highly sensitive to the incremental cost of intervention and was £50 000 or more for the drugs analyzed. Thus, drug treatment did not appear to be a cost-effective intervention.

Conclusions about pharmacological treatment

Four systematic reviews based on published model studies found evidence for neither cost savings nor cost-effectiveness when prescribing donepezil, rivastigmine or galantamine for patients with mild to moderate AD.

The few RCTs on donepezil or memantine, all of which were assigned low study quality, provided insufficient scientific evidence of cost-effectiveness. On the other hand, there was no conclusive evidence that use of the drugs is cost-ineffective.

Discussion

Based on the assessment of economic studies on the treatment of dementia, the general conclusion is that – due chiefly to the lack of studies and the need for methodological development – it is impossible to make any definitive assertions regarding cost-effectiveness. Empirical studies that focus on the cost-effectiveness of dementia treatment are rare. The fact that several methodological questions need to be highlighted complicates the issue even more. The questions include:

- How valid is the information about diagnosis (diagnostic system, type and severity of dementia)?

- What are the relevant outcomes (concerning severity of disease, quality of life, and postponement of nursing home care)?

- Are QALYs useful?

- How should the influence of informal care be assessed and assigned a cost?

- How should the long-term effects be described and assessed?

- What imputation methods are possible for missing data?

All of these questions raise complex methodological considerations for which consensus or resolution cannot be expected in the near future. The ways in which various studies deal with these questions have a considerable impact on both costs and outcomes, and thereby on cost-effectiveness.

The main cost drivers of dementia treatment from a societal point of view are institutional and informal care. Although there is a strong correlation between the costs of dementia care and cognition, many studies have shown that others factors – such as BPSDs and the caregiver's situation – affect the prospects of continuing care at home.

Pragmatic designs have been suggested as an alternative to models when long-term RCTs cannot be conducted [88]. Few such health economic studies on dementia have been performed. AD2000 might be regarded as a pragmatic RCT [62]. With respect to daily care, various treatments are generally used in conjunction. Thus, it would be logical to consider health economic evaluations of combined treatment approaches, such as caregiver support and pharmacological treatment (or combined treatment with a cholinestrase inhibitors (CHEI) and memantine). However, no such study has yet been published. Depending on the design of the evaluation, such studies may include 2–4 treatment arms, making the issue of statistical power essential.

Need for health economic research on dementia

There is a need for research and consensus discussions regarding clinically relevant outcomes to be used in economic evaluations.

A need also exists for randomized clinical trials with prospectively collected resource use and cost data, as well as relevant outcomes.

Health economic studies are often underpowered [89], while the data on resource use is frequently skewed. Thus, there is a need for health economic studies on dementia that cover longer periods and include more patients than those previously published. Methodological development for assessing quality of life in dementia patients is also needed. The issue of costing informal care and its application to dementia needs to be highlighted more transparently. There is a great need for true cost-effectiveness studies with prospectively collected empirical data on resource utilization, costs and outcomes. There is also a need for studies with combined approaches (such as drugs and programs) and comparative strategies (among different CHEIs, CHEIs with other drugs, etc). Studies that focus on BPSDs and depression in patients with dementia are also needed. Finally, it would be of interest to analyze long-term empirical findings in terms of institutionalization, mortality, etc, with models based on interventions.

Abbreviations

$	US dollars
AD	Alzheimer's disease
ADL	Activities of daily living
ADRDA	Alzheimer's disease and related disorders association
AGE	Activities, guidelines, education
AHEAD	Analysis of health economics Alzheimer's disease
BPSD	Behavioral and psychological symptoms in dementia
C	Controls
CA	Cost analysis
CAMDEX	Cambridge examination for mental disorders of the elderly
CBA	Cost benefit analysis
CCA	Cost consequence analysis
CCOHTA	Canadian coordinating office for health technology assessment
CDR	Clinical dementia rating (scale)
C/E	Cost effectiveness
CEA	Cost effectiveness analysis
CGS	Caregiver support (program)
CHEI	Cholinesterase inhibitors
CIBIC	Clinician's interview-based impression of change
CIRS-g	Cumulative illness rating scale-geriatrics
CMA	Cost minimization analysis
COI	Cost of illness
CPI	Consumer price index
CRD	Centre for reviews and dissemination
CT	Computerized tomography
CUA	Cost utility analysis
DRS	Dementia rating scale
DSM	Diagnostic and statistical manual of mental disorders
ERIC	Education resources information center
GDS	Global deterioration scale
GDS	Geriatric depression scale
HEED	Health economic evaluations database
HIPE	Hospital in patient enquiry
HMO	Health maintenance organization
HTA	Health technology assessment
IADL	Instrumental activities of daily living
ICD	International classification of diseases
ITT	Intention-to-treat
LPN	Licensed practical nurse

LTC	Long-term care
MC	Marginal cost
MCI	Mild cognitive impairment
MeSH	Medical electronic search headings
MMSE	Mini-mental state examination
MR (MRT)	Magnetic resonance tomography
MRI	Magnetic resonance imaging
MSQ	Mental state questionnaire
MT	Memory training
NA	Not applicable
NHP	Nursing home placement
NHS	National health service
NHSEED	National health service economic evaluation database
NICE	National institute for clinical excellence
NINCDS	National institute of neurological and communicative disorders
NNT	Number needed to treat
NPV	Negative predictive value
NS	Not significant
OC	Observed case
OECD	Organization for economic cooperation and development
PADL	Personal activities of daily living
PET	Positron emission tomography
PPP	Purchase power parity
PPV	Positive predictive value
QALY	Quality-adjusted life-year
RCT	Randomized controlled trial
RN	Registered nurse
RR	Relative risk
RTO	Retrieved dropout
SBU	Swedish council on technology assessment in health care
SCU	Special care unit
SD	Standard deviation
SDAT	Senile dementia of Alzheimer type
SPECT	Single photon emission computed tomography
SSRI	Selective serotonin reuptake inhibitor
SNRI	Serotonin/noradrenaline reuptake inhibitor
TICS	Telephone interview for cognitive status
TPP	Treated per protocol
VaD	Vascular dementia
WL	Waiting list
WTP	Willingness to pay

Table 30.1 *Cost of Illness.*

Author **Year** **Reference** **Country**	**Type of study**	**Setting**	**Dementia diagnosis and degree**	**Age-groups included, patients**	**Follow-up time**
Kronborg Andersen et al 1999 [35] Denmark	Cost of illness Alzheimer's disease compared to controls	Random sample of Danish population Register interviews	CAMDEX NINCDS-ADRDA CDR	65–84 (3 346 of 5 237 accepted)	1992–1996
Ernst et al 1994 [90] USA	Cost of illness Alzheimer's disease	Data from other published studies and reports	Alzheimer's disease	65+ based on epidemiologic data, 45–64 based on estimates	1991
Fillit et al 2002 [91] USA	Cost of illness Vascular dementia (VD) Alzheimer's disease (AD) vs controls	Medicare database, samples drawn	Vascular dementia and Alzheimer's disease	65+	1997–1999

Direct costs	Indirect costs	Total costs	Total direct costs per demented 2003 Dollars	Reviewers' comments
Danish Kr per person Mild 84 761 Moderate 152 080 Severe 207 421 All 94 456 Incremental Danish Kr per person Very mild 2 947 Mild 59 127 Moderate 131 108 Severe 183 968 All 70 333			11 171	Specified calculations, high transparency, age, gender and severity standardised
Per year/person: 1st year $14 140 of which nursing home $7 570	Per year/person: unpaid home care $20 900 (1 year)	Rest of life/per person: $173 932 (discounted, survival men 3.3 year, women 4.3 year)	18 625	
Hospital: VD $11 226 AD $5 674 C $3 179 Incremental hospital cost: VD $8 047 AD $2 495	Total standardised: VD $16 508 AD $9 711 C $5 963 Incremental costs: VD $10 545 AD $3 748		NA	Age, gender and co-morbidity conditions standardised

The table continues on the next page

Table 30.1 continued

Author Year Reference Country	**Type of study**	**Setting**	**Dementia diagnosis and degree**	**Age-groups included, patients**	**Follow-up time**
Gray et al 1993 [92] United Kingdom	Cost of illness Alzheimer's disease	NHS-data, HIPE Enquiry	Senile dementia and Alzheimer's disease	55+	1990–1991
Hay et al 1987 [93] USA	Cost of illness Alzheimer's disease	Foreign data Clinical findings Assumptions	Alzheimer's disease	45+	1983
Huang et al 1988 [94] USA	Cost of illness Senile dementia	Survey data Other reports	SDAT Mixed type dementia	65+	1985
Hux et al 1998 [95] Canada	Cost of illness including severity differences of AD	Survey data	Alzheimer's disease MMSE	65+ Survey of n = 9 008 randomly selected	14 months

Direct costs	Indirect costs	Total costs	Total direct costs per demented 2003 Dollars	Reviewers' comments
Mental hospitals, total of £177 millions	Residential care, total of £676 millions	Total of all health and social services: £1 039 millions, of which informal care £65 millions (6 %)	NA	
Per person: 1st year $9 578 2nd year $8 704 of which nursing home $5 326	Per person: $8 939 of which informal care $8 684	Per person: $18 517 of which nursing home + informal care $14 010 (76%)	17 156	
$13.26 billion	$31.46 billion	$44.7 billion	2 829	Rough estimates
Annual costs total (of which informal care) MMSE 21–26: $9 451 (5 655) 15–20: $16 054 (7 047) 10–14: $25 724 (5 378) <10: $36 794 (3 506)			18 896	Informal care valued as average industry wage. Severe AD MMSE <10 had 84% nursing

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Table 30.1 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis and degree	Age-groups included, patients	Follow-up time
Leon et al 1999 [96] USA	Cost of illness, managed care perspective	HMO, cross-sectional comorbidity included	Alzheimer MMSE and CDR CIRS-g for comorbidity, clinically verified	60+ n = 150	6 months
Martin et al 2000 [97] USA	Cost of illness Re net costs	Retrospective cross-sectional matched control group Georgia Medicaid Recipients	Alzheimer's disease and dementia defined from ICD-9	50+ n = 8 671 Prevalence 4.4%	1 year retrospective
McNamee et al 2001 [36] United Kingdom	Cost of illness based on epidemiological data	Model study limited to formal care 1994–2031	According to database	65+	Model 37 years

Direct costs	Indirect costs	Total costs	Total direct costs per demented 2003 Dollars	Reviewers' comments
AD, mild: $5 520 AD, moderate: $7 044 AD, severe: $10 992 (annual) Comorbidity increased costs		AD, mild: $14 904 AD, moderate: $19 272 AD, severe: $25 860 (annual) National level estimate $8.8 billions	5 896–10 780	Replacement cost, home health aides average wage Selected patients to HMO's?
Total direct incremental cost of + $9 297/ year of which nursing home +$8 252/year Adjusted for gender, age race, co-morbidity and Medicare eligibility +$8 158/year (nursing home +$7 040/year)			8 714	Based on claims data from Medicaid. Results not presented depending on severity. Adjusted results included
Formal care Men: 1994: £0.95 billion 2031: £1.65 to 2.34 billion 1994: £5.35 billion 2031: £7.87 to 11.20 billion			21 292	Health care planning model. Long term planning period makes the calculation highly uncertain (lower estimate if prevalence rate is reduced and improvements in functioning occur)

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Table 30.1 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis and degree	Age-groups included, patients	Follow-up time
Ostbye et al 1994 [98] Canada	Cost of illness Net costs	Health and aging survey	Neurologic and neuropsychologic examinations using MMSE	65+ Cohort of 10 263	The year of survey
Rice et al 1993 [99] USA	Cost of illness Formal and informal care	Interview Northern California	Alzheimer's disease Disease MMSE	94 institutionalised and 93 non-institutionalised patients	12 months
Scuvee-Moreau et al 2002 [100] Belgium	Cost of illness based on caregiver interview	Prospective cohort study, started from primary care	Alzheimer's disease using CAMDEX, DSM-III-R and MMSE	65+ n = 605 patients in all	12 months

Direct costs	Indirect costs	Total costs	Total direct costs per demented 2003 Dollars	Reviewers' comments
Net costs, Can $3.9 billion, of which community 1.25 ($10 100/pat) and long term institutions 2.18 ($19 100/pat)			12 873	Cohort survey upgraded to the level for Canada
At market value – Community: – formal care $12 572 – informal care $34 517 – total $47 089 ($39 558 to 52 667) Institutional: – formal care $42 049 – informal care $5 542 – total $47 591 ($37 729 to 48 205) info			12 943	If estimation based on market value there was no difference of cost if living at home or at an institution
Home living per month. Ref group 368.5 Euro all AD 445.6 Euro severe AD 556.9 Euro Institution living/month Ref. Group (none) all AD 2 301.7 Euro severe AD 2 465.3 Euro			NA	No cost of informal care if caregiver = husband or wife, ie no opportunity cost

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Table 30.1 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis and degree	Age-groups included, patients	Follow-up time
O'Shea et al 2000 [38] Ireland	Cost of illness, societal costs	Model estimated	Database records on dementia for 1996	21+	12 months
Souêtre et al 1995 [101] France	Cost of illness, cross sectional	University hospital out-patient care	Alzheimer defined from NINCDS-ADRDA, MMSE	60+ n = 51 in outpatient care only	3 months
Souêtre et al 1999 [102] England	Cost of illness, non-institution-alised patients	Cross sectional multicenter, based on interview once	Alzheimer's disease according to criteria incl MMSE	50+, 128 patients with AD. 56 matched controls	3 months

Direct costs	Indirect costs	Total costs	Total direct costs per demented 2003 Dollars	Reviewers' comments
Annual direct cost £8 261/pat, £248.3 million all pat's, of which care family 50%, resident 33%, community 10%, mental hospital 5%, acute hospital 2%			9 067	Opportunity cost for formal care included at 2 Euro/hour
(Per patient) MMSE <15: $1 408 MMSE >15: $762 Caregiver, if pat's <15: $455 pat's >15: $213	(Per patient) MMSE <15: $692 MMSE >15: $527	(Per patient) MMSE <15: $2,100 MMSE >15 Cost of rehabilitation and drugs significantly higher for pat's with MMSE <15 than >15, the contrary for diagnostics	NA	Small study, short period, retrospective cross-sectional
Control non AD £387, AD mild £6 616, AD moderate £10 250, AD severe £13 593			NA	Selected patients for each severity AD-group. High caregiver cost valuation

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Table 30.1 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis and degree	Age-groups included, patients	Follow-up time
Wimo et al 1997 [103] Sweden	Cost of illness, all sorts of dementia	Model based on other published studies + databases	Diagnosis defined in studies referred to	Not indicated	Year basis

Direct costs	Indirect costs	Total costs	Total direct costs per demented 2003 Dollars	Reviewers' comments
	For 1991 estimated 30.68 billion SEK in total, or incremental net costs of 20 billion SEK Per patient 200 000 vs 130 000 SEK (incremental)	Valuation of informal care	19 970	

Table 30.2 *Cost of informal care.*

Author Year Reference Country	**Type of study**	**Setting**	**Dementia diagnosis and degree**	**Age-groups included, patients**
Beeri et al 2002 [46] Israel	Behavioral costs of Alzheimer's disease (BPSD), private costs only	Interview of patient and primary caregivers, patients from memory clinics	NINCDS-ADRDA	Only mean age, 76.4 for patients and 61.2 for caregivers n = 71 pat's
Cavallo et al 1997 [40] Italy	Economic burden on families of Alzheimer's disease, non-medical care	Mailed questionnaires, non-institutionalised patients	Patients and family caregivers associated to Italian Alzheimer-Association	Sample of 1 501 caregivers, response rate 41%
Langa et al 2001 [45] USA	Cost of illness focusing on informal care	National cohort survey, 1993 AHEAD study	TICS over the phone	70+, n = 7 433. Drop out rate 10%
Moore et al 2001 [42] USA	Informal costs of caring, female caregivers only	National longitudinal caregiver study of US veterans	Diagnosis according to medical centers using ICD-9 (AD, VAD)	All ages of US vet's 90% wives n = 2 278, 62% response rate

Follow-up time	Informal care costs	Indirect costs	Total costs	Reviewers' comments
6 months	Average per month $325 of which for BPSD $121 (private costs)	Average per year $10 520 of which BPSD $2 665	Approximately per year $14 420 of which for BPSD $4 120	Valuation of informal care according to replacement costs
None, at time of interview only, but concerned annual costs	Paid non-medical care $8,218 and unpaid non-medical care $44 736 or total of $52 954/year			Valuing of informal care according to replacement costs
Cross sectional 1 week	Informal care based on market price Mild: +8.5 h/week +$3 630/year Moderate: +17.4 h/week +$7 420/year			Validity and reliability of diagnosis over the phone? Limited to people with dementia living at home. One week cross-sectional study only
Inquiry regarding annual informal care	Average, per year: caregiving time $6 292 Increase of caregiving with increase of losses of ADL-functions	Average, per year: caregivers's lost earnings $10 709, not much affected by losses of ADL-functions	Average, per year, direct and indirect costs of caregivers, $17 001. Valuation at market price	Survey data related to ADL and to behavior rating scale

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Table 30.2 continued

Author Year Reference Country	**Type of study**	**Setting**	**Dementia diagnosis and degree**	**Age-groups included, patients**
Weinberger et al 1993 [43] USA	Informal costs of caring. Interview and diary	Caregivers to patients from memory clinics, living at home	Clinic neurologist judged the patient to have a progressive dementia	Mean age 59.3 years n = 141 (of 264 enrolled)

Follow-up time	Informal care costs	Indirect costs	Total costs	Reviewers' comments
6 months	Informal care services, formal $6 986 informal $786. Severity of dementia and time since memory loss correlated most to costs			Informal services estimated at $10 per hour. University setting. Data from diary

Table 30.3 *Health economic evaluations of diagnostic procedures. Costs are expressed as 2003 dollars.*

Author **Year** **Reference** **Country**	**Type of study**	**Setting**	**Dementia, diagnosis and degree**	**Age-groups included, patients**	**Follow-up time**
Foster et al 1999 [47] England	Model using CT as a test for potentially reversible dementia including treatment	Systematic review data used for model of screening program	Reversible dementia	55+	Life expectancy for different age-groups and type of treatment (surgery)
LaFrance et al 1998 [48] USA	Model using contrast MR for detection of Alzheimer compared to SPECT	Data from recent studies (no specified selection)	Alzheimer's disease	65+	NA
MacMahon 2001 [104] USA	Model using functional imaging tests in diagnosis of Alzheimer + treatment (donepezil) vs standard	Data from studies (no specified selection)	Alzheimer's disease	Not indicated	18 months
Retchin et al 1994 [50] USA	Markov model of screening programs. Cost/benefit of screening older drivers	Data from different studies and experts	Not specified but identified by screening test MMSE at different intervals	65	20 years

Primary endpoint	Results from study	Reviewers' comments	Study quality
Cost per QALY C/E	Cost per QALY gained, subdural hematoma had the best C/E (£14 171/ QALY) ($23 759)/QALY compared to tumors (£762 605/QALY) ($1 278 568/ QALY) (baseline cases). Routine CT scans not recommended, but demented people <65 years old or >65 years and onset less than 1 year or a typical presentation/rapid deterioration/recent head injury/focal neurological signs	Concerns only about 1% of all patients with dementia. Model specified in a transparent manner	Model/ High
Positive prognostic value	All >65 years, per accurate diagnosis: MRI plus contrast MRI: $960 MRI plus clinSPECT: $1 355 MRI plus quantSPECT: $1 499 Results more dependent on costs per strategy than sensitivity and specificity	Variable data chosen not well described	Model/ Low
Costs per QALY, CE	Costs per QALY standard examination had better C/E than compared strategies ie visual SPECT, computed SPECT and MR plus contrast MR (standard examination $62 467). Not cost-effective to add functional imaging to the standard diagnostic work-up' examination	Extensive list of data included, and sensitivity analysis. Are QALY's used valid?	Model/ Low
Cost per life year gained	Incremental cost of $7 691 per driver would increase life expectancy by 0.77 days if screening yearly. Cost per life year gained $3 600 000	Definition of dementia not specific as to type nor degree	Model/ Low

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Table 30.3 *continued*

Author Year Reference Country	**Type of study**	**Setting**	**Dementia, diagnosis and degree**	**Age-groups included, patients**	**Follow-up time**
Silverman et al 2002 [51] USA	Decision Tree Analysis. Cost/benefit of early detection of Alzheimer's disease using PET	Data from specific studies and own experience	Alzheimer's disease as defined in epidemiologic data	65+	NA

Primary endpoint	Results from study	Reviewers' comments	Study quality
Cost per accurate diagnosis	Strategy using PET reduced cost per accurate diagnosis by $1 164 (ie PET vs conventional)	Cost per item high MR $600–1 300, how relevant for Scandinavia?	Model/ High

Table 30.4 *Empirical incomplete economical evaluations of programs: Costs are expressed as 2003 dollars (PPPs).*

Author **Year** **Reference** **Country**	**Type of study**	**Program**	**Setting**	**Dementia diagnosis and degree**	**Number of participants (T+C) (drop-out %)**	**Country (for costing)**	**Duration of study (months)**
Challis et al 2002 [55] United Kingdom	CCA	CGS/case management	Home	>70% severe dementia	43+43	United Kingdom	12
Wray et al 1988 [57] USA	Observation study, CA	Medical treatment	Hospital	Severe	63 (10%)	USA	3
Brodaty et al 1991 [56] Australia	RCT, CCA	CGS	Home	Mild-moderate	33+31+32	Australia	39
Maas et al 1998 [52] USA	CA, quasiexp	LTC/SCU	Nursing home	"Irreversible dementia", AD	26+18	USA	12
Rovner et al 1996 [53] USA	RCT, CCA	LTC, AGE (Activities, Guidelines, Education)	Nursing home	DSM-III-R, Severe (?)	42+39 (89 randomized)	USA	6

Societal perspective?	Cost per treated patient	Cost per patient, comparator	Cost difference	Sensitivity analysis	p-value	Quality of study	Reviewers' comments
Yes	36 885	30 030	–6 432	No	NS	1	Some outcomes (eg patient distress, social contacts; caregiver burden) favouring intervention
No	15 554	15 554	0	No	NS	1	Interesting from an ethical perspective
No	?	?	8 371	No	?	1	Non RCT, CCA, cost calculations, lack of transparency, doubtful assumptions
No	79.8/day	61.2/day	–18.6/ day	No	?	1	Low power
No	10.5/day	1.3/day	–9.2	No	?	1	CCA, RCT, ITT and TPP analyzed. Cost calculations lack of transparency

The table continues on the next page

Table 30.4 *continued*

Author Year Reference Country	Type of study	Program	Setting	Dementia diagnosis and degree	Number of participants (T+C) (drop-out %)	Country (for costing)	Duration of study (months)
Weinberger et al 1993 [44] USA	RCT, CCA	CGS	Home		193+71 (14%+13%)	USA	6
Engedal 1989 [54] Norway	RCT, CCA	Day care	Day care	DSM-III	38+39	Norway	12

Societal perspective?	Cost per treated patient	Cost per patient, comparator	Cost difference	Sensitivity analysis	p-value	Quality of study	Reviewers' comments
Yes	9 574	10 723	1 149		NS	1	Cost calculations lack of transparency
No	50.3/day	58.4/day	8.1/day	No	?	1	Low power. Cost calculations lack of transparency

Table 30.5 *Empirical complete economical evaluations of programs. Costs are expressed as 2003 dollars (PPPs).*

Author Year Reference Country	Type of study	Program	Setting	Dementia diagnosis	Severity of dementia	Patients included, attrition (active treatment(s) first, placebo)	Mean/ range (SD), (treatment(s)/ placebo	Study period (months)
Wimo et al 1994 [58] Sweden	Quasi experimental	Day care	Community	Clinical (geriatrician)	Moderate	55+45 (0%)	78 (76–80), 79 (77–81)	12
Wimo et al 1990 [105] Sweden	CUA	Day care	Psychogeriatric day care	Clinical (geriatrician)	Moderate	47		6
Drummond et al 1991 [59] Canada	CUA, RCT	CGS	Community	Clinical, DRS*, GDS	87.90% moderate, moderate-severe	30+30 (27%+ 33%)	77.8 (9.2), 75.9 (7.7)	6

* Dementia Rating Scale

Outcome	Perspective	Cost per treated patient	Cost per patient, comparator	Cost difference	C/E or similar*	Range in sensitivity analysis	Quality of study	Reviewers' comments
QALY	Direct non-medical, direct medical costs	32 809	37 559	4 750	Indifferent	NA	1	Both costs and outcome NS. No sensitivity analysis
Well years	Direct non-medical				9 672/ well year	No	1	Prospective, no control, before/after
QALY	Direct non-medical, direct medical costs	4 237	3 520	–807	24 344/ QALY	NA	1	Good design, low power, high drop out rate

***Table 30.6** Empirical incomplete economical evaluations of drug treatment. Costs are expressed as 2003 dollars (PPPs).*

Author Year Reference Country	**Type of study**	**Drug**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients included, attrition (active treatment(s) first, placebo)**	**Age-groups, mean/ range (SD), (treatment(s)/ placebo) (Years)**
Wimo et al 2003 [60] Europe	RCT, ITT	Donepezil	Community (93%)	Alzheimer's disease (NINCDS, DSM-IV)	Mild-moderate	142+144 (33%, 33%)	72.1 (8.0), 72.9 (8.6)
Wimo et al 2002 [61] USA	RCT, TPP	Memantine	Community	Alzheimer's disease (NINCDS, DSM-IV)	Moderate-severe	126+126 (29%, 40%)	58%, 60% 75+
Courtney et al 2004 [62] United Kingdom	RCT, ITT	Donepezil	Community	DSM-IV (AD)	Mild-moderate	282 (32% withdrawn), 283 (31% withdrawn)	76 (54–93), 75 (46–90)
Feldman et al 2004 [65] Canada France Australia	RCT, ITT	Donepezil	Community/ assisted living	Alzheimer's disease (NINCDS, DSM-IV)	Moderate-severe	144+146 (16%, 14%)	73.2 (8.4), 74 (7.8)

Study period (years)	Perspective	Cost per treated patient	Cost per patient, comparator	Cost difference	Cost difference (%)	p-value	Range in sensitivity analysis	Quality of study	Reviewers' comments
1	Societal	27 139	28 331	1 192/ year	4.2	NS	547– 1 276	1	Rather high attrition
0.5	Societal	7 844	9 048	1 204/ month	13.3	0.01	Yes, but figures not presented	1	RCT. Costs per month. Major cost saving in informal care. High attrition. Major option TPP. 927/ month (ITT option)
60 weeks	Resources collected but not all costed	4 884	4 028	–856	–21.2	NS	Yes, but cost figures not presented	1	RCT. Informal care not costed. Institutionalization endpoint
0.5	Societal	9 138	9 444	306	3.2	NS	71–480 (on website)	1	RCT. Short duration

Table 30.7 *Models: complete economical evaluations of programs. Costs are expressed as 2003 dollars (PPPs).*

Author Year Reference Country	**Pro-gram**	**Setting**	**Seve-rity of demen-tia**	**Model length (years)**	**Model type**	**Out-come**	**Per-spective**	**Cost treated or similar**
Wimo et al 1995 [66] Sweden	Group living	Group living	Mild-moderate-severe	8	CUA/ Markov	QALYs	Direct medical and non-medical costs	280 745/ patient
Nocera et al 2002 [67] Switzerland	Care-giver support	Com-munity	?	NA	CBA	NA	NA	156 million
Martikainen et al 2004 [68] Finland	Care-giver support/ case manage-ment	Com-munity	Mild	5	CUA/ Mar-kov/ Monte Carlo	QALYs	Direct medical and non-medical costs	45 508/ patient

Cost, comparator or similar	Cost difference	Cost difference vs comparator (%)	C/E or similar comparison	Range in sensitivity analysis or similar	Quality of study	Reviewers' comments
384 083/ patient	103 337/ patient	27%	<0	<0 in all options	1	Core sample with rather few patients (26+108)
818 million	663 million	–	<0	<0 in all options	1	Respondents general population (17% had a relative with AD), not caregivers. Programs not implemented in Switzerland. Large sample. WTP distributed on whole population 18+, not only caregivers
48 607/ patient	3 099/ patient	6.3%	<0	71% of marginal cost simulations cost saving and QALY gaining	2	Costs of informal care not included. Differences in QALYs very small

Table 30.8 *Models: Incomplete economical evaluations of drugs. Costs are expressed as 2003 dollars (PPPs).*

Author Year, reference Country	Drug	Severity of dementia	Model length (years)	Model type	Perspective	Cost per treated patient
Lubeck et al 1994 [69] USA	Tacrine		4.4	MMSE-progression	Direct medical, direct non-medical	NA
						NA
Henke et al 1997 [70] USA	Tacrine		5.3	Decision tree	Direct medical, direct non-medical	142 096
Wimo et al 1997 [71] Sweden	Tacrine		9	MMSE-progression	Direct medical, direct non-medical	199 021
Fenn et al 1999 [33] United Kingdom	Rivastigmine		2	Survival	Direct medical, direct non-medical	NA
			1			NA
			0.5			NA
			2			NA
			1			NA
			0.5			NA
Hauber et al 2000 [72] USA	Rivastigmine		2	Survival	Direct medical, direct non-medical, informal care	NA
			1			NA
			0.5			NA

Cost per patient, comparator	Cost difference	Cost difference (%) vs comparator	Range in sensitivity analysis ($ or %)	Quality of study	Reviewers' comments
NA	2 856/ year	17.3	121–7 044	1	Informal care not included. Model not fully transparent
NA	5 159/ year	31.2		1	160 mg tacrine completers
153 571	11 475	7.5	746–28 505	1	Informal care costs not included
201 606	2 585	1.3	0.6–5.2%	1	Informal care costs not included
NA	2 163		NA	1	Informal care costs not included. Mild dementia drug cost not included
NA	150				
NA	18				
NA	1 371				Moderate dementia
NA	628				
NA	18				
NA	4 102		NA	2	Drug cost not included
NA	1 039				
NA	154				

***Table 30.9** Models: complete economical evaluations of drug treatment. Costs are expressed as 2003 dollars (PPPs).*

Author Year, reference Country	Drug	Severity of dementia	Model length (years)	Model type	Outcome	Perspective	Cost per treated patient
Stewart et al 1998 [74] United Kingdom	Donepezil	Mild-moderate	5	Markov	Severity	Direct medical, direct non-medical, informal care	80 454 82 254
O'Brien et al 1999 [75] Canada	Donepezil	Mild-moderate	5	Markov	Severity	Direct medical, direct non-medical, informal care	76 768
Jönsson et al 1999 [63] Sweden	Donepezil	Mild-moderate	5	Markov	Severity	Direct medical, direct non-medical costs	80 024 78 735
Neumann et al 1999 [64] USA	Donepezil	Mild-moderate	0.5 1 1.5 2	Markov	QALYs	Direct medical, direct non-medical, informal care	25 572 57 587 83 089 108 675

Cost per patient, comparator	Cost difference	Cost difference vs comparator (%)	C/E or similar comparison	Range in sensitivity analysis	Estimated evidence	Reviewers' comments
77 953 80 499	–2 501 –1 755	–3.2% –2.2%	10 052 6 289	1 661–17 445	2	Mild; 10 mg Moderate; 10 mg
77 613	844	1.1	<0	<0 to 8 254 (all scenarios)	3	5 mg
80 435 80 434	411 1 701	0.5 2.1	<0 <0	<0 to 3 261 (all scenarios)		10 mg. Costs of informal care not included. 5 mg (several options in paper)
24 958 57 026 82 791 108 759	–614 –561 –298 84	–2.5 –1.0 –0.4 0.1	183 400 36 680 10 660 <0	<0 to 481 424 (all scenarios)	3	Mild dementia at start. (Several options in paper)

The table continues on the next page

Table 30.9 *continued*

Author Year, reference Country	Drug	Severity of dementia	Model length (years)	Model type	Outcome	Perspective	Cost per treated patient
Ikeda et al 2002 [76] Japan	Donepezil	Mild-moderate	0.5 2	Markov	QALYs	Direct medical, direct non-medical costs	18 467 16 539
Hauber et al 2000 [77] Canada	Rivastigmine	Mild-moderate	0.5 1 2	Survival	QALYs	Direct medical, direct non-medical costs	NA
Getsios et al 2001 [78] Canada	Galantamine	Mild-moderate	10	AHEAD***	QALYs	Direct medical, direct non-medical costs	66 583 76 462

Cost per patient, comparator	Cost difference	Cost difference vs comparator (%)	C/E or similar*	Range in sensitivity analysis	Estimated evidence	Reviewers' comments
16 789 16 789	–1 678 250	–10 1.5	43 622 <0	<0 to 43 622 (all scenarios)	2	Mild dementia, efficacy 0.5 years but costing 2 years (several options in paper). Costs of informal care not included
NA	–645 –661 413	NA	0.0337** QALYs 0.0346 ** QALYs <0	NA	1	If 20 000 Can$/QALY. Costs of informal care not included. (Several options in paper)
67 316****	733	1.1	<0	<0 to 40 427	1	Mild-moderate. Model not clearly transparent
79 921	3 459	4.3	<0			Moderate

The table continues on the next page

Table 30.9 *continued*

Author Year, reference Country	**Drug**	**Severity of dementia**	**Model length (years)**	**Model type**	**Outcome**	**Perspective**	**Cost per treated patient**
Caro et al 2002 [79] The Netherlands	Galantamine	Mild-moderate	10.5	AHEAD	QALYs	Direct medical, direct non-medical costs	73 151
Garfield et al 2002 [80] Sweden	Galantamine	Mild-moderate	10.5	AHEAD	NNT*****	Direct medical, direct non-medical costs	NA
Migliaccio-Walle et al 2003 [81] USA	Galantamine	Mildmoderate	10	AHEAD	NNT*****	Direct medical, direct non-medical costs	67 366
Ward et al 2003 [82] United Kingdom	Galantamine	Mild-moderate	10	AHEAD	QALYs	Direct medical, direct non-medical costs	45 818
Jones et al 2004 [83] United Kingdom	Memantine	Moderate-severe	2	Markov model	QALYs, dependency, years in community	Direct medical, direct non-medical costs	94 925

Cost per patient, comparator	Cost difference	Cost difference vs comparator (%)	C/E or similar*	Range in sensitivity analysis	Estimated evidence	Reviewers' comments
74 905	1 754	2.3	<0	–3 110 to 5 099	1	Mild-moderate. Model not clearly transparent. Costs of informal care not included
NA	3 096	NA	<0	NA	1	Costs of informal care not included. No sensitivity analysis. Costs of informal care not included
71 212	3 846	5.4	<0	<0 to 14 296	1	Galantamine 24 mg. Model not clearly transparent. Costs of informal care not included
45 047	–771	–1.7	13 920	9 303–27 910	1	Galantamine 16 mg. Model not clearly transparent
98 004	3 079	3.1	<0	<0 to 231 372/QALY	2	Costs of informal care not included. Few cases in key source (laser study)

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__Table 30.9__ continued

Author Year, reference Country	Drug	Severity of dementia	Model length (years)	Model type	Outcome	Perspective	Cost per treated patient
François et al 2004 [84] Finland	Memantine	Moderate-severe	5	Markov model	Dependency, years in community	Direct medical, direct non-medical costs, informal care	87 115

* A positive value indicates a cost per gained QALY/avoided deterioration in severity;
<0 indicates cost savings and a positive outcome.
** Treshold analysis: how many gained QALYs are needed to obtain cost-effectiveness.
*** The AHEAD model includes Markov modelling.
**** In the original paper there was an error in this figure, but a contact with the authors gave the correct figure.
***** NNT = number needed to treat to avoid 1 year of full time care (FTC).

Cost per patient, comparator	Cost difference	Cost difference vs comparator (%)	C/E or similar*	Range in sensitivity analysis	Estimated evidence	Reviewers' comments
88 797	1 682	1.9	<0	<0 (+ Monte Carlo simulation: <0 in 94%)	1	Costs of paid informal care included. Key study with few cases. Effects not discounted

Table 30.10 *Expert reviews on drug interventions on dementia (x = studies included in systematic review).*

Author, year, reference, country	**CCOHTA [12]**	**McGill [13]**	**NHS [86]**	**NICE [87]**
O'Brien et al, 1999 [75] Canada	X	X	X	X
Fenn et al, 1999 [33] United Kingdom	X	X	X	X
Fillit et al, 1999 [106] USA	X	X		X
Hauber et al, 2000 [72] USA	X	X	X	X
Hauber et al, 2000 [77] Canada	X			X
Jönsson et al, 1999 [63] Sweden	X	X	X	X
Lanctot et al, 1998 [107] Canada	X	X		X
Neumann et al, 1999 [64] USA	X		X	X
Small et al, 1998 [108] USA	X	X		X
Stein, 1997 [6] United Kingdom			X	X
Stewart et al, 1998 [74] United Kingdom				X
Ikeda et al, 2002 [76] Japan				X
Getsios et al, 2001 [78] Canada				X
Caro et al, 2002 [79] the Netherlands				X
Garfield et al, 2002 [80] Sweden				X
Migliaccio-Walle et al, 2003 [81] USA				X
Ward et al, 2003 [82] United Kingdom				X
Jones et al, 2004 [83] United Kingdom				X

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***Table 30.10** continued*

Author year, reference, country	CCOHTA [12]	McGill [13]	NHS [86]	NICE [87]
François et al, 2004 [84] Finland				X
Wimo et al, 2003 [60] Europe				X
Wimo et al, 2003 [61] USA				X
Courtney et al (AD2000), 2004 [62] United Kingdom				X
Feldman et al, 2004 [65] Canada, France, Australia				X

Table 30.11 *Excluded papers (diagnostics, treatment interventions)*.*

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Aita, 1990 [109]	4		
Aronson et al, 1984 [110]	2		
Bachynsky et al, 2000 [111]	10**		
Beck et al, 2000 [112]	4		
Beecham et al, 1993 [113]	4	2	
Challis et al, 1991 [114]	2		
Chaussalet et al, 1998 [115]	3		
Chiu et al, 2001 [116]	4		
Donaldson et al, 1989 [117]	1	2	
Donaldson et al, 1991 [118]	2		
Fillit et al, 1999 [106]	4		
Fillit et al, 2002 [119]	4		
Frank et al, 1982 [120]	2	3	4
Gaugler et al, 2003 [121]	3	5	
Hill et al, 2002 [122]	4		
Hurley et al, 1993 [123]	1	2	
Kaufman et al, 1992 [124]	2		
Knapp et al, 1994 [125]	2	4	5

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***Table 30.11** continued*

Author year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Knopman, 1995 [2]	2	3	
Lanctot et al, 1998 [107]	2		
Marin et al, 2003 [126]	1	4	
Melzer, 1990 [127]	2	4	
Mintzer et al, 1997 [128]	4		
Payne et al, 2003 [129]	4		
Siegler et al, 1991 [130]	4		
Small et al, 1998 [108]	4		
Snell, 1985 [131]	2		
Taylor et al, 2003 [132]	2		
Tousignant et al, 2003 [133]	2		
van Crevel et al, 1999 [134]	4		
Vlietinck et al, 1993 [135]	3	6	
Volicer et al, 1994 [136]	4		
Volicer et al, 2004 [137]	4		
Weissert et al, 1980 [138]	2		
Wimo et al, 1991 [139]	4		
Wimo et al, 1998 [140]	10**		

* Furthermore, 31 papers were excluded due to exclusion class 0 (not relevant for the question of interest) and 62 due to exclusion class 9 (no original data presented), a total of 93 papers excluded due to these reasons.
** Propentofyllin never entered the market.

***Appendix 30.1** Search results.*

Database	Search term 1	Search term 2	Results
PubMed	Dementia	Economics	1 116
		Cost (s)/Cost Analysis	684
		Cost-benefit analysis (Cost-effectiveness not a MeSH term)	134
	Alzheimer('s) (Disease)	Economics	637
		Cost (s)/Cost Analysis	429
		Cost-benefit analysis (Cost-effectiveness not a MeSH term)	81
PsycInfo	Dementia	Economics	15
		Cost (s)	132
		Cost-effectiveness	19
	Alzheimer's) (Disease)	Economics	6
		Cost (s)	30
		Cost-effectiveness	7
CRD: NHSEED/ HTA	Dementia	Economics	12
		Cost (s)	108
		Cost-effectiveness	12
	Alzheimer('s) (Disease)	Economics	13
		Cost (s)	12
		Cost-effectiveness	38
Sociological abstracts/ Social services abstract/ERIC	Dementia	Economics	9
		Cost (s)	39
		Cost-effectiveness	2
	Alzheimer('s) (Disease)	Economics	8
		Cost (s)	42
		Cost-effectiveness	1
Ingenta	Dementia	Economics	9
		Cost (s)	60
		Cost-effectiveness	12
	Alzheimer('s) (Disease)	Economics	4
		Cost (s)	60
		Cost-effectiveness	15

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***Appendix 30.1** continued*

Database	Search term 1	Search term 2	Results
Cochrane	Dementia	Economics	13
		Cost (s)	108
		Cost-effectiveness	81
	Alzheimer('s)	Economics	4
	(Disease)	Cost (s)	39
		Cost-effectiveness	28
HEED	Dementia Alzheimer	–	215

The exclusion list

0 = Outside the research question of interest. This is no quality assessment involved. The exclusion may be due to insufficient coding in databases or an inadequate search strategy
1 = Insufficient number of subjects/low power
2 = Inadequate description or selection of subjects or abstracts
3 = Inadequate methods or instruments to measure outcomes, effects or consequences
4 = Inadequate design
5 = Inadequate data collection, high attrition, high dropout rate, high drop-in rate
6 = Inadequate statistical methods or calculations
7 = Inadequate ethical standards
8 = Serious conflict of interest
9 = No original data (such as reviews)
10 = Miscellaneous

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31. Resource Utilization

Questions of interest

- What are the effects of pharmacological treatment on resource utilization in dementia?
- What are the effects of intervention at an individual level (such as reality orientation and reminiscence therapy) on resource use?
- What are the effects of interventions at a societal level (institutionalization and informal care) on resource use?

Conclusions

There is no scientific evidence that pharmacological treatment or/and programs have any effect on institutionalization, professional home care services or the amount of informal care that is provided.

Background

Institutionalization, professional home care and informal care

Resource utilization is a broad concept that can vary a great deal over time and among different countries. The aim of many studies that analyze resource utilization is to calculate costs. In that sense, resource utilization may be regarded as an input. Nevertheless, some types of resource utilization are of interest to analyze per se, given that they may be clinically relevant outcomes for patients and/or next of kin. From that point of view, analyzing the effects of interventions or treatments on specific resources regarded as relevant and measurable may be of interest. This section focuses on institutionalization, home care services and the impact on the amount of informal care provided. Although these three outcomes are distinct, they interact in a complex manner when various interventions are performed.

Institution is also a broad concept covering both large settings with a lot of residents, staff and equipment small homelike living units with 5–6 residents. Many articles use the concept in a confusing manner. Swedish alone has as many as 20 terms for different kinds of sheltered living – nursing homes, group homes, homes for the elderly, assisted living facilities, etc.

There are three sources of such confusion: linguistic (the number of different terms), administrative (who is running the facility – is it a type of habitation or care?) and resource-oriented (size and competence of the staff, physical environment, medical technology resources, caregiving philosophy, etc). However, certain common features can be identified: several residents live together, the staff is paid and there is a specifically defined building. One distinction may be between an "institution" with a 24-hour staff and "sheltered housing" with a part-time staff.

Assuming an unchanged period of survival, postponing institutionalization enables a patient to stay at home longer. That is in line with the principle of "aging in place" [1]. An extended period at home increases the time that informal caregivers can be involved. Whether the caregivers benefit or not is a complex issue [2].

Home care services are defined as non-medical and medical services provided by professional and employed staff in the patient's home (or any other ordinary living situation, ie, not in institutions or hospitals). That broad definition includes many different kinds of staff and professions with various designations (RN, home aide, orderly, LPN, NA, etc). Different kinds of volunteer services are not included. However, it is far from obvious that the use of home care services should involve fewer hours, etc. There may be unmet needs that produce the opposite result. Thus it is important to look at the research question in studies that analyze the amount of home care service provided.

Dementia patients receive extensive informal care [3–5]. Despite the impact of informal care on the total social costs of dementia, the amount provided may also be regarded as a marker of caregiver burden. However, the quantity of time spent may be a rather imprecise measure of how caregivers are affected. The issues of coping, stress, depression and morbidity are also important topics for both quantitative and qualitative research. Another section of this report focuses on such considerations. The quantification of caregiver time is complex, and transparency is crucial. The methods (diaries, observation, interview, time frame, etc) employed to arrive at such estimates must be clearly presented. PADL and IADL (see list of abbreviations) are part of most time calculations, but supervision and surveillance are more difficult to include [4].

Search strategy

The strategy for searching the literature was based on the questions of interest (see above).

The search of published studies written in English examined the PubMed, Ingenta, Cochrane Library, NHSEED/HTA, HEED, PsycInfo, ERIC, Societal services abstracts and Sociological abstracts. The search terms (MeSH/Subheadings) were dementia/Alzheimer's disease/Alzheimer disease/Alzheimer's combined with utilization, institutionalization, nursing home, nursing home placement, home nursing, informal care and caregiver time. Economic studies that contained data on resource utilization but that had not been identified by means of the above search strategy were also included. The search period was from 1960 (give or take a few years, depending on the database) to July 31, 2004.

The first round found 5 293 hits in the various databases. A second, narrower round identified 2 466. The second round did not exclude duplicates – the search that came up with the most hits (382) was on dementia and utilization in Pubmed. For the search terms and results, see Appendix 31.1. Of the 90 studies that were assessed for quality, 22 were ultimately included (13 on programs and 9 on drug interventions). Table 31.3 lists the articles that were excluded.

A systematic review of informal care in drug trials was performed after the search period, and the results were also included [6].

Results

What are the effects of pharmacological treatment on resource utilization in dementia care?

Background

There were 3 cholinesterase inhibitors (CHEI) (donepezil, rivastigmine, galantamine) on the market in February 2004 and 1 NMDA antagonist (memantine) that had been approved for the treatment of AD. Tacrine is no longer on the market. Other medications that may be effective in treating symptoms of dementia that can impact institutionalization, informal care and mortality are SSRI/SNRI drugs, certain neuroleptics, selegiline and vitamin E.

Results (see Table 31.1)

A total of 10 drug studies including the systematic review were identified. Eight studies were found that assessed the impact on institutionalization, one on professional home care and four on informal care. Three studies analyzed two issues and one analyzed all three issues. None of the studies were assigned high quality and one was assigned medium quality. The RCTs had higher quality than the observational studies but were assigned low quality due to other methodological problems. Both observational follow-up studies with similar designs concluded that institutionalization had been postponed, but the short-term RCTs failed to confirm those findings. The amount of informal care was significantly lower in the memantine study [7] and donepezil study [8] that included patients with severe dementia. Three of the studies had high attrition rates (33–40%). The galantamine study was based on pooled data from two RCTs. The AD2000 trial on donepezil reported various kinds of resource utilization in "units" before costing [62]. The systematic review of informal care that employed a meta-analysis indicated a small (standardised mean difference = 0.15) but significant impact on caregiver time and favored CHEIs as a group. However, 2 of the 6 studies included drugs (velnacrine and metrifonate) that are not available on the market, while the other studies were assigned low but acceptable quality.

Evidence Grade

Postponement of institutionalization

- Selegiline and vitamin E: insufficient scientific evidence
- CHEIs (as a group): insufficient scientific evidence
- Memantine: insufficient scientific evidence.

Decrease in amount of professional care

- Selegiline and vitamin E: insufficient scientific evidence (no studies)
- CHEIs (as a group): insufficient scientific evidence
- Memantine: insufficient scientific evidence.

Decrease in amount of informal care

- Selegiline and vitamin E: insufficient scientific evidence (no studies)
- CHEIs (as a group): limited scientific evidence for a small but significant effect, favoring treatment with CHEIs
- Memantine: insufficient scientific evidence.

What are the effects of intervention at an individual level (such as reality orientation and reminiscence therapy) on resource utilization?

Background

The effects of individually focused programs, such as reality orientation [9], validation therapy [10] and reminiscence therapy [11] on the symptoms of dementia (cognition, ADL, BPSD, etc) have not been clearly identified. Whether such programs can influence resource utilization is also under discussion. The impact on institutionalization and informal care may be worthy of study. How institutions are affected, including the amount of time that the professional staff devotes to caregiving, may also be of interest.

Results

No such study has been identified.

Evidence Grade

- Insufficient scientific evidence (no studies).

What are the effects of interventions at a societal level on resource utilization (institutionalization and informal care)?

Background

Dementia care has employed various kinds of social programs and environmental interventions over the past several decades.

The concept of program refers to a number of interventions, such as day care, caregiver support and counseling, long-term and residential care, etc. The wide variety of programs makes it difficult to say anything that holds true for all of them. Furthermore, each one must be seen in the light of its particular social context. The impact on institutionalization and informal care may again be a fruitful area of study. How institutions are affected, including the amount of time that the professional staff devotes to caregiving or the repercussions on acute hospital care, may also be of interest. Following are brief presentations of 5 types of programs: day care, caregiver support, case management, dementia-specific residential accommodations and long-term institutional care/nursing homes.

Day care

Day care is a wide-ranging concept that varies in meaning. Depending on the focus, it can be provided at hospitals or ordinary residences. The size of the staff may also fluctuate. The emphasis of this presentation is on day care for dementia. In this case, the staff normally provides 5–7 hours a day of supervision, kinship and care to patients with dementia in accordance with specific goals. The goals are generally based on a nursing theory of dementia care (such as managing behavioral disturbances, apraxia, agnosia and memory impairment). Consisting of RNs, LPNs, nurse assistants, home aides or special dementia caregivers, the staff is usually trained in dementia care. Most patients come from their own residences, but some are also from assisted living facilities and homes for the elderly. Generally speaking, there are 2–3 staff members for every 7–12 patients. The patients are often required to have undergone diagnostic procedures for dementia.

Caregiver support

As mentioned above, the next of kin play different roles in dementia care. They provide unpaid informal care, while the particular dementia disorder involved directly impacts their personal lives. Given that family members are so important regardless of the perspective chosen, different approaches to supporting them and improving their circumstances have been presented. Most of the programs focus on counseling, education, emotional support and opportunities for contact when needed. From a broader point of view, day care and respite care may be regarded as part of caregiver support programs.

Case management

Case management programs generally assess individual needs while continuously monitoring and reevaluating individual care plans on a regular basis [12].

Dementia-specific residential accommodations

Various kinds of intermediate or semi-institutional care and residential programs for dementia patients have been introduced over the past few decades [13,14]. Among the terms employed have been group living, group homes, group dwellings and collective living. The basic idea is that a 24-hour staff provides care in a homelike environment, where 4–10 people with dementia usually live in a unit. Normally they have their own rooms or small apartments. Facilities for meals and other group activities are also available. Trained in dementia, the staff provides supervision, kinship, and care in accordance with specific goals. The goals are based primarily on a nursing theory of dementia care (such as managing behavioral disturbances, apraxia, agnosia and memory impairment). The staff may consist of RNs, LPNs, NAs, home aides or special dementia caregivers.

Long-term institutional care/nursing homes

As the result of unsuccessful attempts at long-term dementia care in nursing homes, various programs have been launched to improve the situation. Concepts like Special Care Units (SCUs) in the United States [15] and Domus care in the United Kingdom [16] have been employed. A number of other approaches, often based on nursing theory, have also been tried. Such programs frequently include individual care planning and diagnosis, as well as staff training and support.

Results

Fourteen studies were identified that had analyzed the impact on institutionalization (Table 31.2). Three studies looked at the impact on home services and two on caregiver time. Ten studies were RCTs and four were quasi-experimental. Seven studies were of low but acceptable quality, and seven were of medium quality. The studies had been conducted in the United States (7), Canada (1), Europe (5) and Australia (1). Two programs focused on day care, nine on caregiver support, four on case management and one on respite care. However, this classification includes overlapping. The general problem in most studies is lack of statistical power. For practical reasons, implementing complex social programs with large study groups is difficult. Intervention effects may be underestimated. Three studies (two with moderate quality and one with low quality) provided support for postponing institutionalization with CGS, while four (three with low and one with moderate quality) did not. The day care studies had divergent results. The large US study by Newcomer et al focused on the unfulfilled needs of dementia patients and concluded that an increase in home services etc, was a positive result [17].

Evidence Grade

Postponement of institutionalization

- Day care: insufficient scientific evidence
- Caregiver support: insufficient scientific evidence due to conflicting results
- Case management: insufficient scientific evidence.

Impact on the amount of home service

- Day care: insufficient scientific evidence
- Caregiver support: insufficient scientific evidence due to conflicting results
- Case management: insufficient scientific evidence.

Decrease in the amount of informal care

- Day care: insufficient scientific evidence
- Caregiver support: insufficient scientific evidence (not studied)
- Case management: insufficient scientific evidence.

Discussion

The scientific evidence provides no support for the assertion that pharmacological treatments or program interventions reduce resource utilization in dementia care as defined in this report. While studies on patients with severe dementia found a significant reduction in caregiver time, no conclusion in terms of a specific drug can be drawn. As mentioned in the introduction, the choice of institutionalization, home care services and amount of informal care as outcomes is far from undisputed.

Most studies have been conducted in a handful of Western countries (the United States, Canada, Australia and parts of Europe). Concepts such as institution and informal care are highly correlated with the way that care is organized and the cultural context in general. If a country has no or very few nursing homes, postponing that kind of care becomes a moot question. A particular country may regard informal care as a natural part of family life, so that quantifying and describing it in terms of burden etc, may be irrelevant. Support in terms of PADL may be useful from a global perspective, while IADL and supervision can be more difficult to quantify.

Most drug trials are well-designed, based on established principles of efficacy, safety and ethics. Their internal validity is generally high. Discussions about drug trials focus mostly on external validity (generalizability, inclusion and exclusion criteria) and the presentation of results (such as principles of ITT analysis). Pharmacological trials emphasize efficacy outcomes that are important for approval and sometimes reimbursement issues (including cognition and global judgments such as CIBIC). Because these criteria do not include resource utilization, it has been the subject of only a limited number of studies. However, given that the authorities responsible for reimbursement are interested in cost-effectiveness information, not only from economic models, but from clinical trials with empirical data, the number of such studies is likely to increase.

Mainly due to methodological issues, programs in the broadest sense of the term face many more problems than pharmacological interventions. For practical reasons, it is difficult to include enough patients (leading to low statistical power), the intervention under study may be contaminated by others, drop-ins and dropouts are frequent, the intervention may be difficult to operationalize and demonstrating the extent to which the program has actually been carried out may not be easy. Blindness is difficult to maintain (single-blinded studies are the most that can be hoped for) and randomization is not always possible. Thus, even if a program offers certain advantages, it may have trouble meeting the evidence criteria.

Recommendations for future research

The database on programs is limited and RCTs are badly needed.

There is a need for studies with combined approaches (such as drugs and programs), as well as those that compare different drugs and/or programs.

Most studies have been conducted in few countries (United States, parts of Western Europe, Canada, Japan and Australia). There is a great need for studies from other areas of the world.

Table 31.1 *Studies focusing on effects of pharmacological treatment on resource use in dementia.*

Author Year, reference Country	Type of study	Setting	Dementia/ diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Mean/Range (SD)
Knopman et al 1996 [18] USA	Observational study	Community	Alzheimer's disease (NINCDS)	Mild-moderate	663 (10%)	71.5–73.9 (7.5–8.2)
Sano et al 1997 [19] USA	RCT	Community	Alzheimer's disease (CDR)	Moderate	341 (7%)	72.7–73.9 (7.1–8.9)
Lopez et al 2002 [20] USA	Observational	Community	Clinical	Mild-moderate (?)	135+135	72.7 (7.2) 72.8 (8.4)
Wimo et al 2003 [21] Europe	RCT	Community (93%)	Alzheimer's disease (NINCDS, DSM-IV)	Mild-moderate	142+144 (33%, 33%)	72.1–72.9 (8.0–8.6)
Wimo et al 2003 [22] USA	RCT	Community	Alzheimer's disease (NINCDS, DSM-IV)	Moderate-severe	126+126 (29%, 40%)	58%, 60% 75+
Geldmacher et al 2003 [23] USA	Observational study	Community	Alzheimer's disease (NINCDS, DSM-IV)	Mild-moderate	1 115 (40%)	73.3

Study period	Intervention (end)	Primary outcome*	Effects (end)	Remarks from reviewer	Quality of study
≥2 years	Tacrine high dose vs low dose	Institutionalization (NHP=nursing home placement)	High dose lower risk for NHP vs low dose	Initial RCT not maintained	1
2 years	Selegeline (S), Vitamin E, S + E	Institutionalization	S, E and S + E lower risk for NHP vs placebo. No additative effect of S + E	Significant effects only after baseline adjustments. Vitamin E dose high. No effects on cognition	2
3 years (average)	CHEIs	Institutionalization	CHEI-treatment postpones institutionalization (RR 0,63 (error in original paper, 95% CI 0.57–0.70))	Not a RCT, diagnose accurancy not clear	1
1 year	Donepezil	Institutionalization, informal care	Institutionalization: NS, informal care NS	High attrition. An error in caregiver time calculations corrected	1
6 months	Memantine	Institutionalization, home care services, informal care	Institutionalization: NS (p=0.052), home services NS, informal care (p=0.02)	High attrition, short duration	1
Maximum 96 months	Donepezil	Institutionalization	Median time to NHP favouring maximum use vs minimum use (21 months delay)	High attrition, initial RCT not maintained, pooled data from several studies	1

The table continues on the next page

Table 31.1 continued

Author Year, reference Country	Type of study	Setting	Dementia/ diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Mean/Range (SD)
Sano et al 2003 [24] USA	RCTs (pooled)	Community	Alzheimer's disease (NINCDS)	Mild-moderate	432+428** (5%, 3%)	73.8 (8.3) 73.9 (8.2)
Feldman et al 2003 [8] Canada	RCT	Community/ assisted living	Alzheimer's disease (NINCDS)	Moderate-severe	144+146 (16%, 14%)	73.3, 74.0
Courtney et al (AD 2000) 2004 [25] United Kingdom	RCT	Community	DSM-IV – AD	Mild-moderate	282 (32% withdrawn) 283 (31% withdrawn)	76 (54–93) 75 (46–90)
Lingler et al 2005 [26a] USA	Systematic review of RCTs				2 286 in total	

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* From the perspective of this analysis, these outcomes may be secondary in original trials.

** Randomized in original trials [26b,27]

*** Significane tests for costs, see this section

Study period	Intervention (end)	Primary outcome*	Effects (end)	Remarks from reviewer	Quality of study
6 months	Galantamine	Caregiver time	Various outcomes indicating less caregiver time favouring galan-tamine	Pooled data (RCTs). Problems to compare end-point time with baseline. Time categorization values crucial	1
6 months	Donepezil	Caregiver time	Significantly less caregiver time in donepezil group (52.4 min/day) vs placebo	RCT. Short duration. Validity of time assessments unclear	1
60 weeks	Donepezil	Institutionalization, home services, caregiver time	NS (?) Reported as units with no significance tests***. Informal care reported as not significant (difference 0.6 hours/day)	High attrition, unusual inclusion criteria	1
	Donepezil, velnacrine, metrifonate, galantamine, memantine	Caregiver time	Class effect: small but significant favouring choline esterase inhibitors vs placebo	Two of the drugs, venlacrine and metrifonate are not on the market	

***Table 31.2** Studies focusing on effects of interventions on a societal level on resource use ("programs").*

Author Year, reference Country	**Type of study**	**Setting**	**Dementia/ diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups (patients) Mean (range or SD)**
Engedal 1989 [28] Norway	RCT	Community, Norway	DSM-III	–	38+39 (0%)	79 (75–88) 80 (75–89)
Lawton et al, 1989 [29] USA	RCT	Community, USA	Clinical AD? MSQ***	?	315+317	76.7 76.1
Mohide et al 1990 [30] Canada	RCT	Community, Canada	Clinical, DRS****, GDS	87.90% moderate, moderate-severe	30+30 (0% for institution follow-up)	77.8 (9.2) 75.9 (7.7)
Brodaty et al 1991 [31] Australia	Quasi-experimental	Community, Australia	DSM-III, CDR	Mild-moderate	100 (4%)	70.2 (49–79)
O'Connor et al 1991 [32] United Kingdom	Quasi-experimental	Community, United Kingdom	MMSE, Camdex	Mild-moderate-severe	86+73 (44%, 42%)	83.7 83.7
Weinberger et al 1993 [33] USA	RCT	Community, USA	Clinical (neurologist)	?	193+71 (15%, 13%)	69.7 (9.1) 70.4 (7.4)
Mittelman et al 1996 [36] USA	RCT	Community, USA	Clinical AD, GDS	Mild-moderate-severe	103+103 (0.5%)	(Age class proportions)

Study period (years)	Intervention (end)	Primary outcome*	Effects (end)	Remarks from reviewer	Quality of study
1	Day care	Institutionalization	NS	Low power	1
1	Respite care	Institutionalization	Program patients 22 days longer in community, but habitation after 1 year not significant	Patient description limited	2
0.5	CGS	Institutionalization	NS	Low power	1
4	CGS, memory training (MT), waiting list (WL)	Institutionalization	CGS not significant vs WL, p = 0.001 vs MT**, mean time in nursing home similar	Non-randomized, low power, difference in mortality in groups	1
2	CGS/Social support	Institutionalization	NS**, but subgroup in action group (moderate-severely demented living alone) more institutionalized (p=0.004)	Rather low power, non-randomized, 69% in the action group received the intervention	1
0.5	CGS/Social support	Institutionalization, home services	NS	Patient description limited	2
3.5	CGS/Social support	Institutionalization	329 days longer at home in CGS group (95% CI 47–611)	Rather low power	2

The table continues on the next page

Table 31.2 continued

Author Year, reference Country	Type of study	Setting	Dementia/ diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups (patients) Mean (range or SD)
Wimo et al 1994 [35] Sweden	Quasi-experimental	Community, Sweden	Clinical (geriatrician)	Moderate	55+45 (0%)	78 (76–80) 79 (77–81)
Mittelman et al 1996 [36] USA	RCT	Community, USA	Clinical AD, GDS	Mild-moderate-severe	103+103 (0.5%)	(Age class proportions)
Newcomer et al 1999 [17] USA	RCT	Community, USA	Register	Moderate?	2 682 (8.4%) + 2 527 (8.7%)	78.5 (8) 78.7 (8)
Eloniemi-Sulkava et al 2001 [37] Finland	RCT	Community, Finland	DSM-III-R, MMSE	Mild-moderate-severe	53+47 (0%)	78.8 (65–97) 80.1 (67–91)
Challis et al 2002 [38] United Kingdom	Quasi-experimental	Community, United Kingdom	OBS score	70% severe	43+43 (0%)	79.8–80.4

Study period (years)	Intervention (end)	Primary outcome*	Effects (end)	Remarks from reviewer	Quality of study
1	Day care	Institutionalization, home services, informal care (reimbursed)	56 days lower NHP/year in DC group ($p<0.05$). Home aides and reimbursed informal care: NS	Non-randomized, low power	1
3.5	CGS/Social support	Institutionalization	329 days longer at home in CGS group (95% CI 47–611)	Rather low power	2
1	Case management, CGS	Home services, institutionalization	Purpose to affect unmet needs. Home services increased significantly in treatment group. Institutionalization NS	Results influenced by US system	2
2	CGS	Institutionalization	NS after 2 years. Institutionalization postponed in intervention groups during the first months ($p=0.04$)	Rather low power. Selection of study patients before randomization not population based	2
2	Case management	Institutionalization Informal care	Institutionalization NS ($p=0.08$)**. Informal care: significantly lower ($p<0.05$) in intervention group	Low power	1

The table continues on the next page

Table 31.2 continued

Author Year, reference Country	**Type of study**	**Setting**	**Dementia/ diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups (patients) Mean (range or SD)**
Teri 2003 [39] USA	RCT	Community, USA	Alzheimer's disease (NINCDS)	Moderate-severe	76+77 (41%, 43%)	78 (6) 78 (8)
Bass et al 2003 [40] USA	RCT	Community, USA	Diagnosis of dementia or "memory loss" in register	?	182 in total (14%)	55 or older

* From the perspective of this analysis, these outcomes may be secondary in original trials.
** Chi^2 test own calculations.
*** Mental State Questionnaire.
**** Dementia Rating Scale.

AD = Alzheimer's disease; BPSD = Behavioral and psychological symptoms in dementia; CGS = Caregiver support; CI = Confidence interval; MMSE = Mini-mental state examination; NHP = Nursing home placement; NINCDS = National institute of neurological and communicative disorders; NS = Not significant; RCT = Randomized controlled trial

Study period (years)	Intervention (end)	Primary outcome*	Effects (end)	Remarks from reviewer	Quality of study
2	Case management/BPSD + training	Institutionalization	NS	Rather low power	2
1	CGS/case management	Outpatient physician visits, emergency room visits, hospital days	NS	Diagnostics unclear, study population scantily described	1

Table 31.3 *Excluded papers*.*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Beusterien et al, 2004 [41]	4		
Dellasega et al, 1996 [42]	2		
Donaldson et al, 1989 [43]	1	2	
Droes et al, 2004 [44]	1	4	
Gaugler et al, 2003 [45]	5		
Gaugler et al, 2003 [46]	5		
Knapp et al, 1994 [47]	2	4	5
Maas et al, 1998 [48]	1		
Marin et al, 2003 [49]	1	4	
Metitieri et al, 2001 [50]	4		
Small et al, 1998 [51]	4		
Vernooij-Dassen et al, 1995 [52]	2		
Wallin et al, 2004 [53]	1	4	
Wimo et al, 1991 [13]	1	1	
Wimo et al , 1993 [54]	4		
Wimo et al, 1995 [55]	1		

* Furthermore, 28 papers were excluded due to exclusion class 0 (not relevant for the question of interest) and 24 due to exclusion class 9 (no original data presented), a total of 52 papers excluded due to these reasons.

Appendix 31.1 *Search strategy.*

Database	Search term 1	Search term 2	Search term 3	Results
PubMed	Dementia (MeSH term)	Utilization		382
	Dementia (MeSH term)	Utilization	Controlled clinical trial (publication type)	3
	Dementia (MeSH term)	Institutionalization		393
	Dementia (MeSH term)	Institutionalization	Controlled clinical trial (publication type)	2
	Dementia (MeSH term)	Nursing home		1 498 (only titles reviewed)
	Dementia (MeSH term)	Nursing home	Controlled clinical trial (publication type)	16
	Dementia (MeSH term)	Home nursing		782 (only titles reviewed)
	Dementia (MeSH term)	Home nursing	Controlled clinical trial (publication type)	6
	Dementia (MeSH term)	Caregiver time		23
	Alzheimer Disease (MeSH term)	Utilization		141
	Alzheimer Disease (MeSH term)	Utilization	Controlled clinical trial (publication type)	2

The table continues on the next page

Appendix 31.1 continued

Database	Search term 1	Search term 2	Search term 3	Results
	Alzheimer Disease (MeSH term)	Institutionalization		146
	Alzheimer Disease (MeSH term)	Institutionalization	Controlled clinical trial (publication type)	0
	Alzheimer Disease (MeSH term)	Nursing home		547 (only titles reviewed)
	Alzheimer Disease (MeSH term)	Nursing home	Controlled clinical trial (publication type)	4
	Alzheimer Disease (MeSH term)	Home nursing	Controlled clinical trial (publication type)	4
	Alzheimer Disease (MeSH term)	Caregiver time		20
PsycInfo	Dementia	Utilization		145
	Dementia	Utilization	Controlled clinical trial	0
	Dementia	Utilization	Intervention	5
	Dementia	Resource use		70
	Dementia	Resource use	Intervention	6
	Dementia	Institutionalization		240
	Dementia	Institutionalization	Intervention	22

The table continues on the next page

Appendix 31.1 continued

Database	Search term 1	Search term 2	Search term 3	Results
	Dementia	Nursing home	Intervention	74
	Dementia	Informal care		24
	Dementia	Caregiver time		5
	Alzheimer('s) (Disease)	Utilization		30
	Alzheimer('s) (Disease)	Utilization	Intervention	0
	Alzheimer('s) (Disease)	Resource use		10
	Alzheimer('s) (Disease)	Resource use	Intervention	0
	Alzheimer('s) (Disease)	Institutionalization		30
	Alzheimer('s) (Disease)	Nursing home		54
	Alzheimer('s) (Disease)	Informal care		2
	Alzheimer('s) (Disease)	Caregiver time		4
CRD: NHSEED/ HTA	Dementia	Utilization		3
	Dementia	Institutionalization		3
	Dementia	Nursing home		17
	Dementia	Informal care		5

The table continues on the next page

Appendix 31.1 continued

Database	Search term 1	Search term 2	Search term 3	Results
	Alzheimer('s) (Disease)	Utilization		3
	Alzheimer('s) (Disease)	Institutionalization		9
	Alzheimer('s) (Disease)	Nursing home		26
	Alzheimer('s) (Disease)	Informal care		12
Sociological abstracts/ Social services abstract/ERIC	Dementia	Utilization		63
	Dementia	Institutionalization		37
	Dementia	Nursing home		77
	Dementia	Informal care		17
	Dementia	Home care		43
	Dementia	Caregiver time		1
	Alzheimer('s) (Disease)	Utilization		51
	Alzheimer('s) (Disease)	Institutionalization		31
	Alzheimer('s) (Disease)	Nursing home		64
	Alzheimer('s) (Disease)	Informal care		10

The table continues on the next page

Appendix 31.1 continued

Database	**Search term 1**	**Search term 2**	**Search term 3**	**Results**
	Alzheimer('s) (Disease)	Home care		33
	Alzheimer('s) (Disease)	Caregiver time		0
Ingenta	Dementia	Utilization		59
	Dementia	Institutionalization		44
	Dementia	Nursing home		180
	Dementia	Nursing home placement		20
	Dementia	Home care		43
	Dementia	Informal care		45
	Dementia	Caregiver time		5
	Alzheimer('s) (Disease)	Utilization		53
	Alzheimer('s) (Disease)	Institutionalization		26
	Alzheimer('s) (Disease)	Nursing home		51
	Alzheimer('s) (Disease)	Nursing home placement		10
	Alzheimer('s) (Disease)	Home care		10
	Alzheimer('s) (Disease)	Informal care		5

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Appendix 31.1 *continued*

Database	Search term 1	Search term 2	Search term 3	Results
	Alzheimer('s) (Disease)	Caregiver time		2
Cochrane	Dementia	Utilization		2
	Dementia	Institutionalization		8
	Dementia	Nursing home		11
	Dementia	Nursing home placement		3
	Dementia	Home care		4
	Dementia	Informal care		1
	Dementia	Caregiver time		12
	Alzheimer('s) (Disease)	Utilization		2
	Alzheimer('s) (Disease)	Institutionalization		11
	Alzheimer('s) (Disease)	Nursing home		14
	Alzheimer('s) (Disease)	Nursing home placement		5
	Alzheimer('s) (Disease)	Home care		5
	Alzheimer('s) (Disease)	Informal care		1
	Alzheimer('s) (Disease)	Caregiver time		13

The exclusion list

0 = Outside the research question of interest. This is no quality assessment involved. The exclusion may be due to insufficient coding in databases or an inadequate search strategy
1 = Insufficient number of subjects/low power
2 = Inadequate description or selection of subjects or abstracts
3 = Inadequate methods or instruments to measure outcomes, effects or consequences
4 = Inadequate design
5 = Inadequate data collection, high attrition, high dropout rate, high drop-in rate
6 = Inadequate statistical methods or calculations
7 = Inadequate ethical standards
8 = Serious conflict of interest
9 = No original data (such as reviews)
10 = Miscellaneous

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32. Situation of Caregivers – Economic Aspects

Background

Economic analysis of dementia care is focused mostly on patients. The situation of caregivers among family members is often looked at in terms of stress, burden, coping, morbidity etc. However, a more comprehensive view would broaden the perspective to include the impact on caregivers of resource utilization, costs and cost-effectiveness.

Resource utilization

The utilization of caregiver resources was the focus of a PubMed search on the terms "Utilization" [MeSH] AND "Dementia" [MeSH] AND "Caregivers" [MeSH]. Seven of the 102 abstracts reviewed were selected for a complete reading, and 4 were ultimately included. The main reasons for exclusion were that no intervention had been identified or that the results of the intervention had not been presented in terms of the utilization of caregiver resources.

The 2 articles on programs showed no differences with respect to the use of medical services by caregivers (Table 32.1). However, the use of human services increased in the treatment group of one study [1].

For the 2 drug trials, 1 on memantine [2] and 1 on donepezil [3] (Table 32.2), the utilization of caregivers resources was low, and no differences between the treatment arms were identified.

In summary, no conclusions regarding evidence can be drawn from the included studies.

Costs

In a broad PubMed search 402 studies were identified (the search terms were "Economics" [MeSH] AND "Dementia" [MeSH] AND "Caregivers" [MeSH]. Each abstract was reviewed. Ten studies were selected for a complete reading. An additional 7 studies from other search rounds were also included. The major reasons for not including articles were that no interventions had been identified (ie, they were descriptive studies) and/or they did not include any cost or outcome calculations. Four studies were ultimately included – 3 on drug treatment and 1 on programs. All of these studies have been included in other parts of this project. The initial focus in this case was to examine caregiver costs and cost-effectiveness (Table 32.3). However, only the study by Drummond et al had a caregiver-related primary outcome [4]. Furthermore, given that the costs were based on both patients and caregivers, cost-effectiveness ratios were not deemed relevant here. Thus, only specific caregiver-related costs are presented. The quality of the studies was regarded as the same as for the other parts of the project that included them.

Empirical economic evaluations of programs

Only one study was identified that had at least low but acceptable quality [4] (Table 32.3). This randomized study was well-designed, but the number of participants was low and the attrition rate high. It is possible to extract caregiver-related costs, but no significance tests were presented. The high costs in the treatment group were due to the intervention itself (caregiver support). No conclusions regarding evidence can be drawn from one study only.

Empirical economic evaluations of drug treatment

Three studies were identified, all of which had low but acceptable quality (Table 32.4). Two of them focused on donepezil [3,5] and 1 on memantine [2]. Caregiver-related costs represented a small percentage of the total, which included patient-related and informal care costs. However, no conclusions regarding evidence can be drawn.

Conclusions

The number of economic studies with a caregiver perspective is limited. No conclusions can be drawn regarding resource utilization, costs or cost-effectiveness from a caregiver perspective.

__Table 32.1__ Studies focusing on effects of interventions ("programs") on resource use with a caregiver perspective.

Author Year Reference Country	Type of study	Setting	Dementia/ Diagnosis	Severity of dementia	Number (n) included (attrition)	Age-groups Mean (Range or SD)
McCallion et al 2004 [1] USA	RCT	Community, USA	? (origin: register)	Mild-moderate-severe	608 of 785 screened (attrition 23%), 203 of 608 randomized	Caregivers (all): 60.6 (13.3)
Weinberger 1993 [6] USA	RCT	Community, USA	Clinical (neurologist)	?	Patients: 193+71 (15%, 13%)	Patients: 69.7 (9.1), 70.4 (7.4)

* From the perspective of this analysis, these outcomes may be secondary in original trials.
** Examples: home maker, legal, church or similar, library, transportation, in-home respite, adult day care, meals on wheels, family counceling, Alzheimer's association, support group.
*** Examples: in/out patient health, home health aide, visiting nurse, emergency response system, in/out mental health care, nursing home.

CGS = Caregiver support; NS = Not significant; RCT = Randomized controlled trial

Study period	Intervention (end)	Outcome*	Effects (p-values)	Quality of study	Remarks from reviewer
6 weeks	CGS (by Alzheimer association chapter)	Human services**, health services***	Human services: increase in treatment group, NS in health services	1	Short study period, only one third were randomized. Alzheimer Association contacts part of the "human services"
6 months	CGS/Social support	Caregivers' health services (outpatient physician visits, emergency room visits, hospital days)	NS	1	Patient description limited. Short duration

Table 32.2 *Studies focusing on effects of drug interventions on resource use with a caregiver perspective.*

Author **Year** **Reference** **Country**	**Type of study**	**Setting**	**Dementia/ Diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups Mean/Range (SD)**
Wimo et al 2003 [2] USA	RCT	Community	Alzheimer's disease (NINCDS, DSM-IV)	Moderate-severe	126+126 (29%, 40%)	58%, 60% 75+
Feldman et al 2004 [3] Canada	RCT	Community/ assisted living	Alzheimer's disease (NINCDS)	Moderate-severe	144+146 (16%, 14%)	73.3, 74.0

* From the perspective of this analysis, these outcomes may be secondary in original trials.

NS = Not significant; RCT = Randomized controlled trial; TPP = Treated per protocol

Table 32.3 *Empirical economical evaluations of programs with a caregiver perspective. Costs are expressed as 2003 dollars (PPPs).*

Author **Year** **Reference** **Country**	**Type of study**	**Program**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients included, attrition (active treatment(s) first, placebo)**	**Mean/ Range (SD), treatment(s)/ placebo**
Drummond et al 1991 [4] Canada	CUA RCT	CGS	Community	Clinical, DRS, GDS	87.90% moderate, moderate-severe	30+30 (27% + 33%)	77.8 (9.2), 75.9 (7.7)

CGS = Care giver support; CUA = Cost utility analysis; DRS = Dementia rating scale; GDS = Geriatric depression scale; RCT = Randomized controlled trial

Study period	Intervention (end)	Outcomes*	Effects (p-values)	Quality of study	Remarks from reviewer
6 months	Memantine	Caregivers' direct medical resources (hospital care, outpatient visits)	NS	1	High attrition. Major option TPP
6 months	Donepezil	Caregivers' councelling visits, physician visits, drug use (data supplemented on journal's homepage)	NS	1	Short duration

Study period	Outcome	Perspective	Cost per caregiver, treatment group	Cost per caregiver, comparison group	Cost difference	p-value	Quality of study	Reviewers' comments
6 months	QALYs	Direct non-medical, direct medical costs	943	211	–732	Not presented	1	Good design, low power, high drop out rate

***Table 32.4** Empirical economical evaluations of drug treatment with a caregiver perspective. Costs are expressed as 2003 dollars (PPPs).*

Author Year Reference Country	**Type of study**	**Drug**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients included, attrition (active treatment(s) first, placebo)**	**Age-groups, mean/ range (SD), (treatment(s)/ placebo)**
Wimo et al 2003 [5] Europe	RCT, ITT	Donepezil	Community (93%)	Alzheimer's disease (NINCDS, DSM-IV)	Mild-moderate	142+144 (33%, 33%)	72.1 (8.0), 72.9 (8.6)
Wimo et al 2002 [2] USA	RCT, TPP	Memantine	Community	Alzheimer's disease (NINCDS, DSM-IV)	Moderate-severe	126+126 (29%, 40%)	58%, 60% 75+
Feldman et al 2004 [3] Canada France Australia	RCT, ITT	Donepezil	Community/ assisted living	Alzheimer's disease (NINCDS, DSM-IV)	Moderate-severe	144 (16%) + 146 (14%)	73.2 (8.4), 74.0 (7.8)

ITT = Intention-to-treat; RCT = Randomized controlled trial

Study period (months)	Cost per caregiver, treatment group	Cost per caregiver, comparison group	Cost difference	Cost diff (%)	p-value	Quality of study	Reviewers' comments
12	737/year	1 123/year	386/year	52.4	?	1	High attrition
6	68/month	74/month	6/month	8.8	NS	1	High attrition. Major option TPP
6	127	104	23/6 months	19	?	1	Short duration

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33. Care Interventions

Conclusions

Few studies were found that addressed the same issues in comparable ways. Thus, no evidence can be adduced for special interventions. Based on this systematic review of intervention studies, no scientific evidence was found concerning the efficacy of:

Cognitive rehabilitation and training interventions, given that there was only one article of acceptable quality showing improvement in cognition, while a Cochrane review found no evidence.

Functional interventions – the promising intervention in morning care by Rogers et al included individually adapted measures administered through interaction with each person, but they were not described in detail [1]. Two studies about nutrition reported an effect on body weight, but they were not comparable with respect to input.

Interventions involving walking and exercise – they included different inputs and outcomes.

Interventions affecting the care environment and program – although two studies showed postponed institutionalization, different types of interventions were involved.

Interventions based on communication, interaction and relationship – six studies showed various positive effects. However, designs and outcome measurements differed.

Reminiscence, behavioral therapy and light therapy – because there was only one accepted study of each therapy, no conclusion can be drawn about the scientific evidence, even though all of them identified effects. Cochrane reviews found no effect from reminiscence therapy or light therapy.

Reality orientation and aroma therapy due to poor diagnostics and few randomized controlled trials of acceptable study quality.

Validation therapy and touch and massage, due to methodological weakness. A Cochrane review found no effect of validation therapy, and an SBU Alert review found no effect of touch and massage.

Music and dance interventions – although all five studies that used quantitative methods showed positive effects (particularly reduced agitation and increased wellbeing) during the intervention, they concerned different types of interventions and outcome measurements. Thus, there was no conclusive scientific evidence. Furthermore, two Cochrane reviews found no evidence.

Multisensory stimulation interventions – one study showed no effect, while two studies showed effects from some components of interventions. However those studies were not comparable with respect to type of intervention. The Cochrane review found no scientific evid-ence.

Education, training and supervision of staff and supporters – out of 12 accepted articles, five showed no effect. Three studies reported in four articles led to postponed institutionalization. Two articles were based on the same study, while the third and fourth articles reported on studies that were not comparable to the other. The three remaining studies were not comparable either.

Combination (multimodal) interventions – three studies showed no effect and were not comparable because their inputs were different.

It is striking that studies that used qualitative methods reported that it was possible to communicate with patients, even those with moderate to severe dementia, in a way that helped them use their latent abilities.

Background – views about people with dementia

Views about people with dementia, as expressed in the research literature, change over time as results and professional groups emerge. New aspects of dementia are emphasized. Following is a presentation of some of the arguments that are advanced when addressing the question of what dementia involves for the patient.

At one time, dementia was regarded as part of a normal aging process. Later it was seen as mental disease. In the late 1960s and the 1970s, underlying pathological processes were acknowledged [2]. Given the emphasis on brain damage, environmental factors have also been taken into consideration [3]. A reasonable hypothesis is that views about the person with dementia, views about the caregiver and the care provided are correlated. Thus, we will begin with a brief summary of various views about people with dementia.

Changes in the use of language reflect our evolving views. Because care involves cooperation among patients, their families and professionals, language is an important consideration. For instance, the language used by physicians and nurses differs from that used by social workers [4].

The word dementia comes from the Latin "de" (without) and "mens" (soul). Having severe dementia has been described as "death before death" and a "funeral without end" [5], "living death" [6], "psychological death" [7] and being "socially dead" [8]. This view about people with severe dementia is also mirrored in the choice of words used to describe their symptoms. The term "behavior disturbance" suggests that their behavior is without meaning [9].

Dementia as brain damage

When dementia began to be regarded as brain damage, research sought explanations in the quest for prevention and cure. However researchers tended to focus exclusively on the actual brain damage, leading to the biomedicalization of dementia [10]. The biomedical model focuses on the relationship between neuropathology and symptoms. Deviant behavior (in relation to social norms) is regarded primarily as a medical problem. The label dementia legitimizes the deviant behavior, eases stress, and increases the sense of predictability and control for family and caregivers. The perspectives of patients and their caregivers are not taken into consideration, while the role of caring relationships is ignored.

Using Foucault's theories of power, McLean argued that the biomedicalization and bureaucratization of dementia care leads to depersonalization of the person with dementia [11]. When behavior is described in terms of medical symptoms, it is removed from the circumstances of real life and is described as empty and meaningless. Caregiving based on intersubjective social relationships is reframed and redefined in terms of individual acts.

The biomedical model separates body and mind. Brain damage is seen as explaining the patient's experience and behavior and leading to loss of identity (self, personhood). Brain, rationality, consciousness, self-awareness, ability to communicate, and memory are regarded as the essence of being human [12]. Personal identity is associated primarily with memory [13,14]. In Western culture, loss of identity means loss of value [15].

When people with dementia are viewed as psychologically dead, they receive custodial care and caregivers are not regarded as requiring special skills. When dementia is viewed as primarily a consequence of brain damage, patients receive medical care and the need for caregivers to have medical knowledge is emphasized.

Against the biomedicalization of dementia

Clinical observations and research have shown that not all symptoms of dementia can be explained by brain damage. Brody et al wrote about excess disability [16], and Lawton et al emphasized that the environment affects how easily the elderly can use and demonstrate their skills [17]. Several studies have shown that the environment has a major impact on people with dementia [18].

Ever since the late 1980s, attempts have been made to oppose the biomedicalization of dementia. Lyman wrote about the "myths of Alzheimer's disease", and argued that once someone has been diagnosed, even normal behavior is perceived as pathological [19]. She contends that social factors should be acknowledged as well. Kitwood questioned whether there is a direct relationship between brain damage and symptoms, proposing the existence of a dialectical interplay between neuropathological and sociopsychological factors [20].

Cheston wrote about a shift of emphasis in dementia care [21]. People with dementia are being recognized as having emotional needs, and the social consequences of the diagnosis are being acknowledged. Furthermore, a discussion is under way about how the care of people with dementia can be made more psychotherapeutic. Drug treatment is being supplemented with psychosocial intervention.

Regressive self

A common observation is that people with severe dementia become childlike in some respects and search for their parents [22]. Studies of drawings by people with dementia have shown a negative correlation between the stage of the disease and artistic ability. Such observations have been interpreted as showing recession [23], regression [24], retrogression [25] or ingression [26].

Referring to Piaget's theory of development, De Ajuriaguerra described dementia in terms of a semantic reorganization related to physiological dissolution [27]. Lower layers of mental functioning and more primitive behavior are resorted to when higher layers disintegrate. Matteson et al found that the cognitive function of people with dementia is correlated with the degree of dementia and the developmental level as described by Piaget [28]. The most cognitively impaired people are at the sensorimotor level.

Unterbach addressed dementia from a psychological standpoint [29]. She suggested that we should combine knowledge obtained from an ego-functional model, an ego-developmental model and a self-psychology model. When the brain is impaired, the ego is also impaired. It regresses to a childlike state. The person needs an auxiliary ego (the caregiver role). The support of an ego can prevent psychosis while diminishing panic and catastrophic reactions.

Miesen wrote that when higher layers of psychological functioning decline and bonds with objective reality are disrupted, people feel as though they are strangers in a frightening world [22,30]. They seek security and cling to caregivers, calling for their mother (parent fixation) [31]. Feil suggested that the patient returns to the past in an attempt to resolve old conflicts [32–34]. She also posited that the ego loses contact with objective reality and retreats to a subjective reality inhabited by people and things of particular psychological significance. Feil was not writing about dementia but about disorientation. However, her ideas have been used in caring for people with dementia.

Self, personhood and identity

Although the definitions of self, personhood and identity may differ slightly, we will use them interchangeably.

Self is a central construct for understanding people with dementia. The literature describes self in various ways, for instance as a cognitive construct or social construction. A social cognitive approach sees self as a complex, multidimensional, cognitive construct. This construct is described as containing various components, such as views and schemas. According to the second model, self is a construction that is historically situated and emerges from social processes. Dementia disorders are viewed as threats to the sense of self [35]. The patient searches for meaning, control, and mastery by means of coping strategies. When self is seen as a cognitive structure, memory problems related to dementia are viewed as crucial. The social constructional view implies that the self can survive despite the decline in memory.

Self as described by social constructionalists

Harré described a social constructionistic understanding of self from an ontological and epistemological perspective [36]. He suggested that there is not just a single self, but selves. Self 1 is a particular "sense of self", and Self 2 is self as seen by others – the "fact of self". People exhibit their sense of self by personal indexicals in discourse. They say: “I experience, I think”, etc. The fact of self emerges in the way that people describe themselves. They say: “I am an honest person, I have memory problems”, etc. Sabat wrote about Self 1, self 2, and self 3 when describing a case [37]. Self 3 refers to social personae, which are co-created together with other people in discourse and are thereby vulnerable. If conversational partners focus on the deficits related to dementia, the patient becomes negatively positioned. Sabat found Selves 1 and 2 to be intact even among people with severe dementia, while Self 3 depends on the reactions of others [37].

Self as an empty shell

Fontana et al described the selves of people with dementia as unbecoming [38]. They suggested that those selves become devoid of content and that only the ability to take part in routinized actions remains. The self exists in the eyes of others, and the disease ends with “a total loss of mental functioning and death”. A parallel expression is de-selfing [12].

By filling in the gaps in communication, caregivers or family members can help normalize the self so that patients appear to be more normal than they really are. Routine actions can help both patients and others see them as competent. However, a pronounced difference remains between form and content. Some social rituals may be simply remnants of the self.

Preserved self

Some social constructionistic researchers describe people with dementia as struggling to maintain a sense of personal or social identity, mainly by discursive means. Patients use different coping strategies, from self-protecting to integrative responding [39]. Various types of reactions are described: recognition, concern, denial, anger, guilt, sadness, coping, maturation, separation from self [40], externalization, somatization, and self-blame [41]. However, dementia reduces the ability of people to cope.

Several researchers have analyzed the conversations of people with dementia and found that – despite word finding and other language problems – they speak as if they had preserved a sense of self [42–44] and self-awareness [45] by paralinguistic means such as metaphors [46,47].

The impact of dementia disorders depends very much on how other people respond [48]. People with dementia need help maintaining contact with their previous sense of self. Vittoria described the ways in which caregivers try to preserve the selves of people with dementia by attempting to enter their worlds [49]. Caregivers focus on how patients disclose themselves, their storied self (the selves that the patients narrate), the new self (the self that is exhibited and experienced as new to the patient's family, etc), and the imagined self (the image that the caregiver constructs of what the person with dementia was like before). Vittoria referred to this approach as "communicative care" [49].

The person with dementia is locked in and can be awakened

Analyses of video recordings and audio recordings, as well as observations of interactions with caregivers have shown that it is even possible to each people with severe dementia on occasion. When caregivers support the communication of people with moderate to severe dementia, they demonstrate skills that are usually hidden, ie, latent competence [50–53], and sometimes have episodes of lucidity [54].

This view of dementia suggests that caregivers must be able to communicate with people with dementia, requiring knowledge about brain damage. This view differs from social constructionalism in seeing the self as alive and hidden or imprisoned as opposed to reconstructed.

Need of a comprehensive view

Most of the articles reviewed present only a single view of people with dementia. A more complex approach is needed. People with dementia have damaged brains, their defense mechanisms are affected, and they appear to have regressed (we prefer the term ingressed) to earlier developmental stages. Their social self is dependent on how they are treated by others, although at times they are able to break out of their imprisonment and reveal the preserved self. It would be as dangerous to deny the importance of brain damage in caregiving as it would be to neglect the influence of the environment and the possibility of reaching the preserved self.

Care interventions

Care intervention in this report is an overarching concept that includes nursing, physical therapy, occupational therapy, music therapy, etc. Previously the term non-pharmacological intervention was common. However, that would suggest that normal intervention is pharmacological. Pharmacological and care interventions are appropriate on different occasions and often in combination.

Some researchers use the term psychosocial interventions. Taft et al described psychosocial models as focusing on the person with the disease, as well as their needs and remaining capacities [55]. Among psychosocial interventions are for example art therapy, behavioral therapy, memory training, milieu therapy, movement therapy, music therapy, reality orientation, reminiscence therapy, self-maintenance therapy, staff training, and validation therapy [56].

Some psychosocial interventions are based on theoretical models [57,58]. Some examples are provided below. Erikson's theory of eight stages of man [59] was used by Ekman et al [53], Feil [60,61], and Kihlgren et al [51,52]. Hall et al's Progressively Lowered Stress Threshold (PLST) model is based on the coping theories of Lazarus and Seyles, focusing on the influence of the care environment [62]. The model was used by Hall [63], and Collins et al [64]. Miesen used Bowlby's attachment theory to explain parent fixation in people with severe dementia [22,31].

Experts such as music therapists sometimes perform therapies, elements of which may be incorporated into daily care. Some interventions are direct, the aim being to eliminate or alleviate a symptom, whereas others are indirect, striving to create a more positive care environment at a ward or increase the staff's knowledge about dementia. There are unimodal procedures (music therapy, art therapy, movement therapy, reminiscence therapy, memory training, etc), multimodal procedures (such as a combination of reality orientation, validation therapy and self-maintenance therapy) and general procedures (milieu therapy, behavioral therapy, staff training, etc) [56].

Aim

The aim of the project was to describe and evaluate care intervention studies focusing on patients in dementia care research.

Inclusion criteria

The inclusion criteria were care interventions that focused on people who are diagnosed as having a dementia disorder by means of any of the following tools: DSM III–IV, ICD 9–10, ADRS, NINDS, NINCDS-ADRDA or Lundman-Mancheter, or any of the following rating scales: MMSE, GBS or GDS.

Exclusion criteria

The exclusion criteria were care interventions with primarily biomedical or economic outcomes, psychological or linguistic testing, or a focus on dementia in combination with schizophrenia, Down's syndrome, AIDS or Parkinson's disease.

Strategy for searching the literature

We were interested in non-medical, non-pharmacological, psychosocial interventions with evaluated effect on people with dementia that had been published from 1975 to June 2004. We identified the codes (indexes) associated with the relevant studies in various databases and used them as search terms. However some studies – for example Ekman et al [53] – had such special codes that they did not yield any additional references. We also searched for special researchers who showed up in our searches and manually searched reference lists.

Search terms for CINAHL included Dementia or Alzheimer's disease (DE) with Experimental studies or Intervention trials or Clinical trials

(DE). Special activities and problems were also searched for, such as Eating, Social behavior disorders (DE). Because a search in the reference list of relevant articles and books showed that we had not covered all the literature, we also searched in titles and abstracts with relevant terms such as eating and morning care.

Among the search terms for PsycInfo were Dementia, Alzheimer's disease, Therapeutic processes, and Experimental design (DE).

Among the search terms for Medline were Dementia nursing, Nurse-patient relations, Dementia psychology, Treatment outcomes, Clinical trials and Dementia therapy (MeSH).

Special searches for specific interventions were performed, including Dementia and (Validation therapy or Reminiscence therapy or Reality orientation or Aroma therapy or Cognitive therapy or Multisensory stimulation or Snoezelen or Light therapy) – Medline: MeSH, CINAHL: DE, PsycInfo: Behavioral therapy (DE). Special searches were also performed for special care activities, such as morning care, eating and feeding (TI / AB).

The Sociological Abstracts and Social Services Abstracts databases were searched for (Dementia* or Alzheimer* and intervention [TI/AB]), etc.

The searches yielded many overlaps. Because excluding irrelevant studies from the search was difficult, 5 000–6 000 abstracts were read. As it was not possible to judge whether a study was an intervention by simply reading the abstracts, 550 articles about care interventions were read, 55 intervention studies were deemed to be of good or acceptable quality, 378 articles were excluded due to unacceptable quality.

Systematic reviews, meta-analyses and other reviews from the same period have been evaluated (about 110 articles) and 15 of them were deemed to be of acceptable quality (see Table 33.1). The most common reason for exlusion was that the quality of the original studies has not been evaluated or is not described. In some reviews patients' diagnoses were not clearly stated.

Common quality criteria

The section on Therapeutic Interventions describes the criteria for evaluating studies using quantitative methods.

The common criteria for qualitative research are credibility, transferability (fittingness), dependability (auditability). The parallel terms in the quantitative paradigm are internal validity, external validity and reliability, reflexibility (ongoing self-critique and self-appraisal) [65], participant validation, flexibility, description of context [66], confirmability, descriptive vividness, methodological congruence, analytical precision, theoretical connectedness and heuristic relevance [67]. The requirements for a sound method apply to all stages of research: formulating the research question, reviewing the literature, choosing a design, sampling participants, collecting data, analyzing and interpreting data, and reporting.

Constructing the evaluation scheme and manual

We consulted available criteria lists for evaluation of research using qualitative methods [68] as well as textbooks about qualitative research methods (including Miles and Huberman [69]). We then made a list of requirements for good quality in the qualitative methods used by the reviewed articles: qualitative content analysis, grounded theory, hermeneutics, phenomenology and phenomenological hermeneutics (or hermeneutic phenomenology). After that, we condensed and abstracted the list to requirements that we considered relevant for these methods. We used the list to evaluate a number of articles and compared our evaluations (see Appendix 33.1). Based on the results, we reduced the number of requirements in order to make the evaluation as clear and straightforward as possible.

It turned out that many articles, especially early ones, did not label the method used. They either just described it or called it "qualitative method". In other cases, the authors wrote that they had used a labeled method, but not in a way that is compatible with the actual requirements for the method. Because the labeling of methods has changed in recent decades, we accepted articles with mislabeled or unlabeled methods if the steps taken during the study could be followed and deemed valid.

Checklists are found in the electronic version of the SBU report on Dementia Diseases at www.sbu.se/dementia.

Evaluation of intervention studies – patient's perspective

Interventions using quantitative methods

Cognitive rehabilitation and training (Table 33.2 and 33.3)

Clare et al performed a Cochrane evaluation of studies about cognitive rehabilitation and cognitive training for people with early stage AD and vascular dementia (VaD) [35]. They found no study with statistically significant effects. The rationale behind these therapies is that some types of memory, such as procedural memory, are better preserved than others in people with dementia. The methods focus on either making the most of the remaining memory or finding ways to compensate for various difficulties.

A single-blind, multicenter randomized controlled trial by Spector et al evaluated the effects of cognitive stimulation therapy groups on cognition and quality of life for people with dementia [70]. Significant improvement occurred in cognitive function and quality of life measurements, but behavior did not change.

Functional performance interventions (Table 33.4 and 33.5)

No systematic review of studies about functional performance interventions was found.

ADL rehabilitative care

Rogers et al observed morning care of nursing home patients with dementia in three situations: usual care, skill elicitation (intervention), and habit training (intervention follow-up) [1]. A trained rehabilitation therapist performed the training. The physical and social environment was structured to facilitate the use of skills while dressing. Patients received a hierarchy of individualized and interactive assistance: prompting attention, positive affirmative statements, requesting to initiate, continue, and/or terminate an action or activity with step-by-step instruction – first verbally and then with gestures – and physical assistance. Microtask analyses were performed. A statistically significant increase and improvement in ADL participation was found among patients who received behavioral rehabilitative care. The authors also found an increase in the independent performance of dressing sub-tasks, a decrease in disruptive behavior, and an increase in the incidence of appropriate requests for help with dressing. Caregiver time doubled.

Beck et al studied the effects of behavioral interventions on behavior problems and affect in people with dementia [71]. Three interventions – activities of daily living (ADL), psychosocial activity and a combination of the two – were randomized and compared. The ADL interventions concerned bathing, grooming, dressing, and noon meal, taking the patient's problems and abilities into account. The psychosocial needs addressed were territoriality, communication, self-esteem, safety and security, autonomy, personal identity, and cognitive understanding. Certified, specially trained nursing assistants implemented the interventions. Video recordings were analyzed and assessed by means of scales. Special raters were hired. The treatment groups showed a statistically significant increase in positive effects compared with control groups but no decrease in negative affects. Disruptive behaviors were not reduced.

Eating, feeding and nutrition

Low body weight, which is often used as a proxy indicator of malnutrition in patients with dementia, is known to have serious consequences for health and wellbeing. Many recent papers use weight gain as an outcome.

Riviere et al reported that weight increased in intervention group patients with dementia and decreased in controls after a one-year nutritional education program for caregivers at the day hospital [72]. The program focused on the consequences of weight loss, coping with caregiver stress and assessing nutritional status. Caregivers were also taught eating behavior management techniques. After adjustment for baseline differences (caregiver age, nutritional state, eating behavior disorder, depression), weight change between the two groups was not significant.

Faxén Irving et al studied nutritional status and the effects of nutritional intervention on body weight, cognition and ADL in people with dementia disorders [73]. The residents in the intervention unit received a juicy supplement between meals in the afternoon and a balanced supplement in the evening. The staff at the unit attended a 12-hours program on nutrition and diet for the elderly. Another unit served as control. Underweight was related to low cognitive capacity. The oral supplement and staff training were followed by weight gain but did not affect cognitive or ADL function.

Physical activity interventions (Table 33.6 and 33.7)

Several studies reported that walking or exercise programs are effective in promoting wellbeing, functional ability and positive emotional mood. A meta-analysis on the effects of exercise training by Heyn et al concluded that exercise training resulted in improved physical fitness and cognitive function [74]. Exercise yielded statistically significant positive effects.

Friedman et al studied the effect of planned walking on communication performance [75]. The results showed a significant difference between a planned walking group and an ordinary conversation group. Planned walking improved communication performance in people with AD.

Hopman-Rock et al showed the effects of the Psychomotor Activation Programme (PAP) on the behavior and cognition of elderly people with dementia [76]. The results showed that the PAP had a statistically significant effect on cognition and a very modest effect on non-social behavior.

Tappen et al compared assisted walking, walking combined with conversation and an intervention with conversation [77]. The results showed that assisted walking with conversation contributed to maintaining functional ability in people institutionalized with AD.

Hageman et al reported the effects of moderate intensity strength training on the gait of elderly people with dementia disorders [78]. Although post-intervention scores reflected improvement on all measures, the only statistically significant change observed was in fast-gait time.

Teri et al studied the effects of a home-based exercise program with caregiver training in behavioral management techniques on functional dependence and institutionalization among people with AD [79]. The program improved physical health and helped alleviate depression.

Care environment and care program interventions (Table 33.8 and 33.9)

Price et al made a Cochrane review of articles about subjective barriers to prevent wandering and found no scientific evidence of effect [80].

Wimo et al examined the effects of an extensive care program on psychosocial capacity and orientation as compared to traditional nursing home care [81]. Designed in cooperation with caregivers, the program involved environmental changes, organizational changes, care techniques, care philosophy and principles of individualized care. Despite optimal care, a humanistic approach and support from the staff, the results showed no effect on the progression of dementia symptoms in the intervention group.

Wimo et al examined the effect of day care on patients with dementia who lived at home by comparing those already in day care with those on a waiting list [82]. Changes in cognition, behavior, ADL function and institutionalization after 1 year in day care were studied. The results showed that day care postponed institutionalization and gave spouses the relief they needed to recover their strength.

Volicer et al compared dementia special care units (DSCUs) with an approach inspired by a palliative care philosophy and traditional long-term care [83]. They concluded that dementia care in DSCUs resulted in less patient discomfort and lower costs than management in a traditional long-term setting.

Saxton et al compared the nature of functional decline in residents of a special care setting for AD patients and those staying at a traditional nursing home [84]. They found no differences regarding the overall progression of cognitive and functional decline: Nor did they find that mobility was better preserved in the special care setting.

Communication, interaction and relationship interventions (Table 33.10 and 33.11)

No systematic review of communication, interaction or relationship interventions was found.

Based on the Nursing Assistant Communication Skills Program, McCallion et al trained nursing assistants to communicate more effectively with nursing home residents who had dementia disorders and to use memory books [85]. The assistants were trained both in groups and individually. The assistants in the treatment group acquired greater knowledge of caregiving responses and showed less turnover. Statistically significant improvement was found in terms of wellbeing, behavioral disturbances and symptoms of depression among residents in the treatment group.

McCallion et al trained visiting relatives of residents with mild to severe dementia disorders and evaluated the effects on family members, residents, and staff by means of a single-blind design [86]. Residents and their visitors were randomly assigned to treatment or ordinary care. The results showed that visitors from the treatment group communicated better with residents. The problem behaviors, symptoms of depression and irritability of the residents decreased. No changes were observed in how the staff managed problem behaviors among the residents.

Tappen et al compared the effect of conversation, as well as exercise in combination with conversation, in a treatment and in a control group of patients with AD by means of blinded raters [87]. The results showed that the patients in the conversation-only group performed better when it came to conciseness and the number of non-redundant units of information.

Dijkstra et al taught nursing assistants how to use effective communication techniques and memory books to improve communication with residents who had dementia [88]. The results showed that the quality of the conversations improved compared to that of the control group, ie, residents exhibited greater coherence and lower occurrence of empty phrases. Nursing assistants used more facilitative discourse strategies.

Magai et al studied the effects on patients of training staff in nonverbal communication [89]. A nonverbal sensitivity group, a behavioral placebo group that received instruction about cognitive aspects of dementia and a waiting list group were compared. A statistically significant increase was found in positive affect among patients in the nonverbal communication group. The increase declined over time, and the scores of the three groups converged by the end of 12 weeks. No statistically significant changes were reported in depression, agitation or behavioral symptoms. All groups showed a decline in negative affect. A statistically significant decline was found in negative symptoms over time among the two treatment groups of caregivers. In other words, training caregivers in nonverbal communication had short-term effects on patients with dementia.

Special therapies and care activities (Table 33.12a)

Reminiscence therapy

Based on a work by Butler concerning life review reminiscence therapy involves ways of remembering and reviewing past experiences as a preparation for death [90]. The rationale behind this approach is that remote memory is often better preserved than short-term memory in people with dementia. During reminiscence therapy, people with dementia meet regularly in groups and talk about their past. They may use photographs, videos and other aids. A Cochrane review by Woods et al found several small studies of relatively low quality that examined different types of reminiscence therapy [91].

A randomized controlled trial by Lai et al examined changes in social wellbeing after implementing a specific reminiscence program for subjects with mild dementia [92]. The intervention was designed as an individual treatment based on the person's life history. The hypothesized higher levels of psychosocial wellbeing were not found when using multivariate analysis, while significant improvements were found in the intervention group when using the Wilcoxon sign rank test.

Behavioral therapy

No systematic review of behavioral therapy interventions was found.

Teri et al treated depression among people with AD and their family caregivers by means of behavioral therapy that emphasized pleasant events for patients or problem solving for caregivers [93]. Treatment was individualized. Typical care control and waiting list control were used. Patient-caregiver dyads were randomly assigned to one of four conditions. Assessments were performed pre-treatment, post-treatment and after six months. Depression decreased in the patients and caregivers during behavioral treatment, and the effects remained after six months.

Light therapy

Forbes et al reviewed bright light therapy for the Cochrane Collaboration [94]. The rationale for using bright light to treat sleep disturbances is that, in addition circadian rhythm problems, people with dementia disorders are exposed to less light than healthy people. Furthermore, they may be less sensitive to light. The authors found no RCTs that showed a statistically significant effect on sleep, behavior, mood, or cognitive disturbances in people with dementia.

Ancoli-Israel et al studied the effect of light on agitation in institutionalized patients with severe AD [95]. Patients were randomly assigned to three types of treatment: morning bright light; morning dim red light;

and evening bright light. Morning bright light delayed the peak of the agitation rhythm by over 1.5 hours, and caregivers found decreased agitation after bright light while independent observers did not identify any changes.

Other special therapies and care activities

Reality orientation, validation therapy, aroma therapy, touch and massage are commonly used interventions in dementia care. No evidence is found in four systematic reviews.

Reality orientation

Developed by Taulbee and Folsom, reality orientation (RO) strives to reduce disorientation in patients with dementia by supporting training activities with respect to their position in space and time [96].

Reality orientation (RO) can be undertaken in formal classroom-like training situations or in less formal daily situations. Spector et al reviewed RO in dementia for the Cochrane Collaboration [97]. Six studies were included that showed a statistically significant effect of classroom RO on cognition and behavior but no evidence of long-term effects. One possible risk is that RO will be used in a mechanical way. However, on the basis of our evaluation criteria, none of these included articles could be accepted mostly due to poor diagnostics.

Validation therapy

Neal et al performed a Cochrane review of articles about validation therapy and found no scientific evidence of effects [98].

Feil developed validation therapy between 1963 and 1980 [61]. The method, which uses special techniques, is based on general principles of validation, ie, accepting the reality and truth of another person's experience. The validation theory and its techniques have been called into question [99,100].

Aroma therapy

Aroma therapy stimulates the olfactory sense in an attempt to promote relaxation, comfort, sleep and pain relief. It is also used to reduce disruptive behavior. Thorgrimsen et al reviewed articles about aroma therapy for the Cochrane Collaboration [101]. They accepted one study by Ballard et al, which was excluded here due to poor diagnostics [102].

Touch and massage

Touch massage serves as a general term to cover tactile stimulation, peripheral tactile nerve stimulation, tactile massage, aromatherapy massage, hand massage, expressive physical touch, effleurage, etc [103]. The aims of treatment are to provide patients with a greater sense of wellbeing, reduce stress and relieve pain, thereby decreasing anxiety and aggressive behavior. Touch massage is given to patients with dementia as part of daily care activities. It may be applied to different areas of the body and performed by either staff or family caregivers. The frequency and length of the massage varies. The review by SBU Alert reported poor scientific documentation on the effects of touch massage in people with dementia [103].

Music and dance interventions (Table 33.13 and 33.14)

Music therapy is usually defined as the use of music to improve health or reduce symptoms. The effect of music therapy has been reviewed, and improvement was reported in terms of social skills and emotional state (mood).

Vink et al reviewed articles for the Cochrane Collaboration concerning the use of music therapy in caring for people with dementia [104]. The specific focus was on behavioral problems, cognitive problems, social functions and emotional functions. Five studies were evaluated and, due to methodological weaknesses, no scientific evidence was found.

There are some evaluation differences among systematic reviews as the result of varying inclusion and exclusion criteria. Some of the studies included in the review by Vink et al [104] were excluded in this review because they lacked a diagnostic description [105–107].

Music therapy often includes activities carried out by a therapist trained in the area. Several studies focused on different types of interventions in which music was used by people other than professional therapists, including family caregivers and the nursing staff.

Groene II studied the effectiveness of music therapy compared to reading aloud in people with dementia and wandering behavior [108]. There was a statistically significant increase in seating scores and a decrease in wandering scores over the course of the sessions for both groups, but people remained seated in the session area for a longer time during music sessions than during reading sessions.

Goddaer et al evaluated the effects of relaxing music on four dimensions of agitation [109]. Intervention consisted of one week without any music in order to collect baseline data, one week in which relaxing music was introduced, one week in which it was removed and one week in which it was reintroduced. A statistically significant decrease in agitated behaviors was observed.

Clair studied the effects of unaccompanied, live singing on alert responses in people with severe dementia [110]. The results showed that alert responses were statistically most frequent during singing, followed by alert responses during reading.

Gerdner tested Gerdner's mid-range theory of individualized music intervention in comparison with classical music [111]. The study showed a statistically significant decrease in agitation during and following individualized music compared to classical music.

Sherratt et al studied the effects of social interaction in music listening on the involvement, wellbeing, and challenging behavior of people with moderate to severe dementia [112]. The results showed that live music was statistically more effective in increasing levels of involvement and wellbeing regardless of the level of cognitive impairment.

Multisensory stimulation interventions (Table 33.15)

Sensory stimulation refers to a number of techniques (including aroma therapy and light therapy) that expose patients with dementia to stimuli through one or more senses [113]. The rationale for the use of sensory stimulation is not only that patients experience a disease-related and age-related decline in their sensory and perceptual abilities, but also they frequently live in sensory-impoverished environments, particularly long-term care facilities [114].

Chung et al reviewed articles about Snoezelen (multi-sensory stimulation or MSS) for the Cochrane Collaboration [115]. Snoezelen stimulates the primary senses through lighting effects, tactile surfaces, meditative music and the aroma of essential oils. The rationale for the method is to create an environment that places few demands on the intellect and relies on residual sensory-motor abilities. MSS has become more popular in recent years, particularly at several European centers. Chung et al did not find any scientific evidence for its efficacy.

To investigate the short-term effects of MSS and activity groups, Baker et al studied behavior, mood and cognition in older adults with dementia, generalization of effects to day hospital and home environments, and the persistence of any effects over time [113]. Statistically significant improvement was seen among both the MSS and activity groups in the following areas: more spontaneous speech, relating to people better, more attentive to/focused on the environment, doing more on their own initiative, enjoying themselves, being more active or alert and being less bored or inactive.

Baker et al compared the effects of MSS and activity groups on behavior, mood and cognition in older adults with dementia [116]. There were limited short-term improvements for both the MSS and activity groups immediately after the sessions. No statistically significant differences between the groups were seen when assessing changes in behavior, mood or cognition.

Jackson et al evaluated the impact of Sonas by means of music, gentle exercises, taste, scents, and massage in a group setting [117]. The quantitative evaluations showed no benefit from the use of Sonas on agitation or aggression. Active participation varied widely within groups, and the session notes suggested that Sonas provided an enjoyable activity, allowing different levels of participation based on the amount of cognitive impairment.

Education, training and supervision of staff and support interventions (Table 33.16 and 33.17)

A reasonable assumption is that if the staff has the proper knowledge and skills, the quality of the care of patients with dementia will improve. No systematic review concerning the effect on patients with dementia of staff education, training or supervision was found. Following is a discussion of projects that evaluated the effects of education and training on patients.

Brodaty et al compared caregiver-patient dyads in a dementia caregiver program, a memory retraining group and a waiting list group [118]. The program for caregivers was broad, covering topics such as reducing caregiver distress; combating isolation, guilt, and separation; finding new ways of thinking and new coping skills; fitness; diet; organizing the day and home; medical aspects of dementia; using community services; planning for the future; and coping with problem behaviors. The patient program included general ward activities and group discussions. The result showed that the dementia caregiver program lowered caregiver stress and led to delayed institutionalization for people with dementia.

O’Connor et al investigated whether early intervention reduced the time for admission to long-term care [119]. A resource team offered a wide range of assistance (financial benefits, physical aids, home help, respite admission, practical advice, and psychiatric assessments) to patients with dementia and their families. Controls had access to ordinary services. Early intervention was not found to affect admission rates in subjects who lived with supporters. The rate of institutionalization among people with moderate to severe dementia who lived alone was significantly higher in the treatment group.

A clinical supervision intervention study by Edberg et al showed that the relational quality of patient-caregiver interaction improved after one year of clinical supervision [120]. Two wards at a psychogeriatric clinic for patients with severe dementia were compared. Observation of nurse-patient cooperation was performed and sorted into predetermined categories. Statistically significant improvement was seen in the experimental ward, indicating higher quality nurse-patient cooperation.

Brodaty et al reported on the results of an 8-year follow-up of the study described above [121]. They found that caregiver training programs led to a statistically significant delay in the institutionalization of people with dementia.

Bellelli et al assessed the efficacy of care given to a group of patients with dementia and behavioral problems [122]. A specially designed care program adjusted the environment and provided staff with specific training in identifying behavioral problems and possible causes. The authors reported a statistically significant reduction in behavioral problems, as well as the use of psychotropic drugs and restraints, but no statistically significant improvement in cognition or function.

Cohen et al studied the effects of implementing the Buddy Program, ie, a natural helping network model to enhance the wellbeing of people with dementia [123]. The buddies (patients without dementia) were trained about dementia (dementia disorders, people with dementia, care of people with dementia and the role of buddies). Regular sessions were arranged between the buddies and people with dementia. No effects in comparison with matched controls were noted in either people with dementia or buddies.

Edberg et al evaluated the effects of one-year systematic supervision and individually planned care on the mood and general behavior of patients with dementia in relation to cognitive function and level of confusion [124]. No statistically significant differences were found between the treatment and the control wards.

Bourgeois et al studied the effect of memory aids on conversations between nursing aides and residents with dementia [125]. The duration and quality of verbal interaction for nursing aides trained and not trained to use memory aids were assessed by means of computer-assisted observations and videotapes. The study showed quantitative and qualitative improvement in conversation, including duration of speaking time, but no effect on depression among residents or nursing aides. In the treatment group, assessments by nursing aides concerning the degree of depression among the residents was closer to how the residents rated themselves.

Eloniemi Sulkava et al evaluated a 2-year intervention program of systematic, comprehensive support by a dementia family care coordinator to determine whether community care of patients with dementia could be prolonged [126]. The results showed that the placement of patients with dementia in long-term institutional care could be deferred with the support of a dementia family care coordinator. However, by the end of the 2-year intervention period, the number of institutionalized patients was similar in the intervention and control groups.

Gormley et al found no significant reduction of aggressive behavior as the result of a behavior management training program for family caregivers of people with dementia [127]. The program, which consisted of four sessions over eight weeks, provided caregivers with information about alternative communication and distraction techniques. There was no reduction of aggressive behavior or caregiver burden.

Bourgeois et al trained caregivers to modify their own coping behaviors and problem behaviors among patients with moderate to severe dementia [128]. They compared the efficacy of patient-focused and caregiver-focused skills training with a visiting control group that received no training but comparable attention and support for 12 weeks. Caregivers in the group receiving patient-focused skills training learned to reduce problem behaviors, and caregivers in the self-change group learned to alter their perception of patient behavior. Both types of training reduced problem behaviors in patients and improved the mood of caregivers.

Gitlin et al examined the effects of the Home Environmental Skill-Building Program (ESP) on caregiver wellbeing and care recipient functioning [129]. Caregivers and care recipients were randomized to an ordinary care control group and an intervention group that received five home contacts and one telephone contact by occupational therapists who provided education, problem-solving training and adaptive equipment in accordance with ESP. No statistically significant differences between the two groups were found.

Combination (multimodal) interventions (Table 33.18 and 33.19)

Robichaud et al measured the efficacy of the sensory integration program developed by Ross and Burdick to improve the functioning of people with dementia [130]. The program had no statistically significant effect on the behaviors of the intervention group.

Rovner et al evaluated the AGE dementia care program aimed at reducing behavioral disorders [131]. The program consisted of music, exer-cise, crafts, relaxation, reminiscence, word games, food preparation, drug management and educational rounds with a psychiatrist. Disturbing behavior, as well as the use of antipsychotics and restraints, decreased among patients in the intervention group. No differences were found regarding cost reduction or functional level.

Schrijnemaekers et al investigated the effects on behavior of emotion-oriented care intervention that relied on validation and insights from other approaches, including reminiscence and sensory stimulation [132]. The results showed no behavioral change that would justify the use of emotion-oriented care instead of ordinary care.

Intervention with qualitative methods or a combination of qualitative and quantitative methods

Caregiver interaction interventions (Table 33.20)

Sandman et al videotaped institutionalized patients during meals [133]. A special dining room was prepared with a set of china, cutlery, napkins, dishes and bowls. The aim was to assess the patients' mealtime behavior and social interaction. The same staff members participated and received instructions to help the patients when needed. Patients ate alone during one of three observation periods, nurses wearing street clothes participated in one, and uniformed nurses participated in one. The results showed that two patients with milder dementia helped others when no nurse was available, one helped when the nurses wore street clothes and none helped when the nurses wore uniforms.

Jansson et al interpreted videotapes of two caregivers, each with four patients with dementia [50]. The caregivers stimulated the patients in various ways and tried to establish the most contact possible. The patients were videotaped during morning care, listening to music, sitting in a rocking chair, eating lunch, and while the caregiver was reading aloud. The study showed that it was possible for the caregivers to communicate with the patients. They used a hermeneutic process to interpret the patients' communicative cues, such as facial expressions, vocalizations and single words.

Integrity promoting care interventions (Table 33.21)

A series of studies by Ekman et al and Kihlgren et al examined integrity-promoting care based on the Erikson theory of the eight stages of man [134].

Ekman et al studied relationships between Finnish immigrants with moderate to severe dementia and Swedish-speaking and Swedish/Finnish-speaking caregivers during morning care [53]. The study showed that relationships with the bilingual caregivers tended to be positive and that the patients exhibited latent abilities, while the monolingual caregivers had severe communication problems and found it more difficult to establish positive relationships. Another study showed that bilingual caregivers communicated more multi-dimensionally and that their relationships rapidly progressed in a positive way [135].

Kihlgren et al studied interactions between patients with dementia and caregivers by videotaping morning care sessions before and after the caregivers had been trained in integrity-promoting care, ie, encouraging the experience of trust, autonomy, initiative, industry, identity, intimacy, generativity (concern for others) and integrity. Kihlgren et al found positive, intermediate, and negative patterns of interaction according to whether or not integrity was promoted [51]. When caregivers promoted integrity, patients displayed greater abilities. Positive patterns dominated after training, while negative and intermediate patterns dominated before training. Kihlgren et al found that patients exhibited such virtues as hope, will, purpose, competence, fidelity, love, caring and wisdom [52]. The manifestation of virtues indicates that complex personality characteristics had been preserved and could be elicited in a positive climate of communication.

Singing and social dancing interventions (included studies in Table 33.22 and excluded studies in Table 33.23)

Götell et al compared morning care of patients with dementia during 1) caregiver singing and background music, 2) familiar background music and 3) caregiver singing to and/or with the patient [136]. The results showed effects on posture, movement and sensory awareness [136]. Both background music and caregiver singing had a heavy influence on the body and sensory awareness. Patients had better posture, stronger and more symmetrical movements and greatly increased awareness of themselves and their environment. Patients appeared to regain abilities necessary for daily living and demonstrated that they could perform tasks with intentionality, purpose, and competence. Caregiver singing was very effective at bringing out capabilities that had appeared to be lost, as well as eliciting more mutuality in interactions with patients than background music.

Götell described the influence of vocally expressed emotions and moods from the same videotaped data [137]. The results showed that patients exhibited more vitality during background music listening and caregiver singing. Patients and caregivers expressed a vibrant pattern of emotions and moods during all sessions. All patients except one exhibited positive emotions and moods.

Palo-Bengtsson et al described the qualitative effects of social dancing in the care of people with dementia [138]. The results showed that dance music is a good way to encourage social contact, as well as support communication and interaction. Earlier social patterns and habits, as well as general rules of living, seemed to awaken in people with dementia.

Palo-Bengtsson et al also studied how people with dementia functioned in social dance sessions [139]. The results showed that retained abilities were prominent in dancing. Social dancing promoted positive feelings, communication and behavior while preserving intellectual, emotional, and motor functions. The caregivers' previous understanding of the patients' level of dementia and their situation were important.

Meta-summary of comparable articles using qualitative methods

A meta-summary was compiled of the results of the reviewed and accepted studies using qualitative research methods, primarily mainly in accordance with the approach described by Sandelowski et al [140]. The results of these studies were extracted and abstracted with respect to whether latent abilities manifested, as well as whether communication, interaction and relationships between patients and caregivers or other patients improved. The studies included in the meta-summary are not discussed further, given that they have been reviewed and described above (Table 33.20–33.22).

Results of the meta-summary (Table 33.24)

All included studies focused on communication, interaction (music, singing, dancing, integrity-promoting care, use of native language) and treating patients as competent human beings as the basis for creating positive relationships. All articles demonstrated efficacy during the course of the intervention (the process), an observable phenomenon given that all studies but one used videotaping. All articles showed that it is possible to communicate, establish positive relationship with people with moderate and severe dementia and bring out their latent abilities.

Summary of effects (Table 33.25, 33.26 and 33.27)

Several interventions had effects on various problems. The interventions differed significantly. Because many different instruments were used for assessment and evaluation purposes (Table 33.25), a meta-synthesis was not feasible. Tables 33.26 and 33.27 show the effects of interventions on different care problems and choice of intervention for care problems.

Discussion

This review demonstrated that evidence of the efficacy of care interventions is difficult to prove. First, care research was spread out among several different databases and there was not much logic in the search terms applicable. Thus, various terms were searched in titles, abstracts, etc. Such searches were hard to repeat. However, it seemed more important to find many studies than to specicify the searches. Several studies on care interventions were not listed in PubMed. Second, some characteristics of care make it difficult to conduct controlled studies. For instance, if a ward implements integrity-promoting care, all caregivers need to be involved 24 hours a day [51]. Furthermore, in order to improve care various interventions must be combined. A particular intervention might succeed in one study but not when subsequently combined with other measures.

Due to various methodological problems, we have included only a small percentage of all reviewed studies. Many studies were rejected due to lack of adequate diagnoses. People with dementia are sometimes described as cognitively impaired, residents in a dementia unit, etc. Because the lowest level of diagnostics accepted was that only MMSE, GDS or GBS had been used, we did not always know the types of dementia disorders involved.

Although it can be difficult to evaluate the effects of interventions on people with multiple diagnoses, we did not exclude articles that reported on dementia concomitant with other disorders. Most articles reported on stages of dementia disorders, but groups often included patients at different stages. That gives rise to problems considering that care approaches may be suitable at particular points only. For instance, reality orientation works in early stages and multisensory stimulation in later stages.

The reason for lack of adequate diagnoses may sometimes be that the researchers do not have authorization to diagnose dementia disorders and no physician was involved in the research project. Or the reason might be that a medical diagnosis was not considered important in terms of designing and evaluating the intervention.

Even when there were several studies of acceptable or good quality, it was not possible to juxtapose them in order to obtain scientific evidence due to the fact that the interventions, the people with dementia or the outcome measures were not comparable. The rating scales were generally established ones. The use of many instruments (see Table 33.25) made it impossible to compare the results.

Because of the methodological problems described above, several interesting and good studies were excluded while several studies of acceptable quality were not included for the purpose of scientific evidence. Evaluating the excluded studies based on other criteria could turn out to be worthwhile.

Most articles about care interventions used quantitative methods. They were not based on randomization or used control groups, but examined measurements before and after intervention. Few studies used either qualitative methods or a combination of qualitative and quantitative methods.

Given that people with dementia respond differently to various programs, the reviewed articles sometimes reported on an individualized approach. Some studies adapted care measures to the patient's neurobehavioral level. Because the interventions were generally mixed and adapted to the patient's needs, and even performed in interaction with the patient it is not possible to repeat the study exactly or generalize the results [1,85]. A review of the effects of emotion-oriented care approaches by Finnema et al emphasized the value of tailoring interventions to individual needs, as well as guidelines for determining when to use various approaches [57]. More research about individualization is needed.

Many studies used multi-component packages of care measures. Most reviewed studies were mixed in terms of aim, intervention and outcome. For instance, Rovner et al and Schrijnemaekers et al combined interventions such as reminiscence therapy and validation therapy [131,132]. Activities varied with respect to their objectives. Music was used for instance to improve communication, stimulate cognition, reduce discomfort, ease agitation and increase wellbeing (Table 33.26).

Formal caregivers and family members were usually seen as vehicles for changing a patient's behavior. A few studies focused on families [86,126]. Many of the interventions affected patients by training formal caregivers [79,89]. Other studies influenced the staff through systematic clinical supervision [124]. A few studies concerned training of patients [1,87].

Several articles described difficulties in demonstrating effects over an extended period of time [56]. The studies that used qualitative methods most often focused on what happened during the intervention, not on subsequent outcomes. Ekman et al discussed how interaction between the caregiver and patient differed during morning care sessions according to the caregiver's use of language [53,135].

Care can be described as containing a relationship aspect and a task aspect [141]. Care as a task occurs in relationship. The difficulty that people with dementia have in interpreting sensations, actions and memories affects their relationship with caregivers. Two caregivers can perform similar actions while one succeeds and the other fails. That may be due to different ways of communicating and relating to patients as a result of how they tend to look at people with dementia.

Even though there may be evidence-based knowledge about the task to perform, relationship problems may lead to implementation problems. For instance, the kind of food that a patient with severe dementia should eat may be known, but symptoms such as agnosia and apraxia may stand in the way. In order to help patients receive adequate nourishment, communication and a trusting relationship are needed.

The fundamental role of relationship makes it difficult to evaluate care interventions. In order to retain control of both the task and relationship aspect during interventions, there cannot be too many participants and intensive data collection methods such as direct observation and videotaping are required. If the reactions of people with severe dementia are to be assessed, special time-consuming interviewing techniques are vital [142].

Some case studies and studies using single subject design that were not included would have provided a more profound understanding of individual reactions to care interventions. Moreover, studies using qualitative methods can offer greater insights into complex problems. A combination of qualitative and quantitative methods can provide nuanced knowledge.

The meta-summary of care interventions evaluated by qualitative methods shows that it is possible to communicate with people who have severe dementia in a way that brings out latent abilities.

Many people with dementia suffer from behavioral symptoms that are a common stress factor for family and staff and often the main reason for institutionalization. Thus, it is reasonable that many researchers would use such symptoms as an outcome in various kinds of interventions. Behavioral symptoms are labeled in various ways, including assaultive behavior [143], behavioral and psychological symptoms in dementia [144], challenging behavior [145], demanding behavior [146] and inappropriate behavior [147].

Given that some researchers believe that behavioral symptoms can sometimes be ways of communicating needs [148], it is logical that studies aimed at improving communication between caregivers and patients with dementia disorders would use a decrease in such symptoms as an outcome [89]. People with dementia are sensitive to their environment – they are at risk of both understimulation and overstimulation [149]. Because anxiety, agitation, and boredom are regarded as causes of behavioral symptoms [150], evaluating various activity programs with respect to such symptoms also appears reasonable.

Several of the included studies were evaluated to determine whether the interventions increased the patient's sense of wellbeing (positive affect, quality of life, less discomfort, reduced depression) and reported positive outcomes [70,71,92].

This evaluation of studies about the care of people with dementia did not show any scientific evidence for the efficacy of interventions. That may be related to methodological problems that sometimes depend on the special characteristic of care. Furthermore, criteria based mainly on drug studies do not seem appropriate for evaluating care interventions. Nevertheless, the studies revealed that the view of people with dementia is changing. Most researchers now look at them as full-fledged human beings.

Table 33.1 *Systematic reviews of care interventions of good or acceptable quality.*

Author, year, reference	
Chung et al, 2002 [115]	(Cochrane)
Clare et al, 2003 [35]	(Cochrane)
Forbes et al, 2004 [94]	(Cochrane)
Heyn et al, 2004 [74]	
Koger et al, 1999 [151]	
Koger et al, 2000 [152]	(Cochrane)
Neal et al, 2003 [98]	(Cochrane)
Neal et al, 2003 [153]	(Cochrane)
Price et al, 2000 [80]	(Cochrane)
Roberts et al, 2000 [154]	
Sherratt et al, 2004 [112]	
Spector et al, 2000 [97]	
Thorgrimsen et al, 2003 [101]	(Cochrane)
Vink et al, 2004 [104]	(Cochrane)
Woods et al, 2005 [91]	(Cochrane)

Table 33.2 *Cognitive rehabilitation and training intervention.*

Author Year Reference Country	**Type of study**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups Range (SD)**
Spector et al 2003 [70] United Kingdom	A single-blind, multi-centre, randomized trial	Nursing home/ day centre	DSM-IV MMSE	Mild to moderate: 14.4 (3.8) Treatment group: 14.2 (3.9) Controls: 14.8 (3.8)	201 Treatment group 115 female/male ratio 4.0:1 Controls 86 female/male ratio 3.3:1	Treatment group: 85.7 (6.2) Controls: 84.7 (7.9)

ADAS = Alzheimer's disease assessment scale; CAPE-BRS = Cliffton assessment procedures for the elderly behavior rating scale; CDR = Clinical dementia rating; DSM-IV = Diagnostic and statistical manual of mental disorders, version IV; MMSE = Mini-mental state examination; QALY = Quality-adjusted life-years; QoL = Quality of life; RAID = Rating anxiety in dementia; SD = Standard deviation

Study period	Intervention	Measurements	Effects	Remarks from reviewer	Quality of study
7 weeks	Cognitive stimulation therapy 14 session programs (45 min x 2/week in 7 weeks) cognitive stimulation of patients	Rating scales before and after intervention. Cognition: ADAS. Quality of life, QALY. Communication: Holden. Behavior: CAPE-BRS. Global functioning: CDR. Depression: Cornell scale. Anxiety: RAID scale	The cognitive therapy improved cognition and QoL	Weakness: Number of participants per centre not clear, or how comparable the centres are. Drop out rate high. Strength: Design	1 Acceptable

Table 33.3 *Cognitive rehabilitation and training intervention (excluded articles).*

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Anderson et al, 2001 [155]	1		
Arkin, 1992 [156]	1		
Arkin, 1997 [157]	1		
Arkin, 1998 [158]	1		
Arkin, 2000 [159]	1	2	4
Asplund et al, 1991 [160]	1		
Beck et al, 1988 [161]	1	4	
Bourgeois et al, 2003 [162]	1	2	
Cahn Weiner et al, 2003 [163]	1	2	5
Clare et al, 2000 [164]	1		
Clare et al, 2002 [39]	2	4	
Clare et al, 2003 [165]	1	2	
Clark et al, 2004 [166]	1		
Corbeil et al, 1999 [167]	2		
Davis et al, 2001 [168]	1	4	
Hill et al, 1987 [169]	1		
Koder, 1998 [170]	1		
Mills et al, 1994 [171]	1		
Moniz Cook et al, 1998 [172]	1		
Oriani et al, 2003 [173]	1		
Quayhagen et al, 1995 [174]	2	4	
Quayhagen et al, 1996 [175]	2		
Zarit et al, 1982 [176]	1		
Zarit et al, 2004 [177]	2		

***Table 33.4a** Functional performance interventions (ADL rehabilitative care, eating, feeding and nutrition).*

Author **Year** **Reference** **Country**	**Type of study**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**
Beck et al 2002 [71] USA	Randomized Experimental design, 3 treatment groups (ADL, PSA, combined), 2 control groups (placebo, no intervention)	7 nursing homes, Arkansas, Maryland	MMSE	<20 Mean: 7.9–11.5 SD: 5.4–7.7	179 127 complete data 84 with videotapes
Rogers et al 1999 [1] USA	Individualised behavior intervention, field study	5 nursing homes	Probable AD (19), possible AD (65) MMSE	MMSE Mean: 6.1	58 females, 26 males

Age-groups Range (SD)	Study period	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
Mean: 81.2–86.5 SD: 6.4–9.8	12 weeks, Monday–Friday	DBS, ODAS, AARS, PVAS, analysis of videotapes	Significantly more affect but not reduced disruptive behavior in treatment groups	Power calculations, broad intervention Included relationship, individualisation	1
Range: 64–97 SD: 6.3 Mean: 82	25 days: Usual care (US) 5 days; Skill Elicitation (SE) 5 days. (ET) (behavioral rehabilitation of retained ADL skills), Habit Training (HT) 15 days (intervention follow-up). Individualisation. Reduced assistance during HT, 5 days and HT, 15 days	CMAI; ADL performance: dressing, other ADL, no ADL. Computer-assisted data collection: Real time used by caregivers for assistance (level of assistance), participants' responses to caregiving, including disruptive behavior. Trained rehabilitation therapist (SE, RT) and CNAs (UC)	Increased proportion of time in non-assisted and assisted dressing as well as overall participation in ADL, decrease in disruptive behavior. Functional gains persisted for 3 weeks	Individualisation not described	2

***Table 33.4b** Functional performance interventions (ADL rehabilitative care, eating, feeding and nutrition).*

Author **Year** **Reference** **Country**	**Type of study**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups Range (SD)**
Riviere et al 2001 [72] France	Prospective, case-control. Nutritional education program to prevent weight loss and slow the cognitive decline	Home and day care unit	Alzheimer ADRS NINDS	Moderate MMSE Intervention group: 15.4 (7.1) Controls: 15.4 (6.1)	Intervention group: 151 (52 males, 99 females). Controls: 74 (22 males, 52 females)	IG 77.3 (8.2) CG 75.4 (7.9)
Faxén Irving et al 2002 [73] Sweden	Non-randomized. Nutritional intervention. Combined oral liquid suppl and nutritional education	Group-living dem	Dementia CDR MMSE	Mild, moderate, severe MMSE: 9 (6.6) Controls: 8.5 (6.2)	22/14 Patients that completed: 21/12	83 females 81% controls 85 females 93%

AARS = Apparent affect scale; ABRS = Adaptive Behavior Rating Scale; AD = Alzheimer's disease; ADL = Activities of daily living; ADRS = Adverse drug reactions; BMI = Body mass index; CDR = Clinical dementia rating scale; CG = Caregiver; CMAI = Cohen-Mansfield agitation inventory; CNAs = Certified nurses aid; DBS = Disrupted behavior scale; IADL = Instrumental activities of daily living; IG = Intervention group; MMSE = Mini-mental state examination; MNA = Mini nutritional assessment; NINDS = National Institute of neurological disorders and stroke; ODAS = Observable displays of affect scale; PSA = Protective services for adults; PVAS = Postitive visual analogue scale; SD = Standard deviation

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
1 year	1 year education program (9 one-hour sessions) for caregivers	Weight, MMSE, IADL ADL CMAI MNA Cornell's scale (mood) Blendford scale (eating) Caregivers: Burden interview (Zarit), Nutrition knowledge questionnaire	Mean weight increased sign in I-group, decreased in C-group. MNA maintained in I-group, decreased sign in C-group. After adjustment for baseline difference no significance. Caregiver knowledge increased significance	More family carers in experiment group, and maybe more eager and receptive to training	2
6 months	12 hours educational program about nutrition and diet + suppl provision 410 kcal a day in 5 months	BMI, weight, MMSE, CDR, Katz	Weight incr sign in I-experiment group 3.4 kg, unchanged in C-experiment group. No effect on cogn or ADL. After withdrawn of suppl the control group-education was not effective. BMI <20 in 19% and 44% had BMI <23. BMI correlated with MMSE (range=0.43, p<0.01)	Small material	1

Table 33.5 *Functional performance interventions (excluded articles).*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Altus et al, 2002 [178]	3		
Beattie et al, 2002 [179]	2		
Beck et al, 1997 [180]	4		
Biernacki et al, 2001 [181]	4		
Boylston et al, 1996 [182]	1	4	
Brush et al, 1998 [183]	1		
Corcoran et al, 1996 [184]	2	4	
Coyne et al, 1997 [185]	1	2	
Engelman et al, 1999 [186]	1		
Engelman et al, 2002 [187]	1		
Engelman et al, 2003 [188]	1	2	
Foster et al, 2001 [189]	1	2	
Holmberg, 1997 [150]	3	4	
Josephsson et al, 1993 [190]	1		
Josephsson et al, 1995 [191]	1		
Keller et al, 2003 [192]	2		
Kovach et al, 2004 [193]	3	4	
Lekeu et al, 2002 [194]	6		
Lim, 2003 [195]	3	4	
Lin et al, 1999 [196]	2		
Mickus et al, 2002 [197]	2		
Nygård et al, 2001 [198]	3		
Palleschi et al, 1996 [199]	1		
Rogers et al, 2000 [200]	4		
Rosenstein et al, 1994 [201]	1		
Tappen, 1994 [202]	2	3	
Watson et al, 1997 [203]	2	4	
Wells et al, 2000 [204]	1		
Young et al, 2001 [205]	2		

Table 33.6 *Physical activity interventions.*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Hopman-Rock et al 1999 [76] The Netherlands	Randomized controlled intervention	Different homes for elderly	CST	Moderate to severe	134 Females/ males: 91/43	64–96 Mean= 84.7
Hageman et al 2002 [78] USA	Randomized controlled intervention	Day-care center	MMSE	5–29 Mean=18 SD 6.2	26 Females/ males: 23/3	70–88 Mean= 79.9

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
6 months	PAP (Psychomotor Activation Programme)	Behavioral Observation Scale for Intramural Psychogeriatry (BIP). Social Interaction Scale (SIPO)	PAP had a beneficial effect on cognition (CST-14, F=2.63, p< or =0.05, effect size 0.4) (CST-20, F=3.77, p< or =0.05, effect size 0.5) and increased positive group behavior in participants with relatively mild cognitive problems (SIPO, F=4.46 p< or =0.05	Strength: Randomized controlled trial. Weakness: Insufficient statistical power due to the degree of dropouts	1
6 weeks	Gait performance (resistance training program)	Video-recordings, (TUG "Timed-up-and-go" test)	Statistically significant change observed in fast-gait time. A six-week resistance-training program proved to be of insufficient duration, intensity or specificity to produce significant change in gait outcome measures, with the exception of fast speed gait	Strength: Validated outcome measurement Weakness: No control groups	1

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Table 33.6 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Teri et al 2003 [79] USA	Randomized controlled trial	Community-dwelling	MMSE	Moderate to severe. MMSE 15–17	153 Female: 41%	55–93
Friedman et al 1991 [75] USA	Convenience sample. Randomized to groups. Non-blinded intervention 2-group. Experimental study	2 nursing homes	MMSE NINCDS-ADRDA		30 subjects	
Tappen et al 2000 [77] USA	Randomized experimental study. 3 treatment groups, 1 control group. Blinded raters	Nursing home	MMSE NINCDS-ADRDA	MMSE <23 Mild/ moderate/ severe	71–6=65 Female: 84%	70–105 M=87

ADRDA = Alzheimer's disease and related disorders association; ANOVA = Analysis of variance; CAS = Caregiver activity survey; CST = Cognitive stimulation therapy; MANOVA = Multivariate analysis of variance; MMSE = Mini-mental state examination; NINCDS = National institute of neurological and communicable diseases; SD = Standard deviation

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
12 weeks	Aerobic/endurance activities, strength training, balance, and flexibility training	Physical health and function and affective status	Statistically significant improved physical health and reduction in depression in the intervention group	Good quality. Strength: Description of disease. Weakness: Some problems can be found describing interpretation of the outcomes. Many dropouts	1
3 times a week, 30 minutes, 10 weeks	1) Walking individually 2) Conversation	COS, CAS, ANOVA, MANOVA	No statistically significant changes or differences between groups	Power analysis performed before collecting data. Small, non-blinded study	1
24 weeks	1) Walking 2) Conversation 3) Walking + conversation	Functional ability	Walk group declined 20.9% in functional ability, the conversation group declined 18.8% but in combined walking and conversation group it was only 2.5%	High quality study. Strength: Outcome measurements, statistics clear description of disease	2

Table 33.7 *Physical activity interventions (excluded articles).*

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Alessi et al, 1999 [206]	2		
Arkin, 1999 [207]	1	2	4
Binder, 1995 [208]	1	5	
Brill et al, 1995 [209]	1		
Buettner et al, 2002 [210]	2		
Francese et al, 1997 [211]	1	2	
Lazowski et al, 1999 [212]	2	4	
Namazi et al, 1995 [213]	1		
Pomeroy et al, 1999 [214]	2		
Rolland et al, 2000 [215]	1	4	
Thomas et al, 2003 [216]	1	5	
Toulotte et al, 2003 [217]	2		
Wishart et al, 2000 [218]	1	2	

Table 33.8 *Care environment and care programs interventions.*

Author Year Reference Country	**Type of study**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups Range (SD)**
Saxton et al 1998 [84] USA	SCU compared to traditional nursing home	Special care unit (SCU) Tradition. Long-term care	Dementia DSM-III MMSE	MMSE SCU 11.08 (6.11) Nursery home 11.32 (8.26)	45 SCU 26 16 females Controls 19 males 16 females	80–85 years
Wimo et al 1993 [81] Sweden	A multi approach care program in order to improve in psychosocial, orientation and staff load decline. A controlled prospective study	Nursing home	Dementia GDS	Severe	Exp ward 31 81% females Controls 31 77% females	Exp ward 82 (62–96) Controls 83 (63–92)
Wimo et al 1993 [82] Sweden	A prospective concurrent-control study to examine the effect of day care	Day care/ home care	Dementia MMSE	MMSE Day care mean=17.4 (15.5–19.3) Home care mean=17.5 (15.8–19.3)	99 Day care 54 (19 females) Home care 44 (19 females)	Day care 77.9 (76–79.9) Home care 78.6 (77.1–80.5)

Study period	Intervention	Primary outcome	Effects	Remarks from reviewer	Quality of study
18 months 6 months (interviews)	Care at special Alzheimer units. Facilitate home like atmosphere	Changes in cognitive and ADL functions. Retrospective Collateral Dementia Interview. MMSE Functional Independence Measure	Patients at Alzheimer specific units were not different regarding progression and functional status but had a more preserved mobility	Small sample. No details about content of intervention. Gender differences	1 Quality: Low but acceptable Weakness: Small sample Strength: Complementing knowledge about SCU important
10 months	Changes in organisation, environment, special caring philosophy and technique, principle of ICP (individual care planning) Kahn, ADL, SCAG	No effect on the patients' progression. Negative effects were seen in experiment group – more restless, disoriented and ate less	Hypothesis not proven. Despite optimal care, a humanistic approach, support from staff, the progression of dementia symptoms is inevitable	Limited descriptions of environment	1 Quality: Low but acceptable Weakness: Strategic chosen sample and a complex intervention Strength: The intervention was performed over long time and with a "bottom-up" approach
12 months	Day care versus home care	MMSE MDDAS ADL	No significant effect on ADL or cognitive abilities nor on behavior. Reduce stress in informal caregiver, less institutional care	Drop out unclear. Not randomized subjects	1 Quality: Low but acceptable Weakness: Strategic chosen sample and drop outs unclear Strengths: Complementing knowledge about day care important

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Table 33.8 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Volicer et al 1994 [83] USA	Two-year prospective cohort study DSPCU compared to care inspired by an palliative philosophy and traditional care approach	Special care unit (DSPCU) Traditional long-term care	Dementia DSM-III McKahn criteria MMSE	MMSE 1.9 (4.2) DSCU 1.4 (3.0) Trad care 3.1 (5.8)	163 113/50 controls most men	72.3 (8.3) DSCU 71.5 (6.7) Traditional long-term. 74.1 (10.9)

ADL = Activities of daily living; DSCU = Dementia special care unit; DSM-III = Diagnostic and statistical manual of mental disorders, version III; GDS = Geriatric depression scale; MDDAS = Multi dimensional dementia assessment scale; MMSE = Mini-mental state examination; SCAG = Sandoz clinical assessment, geriatric; SCU = Special care unit

Study period	Intervention	Primary outcome	Effects	Remarks from reviewer	Quality of study
2 years	Care at SCU Compared by tradition. Dementia care in institution (trained staff homogen group differ in medical management affiliated to medical school)	Comfort and costs Mortality rate	Patient at DSCU uses less of health care resources and had less discomfort and could be managed at a lower cost. But a higher mortality rate in DSCU	Most men	1 Quality: Low but acceptable Weakness: Complex intervention and gender not registered (only men? In veteran hospital). Strength: Large sample and a clear study design

***Table 33.9** Care environment and care program interventions (excluded articles).*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Annerstedt, 1994 [219]	4		
Benson et al, 1987 [220]	1	2	
Brodaty et al, 2003 [221]	5		
Bråne et al, 1989 [222]	1	4	
Burdz et al, 1988 [223]	2	4	
Burgio et al, 1996 [224]	1	5	
Chafetz, 1990 [225]	3		
Chafetz, 1991 [226]	1		
Cleary et al, 1988 [227]	1		
Cohen-Mansfield et al, 1998 [228]	1		
Coleman et al, 1990 [229]	1	4	
Cornali et al, 2004 [230]	1	4	
Cornbleth, 1977 [231]	2		
DeYoung et al, 2002 [232]	2		
Dickinson et al, 1995 [233]	2		
Dickinson et al, 1998 [234]	1	2	
Gitlin et al, 2001 [235]	2		
Hewawasam, 1996 [236]	1	2	3
Hirsch et al, 1993 [237]	4		
Hoppes et al, 2003 [238]	1		
Hussian et al, 1987 [239]	1	2	4
Hussian, 1988 [240]	1	2	
Ishizaki et al, 2002 [241]	4		
Karlsson et al, 1985 [242]	1		

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Table 33.9 *continued*

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Karlsson et al, 1988 [243]	1	4	
Kihlgren et al, 1992 [244]	1		
Kim et al, 2002 [245]	5		
Kincaid et al, 2003 [246]	1	2	
Kovach et al, 1994 [247]	1	2	
Kovach et al, 1996 [248]	2		
Kovach et al, 1997 [249]	1	4	
Kovach et al, 1999 [250]	2		
Kutner et al, 1999 [251]	1	5	
Lawton et al, 1998 [252]	5		
Lindesay et al, 1991 [253]	1	4	
Logiudice et al, 1999 [254]	2		
Lund et al, 1995 [255]	1		
Lyons et al, 1997 [256]	4		
Malmberg et al, 1993 [257]	2	3	
Mather et al, 1997 [258]	2		
Matthews et al, 1996 [259]	2	4	5
McAuslane et al, 1994 [260]	2		
McDaniel et al, 2001 [261]	1		
McMinn et al, 2000 [262]	1		
Melin et al, 1981 [263]	1	2	
Middleton et al, 1997 [264]	1	5	
Mintzer et al, 1993 [265]	1		
Mintzer et al, 1997 [266]	4		
Moore, 2002 [267]	2	4	

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***Table 33.9** continued*

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Moore et al, 1999 [268]	1		
Namazi et al, 1989 [269]	1	2	
Noreika et al, 2002 [270]	1	2	
Passini et al, 2000 [271]	1	2	
Rader et al, 2003 [272]	1		
Reid et al, 2003 [273]	4		
Schnelle et al, 1999 [274]	4		
Schwarz et al, 2004 [275]	3		
Snyder et al, 2001 [276]	2		
Snyder et al, 2001 [277]	2		
Thomas, 1996 [278]	1		
Warren et al, 2001 [279]	2	4	
Watkins et al, 1997 [280]	1	2	3
Webber et al, 1995 [281]	1	4	
Wells et al, 1987 [282]	1		
Whall et al, 1997 [283]	1		

Table 33.10 *Communication, interaction, and relationship interventions.*

Author Year Reference Country	**Type of study**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups Range (SD)**
Tappen et al 2001 [87] USA	Randomized intervention with 3 treatment groups and 1 control group. Blinded raters	2 long-term care facilities	NINCDS-ADRDA MMSE	MMSE <23 0–23, mean=11.05	55 participants Females: 87%. Lengths of stay at institution 943 days (SD 731)	71–101 mean=87
Dijkstra et al 2002 [88] USA	Intervention, hypotheses testing, randomisation, controlled	Nursing homes (7)	DSM-III, MMSE	Intervention/control 11/11 early (mean=20.9, SD=2.7), 11/11 middle (mean=13.3 SD=2.1), 11/11 late (mean=5.3 SD=2.8)	66 Female: 55 (40 NAs, 21/19)	Mean= 83–86.5 SD= 5.6–6.5

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
3 times weekly for 30 minutes for 16 weeks	1) Conversation 2) Walking 30 min 3) Walking and conversation	Communicative ability: The Picture Description Test, modified ANOVA, chi-square, ANCOVA	No statistically significant change in decline of number of words used in the three groups, but in the conversation group the number of nonredundant information units used was less declined than in the other groups	Good description of the interventions. Wide range of MMSE scores	1
1 hour didactic inservice and 4 weeks criterion-based hands-on training of 40 nursing assistants	Communication-enhancing strategies, use of personalised memory books, training of nursing assistants	Discourse analysis of conversation	Improved discourse characteristics	Clear exclusion criteria. Detailed description of intervention and data analysis. Treatment and control participants at the same unit, blinding difficult. More females in the treatment group	2

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Table 33.10 *continued*

Author Year Reference Country	**Type of study**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups Range (SD)**
Magai et al 2002 [89] USA	Randomized, 1 treatment group and 2 control groups. Hypotheses testing	3 nursing homes	MMSE	Mid-to-late-stage Mean=3.4 (SD 5)	91 Females: 93%	Mean=86 (SD 7.8)
McCallion et al 1999 [85] USA	Cross-over control group	2 skilled nursing homes were intervention group and control group	MMSE, GDS	MMSE: mean=6.3, SD=6.6/ mean=4.9, SD=6.0 GDS: Mild: 5/0 Moderate: 44/56	NAs: 39+49 (37+46 females) Patients: 49 (42 females), 56 (50 females)	Mean=84.5, SD=9.0/ mean=83.3 SD=9.0

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
10 one-hour lessons for staff. Measures at 3, 6, 9, 12 weeks	Nurse case management, systematic and comprehensive support for patients and caregivers (training in sensitivity to nonverbal communication, home visits etc)	BEHAVE-AD CMAI CDS MAX (facial expressions) BSI Staff's reports about patients' depression, agitation, behavior symptoms	No statistically significant effects concerning patient symptomatology	Different etnicity in groups	1
2 weeks, follow-ups: 3 and 6 months (during training), 9 (after training, NAs) months	Nursing Assistant Communication Skills Program (NACSP), Master level social worker	CSDD, CMAI, MOSES, MDS+ (drugs, restraints)	Improvement in well-being among residents	Detailed description is given of the intervention. Units, not nursing assistants are randomly distributed, thus risk of effects of different work climates	1

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Table 33.10 *continued*

Author Year Reference Country	**Type of study**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups Range (SD)**
McCallion et al 1999 [86] USA	Intervention, single-blind, randomized control group design. Hypotheses testing	5 skilled-care nursing homes	MMSE GDS	MMSE: 5.8 (SD 16.3)/ 8.0 (SD 7.1)	66 residents (52 females) and their primary visitors 32 treatment and 34 usual care 65 visitors (53 females)	Residents: 86.4 (SD 5.6) 85.5 (SD 6.7)

ANCOVA = Analysis of covariance; ANOVA = Analysis of variance; BEHAVE-AD = Behavioral pathology in Alzheimer's disease; CDS = Cognitive dysfunction syndrome; CMAI = Cohen-Mansfield agitation inventory; CSDD = Cornell scale for depression in dementia; DMSS = Dementia management and support system; GDS = Geriatric depression scale; GIPB = Geriatric indices of positive behavior; MDS = Minimal data set; MMSE = Mini-mental state examination; MOSES = Multidimensional observation scale for elderly subjects; MPB = Mental problem behavior scale; NINCDS-ADRDA = National institute of neurological and communicable diseases – Alzheimer's disease and related disorders association; SD = Standard deviation; VSQ = Visit satisfaction questionaire

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
6 months Assessments: baseline, 3 months, 6 months	Family visiting education programme, learn deal with problem behavior	Psychosocial function Depression Agitated behavior Psychotropic drugs and physical restraints: MOSES, CSDD, CMAI, GIPB, MPB, DMSS, CHS-M, VSQ	Problem behaviors and symptoms of depression and irritability reduced Improved communication with residents by visitors, reduced use of restraints	Detailed description of education/training program. Blinding difficult. More females in the treatment group	1

Table 33.11 *Communication, interaction, and relationship interventions (excluded articles).*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Andrews Salvia et al, 2003 [1]	1		
Asplund et al, 1995 [2]	1		
Astell et al, 2004 [3]	1	4	
Athlin et al, 1998 [4]	1		
Bird et al, 1995 [5]	1		
Bourgeois, 1990 [6]	1		
Bourgeois, 1992 [7]	1		
Bourgeois, 1993 [8]	1		
Burgio et al, 2001 [9]	4		
Done et al, 2001 [10]	2		
Götestam et al, 1990 [11]	2		
Hart et al, 1997 [12]	1	4	6
Henry et al, 2000 [13]	1	2	
Hoerster et al, 2001 [14]	1		
Jokel et al, 2002 [15]	1		
Martin et al, 2000 [16]	1	2	
Martin Cook et al, 2001 [17]	1	2	
Mattern et al, 1998 [18]	1		
McPherson et al, 2001 [19]	1		
Nolan et al, 2001 [20]	4		
Nolan et al, 2002 [21]	1	3	

The table continues on the next page

Table 33.11 continued

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Normann et al, 2002 [22]	2		
Ousset et al, 2002 [23]	1		
Runci et al, 1999 [24]	1	2	
Sixsmith et al, 1993 [25]	4		
Tappen et al, 2001 [26]	4		
Williams et al, 1999 [27]	3	4	

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Table 33.12a *Special therapies and care activity interventions.*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Lai et al 2004 [92] China	Psychosocial intervention. A single-blinded study with 3 parallel (intervention, control and no-intervention) groups	Nursing home	Dementia MMSE	MMSE 9.3 (SD: 5.4)	101 3 groups (30+35+36) 68% female	85.6 SD: 7.0
Ancoli-Israel et al 2003 [95] USA	Randomized to 2 treatment and one control group, single blind	Nursing home	NINCDS-ADRDA MMSE	Mean: 5.7; SD: 5.6 Range: 0–22	92 (63 females)	Mean: 82.3; SD: 7.6; range: 61–99

Study period	Intervention	Primary outcome	Effects	Remarks from reviewer	Quality of study
6 weeks	Reminiscence program individualistic design-life story – focusing on the past. Promote well-being by use of a specific reminiscence approach. A positive correlation between intervention and outcome was hypothesized	MMSE, ADL- and home care scale. Scale for social engagement (SES) and well-being scale (WIB)	No sign were shown using multivariate showed sign, improvement in intervention group analysis while Wilcoxon sign test for each group/each examination	Well designed study. Interesting control for social interaction. Not randomized sample. Outcome: Low but acceptable Weakness: Complex intervention Strength: Well done study	1
5 years	Morning bright light, morning dim red light, evening bright light	CMAI ABRS	Delayed acrophase of agitation (over 1.5 hours). Physical and verbal agitation was significantly decreased according to nurses' ratings while independent observers registered no decrease	Homogenoeus concerning severity of dementia	1

The table continues on the next page

Table 33.12a continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Teri et al 1997 [93] USA	Intervention towards depressive problems. A controlled clinical trial. Two types of conditions compared to ordinary approaches and patients from waiting list	Community care	Dementia NINCDS-ADRDA DSM-III MMSE Hamilton Depression rating scale. MMSE 16.5 (7.4)		72 females 34 BT-PE 23 females 16 BT-PS 19 females 5 Trad 10 females 6 Waiting list 20 females 7	76.4 (8.4)

ABRS = Agitation behavior rating scale; ADL = Activities of daily living; BT-PE = Behavior therapy – pleasant events; BT-PS = Behavior therapy – problem solving; CMAI = Cohen-Mansfield agitation inventory; DSM-III = Diagnostic and statistical manual of mental disorders, version III; MMSE = Mini-mental state examination; NINCDS = National institute of neurological and communicable diseases; SD = Standard deviation

Study period	Intervention	Primary outcome	Effects	Remarks from reviewer	Quality of study
9 weeks Pre-, post. 6 months follow up	Comparison between 2 behavioral therapies pleasant events, problem-solving and traditional care and patient from waiting list	Impact on depression symptoms in patient with dementia and their caregivers	Patients in both behavioral interventions showed significant improvement in depression symptoms and also at the 6 month follow up. A significant improvement was also seen in the caregivers depressive symptoms compared to the other conditions	Gender differences in the groups. Weakness: Small sample in groups. Strength: rigorous and good design	1

Table 33.12b *Special therapies and care activities (excluded articles).*

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Ancoli Israel et al, 2002 [1]	5		
Bailey et al, 1986 [2]	2		
Baillon et al, 2004 [3]	4		
Baines et al, 1987 [4]	2		
Baker et al, 1997 [5a]	2		
Baldelli et al, 1993 [5b]	3	4	
Ballard et al, 2002 [6]	4		
Bober et al, 2002 [7]	2		
Boehm et al, 1995 [8]	1	4	
Buettner et al, 1996 [9]	1	4	
Buettner et al, 1997 [10]	1	4	
Buettner, 1999 [11]	2	4	
Butts, 2001 [12]	1	6	
Camberg et al, 1999 [13]	2	5	
Cheston et al, 2004 [14]	1		
Churchill et al, 1999 [15]	2	4	
Colenda et al, 1997 [16]	1		
Colling et al, 2002 [17]	1	2	
Cornell, 2004 [18]	1	6	
Cox et al, 2004 [19]	1		
Curtright et al, 2002 [20]	1		
Edwards et al, 2002 [21]	2		

The table continues on the next page

***Table 33.12b** continued*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Ernst et al, 1978 [22]	1		
Fetveit et al, 2004 [23]	1	4	
Fitzsimmons et al, 2002 [24]	2		
Fontana Gasio et al, 2003 [25]	1	5	
Francis et al, 1986 [26]	2		
Graf et al, 2001 [27]	1	5	
Gray et al, 2002 [28]	1	4	
Greene et al, 1983 [29]	2		
Haffmans et al, 2001 [30]	1	5	
Hanley et al, 1984 [31]	1		
Holmes et al, 2002 [32]	1	4	
Hope et al, 2004 [33]	4	5	
Hopper et al, 1998 [34]	1		
Ingersoll Dayton et al, 1999 [35]	1	2	4
Kanamori et al, 2001 [36]	1		
Katsinas, 2000 [37]	1	3	4
Kilstoff et al, 1998 [38]	4	6	
Kim et al, 1999 [39]	4		
Kongable et al, 1989 [40]	1	4	
Koyama et al, 1999 [41]	2		
Krebs Roubicek, 1989 [42]	2	4	
Langland et al, 1982 [43]	2		

The table continues on the next page

Table 33.12b *continued*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Lantz et al, 1997 [44]	3	4	
Lee, 2002 [45]	1		
Libin et al, 2004 [46]	1		
Lovell et al, 1995 [47]	1		
Lucero et al, 2001 [48]	3	4	
Lyketsos et al, 1999 [49]	1		
Mayers et al, 1990 [50]	1	2	
McCabe et al, 2002 [51]	2		
McGovern et al, 1994 [52]	2		
Metitieri et al, 2001 [53]	2	4	
Miller et al, 2001 [54]	1	4	6
Minner et al, 2004 [55]	2		
Mishima et al, 1998 [56]	1		
Mishima et al, 1994 [57]	4		
Moniz Cook et al, 2003 [58]	1		
Moniz-Cook et al, 2001 [59]	1	4	
Morton et al, 1991 [60]	1	2	
Murray et al, 2003 [61]	1	5	
Orsulic Jeras et al, 2000 [62]	1	5	
Orsulic-Jeras et al, 2000 [63]	1		
Orsulic Jeras et al, 2001 [64]	5		
Peak et al, 2002 [65]	1		

The table continues on the next page

***Table 33.12b** continued*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Pulsford et al, 2000 [66]	4		
Rowe et al, 1999 [67]	1	2	
Sansone et al 2000 [68]	2		
Satlin et al, 1992 [69]	1	4	
Scherder et al, 1995 [70]	1		
Scherder et al, 1998 [71]	1		
Schindler et al, 2002 [72]	1		
Schneider et al, 2002 [73]	1		
Seifert et al, 1998 [74]	2		
Shalek et al, 2004 [75]	1		
Smallwood et al, 2001 [76]	1	2	
Snow et al, 2004 [77]	2		
Snyder et al, 1995 [78]	2	3	
Spaull et al, 1998 [79]	2		
Tabourne, 1995 [80]	2		
Tamura et al, 2004 [81]	1		
Thorgrimsen et al, 2002 [82]	1		
Toseland et al, 1997 [83]	2		
Wallis et al, 1983 [84]	2	4	
Walsh et al, 1978 [85]	2		
Walsh et al, 1995 [86]	1	2	
van Diepen et al, 2002 [87]	1		

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***Table 33.12b** continued*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
van Weert et al, 2004 [88]	3	4	
Wareing et al, 1998 [89]	1		
Watson et al, 1998 [90]	1	2	
Wolfe et al, 1996 [91]	1	2	6
Woods et al, 1995 [91,92]	1	2	
Yamadera et al, 2000 [93]	1	4	
Zanetti et al, 1995 [94]	1		
Zisselman et al, 1996 [95]	2		
Åkerlund et al, 1986 [96]	1		

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Table 33.13 *Music and dance interventions.*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Clair 1996 [110] USA	Intervention Singing, reading and silence	Homes	GDS	Severe (Stage 7 of the GDS)	26 22 female 4 males	Range 62–83
Goddaer et al 1994 [109] Belgium	Intervention Quasi-experimental study	Nursing homes	MMSE (0–17) Katz	Moderate to severe	29 23 females (79.3%)	Range 67–93 Mean=83

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
4 days	Unaccompanied, live singing, reading, and silence	Video-recorded sessions T-test	Alert responses were most frequent during singing, with alert responses during reading being the next most frequent. While there were no statistically significant differences between the number of responses during singing and reading, the number of alert responses during singing was significantly lower than for the other conditions	Good quality Strengths: Detailed description of observation Weakness: Small sample	1
4 weeks	Relaxing music sessions	Cohen Mansfield Agitation Inventory was used for evaluation of agitation and aggressive behavior	Significant change on the cumulative incidence of agitated behavior. Total agitation behavior decreased from week 1 to 2 with 54% (.001) and increased again week 3 38.4% and decreased week 4 with 43%	Good quality Strengths: Clear design Weakness: The patients differ in level of dementia	1

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Table 33.13 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Gerdner 2000 [111] USA	Experimental intervention with crossover design	Long-term care	GDS	Severe (Stage 6 of the GDS)	39 30 female (77%) 9 males	Range 70–99 Mean: 82,6
Sherratt et al 2004 [285] United Kingdom	Experimental, within-participants, repeated measures design. Hypothesis testing	Dementia care unit and day care center	MMSE	MMSE 0–19 Moderate to very severe dementia	24 14 male 10 female, 16 continuing care, 7 at day hospital	Range 53–89 Mean: 74.7 SD 8.8

GDS = Geriatric depression scale; MCMAI = Modified Cohen-Mansfield agitation inventory; MMSE = Mini-mental state examination; SPSS = Statistical package for the social sciences; TPAA = Assessment of agitation scale

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
18 weeks	Individualized music and classic relaxation music	Video-recorded sessions The Modified Hartsock Music Preference Questionnaire TPAA MCMAI Bonferroni post hoc test	Significant reduction in agitation during and following individualized music compared to classic music	Good quality Strengths: Good design Weakness: Diversity with respect to gender A nonprobality convenience sample	1
12 weeks	4 conditions: no music, taped commercial music, taped music played by a musician, live music (96 sessions)	Observations and computerprogram (HARCLAG) SPSS Observations such as: meaningful activity, engagement with music source, interaction with music source, wandering, well-being	Live music was increasing time of responding, levels of engagement and well-being. No effect on challenging behaviors	Good quality Strengths: Detailed description of design Weakness: Interaction between staff and patient was not studied	2

Table 33.14 *Music and dance interventions (excluded articles).*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Brotons et al, 1996 [286]	1	4	
Brotons et al, 2000 [106]	3	4	
Brotons et al, 2003 [287]	2		
Casby et al, 1994 [288]	1		
Christie, 1992 [289]	2		
Clair et al, 1990 [290]	1		
Clair et al, 1990 [291]	1		
Clair et al, 1994 [292]	2		
Clair et al, 1995 [293]	2		
Clair et al, 1997 [294]	1	2	
Clair, 2002 [295]	1	2	3
Clark et al, 1998 [105]	1	2	6
Denney, 1997 [296]	1	5	
Gerdner, 1997 [297]	1		
Gerdner et al, 1993 [298]	1	2	
Hanson et al, 1996 [299]	1		
Hilliard, 2001 [300]	1	2	
Hokkanen et al, 2003 [301]	1		
Kydd, 2001 [302]	1		
Lipe, 1991 [303]	1		
Lord et al, 1993 [107]	2	6	
Mathews et al, 2000 [304]	1	2	
Mathews et al, 2001 [305]	1		
Olderog Millard et al, 1989 [306]	1	6	
Otto et al, 1999 [307]	2		

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Table 33.14 continued

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Pollack et al, 1992 [308]	1		
Quoniam et al, 2003 [309]	1	3	
Ragneskog et al, 1996 [310]	1		
Ragneskog et al, 1996 [311]	1	3	
Richeson et al, 2004 [312]	2		
Silber, 1999 [313]	1		
Suzuki et al, 2004 [314]	1		
Tabloski et al, 1995 [315]	2		
Thomas et al, 1998 [316]	1	3	4

Table 33.15 *Multisensory stimulation interventions.*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included	Age-groups Range (SD)
Baker et al 2001 [113] United Kingdom	RCT		MMSE	0–17	25 exp + 25 controls, 50% females	65–79
Baker et al 2003 [116] United Kingdom	RCT MSS group and activity group	Psycho-geriatric 3 countries	MMSE	MMSE 0–17	136 (93 UK, 26 NL, 16 Sweden)	MSS group: mean=81, activity group: mean=83
Jackson et al 2003 [117] United Kingdom	Intervention with control groups	Long-stay care home	CPS + MMSE	Moderate, severe	75 persons 42 in experiment and 33 in control groups	65–96 (mean=83.3) Control (mean=83.5)
Groene II 1993 [108] USA	Randomized controlled experimental study	Special care units	MMSE GDS	Late Moderate to severe (stage 6–7 of the GDS)	30 16 females 14 males	Range 60–91 Median=77,5

ANOVA = Analysis of variance; BRS = Behavior rating scale; CMAI = Cohen-Mansfield agitation inventory; CPS = Cognitive Performance scale; GIP = Behavior rating scale for psychogeriatric inpatients; GDS = Geriatric depression scale; MMS = Mini-mental status; MMSE = Mini-mental state examination; RCT = Randomized controlled trial; REHAB = Rehabilitation evaluation Hall and Baker tool

Study period	**Intervention (end)**	**Measurement**	**Effects (end)**	**Remarks from reviewer**	**Quality of study**
4 months	MSS vs activity (controls) in eight 30-min sessions, 4 weeks	Both MMS and activity sessions effective and appropriate therapies	MMS group showed signs of improvement in mood and behavior at home. No longer-term benefits	Group differences in MMSE	1
MSS twice a week for 4 weeks	MSS group: Standardized MSS-sessions: light and sound effects, materials for touching and smelling	BRS, REHAB (UK), GIP (NL) BMD (UK)	MSS no more effective in short- or long-term	Difficult to interpret intervention: diff in sample and procedure, different caregivers	1
12 weeks	Sonas a PC programme	Cohen-Mansfield (CMAI) RSAB, CPS + MMSE, Notes	No benefit from the use of Sonas on agitation and aggression. Notes certainly suggested an enjoyable activity for experiment group	Good quality Sonas might have other social and psychological benefits	2
15 weeks	Mostly music attention and mostly reading attention sessions	Video recorded sessions MMSE ANOVA test	Participants remained seating to the session area longer time for music sessions than for reading sessions under all conditions. Significant difference between the mean wandering scores during the music sessions versus reading sessions in favor of the music sessions	Good quality Strengths: Clear and good design. Weakness: The patients differ in level of dementia	2

Table 33.16 *Education/training/supervision of staff and supporters interventions.*

Author Year Reference Country	**Type of study**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups Range (SD)**
Gormley et al 2001 [127] Ireland	A behavior management training program for family carers. A randomized controlled trial. Dyad patient-carer	Home care	Dementia MMSE Blessed Dementia Rating Scale	MMSE Experiment group 13.2 (86.7) Controls 13.5 (6.5)	65 Experiment group 34 Controls 28	75.9 Experiment group 75.6 (5.6) Controls 76.3 (5.3)
O´Connor et al 1991 [119] United Kingdom	A study of effects of a multidisciplinary team. Controlled trial	Home care	Dementia MMSE	Mild, moderate, severe	Mild Action 44 (27 female) Control 38 (25 female) Moderate/ severe Action 44 (34 female) Control 35 (20)	Mild Action 85 Control 83.5 Moderate/ severe Action 82.5 Control 84
Bourgeois et al 2002 [128] USA	Experimental study, 2 training groups and 1 control group. Randomized distribution to groups by gender and severity of dementia	Homes	ADRDA-NINCDs, BEHAVE-AD, MMSE	<20 Mean: 7.3–12.4 SD: 6.11–7.7	22+21+20=63 29 females	Mean: 72.3–75.9 SD: 5.2–7.8

Study period	Intervention	Primary outcome	Effects	Remarks from reviewer	Quality of study
8 weeks	Behavioral management program 4 sessions Dementia education Avoidance or modification Appropriate communication Validation and acceptance Distraction techniques	Changes in behavior measured by Aggressive Behavior in the Elderly rating scale Rage and BEHAVE-AD scales before the program started and 2 weeks after	No significant differences between groups A tendency to reduced agitation	Weakness: Small sample Strengths: Well done study	1
24 months	Financial benefits, physical aids, home help, respite admission, practical advise, psychiatric assessment	Admission rate to long term care	No effect on admission for subjects living with supporters. The multi resource team might have identified moderate/severe people with dementia earlier	Patient over 23 in MMSE assessment Quality: Low but acceptable Weakness: Strategic sampling Strength: Large scale study	1
12 weeks, follow-ups: 3 months, 6 months	Patient-focused skills training group; Caregiver-focused skills training group, control group	BEHAVE-AD, OARS (patient ADL)	Reduced problem behavior in both groups	Small groups (20–22) Lower MMSE rates among controls	1

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Table 33.16 *continued*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Brodaty et al 1997 [121] Australia	Prospective, randomized controlled trial and longitudinal follow-up	Homes	MMSE CDRS IADL ADL	17.0 (SD 6.5) 1.1 (SD 0.6) Decline, decline	93 patients/ carers (about 50% male patients)	Patients (70.1 SD 86.6) Carers (67.5 SD 8.0)
Brodaty et al 1989 [118] Australia	Sequential allocation of subjects to treatment and control group	Psychiatric unit, out-patient clinic	DSM-III 2 scales described by Blessed et al 1968 MMSE	MMSE 17–1, the subjects had at the start mild to moderate dementia that progressed during the project's 12 months	96 patient-carer pairs out of 101. 33 in dementia carers' programme, 31 in memory retraining group, 32 in wait list group	50 male, 46 female Age: mean=70.2 (6.5, range 49–79)
Eloniemi Sulkava et al 2001 [126] Finland	Randomized controlled intervention study with 2-year follow-up	Home	DSM-III-R, MMSE	Mild (21/18) Moderate (13/18) Severe (19/11)	100 53 + 47 (26 females) + (27 females)	Intervention/ control mean=78.8 (65–97/80.1) (67–91)

Study period	Intervention	Primary outcome	Effects	Remarks from reviewer	Quality of study
8 years	10 days memory retraining and activity programme for patients and 10 day intensive comprehensive training programme for carers	Length of stay until hospitalization and death	Carer training delayed hospitalization (p=0.037)	Difficult control what happened after training due to long study period, which is also a strength	1
12 months. Reassessment at 3, 6, 12 months and at 18 for wait list group	1) Dementia carers programme: training of carers in coping with difficulties and patients in memory retraining. 2) Memory retraining programme: carers 20 days respite and patients as 1 3) Wait list	Rate of placement of patients in institutions for carers: general health Patients: 1) 2 scales described by Blessed et al 1968 2) Hamilton rating scale for depression 3) Yesavage et al The geriatric depression rating scale 4) Hughes et al Clinical scale for staging of dementia 5) IADL	Dementia carers programme: Delayed placement of patients in institution without increased used of health services by patient or carer. Reduced carer psychological morbidity	Too many scales	1
Follow-ups, 1 year, 2 years	Training of caregivers in nonverbal sensitivity; Behavior placebo; Wait-list	BEHAVE-AD, CMAI, CDS, MAX, BSI	No significant treatment effects	Small sample size	1

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Table 33.16 *continued*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Bellelli 1998 [122] Italy	A specific designed care program in SCU to reduce problematic behavior	Special care unit	Dementia MMSE	Moderate/ severe M=6.1 SD +–5.0 r=0–14	55 Female=78.2%	Mean=81.4 SD+– 8.3 r=54–94
Cohen et al 1999 [123] USA	Evaluation of a Buddy program	3 nursing homes	GDS MMSE		33 with dementia 36 without	
Edberg et al 1996 [120] Sweden	Intervention clinical supervision Quantitative design	Psycho-geriatric clinic	MMSE	Exp ward Moderate 4 Severe 7 Controls Moderate 2 Severe 9	Exp ward 11 (10 females) Controls 11 (10 females)	Exp ward 87 Controls 78

Study period	Intervention	Primary outcome	Effects	Remarks from reviewer	Quality of study
6 months	Design care program for environment and staff- to help staff identify behavioral problem and find possible causes focus on gentle care and non pharmacological treatment 2.5 hours daily of nursing care, 2.1 of activity program every second day routine check by physician	Cognition, function, behavior, health, use of restrain and drugs	Reduction of behavioral problem and reduced use of restrains and drugs	Complex intervention No controls Quality: Low but acceptable Weaknesses: Complex intervention, small sample and no controls Strengths: Complementing knowledge about SCU is important	1
6 months		Cornell Depression Scale for Dementia, CMAI, Modified, the BEHAVE-AD, the Functional Assessment Staging, and the Environmental Satisfaction Scale			1
1 year	Two days course about dementia and dementia care, an individual caring plan. Clinical supervision every 2nd week during 12 months	Morning care observation of patient-nurse interaction was made blind and was later sorted into 10 categories	Significant improvement was seen in experimental ward and indicates a higher quality of nurse-patient cooperation	Small sample, heterogenic groups, new instrument. Long and systematic intervention	1

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Table 33.16 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of de-mentia	Patients (n) included (attrition)	Age-groups Range (SD)
Edberg et al 1999 [124] Sweden	Intervention Quantitative design	Psycho-geriatric clinic	MMSE	Exp ward median= 1.5 Controls median=2	Exp ward 7 Controls 7	Exp ward 87 83–91 (q1–q3) Controls 78 75–82 (q1–q3)
Gitlin et al 2003 [129] USA	Intervention Environmental skill building program for cargivers wellbeing and recipients functioning. A randomized study. Quantitative design	Home care	MMSE	Experiment group 11.6 (7.3) Controls 12.5 (7.1)	Experiment group 89 71.9 females Controls 101 64.4 females	Experiment group 80.2 (8.0) Controls 81.5 (8.0)

Study period	Intervention	Primary outcome	Effects	Remarks from reviewer	Quality of study
1 year	As above	MMSE Organic BrainSyndrome Scale (OBS), Patient Mood Assessment Scale (PMAS), General Behavior Assessment Scale (GBAS), baseline 6 and 12 month	The patient in experimental ward showed benefit in factors sensibility and euphoria but not in factor accessibility	Small sample pilot study	1
6 months	The intervention group received five home contacts and one telephone contact by occupational therapists that provided education, problem solving training, and adaptive equipment	Self-report measures by the caregivers care recipient problem behaviors and physical function and assessment by the family caregiver of ADL/IADL assistance requirement	There were no statistical differences between the two groups	Weakness: Unclear sample Strengths: A randomized study	1

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Table 33.16 *continued*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Bourgeois et al 2001 [125] USA	Randomized, controlled intervention. Comparisons pre and post treatment	7 nursing homes	MMSE	MMSE below 25		125/126 residents/nursing aides (57 in treatment group and 69 as controls)

ADL = Activities of daily living; ADRDA-NINCDS = Disease and related disorders association – National institute of neurological and communicable diseases; BEHAVE-AD = Behavioral pathology in Alzheimer's disease; BSI = Brief symptom inventory; CDRS = Clinical dementia rating scale; CDS = Cognitive dysfunction syndrome; DSM-III = Diagnostic and statistical manual of mental disorders; GBAS = General behavior assessment scale; GDS = Geriatric depression scale; IADL =Instrumental activities of daily living; MAX = Maximally discrimitive facial movement coding system; MMSE = Mini-mental state examination; MMS = Mini-mental status; OARS = Older american resources and services; OBS = Organic brain syndrome scale; PMAS = Patient mood assessment scale; SCU = Special care unit; SD = Standard deviation

Study period	Intervention	Primary outcome	Effects	Remarks from reviewer	Quality of study
4-week baseline, 4-week training, 4-week post-training, 3-month follow-up phase	Training of NAs in use of memory books during communication. Conversations one-to one with residents. MAs and residents increased number or utterances, effect also during post-treatment period. NAs used their skills also with residents not included in the study. Residents had more informative conversation. No increase of quality of life	5-minute observation periods, videotaped	Communication behaviors on NAs and residents (computer assisted measures) and conversational content measures, quality of life measure as measured with a depression scale and improved as assessed by NAs	Intensive skills training of NAs, no detailed description of intervention. Extensive well described analysis of data	1

***Table 33.17** Education, training and supervision of staff and supporters (excluded articles).*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Brodaty et al, 1994 [317]	2	4	
Burgener et al, 1998 [318]	1	4	
Chung, 2001 [319]	3	4	
Cohen-Mansfield et al, 1997 [149]	2		
Ghatak, 1994 [320]	2	3	
Hagen et al, 1995 [321]	2		
Haupt et al, 2000 [322]	1	4	
Hebert et al, 1994 [323]	1		
Hebert et al, 1995 [324]	2		
Huang et al, 2003 [325]	1	2	
Lintern et al, 2000 [326]	1	2	
Mathews et al, 1997 [327]	1		
McCurry et al, 2003 [328]	1		
Mittelman et al, 1996 [329]	2		
Mittelman et al, 2004 [330]	4		
Palmer et al, 1996 [331]	1		
Proctor et al, 1999 [332]	2		
Seltzer et al, 1988 [333]	4	6	
Snyder et al, 1995 [334]	1	6	

Table 33.18 *Combination (multimodal) interventions.*

Author Year Reference Country	**Type of study**	**Setting**	**Dementia diagnosis**	**Severity of dementia**	**Patients (n) included (attrition)**	**Age-groups Range (SD)**
Rovner et al 1996 [131] USA	Randomized controlled clinical trial. A dementia care program to reduce behavior disorders	Nursing home	MMSE	MMSE Experiment group: 9.1 (7.4) Control group: 8.9 (6.1) controls	89 Experiment group 42 86% females Control group 39 67% females	Experiment group: 82 (8.0) Control group: 81.2 (7.2)
Schrijnemaekers et al 2002 [132] The Netherlands	Controlled study Nursing homes prestratified concerning prognostic characteristics before being randomised to control and treatment group. To investigate the effect of emotion-oriented care	Nursing homes and day care units 8 control units, 8 intervention units	Dementia MMSE	Moderate/ severe MMSE Intervention group 10.8 (5.1), controls 11.3 (5.1)	151, 90% females Intervention 77, females, controls 74	84.3 (5.5) Controls 85.9 (5.6)

Study period	Intervention	Measurements	Effects	Remarks from reviewer	Quality of study
6 months	Activity program (A.G.E): Music exercise Guidelines for psychotropic drug. Educational rounds	PGDRS Behavior disorders, use of antipsychotic drugs and restrains. Cognition and level of nursing care. Patient activity level, costs	The A.G.E program reduces the prevalence of behavior disorders use of drugs and restrains	Weakness: Unclear intervention and many subjective judgements were used in evaluation Strengths: Design, patient were rigorously diagnosed	1
12 months	Training program based on emotion-oriented care. Clinical education 2 hours about emotion-oriented care, training program about validation, reminiscence approaches where relation was focused under supervision	Changes in behavioral outcome measures after 3, 6 and 12 months. GIP, GIP 28, GRGS (parts), CMAI-D, ADL	No significance	Tailored supervision for each nursing home Weakness: Unclear intervention Strengths: Design	1

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Table 33.18 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Robichaud et al 1994 [130] Canada	RCT	Long-term care hospital, psycho-geriatric unit of a nursing home, nursing home	DSM-III-R 3MS	3MS (0–100) Study group: 28.9 (15.7), Control: 29.4 (13.7)	22 (SG) 18 (CG)	Study group Mean: 76.6 (5.8) Control mean: 80.1 (7.9)

ADL = Activities of daily living; CG = Caregiver; CMAI = Cohen-Mansfield agitation inventory; DSM-III = Diagnostic and statistical manual of mental disorders; GIP = Behavior rating scale for psychogeriatric patients; GIP 28 = Behavior rating scale for intramural psychogeriatric inpatients; GRGS = Geriatric resident goals scale; MMSE = Mini-mental state examination; 3MS = Modified mini-mental state examination; PGDRS = Psychogeriatric dependancy rating scale; PSBADL = Psychogeriatric scale of basic activities of daily living; PSPADL = Psychogeriatric scale of basic activities of daily living; RCT = Randomized controlled trial; RMBPC = Revised memory and behavior problem checklist; SG = Scale of geriatrics

Study period	Intervention	Measure-ments	Effects	Remarks from reviewer	Quality of study
10 weeks	Ross and Burdick’s five steps: 3 times per week (30–45 min) structured activities and materials	RMBPC PSPADL PSBADL	No sign effect of the Sensory Intergration programme	Small sample	1

Table 33.19 *Combination (multimodal) interventions (excluded articles).*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Alm et al, 2004 [335]	1		
Arakawa-Davies, 1997 [336]	1	2	
Arno et al, 1994 [337]	2		
Aronstein et al, 1996 [338]	2	4	
Ashida, 2000 [339]	1		
Bakke et al, 1994 [340]	4		
Becker et al, 1978 [341]	2		
Berger et al, 2004 [342]	4		
Brinkman et al, 1982 [343]	1	4	
Brooker et al, 2000 [344]	2	4	
Brooker et al, 1997 [345]	1	2	4
Buettner et al, 2003 [346]	1		
Camicioli et al, 1997 [347]	1		
Carruth, 1997 [348]	1	2	
Clark et al, 2004 [166]	2		
Cott et al, 2002 [349]	3	4	
Crispi et al, 2002 [350]	2	4	
Doyle et al, 1997 [351]	1	4	
Fitzgerald Cloutier, 1993 [352]	1		
Gardiner et al, 2000 [353]	1	2	
Goldsmith et al, 1995 [354]	1		
Goldwasser et al, 1987 [355]	1	4	
Greer et al, 2001 [356]	1	2	3
Groene II et al, 1998 [357]	1	2	
Hanley, 1981 [358]	2		

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***Table 33.19** continued*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Heyn, 2003 [359]	1	4	
Holm et al, 1999 [360]	1	2	
Hughes et al, 2000 [361]	4		
Keady et al, 2004 [362]	1		
Keatinge et al, 2000 [363]	1	2	
Kolanowski et al, 2002 [364]	1		
Kruglov, 2003 [365]	4		
Lloyd-Williams et al, 2002 [366]	2		
MacMahon et al, 1998 [367]	1		
Mahendra et al, 2003 [368]	1		
Martichuski et al, 1996 [369]	2		
Matteson et al, 1997 [370]	3	4	5
McEvoy et al, 1986 [371]	1	2	
Nikolaus et al, 1999 [372]	2		
Norberg et al, 1986 [373]	1	2	
Opie et al, 2002 [374]	3	4	
Pinkney, 1997 [375]	1		
Pomeroy, 1993 [376]	1	2	
Qazi et al, 2003 [377]	1	2	
Quayhagen et al, 1989 [378]	1		
Quayhagen et al, 2000 [379]	2		
Remington, 2002 [380]	2		
Riegler, 1980 [381]	2		
Rosewarne et al, 1997 [382]	2		
Savage et al, 2004 [383]	1	2	
Scanland et al, 1993 [384]	2		

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Table 33.19 continued

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Sival et al, 1997 [385]	3	4	
Smith Marchese, 1994 [386]	1		
Snyder et al, 1996 [387]	1	2	
Van de Winckel et al, 2004 [388]	1		
Wilkinson, 1998 [389]	1	6	
Wisner et al, 1986 [390]	1		
Yesavage et al, 1981 [391]	1	2	
Zanetti et al, 1997 [392]	1		

Table 33.20 *Caregiver interaction interventions.*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Jansson et al 1992/1993 [50] Sweden	Intervention, praxis (during intervention)	Geriatric hospital	MMSE Katz	MMSE: 0 Katz: G	Patients: 2 men, 2 women 2 Caregivers: experienced	57, 76, 78, 89
Sandman et al 1988 [133] Sweden	Intervention, qualitative	Psycho-geriatric	Alzheimer DSM–III	Mild, moderate, severe	5	63–80

DSM-III = Diagnostic and statistical manual of mental disorders; MMSE = Mini-mental state examination

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
3 weeks	Morning care, music-listening, rocking in a rocking-chair, having lunch, listening to reading aloud, resting between activities	Pheno-meno-logical hermeneutic interpretation of video-recorded interactions	Patients seemed capable to communicate their experiences to the caregivers	Detailed description of patient reactions No description of caregivers	1
3 weeks, 4 periods	A spec dining room; set of china, cutlery, napkins, dishes and bowls	Video analysis	The least demented patients gave help but dropped the role when caregiver was present. Conversation was incomplete and concerned the present	New findings	1

Table 33.21 *Integrity promoting care interventions.*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Ekman et al 1993 [53] Sweden	Intervention Qualitative methods	Nursing homes, geriatric hospital, health service centres	MMSE GDS Katz Index	3, 3, 5, 6, 7, 13, 16 5, 6, 6, 6, 6, 7, 7 B, D, D, E, E, F, F	7 bilingual patients (females), 16 caregivers (1 male)	Patients: 71–85 years (Mean=74) Caregivers: 15–64 years (Mean=34–35). 2 RNs, 4 LPNs, 10 NAs. Time in dementia care: 1–21 years (Mean=5)
Ekman et al 1995 [135] Sweden	Intervention Qualitative methods	Nursing homes, geriatric hospital, health service centres	MMSE GDS Katz Index	3, 3, 5, 6, 7, 13, 16 5, 6, 6, 6, 6, 7, 7 B, D, D, E, E, F, F	7 bilingual patients (female), 16 caregivers (1 male)	Patients: 71–85 years (Mean=74) Caregivers: 15–64 years (Mean=34–35). 2 RNs, 4 LPNs, 10 NAs. Time in dementia care: 1–21 years (Mean=5)
Kihlgren et al 1994 [51] Sweden	Intervention by training caregivers in integrity promoting care, control group, no randomisation	Nursing home	MMSE ADL	3–10 E–G	5 patients (1 male), 5 caregivers (2 males, 1 EN, 4 NAs)	Patients: 71–90, median=81 Caregivers: 23–45, median=34

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
Single morning care sessions compared	Care by bilingual caregiver Compared with monolingual	Content analysis (mislabelled phenomenological hermeneutic), 2 minutes sequences coded according to the Erikson theory "eight stages of man"	More positive (positive poles coded) and mixed relationships and negative (positive and negative poles coded) together with bilingual caregivers	Detailed description of coding	1
Single morning care sessions compared	Care by bilingual caregiver, compared with monolingual	Content analysis as Ekman 1993, coding according to how caregivers supported positive poles. Factor analysis and graphs of progress of interaction	Bilingual caregivers communicated more multidimensionally and positively than monolingual caregivers	Detailed description of coding	1
Each patient cared by each caregiver (n=25), video-recorded morning care	Training of caregivers in integrity-promoting care according to Erikson's theory "eight stages for man"	Video recorded morning care sessions, coding according to Erikson's theory, content analysis mislabelled as phenomenological hermeneutics	Number of positive interaction patterns increased after intervention	Thick descriptions	1

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Table 33.21 *continued*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Kihlgren et al 1996 [52] Sweden	Intervention by training caregivers in integrity promoting care, control group, no randomisation	Nursing home	MMSE ADL	3–10 E–G	5 patients (1 male) 5 caregivers (2 males, 1 EN, 4 NAs)	Patients: 71–90, median=81 Caregivers: 23–45, median=34

ADL = Activities of daily living; GDS = Geriatric depression scale; MMSE = Mini-mental state examination

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
Each patient cared by each caregiver (n=25), video-recorded morning care	Training of caregivers in integrity-promoting care according to Erikson's theory "eight stages for man"	Video recorded morning care sessions, coding according to Erikson's theory, content analysis mislabelled as phenomenological hermeneutics	Patients disclosed more basic strengths during care of trained caregivers	Detailed descriptions of disclosed basic strengths and weaknesses	1

Table 33.22 *Singing and social dancing interventions.*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Götell et al 2003 [136] Sweden	Intervention Singing and background music	Nursing home SCU	MMSE	Severe (MMSE 0–12)	9 persons 7 females	80–90 years (Mean= 84)
Götell 2003 [137] Sweden	Intervention Singing and background music	Nursing home SCU	MMSE	Severe (MMSE 0–12)	9 persons 7 females	80–90 years (Mean=84)
Palo-Bengtsson et al 1997 [138] Sweden	Intervention Social dancing	Nursing home	DSM-III-R scale (ref from paper 1998) GBS	Moderate to severe	6 2 females (33%)	Range 76–94 (76, 77, 80, 91, 93, 94)

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
3–49 days	Video-recording of morning care sessions	Descriptions on the posture, body movements, and sensory awareness of patients with dementia Qualitative content analysis	Increased body movements and sensory awareness, and awareness of self and environment. Patients appeared to show abilities that had seemed lost	Good quality Weakness: Method description weak	1
3–49 days	Video-recording of morning care sessions	Descriptions on vocally expressed emotions and moods in patients with dementia. Qualitative content analysis	For eight patients enhanced expression of positive emotions and for one patient enhanced expression of negative emotions. Singing most influence	Good quality Weakness: Brief discussion and conclusions	1
8 weeks	45 min social dancing in 5 sessions	Descriptions of interventions used the phenomenological analysis (by Giorgi)	Earlier trained social patterns, old social habits, and general rules seemed awakened and the patients appeared more "normal"	Good quality Strengths: Good descriptions of the analytical method Weakness: Some difficulties are associated with interpreting the data from videotapes	1

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***Table 33.22** continued*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups Range (SD)
Palo-Bengtsson et al 1998 [139] Sweden	Intervention Social dancing	Nursing home	DSM-III-R scale GBS	Moderate to severe	6 2 females (33%)	Range 76–94 (76, 77, 80, 91, 93, 94)

DSM-III = Diagnostic and statistical manual of mental disorders; GBS = Gottfries – Bråne – Steen (scale); MMSE = Mini-mental state examination; SCU = Special care unit

Study period	Intervention (end)	Primary outcome	Effects (end)	Remarks from reviewer	Quality of study
8 weeks	45 min social dancing in 5 sessions	The qualitative content analyses were carried out deductively, using a guide developed from the variables from the GBS scale using evaluation of motor functions, intellectual functions, emotional functions, and dementia symptoms	GBS increased during dancing: Motor, intellectual, and emotional functions, decreased symtoms	High quality Weakness: Few patients due to the qualitative design	2

Table 33.23 *Studies with qualitative methods (excluded articles).*

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Götell et al, 2000 [393]	2	4	
Götell et al, 2002 [394]	3	4	
Kihlgren et al, 1990 [395]	3	6	
Kihlgren et al, 1993 [396]	2		
Nyström, 2002 [397]	2		
Palo-Bengtsson et al, 2002 [398]	3		
Ragneskog et al, 2001 [399]	3	4	

***Table 33.24** Results of the meta-summary.*

Author Year Reference Country	Theory	Intervention	Method
Sandman et al 1988 [133] Sweden	–	Change of caregivers' appearance	Content analysis
Jansson et al 1992/1993 [50] Sweden	–	Sensory stimulation	Hermeneutics
Ekman et al 1993 [53] Sweden	EHE*	Integrity promoting care, use of mother tongue	Content analysis
Kihlgren et al 1994 [51] Sweden	EHE	Integrity promoting care	Content analysis
Ekman et al 1995 [135] Sweden	EHE	Integrity promoting care, use of mother tongue	Content analysis + factor analysis
Kihlgren et al 1996 [52] Sweden	EHE	Integrity promoting care	Content analysis
Palo-Bengtsson et al 1997 [138] Sweden	–	Social dancing	Phenomenological analysis

Themes	Latent ability becomes manifest	Communication, interaction relationship, wellbeing improvements
Cooperation	Yes	No
Level of alertness Moments of lucidity	Yes	Yes
Integrity** Moments of lucidity	Yes	Yes
Integrity* Moments of lucidity	Yes	Yes
Integrity* Moments of lucidity	Yes	Yes
Basic strengths*** Moments of lucidity	Yes	Yes
Moments of lucidity	Yes	Yes (communion)

The table continues on the next page

Table 33.24 continued

Author **Year** **Reference** **Country**	**Theory**	**Intervention**	**Method**
Palo-Bengtsson et al 1998 [139] Sweden	–	Social dancing	Content analysis
Williams et al 1999 [400] USA	Peplau's nursing theory****	Conversation sessions	Content analysis
Götell et al 2003 [136] Sweden	–	Background music Caregiver singing	Content analysis
Götell 2003 [137] Sweden	–	Background music Caregiver singing	Content analysis

* Erikson EH. The life cycle completed: a review. New York: WW Norton & Co; 1982.
** Integrity: trust, autonomy, initiative, industry, identity, intimacy, generativity, integrity according to Erikson EH (1982).
*** Wisdom: hope, will, purpose, competence, fidelity, love, care, wisdom according to Erikson EH (1982).
**** Peplau HE. Interpersonal relations in nursing: A conceptual frame of reference for psychodynamic nursing. New York: Springer; 1991. Original work published in 1952. Peplau HE. Peplau's theory of interpersonal relations. Nurs Sci Q 1997;10:162-7.

Themes	Latent ability becomes manifest	Communication, interaction relationship, wellbeing improvements
Moments of lucidity Decreased confusion	Yes	Yes
Decreased: Resistance to relationship Anxiety Low self-esteem	No	Yes
Balance and sensory awareness Physical strength and body symmetry Use of space Caregivers helping patient's life in their bodies	Yes	Yes
Emotions, moods, and vitality contribution	Yes	Yes

***Table 33.25** Different scales used in studies on dementia – patient’s perspective.*

Name of scale	Reference
Activities of Daily Living (ADL)	Katz S, Apkom CA. A measure of primary sociobiological functions. Int J Health Serv 1976;6:493-507.
Adaptive Behavior Rating Scale (ABRS)	Ward T, Murphy E, Procter A. Functional assessment in severely demented patients. Age Aging 1991;20;212-6.
Agitated Behavior Rating Scale (ABRS)	Bliwise DL, Lee KA. Development of an agitated behavior rating scale for discrete temporal observation. J Nurs Meas 1993;1:115-24.
Agitation Self Efficacy Scale	Corrigan JD, Bogner JA, Tabloski PA. Comparison of agitation associated with Alzheimer’s disease and aquired brain injury. Am J Alzheimers Dis 1996;11:20-4.
Aggressive Behavior in the Elderly and Behavior Rating Scale	Mungas D, Weiler P, Franzi C, Henry R. Assessment of disruptive behavior associated with dementia: the Disruptive Behavior Rating Scales. J Geriatr Psychiatry Neurol 1989;2:196-202.
Alzheimer’s Disease Assessment Scale (ADAS)	Schwarb S, Koberle S, Spiegel R. The Alzheimer’s Disease Assessment Scale (ADAS): An instrument for early diagnosis of dementia? Int J Geriatr Psychiatry 1988;3:45-53.
Barthel Index	Mahoney RI, Barthel DW. Barthel Index (BI). Professor Surya Shah, School of Health, University of Teesside, Middlesbrough, TS1 3BA, UK; 1965.
Barthel Self Care Rating Scale (Barthel)	Mahoney F, Barthel DW. Functional evaluation: The Barthel Index. Md State Med J 1965;14:61-5.
Bedford Alzheimer Nursing Severity Scale (BANS-s)	Volicer L, Hurley AC, Lathi DC, Kowall NW. Measu-rement of severity in advanced Alzheimer´s disease. J Gerontol 1994;49:223-6.

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Table 33.25 *continued*

Name of scale	Reference
Behavioral Pathology in Alzheimer's Disease (BEHAVE-AD) rating scale	Reisberg B et al. BEHAVE-AD: A clinical rating scale for the assessment of pharmacologically remediable behavioral symptomatology in Alzheimer's disease. Altman, Harvey J (Ed). Alzheimer's disease: Problems, prospects, and perspectives (pp 1–16). New York, NY, US: Plenum Press. xiii, 397;1987.
Behavioural Observation Scale for Intramural Psychogeriatry (BIP)	Hopman-Rock M, Staats PG, Tak EC, Droes RM. The effects of psychomotor activation programme for use in groups of cognitively impaired people in homes for the elderly. Int J Geriatr Psychiatry 1999;14:633-42.
Berg Balance Scale	Maki BE, Holliday PJ, Topper AK. Fear of falling and postural performance in the elderly. J Gerontol 1991;46:123-31.
Blandford Scale	Blandford G, Watkins L, Mulvihil MN. Assessing abnormal feeding behavior in dementia: a taxonomy and initial findings. In: Velas B, Riviere S, Fitten J (eds). 1998 Weight loss & eating behavior in Alzheimer´s patients. Research and Practice in Alzheimer Disease, Paris: SERDI, 49-66.
Boston Aphasia Diagnostic Evaluation (BANS)	Goodglass H, Kaplan F. In Lea & Febinger. The assessment of aphasia and related disorders. Philadelphia 1972.
Brief Symptom Inventory (BSI) (for caregivers)	Anthony-Bergstone CR, Zarit SH, Gatz M. Symptoms of psychological distress among caregivers of dementia patients. Psychol Aging 1988;3:245-8.
Caregiving Hassles Scale (CHS-M)	Kinney J, Stephens M. Caregiving Hassles Scale. Assessment of daily hassles of caring for a family member with dementia. Gerontologist 1989;29: 328-32.
Caregiver Activity Survey (CAS)	Davis KL, Marin DB, Kane R, Patrick D, Peskind ER, Raskind MA et al. The Caregiver Activity Survey (CAS): development and validation of a new measure for caregivers of persons with Alzheimer's disease. Int J Geriatr Psychiatry 1997;12:978-88.

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***Table 33.25** continued*

Name of scale	Reference
Clifton Assessment Procedures for the Elderly-Behavior Rating Scale (CAPE-BRS)	Moran SM, Cockram LL, Walker B, McPherson FM. Prediction of survival by the Clifton Assessment Procedures for the Elderly (CAPE). Br J Clin Psychol 1990;29:225-6.
Clinical Dementia Rating (CDR)	Rockwood K Strang D, MacKnight C, Downer R, Morris JC. Interrater reliability of the Clinical Dementia Rating in a multicenter trial. J Am Geriatr Soc 2000;48:558-9.
Clinical Dementia Rating Scale (CDRS)	Hughes CP, Berg L, Danziger WL, Coben LA, Martin RL. A new clinical scale for staging of dementia. Br J Psychiatry 1982;140:566-72.
Clinical Dementia Rating Scale (CDRS)	Burke WJ, Houston MJ, Boust SJ, Roccaforte WH. Use of the Geriatric Depression Scale in dementia of the Alzheimer type. J Am Geriatr Soc 1989;37:856-60.
Cognitive Performance Scale	Morriss RK, Rovner BW, Folstein MF, German PS. Delusions in newly admitted residents of nursing homes. Am J Psychiatry 1990;147:299-302.
Cohen-Mansfield Agitation Inventory (CMAI)	Cohen-Mansfield J, Marx MS, Rosenthal AS. A description of agitation in a nursing home. J Gerontol 1989;44:77-84.
Cornell Scale for Depression in Dementia (CSDD)	Kurlowicz LH, Evans LK, Strumpf NE, Maislin G. A psychometric evaluation of the Cornell Scale for Depression in Dementia in a frail, nursing home population. Am J Geriatr Psychiatry 2002;10:600-8.
Daily Living Assessment, Minimal-Data-Set Home Care (MDS–HC)	Hirdes J. Commentary on the proposed Common Assessment Instrument (CAI) for long term services. Canada: Research Department and Canadian Collaborating Center; 1996.
Dementia care Mapping (DCM)	Bradford Dementia Group. Evaluating dementia Care: The DCM method (7th ed) Bradford, UK: Bradford University; 1997.

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***Table 33.25** continued*

Name of scale	**Reference**
Dementia Management Strategies Scale (DMSS)	Hinrichsen GA, Niederehe G. Dementia management strategies and adjustment of family members of older patients. Gerontologist 1994;34:95-102.
Depressive Sign Scale	Katona C, Aldridge CR. The dexamethasone suppression test and depressive sign in dementia. J Affect Disord 1985;8:83-9.
Discomfort Scale for Patient with Advanced DAT (DS-DAT)	Hurley AC, Volicer BJ, Hanrahan PA, Houde S, Volicer L. Assessment of discomfort in advanced Alzheimer patients. Res Nurs Health 1992;15:369-77.
Disruptive Behavior Scale (DBS)	Beck C et al. Assessing disruptive behavior in older adults: The disruptive behavior scale. Aging Ment Health 1997;1:71-9.
Environment Satisfaction Scale (ES)	Kane RA, Kane RL. Term Care: Principles, Programs, and Policies. New York: Springer Publishing Company; 1987.
Functional Assessment Staging of Dementia (FAST)	Reisberg B, 1988. In: Burns A, Lawlor B, Craig S. Assessment scales in old age psychiatry. London Martin Dunitz. p 164-65; 1999.
Functional Independence Measure (FIM)	Granger CV, Hamilton BB. The Uniform Data System for Medical Rehabilitation report of first admission. Am J Phys Med Rehabil 1992;73:51-5.
General Health Questionnaire	Goldberg DP, Hillier VF. In Burns A, Lawlor B, Craig S. Assessment scales in old age psychiatry. London Martin Dunitz. p 246-47; 1999.
Geriatric Resident Goals Scale (GRGS)	Cornbleth T. Evaluation of goal attainment in geriatric settings. J Am Geriatr Soc 1978;26:404-7.
GIP (Dutch Behaviour Observation Scale for Psychogeriatric Patients)	Verstraten PF. The GIP: an observational ward behavior scale. Psychopharmacol Bull 1988;24: 717-9.
Hamilton Rating Scale for Depression	Hamilton M. A rating scale for depression. J Neurol Neurosurg Psychiatry 1960;23:56-62.

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Table 33.25 *continued*

Name of scale	Reference
Holden Communication Scale	Holden UP, Woods RT. Positive approaches to dementia care (3rd ed). Edinburgh: Churchill Livingstone; 1995.
Instrumental Activities of Daily Life (IADL)	Lowton M, Brody E, 1969. In Burns A, Lawlor B, Craig S. Assessment scales in old age psychiatry. London Martin Dunitz. p 128-29; 1999.
INTERACT	Baker R, Dowling Z. INTERACT. A new of response to multi-sensory environment. Research Publ. Research and Development Support Unit, Poole Hospital, Dorset.
Kahn's test	Kahn RL, Goldfarb AI, Pollack M, Peck A. Brief objective measures for the determination of mental status in the aged. Am J Psychiatry 1960;117:326-8.
Knowledge of Alzheimer Test (KAT)	Maas ML, Hardy MA, Craft M. Some methodologic considerations in nursing diagnosis research. Nurs Diagn 1990;1:24-30.
Maximally Discrimitive Facial Movement Coding System (MAX)	Izard C. The maximal discriminative facial movement coding system. Instructional Resource Center Uni-versity of Delaware, Newark, Delaware; 1979.
Mattis Dementia Rating Scale	Mattis S et al. Assessment scale in old age psychiatry. London. Martin Dunitz. p 26-28; 1999.
MDDAS (Multi-Dimensional Dementia Assessment Scale)	Sandman PO, Adolfsson R, Norberg A, Nystrom L, Winblad B. Long-term care of elderly. A descriptive study of 3 600 institutionalized patients in the county of Vasterbotten, Sweden. Compr Gerontol A 1988;2:120-33.
Mini-Mental State Examination (MMSE)	Folstein M, Folstein S, McHugh PR. Mini-Mental State: a practical method for grading the cognitive state of patients for the clinicians. J Psychiatr Res 1975;12:189-98.

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Name of scale	Reference
Mini-Nutritional Assessment (MNA)	Guigoz Y, Vellas B, Garry PJ. Mini Nutritional Assessment: A practical assessment tool for grading the nutritional state of elderly patients. Facts Res Gerontol 1994;4:(suppl 2)113-43.
Multidimentional Observation Scale for Elderly Subjects (MOSES)	Helmes E, Csapo K-G, Short JA. Standardization and Validation of the Multidimensional Observation Scale For Elderly Subjects. J Gerontol 1987;42:395-405.
Nursing Stress Scale (NSS)	French SE, Lenton R, Walters V, Eyles J. An empirical evaluation of an expanded Nursing Stress Scale. J Nurs Meas 2000;8:161-78.
Observable Displays of Affect Scale (ODAS)	Vogelpohl TS, Beck CK. Affective responses to behavioral interventions. Seminars in Clinical Neuropsychiatry 1997;2:102-12.
Older Americans Rescores and Services Multidimentional Functional Assessment Questionnaire (OARS)	Fillenbaum GG, Smyer MA. The development, validity and reliability of the OARS multidimensional functional assessment questionaire. J Gerontol 1981;36:428-34.
Organic Brain Syndrome Scale (OBS)	Jensen E, Dehlin O, Gustafson L. A comparison between three psychogeriatric rating scales. Int J Geriatr Psychiatry 1983;8:215-29.
Penn State Mental Health Questionnaire (MHQ)	Spore DL, Smyer MA, Cohn MD. Assessing nursing assisstents knowledge of behavioral approaches to mental health problems. Gerontologist 1991;31: 309-17.
Philadelphia Geriatric Center Morale Scale (PGC)	Lawton MP, 1972. In Burns A, Lawlor B, Craig S. Assessment scales in old age psychiatry. London Martin Dunitz. p 268-69; 1999.
Positive Visual Analogue Scale	Wewers ME, Lowe NK. A critical review of visual analogue scales in the measurement of clinical phenomena. Res Nurs Health 1990;13:227-36.

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Name of scale	Reference
QoL-AD	Hoe J, Katona C, Roch B, Livingston G. Use of the QoL-AD for measuring quality of life in people with severe dementia, the LASER-AD study. Age Ageing 2005;34:130-5.
Rating Anxiety in Dementia (RAID)	Shankar K et al. Development of a valid and reliable scale for anxiety in dementia. Aging Ment Health 1999;3:39-49.
Ratings scale for aggressive behavior in the elderly (RAGE)	Patel V, Hope RA. A rating scale for aggressive behavior in the elderly – the RAGE. Psychol Med 1992;22:211-21.
Record of Independent Living (RIL)	Weintraub MI. Computer-assisted communication. Arch Neurol 1982;39:740.
Rehabilitation Evaluation Hall and Baker tool (REHAB)	Baker R, Hall JN. Rehab: a new assessment instrument for chronic psychiatric patients. Schizophr Bull 1988;14:97-111.
Resident Assessment Instrument (RAI) include Well-being/Ill-being Scale (WIB)	Morris JN, Fries BE, Steel K, Ikegami N, Bernabei R, Carpenter GI, et al. Comprehensive clinical assessment in community setting: applicability of the MDS-HC. J Am Geriatr Soc 1997;45:1017-24.
Resources Utilization Groups (RUGS-II)	Foley WJ. Dementia among nursing home patients. Defining the conditions, characteristics of the demented, and dementia on the RUGS-II classification system. Troy, NY: Rensselaer Polytechnic Institute; 1986.
Retrospective Collateral Dementia Interview (CDR)	Washingon University Alzheimer Center St. http://www.alzheimer.wustl.edu/adrc2/
Revised Memory and Behavior Problem Checklist (RMBPC)	Teri L, Truax P, Logsdon R, Uomoto J, Zarit S, Vitaliano PP. Assessment of behavioral problem in dementia: the revised memory and behavior problems checklist. Psychol Aging 1992;7:622-31.

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***Table 33.25** continued*

Name of scale	**Reference**
Robinson Five Step Scale	Robinson RA. Some problems of clinical trail in the elderly people. Gerontol Clin 1961;3:247-57.
Sandoz Clinical Assessment Geriatric Scale (SCAG)	Shader R, Harmatz J, Salzman C. A new scale for clinical assessment in geriatric population (SCAG). J am Geriatr Soc 1974;22:107-13.
Schedule for Affective Disorders and Schizophrenia (SADS)	Endicott J, Spitzer RL. A diagnostic interview: the schedule for affective disorders and schizophrenia. Arch Gen Psychiatry 1978;35:837-44.
Sheltered Care Environment Scale (SCES)	Lempke S, Moos RH. Validity of the Sheltered Care Environment Scale: conceptual and methodological issues. Psychol Aging 1990;5:569-71.
Sickness Impact Profile (SIP)	Bergner M, Bobbitt RA, Pollard WE, Martin DP, Gilson BS. The sickness impact profile: validation of a health status measure. Med Care 1976;14:57-67.
The Apparent Affect Scale (AARS)	Lawton MP et al. Observed affect and quality of life in dementia: further affirmations and problems. J Ment Health Aging 1999;5:69-81.
The Beck Depression Inventory (BDI)	Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. Arch Gen Psychiatry 1961;4:561-71.
The Behaviour and Mood Disturbance Scale (BMD)	Wyatt R, Kupfer DJJ. A fourteen-symptom behavior and mood rating scale for longitudinal patient evaluation by nurses. Psychol Rep 1968;23:1331-4.
The behavior rating scale for intramural psychogeriatric inpatients (GIP-28) in homes for the elderly	Eisses A-M, Kluiter H. De gedragsobservatieschaal voor de intramurale psychogeriatrie (GIP-28) in het verzorgingshuis. Een psychometrische evaluatie. [The behavior rating scale for intramural psychogeri-atric inpatients (GIP-28) in homes for the elderly. A psychometric evaluation]. Tijdschr Gerontol Geriatr 2002;33:112-8.

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Table 33.25 *continued*

Name of scale	Reference
The Cumulative Illness Rating Scale (CIRS)	Parmelee PA, Thuras PD, Katz IR, Lawton MP. Validation of the Cumulative Illness Rating Scale in a geriatric residential population. J Am Geriatr Soc 1995;43:130-7.
The Dementia Scale	Blessed G et al, 1968. In Burns A, Lawlor B, Craig S. Assessment scales in old age psychiatry. London Martin Dunitz. p 40–41; 1999.
The General Behaviour Assessment Scale (GBAS)	Hallberg IR, Norberg A. Strain among nurses and their emotional reactions during 1 year of systematic clinical supervision combined with the implementation of individualized care in dementia nursing. J Adv Nurs 1993;18:1860-75.
The Geriatric Depression Scale (GDS)	Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey M. Development and validation of a geriatric depression screening scale: a preliminary report. J Psychiatr Res 1982;17:37-49.
The Medical Outcome Study 36-item Short Form Health (SF-36)	Ware JE, Sherbourne CD. The MOS 36-item short-form health survesurvey (SF-36). Med Care 1992;30:473-83.
The Orientation, Information, Memory, Concentration Scale (IMC) included in The Dementia Scale	Blessed G et al, 1968. In Burns A, Lawlor B, Craig S. Assessment scales in old age psychiatry. London Martin Dunitz. p 40-41; 1999.
The Patient Mood Assessment Scale (PMAS)	Hallberg IR, Norberg A. Strain among nurses and their emotional reactions during 1 year of systematic clinical supervision combined with the implementation of individualized care in dementia nursing. J Adv Nurs 1993;18:1860-75.
The Picture Description Test	Bayles KA, Tomoeda CK. Caregiver report of prevalence and appearance order of linguistic symptoms in Alzheimer´s patients. Gerontologist 1991;31:210-6.

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Table 33.25 continued

Name of scale	**Reference**
The Picture Description Test, modified	Benton AL, Elithorn A, Fogel ML, Kerr M. A Perceptual Maze Test Sensitive to Brain Damage. J Neurol Neurosur Psychiatry 1963;26:540-4.
The Psychogeriatric Dependency Rating Scale (PGDRS)	Wilkenson IM, Graham-White J. Psychogeriatric dependency rating scale: A method of assessment for use by nurses. Br J Psychiatry 1980;137:558-65.
The Psychogeriatric Scale of basic Activities of Daily Living (PSBADL)	Gauthier L, Gauthier S. Assessment of functional changes in Alzheimer's disease. Neuroepidemiology 1990;9:183-8.
The Quality of Life – Alzheimer´s Disease Scale (QoL-AD)	Logsdon R, et al. Quality of life in Alzheimer's disease: patient and caregiver reports. J Ment Health Aging 1999;5:21-32.
The Social Engagement Scale (SES)	Mor V, et al. The structure of social engagement among nursing home residents. J Gerontol Psychological Services 1995;50:1-8.
The Zarit Burden Inventory (BI)	Zarit SH, Reever KE, Bach-Peterson. Relatives of the impaired elderly: correlates of feeling of burden. Gerontologist 1980;20:649-55.
Visit Satisfaction Questionnaire (VSQ)	McCallion P, Toseland RW, Freeman K. An evaluation of a family visit education program. J Am Geriatr Soc 1999;47:203-14.
Visual Analogue Scale	Lee K, Hicks G, Nino-Murcia G. A visual analogue scale to evaluate fatigue severity. Psychiatry Res 1989;36:291-8.
Wechsler Memory Scale	Ryan JJ, Morris J, Yaffa S, Peterson L. Test-retest reliability of the Wechsler Memory Scale. Form I. J Clin Psychol 1981;37:847-8.
Well-being/Ill-being Scale (WIB)	Bowling A. Measuring Health: A Review of Quality of Life Measurement Scales. Open University Press: Milton Keynes, UK; 1992.

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Table 33.25 continued

Name of scale	Reference
Y-scale Nursing Load Scale	Wimo A, et al. A nursing load scale for the home nursing care in the county of Västernorrland, Sweden. Validity and Reliability. FoU report 25, Research Unit of Primary Health care, Sundsvall; 1991.
Zung Self Rating Depression Scale	Zung WW, Durham NC. A Self-Rating Depression Scale. Arch Gen Psychiatry 1965;12:63-70.

Table 33.26 *Specific interventions with effect on different care problems.*

Intervention	Effect
Cognitive rehabilitation and training	
Cognitive stimulation therapy group	* Cognition and quality of life [70]
Psychomotor activation programme	* Cognition and non-social behavior [76]
Functional performance interventions	
ADL rehabilitative care	* Increased activity and independence in performing dressing sub-tasks, a decrease of disruptive behavior. Caregiver time doubled [1]
Activities of daily living, psychosocial activity, and a combination	* Increased positive affects but no decrease in negative affects [71]
Nutritional education program/ nutritional supplement	* Increased weight [72,73]
Physical activity	
Planned walk	* Increased communication ability [75]
Psychomotor activation programme	* Cognition and non-social behavior [76]
Walking combined with	* Maintaining functional ability [77]
Home-based exercise program	* Physical health and decreased depression [79]
Care environment and care program	
Day care	* Postponed institutionalization by relief for spouses [82]
Dementia special care units	* Less patient discomfort, and lower costs [83] * Mobility better preserved [84]

The table continues on the next page

***Table 33.26** continued*

Intervention	Effect
Communication, interaction and relationship interventions	
Education to communicate and use of memory books	* Well-being, as was a greater decrease in behavioral disturbances and symptoms of depression [85] * Visitors improved in communication. Residents' problem behaviors, symptoms of depression, and irritability decreased [86] * Improved quality of the conversations [88]
Conversation and exercise	* Improved conversation [87]
Training caregivers in nonverbal communication	* Increased positive affect and a decline of negative affect [89]
Change of caregivers' appearance	* Patients with less degree of dementia helped co-patients when no nurse was available and one patient even when the nurses were dressed in civil dresses [133]
Sensory stimulation	* Increased communication [50]
Integrity promoting care	* Increased positive communication, interaction and relationship, complex qualities of the patient's personality preserved, latent competencies appears [51–53,135]
Use of mother tongue	* Decreased problems to communicate and less difficulties to create a positive relationship, latent competencies appears [53,135]
Special therapies and care activities	
Reminiscence therapy	* Increased psychosocial well-being [92]
Behavioral therapy	* Decreased depression [93]
Light therapy	* Decreased agitation [95]

The table continues on the next page

Table 33.26 *continued*

Intervention	**Effect**
Music and dance	
– Music therapy	* Decrease wandering [108]
– Relaxing music	* Decreased agitation [109]
– Unaccompanied, live singing	* Increased alert responses [110]
– Individualized music	* Decreased agitation and confusion [401]
– Life music listening	* To increase the levels of engagement and well-being [112]
– Caregiver singing and background music	* Effects on posture, movement, and sensory awareness and larger degree of mutuality in the interaction [136] * Vocally expressed emotions and moods [137]
– Social dance	* Increased communication and interaction, higher awereness, support intellectual, emotional, and motor functions [138,139]
Multisensory stimulation	* Decreased behavior symptoms, increased mood and cognition [113]
– Sonas using music, (gentle exercises, taste, scents, and massage)	* Decreased agitation and aggression [117]
– Sensory stimulation	* Higher alertness [50]
Education/training/supervision of staff and supporters	
Training group programme	* Increased ward activities [118] * Delayed institutionalization [121]
Clinical supervision	* Higher quality of nurse-patient cooperation [120]
A special design care program	* Reduction in behavioral problems, psychotropic drugs, and use of restraints [122]
Trained to use memory aides	* Qualitative improvement in conversation [125]
Program of systematic, comprehensive support with a dementia family care coordinator	* Delayed institutionalization [126]
Patient-focused skills training	* Reduced problem behavior [128]

Table 33.27 *Specific care problems and choice of interventions.*

Intervention	**Effect**
Cognitive dysfunction	* Cognitive function improved after cognitive stimulation therapy groups [70] * Implementation of a psychomotor activation programme [76]
ADL function	* Improved after individualized skill elicitation and habit training of morning care [1] * Fast-gait time after moderate-intensity strength training [78] * Assisted walking with conversation [77] * Multisensory stimulation and activity group [113] * Unaccompanied, live singing, listening to reading and during silence [110] * Social dancing [138,139] * Change in caregivers' appearance [133] * Singing [110,136,137]
Physical health	* Physical health improved by exercise training combined with teaching caregivers behavioral management techniques [79] * Weight gain was noted after educating staff about nutrition and giving oral fluid supplement to patients [73]
Behavior symptoms	* Education of nursing assistants to communicate more effectively and to use memory books [85] * Training of family visitors [86] * Individualized skill elicitation and habit training of morning care [1] * Adjusting the environment and giving specific training to staff to help them identify behavioral problems [122] * Psychomotor activation programme [76] * Music [108,111] * An AGE dementia care program consisting of, eg, music, exercise, crafts relaxation, reminiscence, word game, food preparation, drug management, and education rounds [131] * Relaxing music [109] * Training caregivers in patient-focused skills on perception of patient behavior [128] * Bright light therapy [95] * Day care [82]

The table continues on the next page

***Table 33.27** continued*

Intervention	Effect
Institutionalization	* Support of a dementia family care coordinator [126] * A dementia carers' training programme [118,121] * Offered practical help [119]
Communication, interaction, relationship difficulties	* Walking program [75] * Conversation [77,87] * Caregiver's use of patient's mother tongue [53,135] * Training of personnel in integrity promoting care [51,52] * During background music listening and caregiver singing [136,137] * Social dancing [138,139] * Teaching nursing assistants to use effective communication techniques and memory book [88,125] * Clinical supervision of staff [120] * Multisensory stimulation [50,113] * Dressing skill elicitation, and habit training [1]
Low quality of life, discomfort	* Sessions in both the multisensory stimulation and activity groups [113] * Training staff in nonverbal communication [89] * Educating nursing assistants to communicate more effectively and to use memory books [85] * Educating and training family visitors [86] * Cognitive stimulation therapy [70] * Music listening [112] * Behavioral treatment emphasizing pleasant events [93] * Teaching caregivers behavioral management techniques [79] * Behavioral interventions (activities of daily living, psychosocial activity, and a combination) [71] * Care in dementia special care units [83] * Reminiscence program [92] * Being cared by a nurse speaking patients' native language [53,135] * Caregiver singing [136,137] * Integrity promoting care [51,52] * Multisensory stimulation [117]

Appendix 33.1 Manual for evaluation of articles using qualitative methods

Evaluation Rating Scale

0 = not acceptable (relevant information is missing or is reported in an inadequate way)
1 = low but acceptable quality (relevant information is reported in a correct way)
2 = medium or high quality (relevant information is reported in a correct, clear, logical, and critical way)
3 = not relevant (in relation to perspective, research question, method, etc).

The evaluations of all aspects in each article are weighed to form an evaluation of the article as a whole.

Perspective/theory

The article clearly describes the theoretical perspective and how it relates to the research question. The article also describes the type of knowledge that the researcher is searching for (eg, description, understanding, explanation).

Research question

The article states the research question, and the question is congruent with the chosen perspective/theory. The chosen method and research participants have the potential to answer the research question.

The research question is grounded in a literature review that is adequate for the chosen method, addressing perspective (eg, critical theory), type of knowledge (eg, knowledge of understanding), and research area (eg, people with advanced Alzheimer's disease). When referring to literature on types of knowledge other than that sought, the article describes how this literature is used, eg, to add another dimension to the main research focus.

Design (intervention)

Interventions are designed to be relevant in relation to the research question and are described clearly so that it is possible to evaluate their effects. Effects are evaluated within the chosen type of knowledge, eg, opinion versus understanding, and effects of care derived from a particular theory are evaluated in relation to that theory.

Setting

Choice of setting (context) is described and relevant to the research question, and it enhances the interpretation and understanding of the results. The article describes aspects of the setting that are important in answering the research question (eg, care organization, educational level of staff, caregiver-patient ratio, cultural and religious factors). If more than one setting is used, the article describes how the settings are comparable. Adequate description of the setting is a prerequisite for transferring the knowledge to another context.

Participants

The selection of participants is described and relevant in relation to the research question (eg, participants have had the experiences, or performed the actions, studied) and method (eg, theoretical cumulative selection of participants when grounded theory method is used). The article describes participants' characteristics (eg, gender, ethnicity, age, dementia diagnosis, extent of cognitive impairment, type of care) and describes and evaluates dropout in relation to chosen method.

Data collection

Methods of data collection and registration are described and relevant to the research question and method of analysis. If the researcher modifies the methods of data collection during the study, the article notes how, when, and why this was done. If more than one method is used, each one is evaluated separately. The methods should be adequate for the aim of the study (eg, different interviews depending on if depth or width is sought). The article describes the scope and depth of data (eg, number of words, pages, citations) and the quality of data (eg, technical problems, problems in establishing contact with interviewees).

Data analysis/interpretation

Methods of data analysis and interpretation are described and relevant to the research question and the possibilities of the material. The article shows how categories, themes, etc have been constructed. If the researcher modifies the methods of data analysis and interpretation during the study, the article notes how, when, and why this was done. If more than one method is used, each one is evaluated separately.

Results

The description of results is relevant in relation to perspective, research question, and in line with the methods. For example, if staff opinions of patient experiences are studied, the results are described as patients' experiences. If the research question concerns subjective experiences, the results are not be stated as facts. The results contain illustrative citations, etc. The results are clear, comprehensible, and logical in relation to the description of data collection, analysis, and interpretation.

Discussion

The discussion is in line with the research question and methods. It includes reflections on the weaknesses and strengths of the study. The discussion connects to related literature, and the researcher discusses alternative interpretations when relevant.

Literature

The selection of literature is in line with the perspective and research question and is used in an adequate way. The results in the referred articles are focused. The literature is reviewed critically in relation to the research question.

Conclusion

The conclusion is relevant in relation to the perspective, research question, and method and is based on described data. Universality, transferability etc are discussed when relevant.

Internal logic, trustworthiness, transferability (evaluation of the article as a whole)

Perspective, research question, methods, description of results, and conclusions are aligned (internal logic). Data collection, analysis, and interpretation are trustworthy (eg, description of the data, researcher knowledge and experience, illustrative citations).

Trustworthiness is discussed (eg, description of researcher qualifications, step-by-step description of method, examples of data, relation to relevant science, proven experience, logic, strength of arguments).

The researcher describes the setting for data collection and discusses transferability (the possibility to apply the results in settings other than the one studied).

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34. **Formal and Informal Caregivers**

Background

The personal, social, and health impacts of dementia caregiving have been well documented in recent years. However, little attention has been paid to the differences between professional and informal caregivers. Several different terms appear in the literature to designate professional and informal caregivers. Professional designations for caregivers in settings providing care for people with dementia refer to formal caregivers, such as community family caregivers, and various staff/professional occupations, including community health nurses, primary healthcare nurses, registered nurses, licensed practical nurses, auxiliary professionals, nursing aides, nursing assistants, certified nursing assistants, licensed mental nurses and enrolled nurses. These staff/professional caregivers are employed by facilities for the care of people with dementia, including day care centers, group living facilities, assisted living, nursing homes and home care. Informal, unpaid, unemployed caregivers include next-of-kin and family caregivers for non-institutionalized people with dementia. Studies refer to these participants as spouses, non-spouses, husbands, wives, adult children, daughters, daughters-in-law, etc.

Aim

The aim of this section is to describe and evaluate care intervention studies that focused on formal and informal caregivers concerning the benefits and adverse effects of interventions.

Methods

Inclusion criteria

Studies using an intervention design were included when the outcome was assessed for formal and informal caregivers – sometimes for both the caregiver and care recipient. The care recipients, ie, people with dementia in facilities and at home, were not individually selected to meet the criteria for clinical diagnosis. An article was included if the authors emphasized that the caregivers worked with dementia care.

Exclusion criteria

Excluded papers were cross-sectional interviews and questionnaire studies that did not include interventions (non-intervention studies). Such studies assessed and described the needs and levels of caregiver burden, grief, strain, burnout, coping skills, effects of stress, and socio-emotional support. Few studies reported systematic methods for evaluating several educational programs in combination, making it difficult to interpret findings or draw conclusions about the efficacy of the programs. Thus, studies with methodological and conceptual limitations were excluded, as were studies concerning changes of organization. Dissertation abstracts were also excluded. Tables 34.2 and 34.10 list the excluded intervention studies. Studies concerning economic aspects of caregiver perspectives are presented in the economic section of this systematic review.

Strategy for searching the literature

In order to optimize identification of studies with formal and informal caregiver perspectives, a broad, multi-component search strategy of articles from January 1975 to June 2004 was undertaken.

- PubMed, PsycInfo, Eric and Cochrane Library (November 2004) were searched for the terms "Dementia" and "Alzheimer's Disease" combined (AND) with the keywords "Nursing Staff", "Health Personnel", "Nurses", resulting in 111 abstracts and 3 Cochrane reviews.

- Cinahl was searched for the terms “Dementia”, “Health Personnel” combined (AND) with the keywords “Intervention” and “Education”, resulting in 37 abstracts.
- SveMed+ Allied & Complementary Medicine, and Arbline were searched for the terms “Dementia” combined with (AND) “Nursing Staff”, resulting in 2 abstracts.
- SciSearch(R) Cited Ref Sci was searched for the term “Dementia” combined with (AND) “Staff”, “Educating”, “Personnel”, “Training”, “Intervention”, “Nurse” and “Program”, resulting in only a few abstracts.
- Cinahl, Medline, PsycInfo were searched for the terms “Dementia” or “Alzheimer” combined with (AND) “Burnout or Tedium”, resulting in 37 abstracts.
- Social Services Abstracts (December 2004 and January 2005) were searched for the terms “Dementia” or “Alzheimer” combined with (AND) the keywords “Personnel”, “Professional”, “Staff” ,”Nurse”, “Physician”, “Caregiver”, “Care Provider” or “Carer”, resulting in 1 342 abstracts.
- Sociological Abstracts (December 2004 and January 2005) were searched for the terms “Dementia” or “Alzheimer” combined with (AND) the keywords “Personnel”, “Professional”, “Staff”, “Nurse”, “Physician”, “Caregiver”, “Care Provider” or “Carer”, resulting in 305 abstracts.
- PubMed and Cochrane Library (January 2005) were searched for the terms “Dementia” combined (AND) with the keyword “Caregivers”, resulting in 1 710 references.
- PubMed (May 2005) was searched for the terms “formal caregiver and dementia” resulting in 109 references, “informal caregiver and dementia and intervention” resulting in 16 references, “formal caregiver and dementia and intervention” resulting in 14 references, “controlled study and dementia and intervention” resulting in 133 references and “caregivers and dementia and Cochrane” resulting in 9 references.

About 1 500 abstracts were examined by two independent reviewers and 136 articles on formal, and 380 articles on informal caregivers were found to be relevant for research questions. The full text copies were ordered for them. Two people independently assessed each study using the format for study quality assessment. The project coordinator also assisted in reviewing some papers. The studies were then classified for inclusion or exclusion.

Assessment of study quality

Quantitative research methods

The assessment of quantitative studies follows the same principles as that of treatment interventions. See Chapter 22.

The assessment of qualitative studies follows the same principles as that of caregiving from the patient perspective. See Chapter 33.

Results – formal caregivers

Current reviews of the caregiver intervention literature focused on informal caregivers and therefore are presented in the chapter on informal caregivers.

Two types of interventions were found:
I. Systematic clinical supervision, including educational programs
II. Specific training programs focusing on particular skills and professional topics in dementia care.

Many of the interventions were mixed, with clinical supervision and education designed to provide specific information about patients and their behavior, as well as caregiving skills.

I. Studies involving systematic clinical supervision (Table 34.1)

Two types of supervision were identified:

1. Psychoeducational, supportive group supervision that focused on the emotional reactions of formal caregivers.
2. How formal caregivers used their resources, expertise and knowledge to provide individualized care.

Studies using qualitative methods

Hansebo et al aimed to illuminate the reflections of formal caregivers about their videotaped interactions and whether or not any changes in their thinking took place during and after a 1-year intervention [1]. The intervention, which was in a single nursing home, included a change in ward organization at the outset in order to introduce care teams and a contact person for each patient. All caregivers received training in using Resident Assessment Instrument/Minimum Data Set (RAI/MDS), including with individual residents and in the nursing process. The researcher, a Registered Nurse Tutor (RNT), separately supervised each care team once a month during the intervention. The supervision concerned patient RAI assessments as a starting point for discussions about individual needs and problems, as well as the resources necessary for a care plan.

Caregivers were videotaped during their morning care sessions with dementia patients. Data were collected by stimulated recall interviews with caregivers while viewing their videotaped morning care sessions from the data collection periods. These interviews were tape recorded and transcribed verbatim. The phenomenological-hermeneutical approach was used to analyze the data. Results are described as changes within themes and sub-themes. The authors observed an improvement in the ability of formal caregivers to verbalize their reflections about working with patients with dementia. These caregivers also found awareness and knowledge about their own influence on the quality of care. The self-confrontation situation, which was a new experience for the caregivers, was viewed as positive. Their reflections kept referring to their efforts to maintain a sense of dignity for both the patients and themselves. The strengths of the study included the long intervention period, good planning and the creative use of stimulated recall interviews. It was useful to assess the influence of formal caregivers on the quality of care. However, the change was not described after the intervention. The role of the supervisor was not adequately discussed.

Studies using qualitative and quantitative methods

Alfredson et al compared knowledge, attitudes, and job satisfaction between staff in group living (GL) units and traditional institutions (TI) – a stratified sample based on the same occupations as the GL staff [2]. The intervention given GL staff was an educational and support training program. The initial training covered psychodynamic concepts, staff/patient relationships, gerontology, the psychopathology of different dementia diseases, various treatment strategies and day care ideologies. During the ongoing program, the staff was supported and supervised monthly. Three independent raters grouped questionnaire items into four themes that covered important aspects or content areas with direct effects on the caregivers; staff knowledge about characteristics of dementia symptoms and treatment strategies, attitudes toward the form of care and patient/resident well-being, staff suggestions about different ways to improve the quality of care, attitudes toward work and job satisfaction. Significant differences among staff groups were seen. Increased knowledge, as well as new emotional and social attitudes, led to greater expertise and more professional conduct with patients. The program increased motivation, job satisfaction, and the quality of work by staff in the GL setting, but not in the TI setting. The authors did not find the change in staff turnover that had been hypothesized.

The study suggests that educational programs at institutions with traditional aims and methods do not usually yield favorable results. Expertise and professional conduct can be enhanced through educational intervention. Mixed intervention in several parts of the educational training programs, individualized care plans and support for dealing with staff burnout and stress appeared to be the strengths of the study. However, the analysis of observation data is not clearly described. It is difficult to glean the effect of the intervention as regards attitudes and job satisfaction.

Welander Berg et al aimed to identify how nurses experienced systematic clinical group supervision and supervised, individually planned, nursing care [3]. The ward housed 11 patients, diagnosed mainly with severe dementia. The 1-year intervention started with a 2-day course, followed by 2 single days during the year. The course reviewed the current knowledge about dementia diseases, as well as planning and caring for people with dementia, followed by supervised, individually planned nursing care.

The experiences of nurses when it comes to clinical supervision were reported in thematic components. The nurses were satisfied with their supervisors, as well as the length and intervals of the sessions. They found the group discussions valuable. Two main themes concerning the experiences of nurses emerged from the qualitative analysis: confirmed uniqueness and a consolidated sense of community. The results of the questionnaire concerning their views on the effects of clinical group supervision showed that they regarded the intervention as tackling a "multitude of things", including support for professional and personal growth, ethical issues, clinical practice and education. Both qualitative and quantitative paradigms were used. The latent content analysis was well executed and included examples of the analysis. The quantitative description of the intervention effect, based on 13 responses to a questionnaire, was methodologically weak, making it difficult to draw any conclusions.

Studies using quantitative methods

Hallberg et al explored how registered nurses viewed the characteristics of severely demented patients, the difficulties generated by their views, the emotional reactions evoked while providing care and their feelings when caring for these patients [4]. A further aim was to explore any changes after supervision and implementation of individualized care at an experimental ward versus a control ward. The intervention consisted of: 1) A 2-day course on dementia diseases, care of people with dementia, ideas and methods for individualized care and discussions concerning the problems at each ward; and 2) Systematic clinical supervision with individually planned nursing care between 1.5 and 2 hours at the experimental ward – first every 3 weeks for 6 months and then every other week for an additional 6 months. Significant differences emerged in the change of mean from baseline to 6 months when it came to perceiving the patients less as victims of nihilation and more as responsive. There were no significant changes in the ratings of the emotional reactions evoked during the year of intervention. The mean values improved significantly in several aspects at the experimental ward as compared to the control ward. Despite the small sample, the well-planned intervention represented a strong point in the design of this study.

II. Studies with specific training programs

These interventions focused on specific skills (communication) or learning methods from an interactive multimedia program, as well as professional nursing skills (Snoezelen).

Studies using quantitative methods

Bourgeois et al investigated the effectiveness of specific components of a communication skills intervention program, as well as the amount of training required to teach and maintain each skill for 3–4 months post-training [5].

The study is from a larger, two-group comparative study. The components of the training program were:

1) A didactic in-service to present content about effective communication and memory aids, behaviors related to dementia and strategies for responding effectively to them;
2) One-on-one, criterion-based training to apply the new strategies with residents during care interactions;
3) The use of memory books with residents as an aid and instructional tool during care interactions;
4) A staff management system, including self-monitoring and supervisory feedback.

The authors collected two types of data to analyze the skills of nursing aides: paper-and-pencil and computer-based observational data. Results indicated that the communication skills program significantly improved the skills, instructional effectiveness and communication of nursing aides during care interactions with residents. Trained nursing aides performed consistently better than controls, although some evidence showed improvement in the control nursing aides. One-on-one performance training and feedback were required to master and maintain the skills 3 months after the program was over. This was a large, well-described study, but it suffered from an understaffed comparison group, given that nursing aides were diverted to treatment.

Irvine et al developed and evaluated an interactive multimedia program [6]. The content of the program included specific communication and behavior management skills for staff, including speaking, reacting, redirection, and use of communication cards. The hypothesis was that caregivers who received training would demonstrate increased knowledge of the trained skills, more intention to use them and greater perception of self-efficacy than a group of caregivers who received similar content through another form of individualized training – a 55-minutes videotape of an in-service training lecture. Participants were randomly assigned to one of two training groups. The result showed that those who viewed the interactive program were significantly more likely to identify the correct responses, intend to use correct strategies and have increased self-efficacy in using correct strategies than participants who watched the videotaped lecture. The study presented a large body of data and sufficient analysis quality, but additional psychometric testing is needed.

Rosen et al designed and assessed an accessible, educational, and relevant curriculum of staff training on depression and dementia [7]. A core curriculum of computer-based, interactive video training modules was created, including the aging process, understanding depression, management of dementia, agitation, communication, medication and abuse. Sessions included individual, self-paced training using interactive video modules. A randomized trial of the modules was conducted at computer, lecture and control sites. The knowledge of the participants was deemed to be similar prior to the study. Compliance and satisfaction with training were monitored at both intervention sites. Knowledge was assessed before each monthly training session and by means of a cumulative post-training exam administrated at the end of the study. The effect of the intervention was measured by using a satisfaction/relevance questionnaire with possible responses of “very much”, “somewhat”, or “not at all”. Knowledge was assessed by means of the test developed for the study. The results showed that individual, self-paced, interactive video education for nursing home staff resulted in greater compliance and satisfaction with training than staff that received lectures. The study used an innovative approach but poorly described the control group.

van Weert et al aimed to gain insight into the implementation process of snoezelen in dementia care [8]. The intervention consisted of training sessions in snoezelen for caregivers. Interventions were subdivided according to caregiver level:

1) Knowledge, theoretical information;
2) Skills, applying the theory in practice;
3) Motivation to change, techniques, achieving consensus;
4) Habits, changing behavior and style; and according to organizational level;
    1) Organizational structure in which the intervention is implemented;
    2) Establishment of implemented changes.

On the last day of training, a study group was set up and started to use snoezelen. The implementation period was 10 months, and the caregivers were offered three in-house follow-up meetings under the guidance of the same professional trainer. Data were collected by means of a questionnaire about the training, interviews about implementation and follow-up meetings (including those regarding implementation). Descriptive statistics were used to describe the effects of snoezelen. The results showed that the new snoezelen model can be successfully implemented in daily care. All participating wards reported changes at the organizational, caregiver level and resident level. The results indicated that implementation effected a change from task-oriented to resident-oriented care. The study focused well on specific professional formal caregiver skills but offered poor analyses.

Discussion

Two main categories of interventions were found: clinical supervision of formal caregivers and specific training programs that focused on improving the professional abilities of formal caregivers to meet the requirements of dementia care.

Four studies were identified that used the perspective of clinical supervision [1–4]. The quality of all four studies was considered to be limited, yielding no evidence. The overall aim of the studies was to increase well-being among both people with dementia and their professional caregivers. These kinds of interventions were often based on the theoretical assumption that the program (support, supervision, education) would initiate a process toward personal growth among the staff, thereby raising the quality of care. The studies were also based on the assumption that caregivers for people with dementia are at risk of burnout. All of the studies used a 1-year intervention for supervision.

The training programs focused on improving the abilities of caregivers to meet the specific requirements of dementia care. Four areas were identified: communication skills [5], the interactive multimedia program [6], a curriculum for staff training on depression and dementia [7] and the implementation process for snoezelen [8]. All of the studies were quantitative. Because these training programs were multifaceted, no evidence could be presented, although the study by Bourgeois et al was of medium quality [5]. The study, which focused on communication skills, indicated that programs that concentrate on such skills can improve the ability of nursing aides to communicate with people with dementia. However, including the other three studies –which were assessed as having limited quality – there is insufficient evidence regarding communication skills training programs.

Formal/professional caregivers provide skilled, complex, care services when informal/family caregivers were no longer capable of providing such services. Thus, the scarcity of intervention studies on formal caregivers was surprising. Descriptive studies about burnout and attitudes toward patients are well documented in research on dementia care for the elderly [9]. Åström et al studied staff burnout in dementia care, as well as its relation to empathy and attitudes [10]. The results showed that a considerable number of staff members were at risk of burnout, possibly related to deep involvement with patients for whom care was not perceived to be meaningful. Another descriptive study found that work environment characteristics accounted for more than 60% of the explained variance in burnout [11].

The first type of supervision that was identified focused on the emotional reactions of formal caregivers to harmful/stressful situations, attitudes, job satisfaction, self-efficacy and coping strategies. This type of supervision deals mostly with the feeling of stress and burnout that formal caregivers experience due to agitated or aggressive behavior on the part of dementia patients, as well as psychotic and other symptoms. Interactions and exchanges among the support group members were used to normalize their experiences, provide mutual support and promote bonding. This approach differs from educational interventions in that the supervisors do not provide standardized information, but focus on individual needs and problems in order to help formal caregivers understand and resolve their own reactions. The educational interventions were always provided in a group setting by caregiving experts or professionals. Important to note is that the pedagogical research approach was poor in the identified studies, given that they seldom addressed the background and educational level of the caregivers. Future studies should be congruent with pedagogical theory, concepts, and philosophy. Previous research has shown that knowledge of dementia has important implications for the well-being of caregivers [12].

The second identified type of supervision focused on how formal caregivers used theoretical and practical knowledge in their professional work. The formal caregivers learned what kinds of strategies were useful in the nursing process and how to draw up individual care plans for people with dementia. This kind of supervision, which was based on professional knowledge, required a supervisor with a professional background, as well as knowledge about both the nursing process and documented, individualized care plans. Supervision involved assessing care recipients as individuals, the starting point being their needs, problems and the resources required for their particular care. Furthermore, supervision was designed to provide standardized information about the disease process and disruptive behaviors. Intervention in these studies focused on people with dementia and how caregivers documented, managed, and planned their care. It also concentrated on drawing up individually oriented care plans, as well as caregiver knowledge of, and relationship to, each particular person with dementia. These skills are part of daily caregiving, the nursing process, and individual care planning. Professional nursing literature refers to them as “nursing interventions” or “nursing actions”. Little attention has been paid to the role of the supervisor. Future studies should further address leaders of training programs.

Conclusions – formal caregivers

Because so few studies were identified as having sufficient quality, there is inadequate scientific evidence to show that systematic clinical supervision, in-service education or training programs have any effect on formal caregivers.

Table 34.1 *Formal caregivers: characteristics of studies selected for inclusion.*

Author Year Reference Country	Overall aim/ purpose	Sample/ study group	Intervention/ study period
Alfredson et al 1994 [2] Sweden	To compare knowledge, attitudes and job satisfaction with traditional care providers	34 staff in group living, compared with 19 staff in traditional institutions. Mean age 40 years	2 weeks of initial training and 1 year of monthly supervision by a nurse, geriatrician, and social worker
Welander Berg et al 2000 [3] Sweden	To reveal nurses' experiences of systematic clinical group supervision, and supervised, individually planned, nursing care	13 RNs who worked in 1 ward at a psychogeriatric clinic	Systematic clinical group supervision and supervised, individually documented planned nursing care for 1 year
Bourgeois et al 2004 [5] USA	To investigate the effectiveness of specific components of communication skills	57 nursing aides in treatment group, 69 in control group. Mean age 33–35 years	Specific training program for communication. Baseline (4 weeks), treatment (2–3 weeks), post-treatment (4 weeks), follow-up (3 months)
Hansebo et al 2001 [1] Sweden	Whether or not there were changes in the caregivers' reflections concerning individualized nursing care	4 professional carers from 3 wards at 1 nursing home	Changed ward organization and supervision with education on individual care plans

Method Data collection/ analysis	Results Outcomes	Quality of study
44 semistructured interviews Statistics	Significant differences between staff groups. Competence and professional conduct can be enhanced through educational intervention	1
Open questionnaire and structured questions. Latent content analysis	The nurses viewed the intervention as tackling a "multitude of things", professional and personal growth, moral issues, clinical practices, and education	1
Observation and communi-cation skills checklist. Treatment implementation measures. Memory books. Statistics	Result indicated significant improvement. The program proved to be successful in improving skills, instructions, and manner of communication	2
Stimulated recall (n = 24) interviews with video-recorded morning care sessions (mean 18 min) recorded at the outset, after 6 months and after the 1-year intervention. Each caregiver participated in 2 morning care sessions on each occasion. Phenomenological – hermeneutical analysis	Improvement found in the ability of carers to verbalize their reflections about working with the patients. Awareness about their own influence on the quality of care	1

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Table 34.1 continued

Author **Year** **Reference** **Country**	**Overall aim/ purpose**	**Sample/ study group**	**Intervention/ study period**
Hallberg et al 1993 [4] Sweden	Explore factors that nurses vs controls, regarded as easy vs difficult, and their emotions	19 RNs at experimen ward, 19 RNs controls. Psychogeriatric clinic	1. 2-day course 2. Systematic clinical supervision for 1 year, 30 hours in total
Irvine et al 2003 [6] USA	To test the effectiveness of an interactive multimedia training program on CD-ROM compared to a standard type of in-service training program	44/44 NAs working in long-term care facilities. Mean age 44 years	Interactive multimedia program. Video taped lectures for controls
Rosen et al 2002 [7] USA	To design and assess a curriculum of staff training on depression and dementia	Certificated nursing assistants and other “core” staff members, 70 at computer site (CS), 103 at lecture site (LS), and 106 at control site (CON)	Monthly educational sessions with 12 interactive video education, 45 min for 6 months
van Weert et al 2004 [8] The Netherlands	To gain insight into the implementation process of “Snoezelen”	80 caregivers on 12 psychogeriatric wards, in 6 Dutch nursing homes	The training program comprised of 4 weekly, 4-hour sessions

NA = Nursing aides; RN = Registered nurses

Method Data collection/ analysis	Results Outcomes	Quality of study
Strain in Nursing Care Scale (SNC), Emotional Reactions in Nursing Care scale (ERNC) Statistical analysis	Nurses perceived, significantly, their patients increasingly responsive and to a lesser degree as victims of nihilation. No significant changes in emotional reactions	1
Results were measured in: – Participants' program use – Knowledge – Intention to use the correct responses – Self-efficacy to use the correct responses – User satisfaction	The interactive program was significantly found to be superior in all comparisons	1
Questionnaires	Individual self-paced, interactive video education resulted in greater compliance compared to traditional lectures	1
Questionnaires and interviews Descriptive statistics	Results indicated a change from task-oriented care to resident-oriented care. The "new" care model can be successfully implemented	1

Table 34.2 *Excluded intervention studies – formal caregivers.*

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Brooker et al, 1998 [13]	4		
Burgio et al, 2001 [14]	3	5	
Grant et al, 1996 [15]	4		
Götell et al, 2002 [16]	3	4	
Edberg et al, 2001 [17]	4		
Hansebo et al, 2000 [18]	3		
Hansebo et al, 2002 [19]	4		
Kihlgren et al, 1992 [20]	2	3	
Kihlgren et al, 1993 [21]	4		
Kovach et al, 1996 [22]	2		
Maas et al, 1994 [23]	6	2	1
Mathews et al, 1997 [24]	3	4	
Mackenzie et al, 2003 [25]	4		
Olsson et al, 1998 [26]	4	2	
Pillemer et al, 2002 [27]	4		
Rankin et al, 1996 [28]	4		
Shanley et al, 1998 [29]	4		
Skog et al, 1999 [30]	3		
Teri, 1999 [31]	4		

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Table 34.2 continued

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Wells et al, 2000 [32]	2	4	
Ardern, 1999 [33]	3		

Explanation of reasons for exclusion:

0. Outside the research question of interest. This is not a quality level, it just means that the paper is unrelated to the question of interest. It may be a result of inadequate coding in databases or an insufficient search strategy.
1. Insufficient number of subjects/low power.
2. Inadequacies in description/selection of subjects, abstracts.
3. Inadequacies in methods/instruments to measure outcomes/effects/consequences.
4. Inadequacies in design.
5. Inadequacies in data collection/high attrition/drop out/drop in rate.
6. Inadequacies in statistical methods/calculations.
7. Inadequacies in ethics.
8. Serious conflict of interest.
9. No original data.
10. Miscellaneous.

Results – informal caregivers

Results of evaluated systematic reviews

To assess the effectiveness of interventions for informal caregivers (such as family members) of people with dementia, an assessment of other published systematic reviews was conducted. Seventeeen review studies were found, of which 10 were excluded (see Table 34.3). The most common reason for exclusion was that the accepted studies also included caregivers for elderly, such as cognitive impaired psychiatric patients, other than those with dementia. The studies measured both caregiver and patient variables.

Table 34.3 *Excluded review studies – informal caregivers (such as family members).*

Author, year, reference	**Exclusion reason**
Acton et al, 2002 [34]	Unclear if caregivers of people with cognitive impairments included in the accepted studies. Unpublished research reports were included
Baumgarten, 1989 [35]	Not only studies within dementia care. Caregivers of frail elderly, impaired elders and depressed elderly were accepted in the study
Bourgeois et al, 1996 [36]	Not only studies within dementia care. Caregivers of elderly patients with cognitive impairments with chronic brain syndrome were accepted in the study
Carradice et al, 2003 [37]	Not systematic review. General overview of current knowledge
Mann, 1986 [38]	Not systematic review
Pinquart et al, 2004 [39]	Meta-analytic study. Not systematic review. Discussion article
Schulz et al, 2002 [40]	Articles selected for this study were not described. Unclear if book chapters included as well
Sörensen et al, 2002 [41]	Meta-analysis including caregivers of older adults. Intervention effects for caregivers of people with dementia were smaller than those for other groups
Teri, 1999 [31]	Not systematic review. General overview and discussion
Jeon et al, 2005 [42]	Not only studies within dementia care. Respite care for people affected by severe mental illnesses were accepted

Six systematic reviews and one meta-analysis were accepted (see Table 34.4).

***Table 34.4** Included systematic review studies and meta-analysis – informal caregivers (eg family caregivers).*

Author Year Reference	Overal aim/ purpose	Number of studies included	Search strategy
Brodaty et al 2003 [43]	To review published reports of interventions for caregivers. Meta-analysis	30	Medline (1985–2000), PsycInfo (1984–2000) Ageline (1985–2000) Cinahl (1985–2000) EBM Reviews-Best Evidence (1991–November/ December 2000) Cochrane Library (4th Quarter 2000) EmBase (1988–2000)
Cooke et al 2001 [44]	To identify the type of variables in psychosocial and educational interventions for dementia caregivers and the effect of them	40	PsycLIT (1970–2000), Medline (1966–2000) the ISI Science Citation Index and Social Sciences Citation Index (1980–2000) Cochrane Library (Issue 3, 2000)
Flint 1995 [45]	To determine the effect of formal respite care	4	Medline, PsycInfo, Cinahl (1975–1994)
Lee et al 2004 [46]	To assess the effects of respite care	3	The trials were identified. From a last updated search of the Cochrane Dementia and Cognitive Improvement Group specialized register on 2 July 2003
Peacock et al 2003 [47]	To assess the effectiveness of caregiver interventions such as education, case management, psychotherapy and computer networking	36	Cinahl, PubMed, PsycInfo for the period 1992 to April 2002

Outcome domains	Results
Psychological morbidity and burden	Implications that caregiver interventions have the potential to benefit the caregivers, but further methodological improvement is required
Levels of knowledge Psychosocial well-being Caregiver burden Social outcomes	Psychological well-being (29 studies). Caregiver burden (22 studies). Social outcomes (13 studies). No general improvements in the well-being of caregivers were found
Caregiver burden, stress, mood, attitudes, physical health, depression, quality of life and anxiety	Little evidence was found that respite care has a significant effect on caregivers´ burden, psychiatric status or physical health
Caregiver burden, psychological stress and health, physical health, economic impact, quality of life	No significant effects of respite care on any variable were found
Caregiver depression, strain, ,stress and use of formal services	No one intervention had an overall significant effect on the caregivers´ well-being. Several interventions had benefit for the caregivers

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Table 34.4 continued

Author Year Reference	Overal aim/ purpose	Number of studies included	Search strategy
Pusey et al 2001 [48]	To assess the evidence of effectiveness of psychosocial interventions	30	Medline, EmBase, and PsycLIT were searched up to 1999
Roberts et al 2000 [49]	To determine the effects of models of respite services, day programs and assisted living programs	20	Data sets for 1986–1996 Medline, Cinahl and HEALTH

Outcome domains	Results
Eg caregiver burden, strain, stress, depression, knowledge, physical and mental health, social networks, quality of life, sleep quality	Technology-based interventions (2 trials) show positive effects. Individualized interventions utilizing problem solving and behavioural management demonstrated the best evidence of effectiveness
Quality of life including measures of distress, burden, mood and satisfaction	Little reduction in burden for the caregivers was found, being usually satisfied with the respite program

The study by Brodaty et al was a meta-analysis [43]. The results indicated significant benefits when it came to caregiver distress, knowledge and mood, but not burden.

Two of the systematic reviews were about psychosocial interventions. The study by Cooke et al found three outcome components: psychological well-being, caregiver burden and social [44]. The results showed that no intervention studies produced generally consistent improvements in the well-being of the caregivers. Approximately one-third of the caregivers had improvements in outcomes. Thus, there was little evidence that psychoeducational interventions consistently generate positive benefits for dementia caregivers. But the study by Pusey et al found some evidence of a reduction in depression [48].

The study by Peacock et al gathered and synthesized information on interventions designed to enhance the well-being of informal caregivers of people with dementia [47]. Different types of interventions were included: education, case management, psychotherapy and computer networking. Caregiver depression, strain, stress and use of formal services were measured. No intervention had a significant impact on caregiver well-being. The authors concluded that it is essential to determine which intervention best fits the particular needs of caregivers.

One of the reviews concerned specific care models – such as respite care, day programs and assisted living centers/congregate homes – for people with dementia that measure caregiver distress, burden, mood and satisfaction [49]. Some evidence was found to support the effectiveness of the programs. The systematic review on respite care by Flint shows some evidence that it has an effect on caregiver burden, psychiatric status or physical health [50].

The Cochrane Database of Systematic Reviews has published one systematic review on respite care [46]. Only three trials were accepted in the review, and no significant effects of respite care on informal caregivers were found.

The systematic reviews show conflicting results for respite care. Roberts et al [49] and Flint [50] were in favor of respite care. Lee et al [46] and Flint [45] found no significant effects. Peacock et al found no effects but were looking at several aspects [47]. Results concerning the improvement of well-being of caregivers were also conflicting – Brodaty et al [43] vs Cooke et al [44].

Results of the evaluated original studies

Fortysix intervention studies were accepted, 4 of them were assessed as high, 18 as moderate and 24 as low quality. Studies accepted of limited quality that were included in the accepted systematic review (Table 34.4; [43,44,48,49]) are not described in the present systematic review but mentioned in Table 34.5 of included studies.

Types of intervention

The intervention domains were broken down into four categories.

1. Psychoeducational and psychosocial interventions

A primary purpose of the psychoeducational and psychosocial interventions was to maintain and improve the emotional well-being of caregivers. The treatment programs included comprehensive psychosocial interventions with three major components: individual and family counseling, support group participation and ad hoc consultation and education. Counseling was defined and developed by the British Association for counseling as the skilled and principled use of relationship to facilitate self-knowledge, emotional acceptance and growth, as well as the optimal development of personal resources [51].

2. Skills training programs

These interventions were designed on the assumption that problems caused by the dementia disease could be managed and reduced by the caregiver using targeted cognitive-behavioral prompts. These interventions used the methodology that is based on the caregiver's targeted actions and knowledge about the patient's personality, life history and disease progression, in combination with the caregiver's cognitive interpretation of the current situation using encouragement, reinforcement and a systematic application of environmental, verbal, and tactile prompts for varying levels of cognitive deficits. Many of the cognitive-behavioral interventions were based on action-oriented (such as validation) methods [52,53].

3. Technological support programs

These interventions included programs that used technical equipment such as phones [52,54,55], computers [56,57] and telecommunications [58,59].

4. Out-of-home activities and care placement

These studies focused on interventions with access to supportive out-of-home care and care placement, including respite care and nursing home placement, as well as memory clinics and family-oriented care.

Assessed outcomes

The outcomes were assessed for the variables concerning both the caregiver and the care recipient. Only the results concerning the caregivers are described here. The outcomes were measured with different rating scales according to several caregiver variables, such as anxiety, strain, self-efficacy, stress, depression and health status. A total of 66 scales were used (Table 34.9), though not all of them in the included studies.

Results of review of studies focusing on psychosocial and psychoeducational, as well as skills training, intervention

Combined interventions were found in several studies of these two strategies and are therefore described together (Table 34.5). Table 34.10 presents the excluded studies.

Studies using quantitative methods

Akkerman et al examined the effectiveness of cognitive-behavioral therapy, including didactic skills training, in small groups [60]. The report suggested that intervention reduces anxiety, as measured by self-reporting and clinician-administrated assessment scales.

Bourgeois et al evaluated the effectiveness of written cues to manage repetitive verbalizations, a patient behavior that is particularly upsetting to caregivers [61]. The results revealed that caregivers easily learned to apply the treatment and were generally successful at reducing repetitions even when not receiving weekly feedback from program staff. A hypothesis for the success of written cues is that they access recognition memory processes that do not require purposeful or conscious processing by the patient. Hence, the processes do not need to be learned, or relearned, by the patient. The study included few participants who exhibited a wide range of cognitive abilities.

Buckwalter et al evaluated a community-based psychoeducational nursing intervention designed to teach home caregivers to manage behavioral problems of people with dementia by using the Progressively Lowered Stress Threshold model (environmental demands need to be modified for people with dementia because of their declining cognitive and functional abilities) [62]. A primary aim was to evaluate the impact of the intervention on the affective responses, especially depression, of caregivers. This intervention was compared with routine information and referrals for case management, community-based services and support groups. For purposes of the study, the model was tailored more specifically to the individual needs of caregivers in the home/community setting. The data support effectiveness in reducing depression among caregivers who received the experimental training. The intervention was well-focused.

Burns et al explored the effect of brief, targeted interventions to improve caregiver management of the care recipient's behavioral problems, such as repeated questions or wandering [54]. Comprehensive pamphlets on managing dementia problems or addressing stress and coping were written in large print at a fifth-grade reading level. Each 5–6 page pamphlet provided information about possible triggers of, and strategies for, coping with specific behaviors or issues. During the 24 months period, the behavior care that caregivers received averaged approximately 3 hours of intervention. Enhanced care caregivers received approximately 4 hours of face-to-face and phone contact. The outcomes were measured in terms of caregiver well-being and depression, as well as how dementia manifested in the patient and affected the caregiver. The results showed that caregivers who had information about both managing the care recipient's behavioral problems and their own coping experienced significantly greater distress as measured by the quality-of-life instrument. The intervention was well described and based on Lazarus and Launier's action-oriented, individual-environment model of stress and coping.

Burgio et al evaluated manual-guided, replicable educational materials based on common needs and cultural preferences of Caucasian and African-American family caregivers [63]. The intervention was delivered through a group workshop, followed by 16 in-home treatment sessions over a 12-month period. However, the present paper reports only 6-month outcomes. Randomly assigned educational materials were provided in three phases. Phases 1 and 2 included general information on dementia diseases and caregiving. Phase 3 materials consisted of single-page fact sheets that presented suggestions for addressing behaviors such as wandering and repetitive questions. The degree of treatment implementation was measured in terms of problem behaviors and their appraisal, social network satisfaction, leisure time satisfaction, well-being, anxiety and desire to institutionalize. The results showed that interventions, skills training, brief supportive phone calls and written information can reduce the number of problem behaviors and the nuisance associated with them. These actions can also increase satisfaction with leisure activities. The authors were unable to blind the study personnel to group assignments, given that the participants often spontaneously discussed their intervention experiences with assessors.

Coon et al examined the short-term impact of two theoretically based, psychoeducational, small group interventions with distressed female caregivers [64]. The primary outcomes examined were anger or hostile mood, depressed mood, frequency of positive and negative coping strategies and perceived self-efficacy. Significant main effects in the expected direction were found in most of the measurements. Participants in anger management and depression management groups experienced significantly greater reductions in levels of anger or hostility and depression than those in the control group.

Coen et al evaluated the impact of a dementia caregiver educational program on quality of life, burden, and well-being [65]. The program consisted of 8 weekly, 2-hours education and support sessions covering general information about dementia and available services, management of everyday problems, reality orientation, communication techniques, coping with loss, stress management, hospitalization and legal issues. The measures included quality of life, burden, well-being, tolerability of the perception that patient problems had improved, and decline. The only significant impact of the program was an increase in knowledge about dementia.

Corbeil et al evaluated the adequacy of a stress adaptation framework for guiding intervention research on caregivers and patients coping with Alzheimer's disease, as well as for testing the effect of cognitive stimulation intervention as an interactive outcome [66]. The results showed that the intervention group caregivers were more satisfied with their interaction with the impaired member. The improvement in caregiver satisfaction was attributed to an attenuation of the behavioral stressor effects through the increased use of a problem-focused coping strategy, ie, positive reappraisal of the stressful situation.

Done et al evaluated whether or not a short workshop in communication techniques would be more effective than an informational booklet for improving the communications skills of informal caregivers [59]. The results showed that the levels of caregiver stress did not change between pre-intervention and follow-up, a pattern that was similar for both groups. However, there was a significant decrease in reports of problem communications, whereas reports of problem behaviors remained stable.

Dröes et al tested the hypothesis that integrated support of patients and caregivers by a professional staff member is more effective in reducing the sense of (excess) burden on caregivers and positively impacting some potential determinants of experienced burden than nonintegrated support, such as psychogeriatric day care [67]. No effect was found on feelings of stress, dissatisfaction or psychological and psychosocial complaints.

Finnema et al examined integrated emotion-oriented care versus ordinary care for elderly people with dementia in nursing homes [53]. Does application of integrated emotion-oriented care have a positive impact on how the families of residents view the quality of care offered? Among emotion-oriented approaches are validation (responding to and affirming emotions), reminiscence (old photographs) and snoezelen (sensory stimulation). In addition to training in working with the principles of the Model-Care plan, the experimental wards received instruction and supervision in applying integrated emotion-oriented care. The nursing consultant visited the wards four times to provide supervision. Because the authors found no relevant measurement instrument, a new questionnaire was designed based on instruments by Bass et al (see list of measurement instrument). That instrument measures the quality of nursing and the care of psychogeriatric residents. Only one significant difference was found: caregivers in the emotion-oriented group asked family members more frequently about the life histories of residents.

Fung et al examined the effectiveness of a mutual support group program for family caregivers of people with dementia compared with a conventional family service available to this group in Hong Kong [68]. All group sessions consisted of education, sharing, discussion, psychological support and problem solving, similar in design to previous support group studies for caregivers. Data collected by means of a questionnaire with 2 outcome measures (caregiver distress scale and quality-of-life) were included pre-test and post-test. The results showed that family caregivers in the experimental group experienced a significantly greater reduction of distress levels when managing patient symptoms of delusion, hallucinatory behavior, agitation and violent behavior than the control group. The intervention is based on evidence from other studies, though not those of people with dementia. However, the cultural context is not discussed.

Gerdner et al evaluated the efficacy of a longitudinal, multi-site, community-based intervention designed to teach home caregivers to manage behavioral problems in people with Alzheimer's disease [69]. The experimental group received a psychoeducational nursing intervention that was conceptually grounded in the progressively lowered threshold model. The comparison group obtained routine information and referrals for case management, community-based services and support groups. The results showed that the intervention had a statistically significant effect on spousal response to memory/behavioral problems for all caregivers and on the response to problems for spousal caregivers in regard to activities of daily living. No intervention effect on activities of daily living was reported for either spouses or non-spouses.

Gitlin et al examined the effects of a home environmental skill-building program on caregiver well-being and care recipient functioning, as well as whether effects vary by caregiver gender, race (white or non-white) or relationship (spouse or non-spouse) [70]. Intervention caregivers reported less upset than the controls with memory-related behaviors, needed less assistance from others and experienced better affect. Intervention spouses also reported they were less upset with disruptive behaviors. Men reported spending less time on daily supervision, and women reported less need for help from others, better affect, enhanced management ability, overall well-being and mastery than the control group.

Hébert et al assessed the impact of a support group program for caregivers on the institutionalization of patients with dementia [71]. Subjects assigned to the control group were referred to the informal monthly meetings of the Alzheimer Society. Based on survival analysis, the median length of time until institutionalization was 30 months after entering the study. The results emphasized the lack of scientific evidence on the efficacy of the program and the need for a large, multi-center study on this topic.

Hepburn et al tested role-training intervention as a way of helping family caregivers appreciate and assume a more clinical belief set about caregiving, thereby ameliorating the adverse outcomes associated with caregiving [72]. The training program curriculum was based on theories related to stress and coping. Standard measures of beliefs about caregiving, burden, depression, and reaction to care recipient behavior were administered to caregivers. A significant, positive association was found between the strengthened mediator, caregivers having less emotionally enmeshed beliefs about caregiving roles and responsibilities, and the outcome, ie, improvements in burden.

Jang et al examined the impact of caregiver neuroticism on longitudinal change in depression among spousal caregivers, whether high levels of such neuroticism would diminish the response to enhanced treatment, and whether it affected longitudinal course or caregiver depression regardless of intervention [73]. The results showed the longitudinal course of depression to be worse among caregivers with high neuroticism than those with low neuroticism.

King et al examined the health and quality-of-life effects of moderate-intensity exercise (such as walking) among older, female family caregivers [74]. Each participant in the exercise group (n = 51, average age 63) received a regimen that gradually increased in intensity over the initial 6-week period to 40–59% of heart rate reserve, based on the peak achieved during symptom-limited treadmill testing. Participants were instructed to engage in at least four 30–40 minute exercise sessions per week – primarily brisk, home-based walking. Participants were also encouraged to increase other forms of routine activity, such as leisurely walking and gardening. People in the control group received a phone-based nutritional education program. The findings showed that interventions tailored to the situational constrains of caregiving resulted in significant, sustained improvements in health behaviors critical to caregiver health and functioning.

McCurry et al examined the feasibility of training caregivers to implement sleep hygiene recommendations in dementia patients [75]. Caregivers in active treatment received specific recommendations about setting up and implementing a sleep hygiene program. Control subjects received general dementia education and caregiver support. Success in implementing sleep hygiene recommendations was measured by using daily log reports to calculate the percentage of days that caregivers reported that patients met individualized sleep scheduling, daytime napping and walking goals. Caregivers in active treatment were more successful when setting goals related to sleep scheduling and increasing daytime activity than control caregivers who received written materials only.

The aim of Mittelman et al was to examine the effects of a comprehensive support program on depression in spousal caregivers [76]. More than 40% of the caregivers in the study had potentially significant levels of depressive symptoms at baseline. The counseling component of treatment consisted of six individual and family sessions after intake into the program, including role playing and education about how to prevent problem behaviors among patients, thereby enabling caregivers to have greater control of their environment. Counselors were available for phone consultation at any time, including evenings and weekends in the event of a crisis. The analyses were designed to investigate whether the change in the number of symptoms of depression was significantly different among caregivers in the treatment group and the control group during the first year after entry into the study. The study demonstrated that the intervention that enhances social support has potential for alleviating some of the deleterious effects of caregiving on mental health. Important to note is that the effect was not immediate in most cases, so that the average difference between the change in the treatment and control groups became statistically significant only 8 months after caregivers had entered the study.

Mittelman et al examined the long-term effect of counseling and support on symptoms of depression in spousal caregivers [77]. Enhanced counseling and support treatment was provided by counselors with advanced degrees in social work or allied professions. Caregiver depression was assessed at baseline and at every follow-up assessment by means of the Geriatric Depression Scale, a 30-item self-report questionnaire. During the first year after baseline, there was a gradual decrease in symptoms of depression among the group receiving enhanced treatment and an increase among the group receiving usual care. After the 1-year follow-up, the difference in the change on the score between the enhanced treatment group and the usual care group was statistically significant. Sustained improvements were detectable more than three years after enrollment. The results suggested that a short course of intensive counseling and readily available supportive maintenance can have long-lasting effects with respect to reducing symptoms of depression among informal caregivers.

Toseland et al summarized the first phase of a 3-year clinical intervention study designed to examine the effectiveness of peer-led and professionally led groups for supporting adult women who provide care for a frail parent [78]. Both professional and peer leaders relied heavily on supportive interventions, such as encouraging ventilation of stressful experiences, validation and confirmation of similar caregiving experiences, affirmation of the ability of members to cope, praise for providing care, and support and understanding for those struggling with difficult situations. The professional leaders received training in a detailed protocol covering the topics outlined previously, background reading material, and phone consultation with the first author between group meetings. Effects of group interventions were measured in burden, psychological functioning, social support, personal changes and participant satisfaction. No significant differences were found among the three treatment conditions on either measure of perceived burden. Participants in both treatment conditions reported increases in well-being. A majority indicated that the number of people they could call on for help with caregiving had increased, and none reported a decrease.

Mohide et al aimed to determine the effectiveness of the Caregiver Support Program in reducing burden [79]. The experimental set of supportive interventions was directed at helping caregivers enhance their skills and achieve a sense of control in their roles. The caregivers received dementia and caregiving education using content and teaching methods tailored to their knowledge level, caregiving situation and learning style. In the control group, conventional (existing) community nursing focused on patients with dementia rather than family caregivers. The results favored the experimental group, including improved caregiver quality of life, decreased impact on their day-to-day lives, delayed long-term institutionalization and greater consumer satisfaction with nursing care.

Ripich et al examined the effectiveness of a training program [58]. In a focused training program, 19 caregivers participated. It was designed to improve their communication skills with family members. Training procedures and materials included discussion questions, videotaped vignettes and role-playing activities for practicing specific strategies. No significant changes were found in the control group.

Stolley et al described the impact of theoretically driven, psychoeducational intervention based on the Progressively Lowered Stress Threshold (PLST) model for caregiving appraisal among community-based caregivers [80]. Caregiving appraisal was measured in terms of mastery, burden, satisfaction, and impact. An analysis showed that the intervention had a positive effect on impact, burden and satisfaction, but none on mastery in comparison with the comparison group. The PLST model was influential in increasing positive appraisals and reducing negative appraisals of the informal caregiving situation.

Studies using qualitative methods

Only two qualitative studies were found, both from Sweden.

Brännström et al evaluated a counseling program carried out by nurses for spousal caregivers of people with dementia [51]. The intervention program, which was developed at a local healthcare center, strove to educate the participants about dementia, as well as offer them emotional and practical support for dementia-related problems in daily life. One intention was to provide advice and support according to a spouse's individual situation. The program also offered participants a reduction in their level of isolation. The counselors were nurses with experience of dementia care. Data were collected by means of interviews and analyzed following the procedure described by Strauss and Gorbin. The results were presented according to three categories that described the counseling sessions and the situation after the program. During the sessions, participants experienced a sense of support, insight, strength and mutual understanding.

Jansson et al had a twofold aim – to develop and test a model that met the needs of family caregivers, and to assess the experiences of each group of Circle Model participants [81]. Family members and volunteers were trained together in study circles led by deacons and arranged in collaboration with the Swedish Christian Educational Association. They met weekly and focused on the following pertinent topics: (a) dementia; (b) interaction and establishment of contact with people with dementia; (c) resources and services available from the community; (d) ethical and confidentiality considerations. The experience sharing category was emphasized as highly important. The experiences were expressed in positive statements. The role of the deacons was described and discussed, but the level of analysis was limited.

Results of review of studies focusing on technological support

No systematic review was found concerning technology-supported interventions. Six studies using quantitative methods were found [52, 55–57,82,83].

Bass et al examined patterns of computer use, whether a computer support network for family caregivers reduced the level of care-related strain (conceptualized as a multidimensional construct that included caregiver perceptions of physical and relationship strain attributed to caregiving) [57]. The network was named "Computer Link". Half of the caregivers were randomly assigned to an experimental group that could access Computer Link. The remaining caregivers served as a control group and did not receive a computer or the Computer Link software. The results showed that use of the solitary function was related to reduced strain on caregivers living alone with care recipients and on spousal caregivers. The assumption that more vulnerable caregivers would experience greater benefits was not consistently supported. Computer Link was more beneficial for caregivers with greater informal support. The authors did not describe the scales used.

Brennan et al evaluated the effects of computer network support on confidence in decision-making skills and social isolation [56]. Computer support provided certain functions to caregivers – information, decision support and communication. Outcomes were measured with respect to decision-making confidence and skills. The result showed that subjects with access to computer support experienced greater improvement with regard to confidence in decision making than those in the comparison group. However, access to Computer Link did not significantly improve decision-making skills or change the social isolation experienced by caregivers. The study was an innovative approach to technological support.

Chang examined the effects of phone and video programs on caregivers [52]. The video program was designed to support specific problem areas, such as eating and dressing. The Nurse-line video-assessed modeling intervention program consisted of two parts: 1) videotapes demonstrating assisted modeling behavior (eating and dressing); 2) a Nurse-line support program to reinforce the video information and help the caregiver explore coping strategies. All caregiver dyads were English-speaking and had access to a phone and a video recorder. The effects were measured by rating caregiver burden, satisfaction, anxiety and depression. Depression and anxiety were the outcomes that showed the most change. A significant main effect involved differences in depression and anxiety over time. No difference was found between groups in the outcomes of satisfaction and caregiver burden over time that could be related to the chronic nature of dementia and progressive caregiver involvement. The intervention was well described and theoretically based, but the effects of the videos were difficult to disentangle from those of the Nurse-line calls. The study lacked a second comparison group that did not receive a phone call.

Eisdorfer et al examined the efficacy of an intervention based on family therapy and technology in reducing depressive symptoms among family members [82]. All intervention materials were made available in Spanish for the Hispanic participants by using established techniques for forward and backward translation. An information network was implemented that used computer-phone technology. The system permitted the participation of family members who were unable to attend sessions: those who were far away, had physical disabilities or were too frail to leave home. The family therapy intervention alone did not have a significant effect on depressive symptoms for most of the caregivers.

The aim of the study by Gendron et al was to evaluate the effectiveness of a skills training cognitive-behavioral group intervention, which focused on assertion, problem-solving and cognitive restructuring [83]. This intervention was compared to a support group that emphasized information-giving and social exchanges among participants. The intervention programs were based on two kinds of support groups. Cognitive-behavioral support groups were led by two experienced clinicians trained in cognitive-behavioral therapy. This intervention program, which aimed at enhancing the coping skills of caregivers, focused particularly on the difficulties of participants in dealing with an affected spouse and on personal problems encountered in fulfilling the caregiver role. Information support groups were led by two experienced animators. Each session began with a live or videotaped presentation of different topics concerning health and aging, dementia, community resources, social and leisure activities and legal issues. Speakers included social workers, lawyers, nutritionists and psychologists. Socialization among participants was a key element of this intervention. The results showed significantly lower ratings of marital adjustment and satisfaction by the cognitive-behavioral group. Spouses in the information support group showed improved scores on perception of both maladjustment and somatization, two symptoms frequently associated with depression. The intervention content was revealing.

Mahoney et al examined the main outcome effects of a computer-mediated, automated, interactive voice response intervention designed to assist family caregivers who managed people with disruptive behaviors related to dementia [55]. The system provided caregiver stress monitoring, counseling information and personal voice-mail linkage to Alzheimer's disease experts. It also included a voice-mail phone support group and a distraction call for care recipients. There was a significant intervention effect for participants with lower mastery at baseline on all three outcomes: bother, anxiety, and depression. Wives exhibited a significant intervention effect in the reduction of bother. This was an important technological support study.

Results of studies focusing on out-of-home activities and care placement

These intervention studies focused on research about services that offer a planned break from the ongoing responsibilities of informal caregivers.

Three studies were found about nursing home placement [84], attendance at memory clinics [85] and family involvement in special care units [86].

Lieberman et al examined the effects of nursing home placement for patients with Alzheimer's disease as compared to the maintenance of community placement on changes in the health and well-being of family caregivers [84]. The results showed that their health and well-being did not improve over time, and there were no significant differences between those who placed elderly care recipients in a nursing home and those who kept them at home or in the community. The study presented an important intervention topic.

Maas et al tested the effects that involvement in care partnership intervention had on the perceptions of family members concerning their caregiving role, relationships with staff and satisfaction with the care provided by special care units, as well as the effects on caregiving satisfaction and attitudes toward families among staff members [86]. Family caregiver outcomes were measured by means of instruments that were pre-tested for reliability and validity. Statistically significant beneficial intervention effects were found in three areas: emotional reactions to the caregiver role, perceptions of relationships with staff and perceptions of the care received by relatives.

Logiudice et al examined the effects that memory clinic attendance had on the psychosocial health of caregivers [85]. Fifty community dwelling subjects with mild to moderate dementia and their caregivers were recruited. Participants were randomized to attend a memory clinic or control group. The main outcome measures were burden, psychological morbidity and psychosocial health related to quality of life. A positive effect on psychosocial health status was demonstrated by the use of a generic health-related quality of life tool. The greatest impact, which appeared to persist throughout the year, was in the area of social interaction. Improvement in health was not mirrored in the other measures of psychological morbidity or burden. The purpose of memory clinics has traditionally been assessment and research. A positive effect for caregivers had not been previously documented.

Conclusions – informal (such as family) caregivers

The aim was to describe and evaluate caregiver intervention studies in dementia care research, as well as to examine beneficial and adverse effects for informal (such as family) caregivers. A search of the literature generated 7 accepted review studies and 46 articles. Four of them were assessed as high, 15 as medium and 26 as low quality.

Four main categories of interventions were found:
1) Those aimed at improving caregiver well-being and emotional health;
2) Those that strove to reduce individual problems caused by the care recipient and the amount of care provided by the caregiver;
3) Those that had access to technological support;
4) Supportive out-of-home care and care placement.

A wide range of assessed outcomes were measured with scales of mostly negative variables, such as caregiver depression, strain and stress. That is consistent with the view that social isolation is part of the lives of people with dementia and their caregivers.

Conclusions regarding evidence for psychosocial and psychoeducational programs

Based on three high-quality studies [62,68,69], there is moderate strong evidence regarding psychosocial and psychoeducational interventions. Outcomes were measured in terms of caregiver distress, depression and response to behavioral problems. The results showed a significant reduction in distress levels and response to memory behavioral problems, as well as a decrease in depression. These results were also supported by studies of medium quality, such as Coon et al [64] on anger or hostility and depression, Whitlatch et al [87] – who suggested that the benefits may be long-lasting when caregivers respond positively to psychoeducational interventions – and Chang [52], who suggested that depression and anxiety were the outcomes that changed the most. Mittelman et al demonstrated that a support program on depression in spousal caregivers alleviated some of the deleterious impact of caregiving on mental health. But the effect was not immediate – the benefit became statistically significant 8 months after the caregivers entered the study [76]. The other intervention study by Mittelman et al revealed the same tendencies [77]. While no group differences were evident at the first follow-up (4 months after baseline), increasing differences were apparent at 8 and 12 months. Stolley et al stated that psychoeducational intervention contributed to increasing positive appraisal and reducing negative appraisal of the informal caregiving situation [80].

Conclusions regarding evidence for skills training programs

Several studies of medium quality yielded limited scientific evidence for the benefit of different skills training and cognitive-behavioral programs [63,66,70,83]. When caregivers were taught specific behavioral skills, they demonstrated less depression and perceived stress [88]. Brief targeted interventions improved caregiver management of behavioral problems (such as repeated questions or wandering) in care recipients [54]. Qualitative studies described how the sense of well-being improved among family caregivers as their understanding of the disease and condition increased [51,81].

Conclusions regarding evidence for technological support

The high-quality study by Brennan et al showed that subjects with access to computer support experienced greater improvement in decision making confidence than the comparison group, but access to Computer Link did not significantly improve either decision making skills as such or the sense of social isolation [56]. The medium-quality study by Chang [52] supported Brennan's. However, the outcomes were not defined in the same way (decision making confidence vs depression). Although two studies supported the effects of technological support, no evidence can be stated given their differing outcomes.

Conclusions regarding evidence for out-of-home activities and care placement

The results showed that caregiver health and well-being did not improve over time, and there were no significant differences in health and well-being between family caregivers who placed elderly relatives in a nursing home and those who kept them at home or in the community. Although a positive effect on psychosocial health of attendance at a memory clinic and family involvement in special care units was demonstrated, the results of systematic reviews showed no evidence of benefits from respite care and special care units.

Discussion – informal caregivers

The results showed that psychoeducational and psychosocial interventions alone did not have a significant effect on depressive symptoms for most caregivers. The measurement instruments were based mostly on the documented knowledge of family caregiving that was seen as a pressing issue, ie, caregivers were more burdened, depressed, socially isolated and anxious than non-caregivers. However, some of the instruments measured positive variables, such as leisure time satisfaction and well-being [63]. Questions have arisen as to whether the commonly applied general indicators of a sense of burden (such as stress and dissatisfaction, as well as psychological and psychosomatic complaints) are the most relevant and discriminating outcome measures in researching support programs for informal caregivers. Perhaps more attention should be paid to the period during which caregivers are able to perform their tasks, variables that seem to be determined by situational and relation-specific factors, such as feelings and experiences associated with caring for people with dementia (see Dröes et al [67]).

However, when interventions are multifaceted (not focused), it is difficult to identify which component is the most effective. Interventions that focus on the emotional coping strategies (such as wishful thinking) of caregivers differ from targeted cognitive-behavioral strategies (such as validation therapy) that focus on the care recipient. According to Cooke et al, it is possible to ensure consistent improvements in caregiver knowledge of the care recipient's disease, but such knowledge seems to be unrelated to psychological and social outcomes [44]. Thus, psychosocial interventions did not generally produce consistent improvements in the well-being of informal caregivers.

The findings suggested that future interventions should assess the individual caregiver's specific training needs and tailor interventions to directly address those issues in order to maximize the desired outcomes, such as reducing behavioral problems. For example, intervention based on the Progressively Lowered Stress Threshold model had a positive impact on both frequency and response to problem behavior among spousal caregivers [69]. Outcome measures that were specific to the training targets showed obvious benefits when the general measures – such as quality of life and stress – did not. The results of the review by Cooke et al showed that studies that appeared to be effective for caregiver well-being also included social and cognitive components (such as problem-solving) [44].

Length of intervention was another factor that may impact the outcome. It might be unrealistic to expect significant changes in lifelong coping patterns and habits after only 8–10 weeks, as commonly offered by these research programs. A short support group program (such as Hébert et al, 2 hours weekly for 8 weeks) seemed to have only a minimal impact on caregiver morbidity and burden [89]. Perhaps a typical informal caregiver, who has little or no experience of individual or group counseling, is unprepared to confront deeply personal issues during a brief group discussion [78]. Important to note is that the effect was not immediate in most cases, and the average difference, as in the study by Mittelman et al, became statistically significant only 8 months after caregivers entered the study [76]. Moreover, some caregivers did not benefit from psychoeducational interventions [87]. A Cochrane systematic review suggested that effectiveness trials should be longer, perhaps by several years [46]. Strategies focusing on out-of-home interventions included 2 studies about formal respite care designed to provide rest or relief to caregivers. The amount of respite care received had no significant impact on well-being, caregiving attitudes or physical and mental health. Respite care services were ineffective for caregiver burden and mental health but nevertheless generated a high degree of satisfaction. These findings supported the results of 2 review articles on respite care [45,46]. The type of respite care being studied should be well-defined and, to the extent possible, related to the needs of the caregiver. High-quality research in this important area is lacking. These results are consistent with the review by Jeon et al over the past 10 years concerning respite care for people affected by severe mental illness, given that contradictory findings on the outcomes of respite care services and a lack of controlled empirical studies were found [42]. The need for greater sensitivity to the requirements of caregivers should be recognized and addressed.

Study results indicate that telecommunications technology is easy to use and that caregivers find it valuable in dementia care [90]. According to Pusey et al, phone and computer networks yielded positive effects in terms of decision-making confidence and subjective measures of social support and knowledge among dementia caregivers [91]. Many innovative applications of telecommunications technology have emerged in health care, but the evidence is limited [92].

***Table 34.5** Characteristics of included studies about informal caregivers – psychosocial/psychoeducational and skills training.*

Author Year Reference Country	**Overal aim/ purpose**	**Sample/ study group**	**Intervention/ study period**
Akkerman et al 2004 [60] USA	To assess brief group cognitive-behavioural therapy	38 caregivers	Nine weeks of skills training
Bourgeois et al 2002 [88] USA	To evaluate the effects of a patient and caregiver-skills training group	Adaptive randomization groups. Patient change (N = 22), Self-change (N = 21), Control (N = 20)	Skills training. The 12-week intervention phase
Bourgeois et al 1997 [61] USA	To evaluate the effect of written cues to manage repetitive verbalizations	Seven spouse caregivers	Written cues to manage repetitive verbalizations during the 12-week intervention phase
Buckwalter et al 1999 [62] USA	To evaluate a psychoeducational-nursing intervention	A total of 245 caregivers completed the study	Psychoeducational program. During 4-years, a longitudinal study
Burns et al 2003 [54] USA	To explore the effect of brief targeted interventions	433 caregivers were telephone screened for the study and 167 caregivers-patient dyads were randomized to the study (n = 85 and 82)	Written pamphlet provided information on possible triggers for and strategies for coping during the 24-month phase
Brännström et al 2000 [51] Sweden	To evaluate a counseling program	Seven to eight in each group 28 spouses (husbands and wives), completed the program. The sample consisted of 18 spouses from this group	Counseling group meetings during 13 or 14 times

Method Data collection/analysis	Results Outcomes	Quality of study
Self report and clinician administrated scales	The intervention reduced anxiety	1
The outcomes were measured as indirect intervention effects such as depression and other negative effects at the treatment phase and 3- and 6-months post intervention	The study demonstrated the effectiveness of teaching caregivers in specific behavioural skills which were related to reduced caregiver strain	2
The caregiver outcomes were measured in perceptions of self-efficacy, satisfaction and daily frequency of repetitive verbalization	The success of written cuing systems may access recognition memory process in patients being beneficial for the spouses	1
The subjective affect was measured by the 65-item POMS. Profile of Moods States and the Geriatric Depressions Scale	The positive impact on caregiver depression was significant	3
The outcomes were measured in care-giver general well-being and depression	Changes in the level of depression or quality of life during a period of 1 to 2 which show that potentially beneficial interventions can be administrated	2
Qualitative study. Data was collected by interviews and analyzed following the analytical procedure described by Strauss and Gorbin	The results are described in three main themes: 1) The situation before the programme 2) The counseling sessions 3) After the programme	1

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Table 34.5 continued

Author Year Reference Country	**Overal aim/ purpose**	**Sample/ study group**	**Intervention/ study period**
Burgio et al 2003 [63] USA	To evaluate educational materials based on common needs and cultural preferences	Randomly assigned white (n = 70) and African American (n = 48) family caregivers	Educational material during 16 in-home treatment sessions over a 12-month period
Chang 1999 [52] USA Described also in Brodaty et al 2003 [43]	To examine the effects of the telephone and video supported program, specific for eating and dressing	A two-group randomized trial. The subjects were 65 female spouses	The telephone and support group program during 12-weeks
Chiverton et al 1989 [93] USA Described in Cooke et al 2001 [44]	To evaluate the impact of an educational program	The sample consisted of 40 spouses, 20 in the educational program and 20 controls	Educational program of three sessions for each participant approximately 2 hours in duration
Coon et al 2003 [64] USA	To examine 2 theoretically-based psychoeducational small groups interventions	169 distressed female caregivers	Psychoeducational program of during over a 3- to 4-months period
Coen et al 1999 [65] USA	To evaluate the impact of a dementia caregiver educational program	The 28 caregivers	Psychoeducational program during 8 weekly of 2 hours
Corbeil et al 1999 [66] USA	To test the effect of a cognitive stimulation	87 caregivers-patient dyads were randomized to active stimulation group, passive or control group	Cognitive stimulation intervention during 12-weeks consisting of 1 hour daily for 6 days each week

Method Data collection/analysis	Results Outcomes	Quality of study
The degree of treatment implementation was measured in social networks and leisure time satisfaction and well-being, anxiety and desire to institutionalise	The results swow that the intervention can reduce the number of problems and increase satisfaction with leasure activities	2
The measurements were taken at baseline, 4, 8 and 12 weeks in the ratings of caregiver burden, satisfaction. Anxiety, and depression	Depression and anxiety were the outcomes that showed the most change	2
Several measurement instruments were used measuring in health specific family coping index	The findings suggested that the educational program was beneficial in assisting spouses to feel more competent in the face of the disease process	1
Primary outcomes were measured in anger or hostile and depressed mood, coping strategies and self-efficacy	Significant main effects were found for changes in most measurements	2
Quality of life, burden and well-being were measured	The only significant impact was an increase in knowledge of dementia	1
The caregivers perception of stress was measured as the degree to which the caregiver perceived stress and used positive reappraisal as a cogni-tive coping method	The improvement in caregiver satisfaction was attributed to an attenuation of the behavioural stressor effects through increased use of problem-focused coping strategy, namely, positive reappraisal of the stressful situation	2

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Table 34.5 *continued*

Author Year Reference Country	Overal aim/ purpose	Sample/ study group	Intervention/ study period
Done et al 2001 [59] USA	To evaluate a workshop in communication skills	30 informal caregivers were allocated to the workshop sessions and 15 to the booklet	A short workshop in communication techniques improving communication skills during 6 weeks
Dröes et al 2004 [67] The Netherlands	To examine if integrated support was effective in reducing the feelings of burden	Treatment group (n = 36) and control group (n = 19)	Both patients and the caregivers were supported by one professional staff member during 7 months
Finnema et al 2001 [53] The Netherlands	To examine the integrated emotion-oriented care versus usual care on the residents' relatives in the nursing home	The sample included 339 and a total of 256 questionnaires were returned (75%)	In addition to training in working with the principles of the Model-Care plan, the experimental wards received training and supervision of integrated emotion oriented care
Fung et al 2002 [68] Hong Kong	To examine the effectiveness of a mutual support group program for family caregivers in Hong Kong	52 family caregivers from two centres participated in the study	The support group program intervention group met weekly, for a total of 12 1-hour sessions
Gendron et al 1996 [83] Canada Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To evaluate the effectiveness of a skill training cognitive-behavioural program	The sample consisted of 35 spousal. A total of 18 caregivers participated in the treatment group and 17 in the control group	8-week group intervention focused on problem-solving and cognitive restructuring

Method Data collection/analysis	Results Outcomes	Quality of study
The caregiver stress, communication problems were measured. Consumer evaluation of the training workshop was carried out	Levels of stress did not change between the pre-intervention and follow-up measurements but significant reduction of problem communications whereas the reports of problem behaviours remained stable and similar	1
Feelings of stress, dissatisfaction or psychological and psychosocial complaints were measured	No effect was found	1
Since no relevant measuring instrument was found the new questionnaire was designed from the instrument by Bass et al (see Table 34.9)	Only one significant difference was found between the treatment group and control group: in the treatment group the caregivers asked family members more frequently about residents life histories	2
Data was collected via a questionnaire with two outcome measures (caregiver distress scale and quality of life measure)	The findings showed a significant reduction in distress levels	3
The results were measured in marital adjustment, psychological distress, negative thoughts coping styles, perceived burden and care receiver problems	The results show significantly lower ratings of marital adjustment and marital satisfaction by the Cognitive-Behavioural group	2

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Table 34.5 *continued*

Author Year Reference Country	Overal aim/ purpose	Sample/ study group	Intervention/ study period
Gerdner et al 2002 [69] USA	To evaluate the efficacy of a longitudinal psycho-educational program	237 caregiver/care recipient dyads (132 treatment and 105 comparison group) included	The intervention was grounded in the Progressively Lowered Threnshold model. The comparison group received routine information
Gitlin et al 2003 [70] USA	To examine the effects of an home environmental skill-building program	190 family caregivers participated (89 in treatment group compared with 101 controls)	
Hepburn et al 2001 [72] USA	To test a role-training program	94 caregiver/care receiver dyads	The training program curriculum was built on stress and coping theory based including 14-hour training program provided 7 weekly 2-hour sessions
Jansson et al 1998 [81] Sweden	To develop and test a model to meet the needs of the family caregivers as well as to assess the experiences of the model	The groups consisted of four or five relatives and the same number of volunteers being 27 in the studied group	5 occasions, weekly for 3 hours
Jang et al 2004 [73] USA	To examine the impact of caregiver neurotism among spouse-caregivers	The study analyzed data from 320 caregivers, 160 in each group	The counseling support group and consultation

Method Data collection/analysis	Results Outcomes	Quality of study
Data was obtained from Memory and Behavioral Problems Checklist	The intervention had statistically significant effect on spousal response to memory/behavioural problems for all caregivers and on response to activities of daily living problems for spousal caregivers	3
Caregiver well-being, and whether effects vary by caregiver gender, race and relationship	Compared with controls the caregivers reported less upset with memory-related behaviours, less need for assistance of other and better affect	2
Measures of care-giving, burden, depression and reaction to care receiver behaviour were administrated	There was a significant positive association between the strengthened mediator, the caregivers having less emotionally enmeshed beliefs about care giving roles and responsibilities, and the outcome, namely improvements in burden	1
Qualitative study. The transcribed interviews were analyzed using the methodology of Strauss and Corbin	The results were presented in various themes: The relatives and volunteers experiences of the study circle. The relatives experiences of the relief provided and the volunteers´experience of providing relief care as well as the deacons experience of being leaders	1
Changes in depression level was analysed	Caregivers high neuroticism showed a worse longitudinal course of depression compared with those with low neuroticism. Caregiver showed benefits from the enhanced treatment compared with usual care, regardless of neuroticism score	2

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Table 34.5 continued

Author Year Reference Country	**Overal aim/ purpose**	**Sample/ study group**	**Intervention/ study period**
King et al 2002 [74] USA	To determine the effects of moderate-intensity exercise among older women	100 women participated being 51 in the exercise group	The exercise intensity was gradually increased over the initial 6-week period. At least 30- to 40-minute weekly exercise
McCurry et al 2003 [75] USA	To examine the feasibility of training caregivers to implement sleep hygiene recommendations	22 family caregivers (active treatment group = 10 and control = 12) participated in the study	Written materials describing age- and dementia related changes in sleep and standard principles of good sleep hygiene and support to implement these recommendations
Mittelman et al 1995 [76] USA Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To examine the effects of a support program	There were 206 spouse-caregivers	1 years intervention or until the institutionalization or the death
Mittelman et al 2004 [77] USA	To examine the effects of an enhanced counseling and support group intervention	Of the original 406 subjects, were assessed 380 at 1 year, 328 at 3 years and 223 at 5 years of follow-up	The enhanced counseling and support treatment was delivered by counsellors with advanced degrees in social work
Mohide et al 1990 [79] Canada Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To determine the effectiveness of an Caregiver Support Program	60 caregivers were enrolled in the trial but only 42 completed the trial (n = 22 experimental group and n = 20 control group)	The caregivers received dementia and care giving education tailored to the subjects´ knowledge level, caregiving situation and learning styles

Method Data collection/analysis	Results Outcomes	Quality of study
Measurements in health	The findings show that interventions tailored to the situational constrains of care giving result in significant improvements in health	2
Self-ratings of the caregivers own sleep using the Pittsburg Sleep Quality Index	Many caregivers need active assistance setting up and implementing a sleep hygiene program. Simply providing caregivers with education is often insufficient	1
The change in the number of symptoms of depression	The average difference between the change in the treatment and control groups only became statistically significant 8 months after caregivers entered the study	2
Symptoms of depression were measured	A short course of intensive counseling and readily available supportive maintenance can have long-lasting effects in reducing symptoms of depression among informal caregivers	2
The outcomes were measured in depression, anxiety and quality of life. Descriptive data was collected regarding the health history	The results showed improved caregiver quality of life, decreased impact on the day-to-day lives, delayed long-term institutionalization, and greater consumer satisfaction with nursing care	1

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Table 34.5 *continued*

Author Year Reference Country	Overal aim/ purpose	Sample/ study group	Intervention/ study period
Toseland et al 1989 [78] USA	To examine the effectiveness of peer-led and professionally led groups for supporting adult women caregivers	56 participants were randomly assigned to a professionally led group (n = 18) and peer-led conditions (n = 18) or a respite-only control (n = 20)	All groups met for a total 8, 2-hour sessions weekly. Support for the 2 first groups included encourage of ventilations of stressful situations
Ostwald et al 1999 [94] USA Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To test the effectiveness of an psychoeducational intervention	94 caregivers participated	The intervention consisted of seven weekly, 2-hour multi-media training sessions including education support
Quayhagen et al 2000 [95] USA Described in Brodaty et al 2003 [43] and Brodaty et al 2003 [96]	To evaluate a psychoeducational support program	103 caregivers participated	The 8-weeks program consisted of role-playing, videotaping and on-site supervision. Licensed clinical personnel from psychology, social work and nursing were trained and supervised
Ripich et al 1998 [58] USA	To evaluate the effectiveness of a training program	19 caregivers in the treatment group and 18 in the control group participated	A focused communication-training program to improve communication skills
Stolley et al 2002 [97] USA	To describe the impact of a psychoeducational program	A total 241 subjects completed the study	One year intervention based on the Progressively Lowered Stress Threnshold model

Method Data collection/analysis	Results Outcomes	Quality of study
Burden, psychological functioning, social supports, personal changes and participant satisfaction were measured	No significant differences were found among the three conditions on perceived burden	1
Burden and depression were measured	The intervention was successful in reducing caregivers negative reactions to disruptive behaviours and reducing burden over time	1
Caregivers were assessed on marital interaction, emotional status and physical health along with stress, coping and social support. Both qualitative and quantitative data was analyzed	Analysis for specific changes within each condition over time revealed a significant decrease in symptoms of hostility among the caregivers	1
The outcomes were measured in positive and negative affect, depression, health status, general hassles, communication hassles and knowledge assessment	No significant changes were found	1
Caregiver appraisal was measured in mastery, burden, satisfaction	Analysis of trends over time showed that the intervention positively affected impact, burden and satisfaction but had no effect on mastery	2

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Table 34.5 continued

Author Year Reference Country	**Overal aim/ purpose**	**Sample/ study group**	**Intervention/ study period**
Whitlatch et al 1995 [87] USA	To investigate whether counseling and support were associated with positive long-term outcomes	Participants were 132 caregivers	Eight sessions in three groups: Individual and family counseling, support group and wait list control group
Zarit et al 1987 [98] USA Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To evaluate a support group program	A total of 184 subjects participated	The intervention was provided through either support groups or a program of individual and family counseling

Method Data collection/analysis	Results Outcomes	Quality of study
Caregivers were assessed in current use of informal and formal service, and feelings of burden and distress	The results suggest that when caregivers respond positively to psychoeducational interventions, the benefits may be long lasting	2
Outcome was assessed in stress, frequency of behaviour problems, use of social support, perception of treatment benefits	The distress ratings were significantly related to time, mean distress decreased and a significant effect for time was found for the social support measures	1

Table 34.6 *Characteristics of included studies about informal caregivers – technological support.*

Author **Year** **Reference** **Country**	**Overal aim/ purpose**	**Sample/ study group**	**Intervention/ study period**
Bass et al 1998 [57] USA	To examine patterns of computer use and impact on strain	102 caregivers	The 12-months intervention phase of computer support network
Brennan et al 1995 [56] USA	To evaluate the effects of computer network support on confidence in decision making skills and social isolation	102 caregivers were randomly assigned to Computer Link group (n = 51) and comparison group (n = 51)	Computer network support during 1-year study phase
Eisdorfer et al 2003 [82] USA	To examine the efficacy of a family therapy and technology-based intervention	The sample included 225 Hispanic family caregivers	The computer-telephone therapy intervention, translated into Spanish, took place during 12 months, with weekly sessions
Mahoney et al 2003 [55] USA	To evaluate an interactive technology intervention	A randomized controlled study of 100 caregivers, 51 in usual group and 49 in the treatment group	The computer-mediated auto-mated interactive voice response assisted the caregivers during 1 year

Method Data collection/ analysis	**Results Outcomes**	**Quality of study**
Initial in-person interview, structured protocol and a mix of standardized measures and items developed for this project	Computer support was related to reduced strain for caregiver living alone with care receiver	1
Decision-making confidence and skills, burden, depression, and caregiver contact with community	Access to Computer Link did not significantly improve decision-making skills and the caregiver experiences of social isolation. Increased confidence in decision-making	3
Levels of depression scores were evaluated at baseline, 6-months and 18-months follow-up	The intervention by itself did not have a significant effect on depressive symptoms for most of the informal caregivers. The efficacy of the intervention differed according to the ethnicity and type of caregiver	2
The outcomes were measured in caregiver bother, anxiety and depression	There was a significant effect with lower mastery at baseline on all 3 outcomes. Wives exhibited a significant effect in the reduction of the bothersome nature of care giving	1

__Table 34.7__ Characteristics of included studies about informal caregivers – out-of-home activities.

Author **Year** **Reference** **Country**	**Overal aim/ purpose**	**Sample/ study group**	**Intervention/ study period**
Lieberman et al 2001 [84] USA	To determine the effects of the nursing home placement	235 families participated	The 2-year longitudinal study with baseline and four follow-up assessments
Logiudice et al 1999 [85] Australia Described in Brodaty et al 2003 [43]	To determine the effects of the attendance at the memory clinic	Participants were randomized to attend a memory clinic or a control group	Attendance at memory clinic. The measurements were carried out at 6 and 12 months post intervention
Maas et al 2004 [86] USA	The effects of the family involvement	The study recruited 14 nursing home special care units including 185 family members	Specific family involvement in care partnership intervention on family members perceptions of nursing home care

Method Data collection/ analysis	**Results Outcomes**	**Quality of study**
Changes in the caregiver health status	The caregiver health and well-being did not improve over time, and it was no significant differences in health and well-being between family caregivers who placed their ill elder in a nursing home	1
Main outcomes were measured in burden, psychological morbidity and psychological health related to quality of life	The greatest impact was in area of social interaction, which appeared to be maintained over one year. The improvement in health was not improved in the measurements of psychological morbidity and burden	2
Perception of caregiver role, relationships with staff, and satisfaction with the care of relatives	Statistically significant beneficial effects were found within emotional reactions to the caregiver role, perceptions of relationships with staff, and perceptions of care for relatives	1

Table 34.8 *Characteristics of included studies about informal caregivers – included in other systematic reviews.*

Author **Year** **Reference** **Country**	**Overal aim/ purpose**	**Sample/ study group**	**Intervention/ study period**
Hébert et al 1994 [89] Canada Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To measure the efficacy of a support group program	41 caregivers were randomly assigned in the the treatment group (n = 23) and 21 in the control group	A structured program of eight 2-hours sessions weekly including information of disease, role-playing, emotional impact of caring and learning of stress management techniques
Kahan et al 1985 [99] USA Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To investigate the efficacy of specifically designed group support program	22 subjects participated in the treatment group and 18 controls received no treatment	The 8-session program included educational/ supportive activities
Mittelman et al 1995 [76] USA Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To examine the effects of a support program	There were 206 spouse-caregivers	One years intervention or until the institutionalization or the death
Mohide et al 1990 [79] Canada Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To determine the effectiveness of an Caregiver Support Program	Sixty caregivers were enrolled in the trial but only 42 completed the trial (n = 22 experimental group and n = 20 control group)	The caregivers received dementia and care giving education tailored to the subjects´ knowledge level, caregiving situation and learning styles

Method Data collection/ analysis	Results Outcomes	Quality of study
The outcome variables were measured in burden, memory and behavioural problems, disease knowledge and the health care utilization	The study group yield only a significant increase in knowledge about the disease but not on the other outcome variables	1
Caregiver and depression levels were measured	The experimental subjects showed a significant decrease in total family burden and reduction in their level of depression	1
The change in the number of symptoms of depression	The average difference between the change in the treatment and control groups only became statistically significant 8 months after caregivers entered the study	2
The outcomes were measured in depression, anxiety and quality of life. Descriptive data was collected regarding the health history	The results showed improved caregiver quality of life, decreased impact on the day-to-day lives, delayed long-term institutionalization, and greater consumer satisfaction with nursing care	1

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Table 34.8 continued

Author **Year** **Reference** **Country**	**Overal aim/ purpose**	**Sample/ study group**	**Intervention/ study period**
Ostwald et al 1999 [94] USA Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To test the effectiveness of an psychoeducational intervention	94 caregivers participated	The intervention consisted of seven weekly, 2-hour multi-media training sessions including education support
Quayhagen et al 2000 [95] USA Described in Brodaty et al 2003 [43] and Brodaty et al 2003 [96]	To evaluate a psychoeducational support program	103 caregivers participated	The 8-weeks program consisted of role-playing, videotaping and on-site supervision. Licensed clinical personnel from psychology, social work and nursing were trained and supervised
Zarit et al 1987 [98] USA Described in Cooke et al 2001 [44] and Brodaty et al 2003 [43]	To evaluate a support group program	A total 184 subjects participated	The intervention was provided through either support groups or a program of individual and family counseling

Method Data collection/ analysis	Results Outcomes	Quality of study
Burden and depression were measured	The intervention was successful in reducing caregivers negative reactions to disruptive behaviours and reducing burden over time	1
Caregivers were assessed on marital interaction, emotional status and physical health along with stress, coping and social support. Both qualitative and quantitative data was analyzed	Analysis for specific changes within each condition over time revealed a significant decrease in symptoms of hostility among the caregivers	1
Outcome was assessed in stress, frequency of behaviour problems, use of social support, perception of treatment benefits	The distress ratings were significantly related to time, mean distress decreased and a significant effect for time was found for the social support measures.	1

Table 34.9 *Measurements and scales used in the studies.*

Name of scale	Author, year*
Caregiver Strain Scale	Zarit & Zarit 1982 and Poulshock & Deimling 1984
Spilberger Anger Expression Scale	Spilberger et al 1985
Spilberger Anxiety Inventory Scale	Spilberger 1983
Caregiver Self-Efficacy Assessment	Steffen et al 1994
Perceived Stress Scale	Cohen et al 1983
Caregiver Hassles Scale	Kinney & Stephens 1989
CES-D (Center for Epidemiological Studies Depression Scale)	Radolff & Teri 1986
CES-D (Center for Epidemiologic Studies Depression Inventory)	Radloff 1977
Self-Rating Depression Scale	Zung 1965, 1967
Depression Scale	Hamilton 1960
GDRS, Geriatric Depression Scale	Yesavage, Brink, Rose, Lum, Huang, Adey, Leirer 1983
Caregiver Health Index	Brook et al 1979
Modified General Well-Being Scale	Applegate et al 1991, Brook et al 1979, Burns et al 2000
General Health Questionnaire (GHQ)	Goldberg 1972, 1978

Amount of items	Outcome variables
41 items Range from 0 to 164	Frequency of patient behaviors and how upsetting that behavior is to the caregiver Strain
Anger 1 (not at all) to 4 (very much) Anxiety 20 items	Caregiver negative effect Anger Anxiety
15 items Subscales with 12 items	Caregivers' perceptions of their confidence in their own ability to handle 4 skill domains (pleasant activi-ties, problem solving, relation, and patient management) Self-efficacy
4 items	To assess how unpredictable, uncontrollable, and overloading respondents find their lives Stress
42 items	General hassles
20 items	Depressive symptoms Depression
20 items self-report scale	How often the caregivers felt a certain way during the past week Depression
20 items	Depression
?	Depression
30 items	Depression
A scale rating from 1 (excellent) to 5 (poor)	Caregivers' overall physical and emotional health Health status
22 items	General health and mental health Well-being
30 items	Well-being

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Table 34.9 continued

Name of scale	Author, year*
Revised Memory and Behavior Problems Checklist (RMBPC)	Teri et al 1992
POMS (Profile of Mood States Scale)	McNair, Lorr & Droppelman 1971
Modification of a Decision Confidence Scale	Saunders & Courtney 1985
Decision-making Skills	Brennan 1986, Ripich et al 1991
The Instrument and Expressive Social Support Scale (TESS)	Ensel & Woelfel 1986
Social Support Questionnaire	Schaefer, Coyne, Lazarus 1981
Impact of Caregiving Scale	Poulshock & Deimling 1984
Family Burden Interview	Zarit et al 1980
Family Burden interview	Zarit & Zarit (1990)
Caregiver Appraisal Tool	Lawton et al, Lawton, Kleban, Moss, Rovine, Glicksman 1989
Lubben Social Network Index (LsNI)	Lubben 1988
LSNI scale	Berkman & Syme 1979
Social Support Questionnaire	Schaefer et al 1981
The leisure Time Satisfaction measurement	Stevens et al 2001
Desire to Institutionalize	Morycz 1985

Amount of items	Outcome variables
5-point scale From 0 (not at all) to 4 (extremely bothered)	How the dementia was manifested for the patient and affected the caregiver Psychological distress
65 items	Subjective affect
14 items	Decision-making confidence
Self-reported instrument	Decision-making skill
27 items	Social isolation
64 items	Perceived emotional support Emotional support
Lickert scale	Family relationships and physical health Burden
22 items	Burden
22 items	Burden
47 items	Burden and satisfaction
28 items	Family, friends, confidants Social networks
8 items	Satisfaction with support Support
–	Social support
6 items	Leisure time satisfaction
7 items	Desire to institutionalize

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Table 34.9 continued

Name of scale	Author, year*
Indices of Coping (IC) scale	Moss and co-workers 1984
Coping Strategies Inventory-Revised	Quayhagen & Quayhagen 1988
Ways of Coping Scale Revised	Folkman, Lazarus, Dunkel-Schetter, DeLongis, Gruen 1986
Brief Symptom Inventory	Derogatis & Spencer 1982
Brief Symptom Inventory (BSI)	Derogatis 1992
Brief Symptom Inventory (BSI)	Derogatis & Spencer 1982
State Anger Scale	Spielberger 1988, 1999
Schedule for the Evaluation of Individual Quality of Life – Direct Weighting, SEIQoL-DW	O'Boyle et al 1996
World Health Organization Quality of Life Measure, Brief Version Modified and Translated to Chinese	Leung, Tay, Cheng, Lin 1997
Quality of Life Instrument (CQLI)	Mohide, Torrance, Streiner, et al
Tolerability of Patient Problem Behaviors, DBD Scale	Zarit et al 1986, Coen et al 1997
Vaux Social Support Appraisal Scale SS-A	Vaux et al 1988
Carers' Perception of Improvement or Decline in Situation	Zarit et al 1987
Memory and Behavior Problems Checklist	Zarit 1980, 1985

Amount of items	Outcome variables
32 items	Coping styles
39 items	Coping
7-item subscale	Positive reappraisal Coping
4-point Lickert scale	Emotional status
53 items	Physical health
22 items	Burden
10 items	Anger
	Quality of life
28 items	Quality of life
Health rate score ranges from 0 to 1 with indicating the highest quality of life	Quality of life
–	Tolerability of patient problem behaviors
	Appraisal of informal social support
7-point scale	Perception
30 items	Perceived stress

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***Table 34.9** continued*

Name of scale	**Author, year***
Memory and Behavior Problems Checklist (MBPC)	Zarit & Zarit 1982, 1990
Marital Needs Satisfaction Scale	Stinnett, Collins, Montgomery 1970
Health Specific Family Coping Index for Non-institutional Care	Choi 1983
Cambridge Examination for Mental Disorders in the Elderly	Roth et al 1986
Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)	Jorm et al 1989
The Clifton Assessment Procedures for Elderly (CAPE), Behavioral Rating scale (BRS)	Pattie 1981
Psychosocial Dimension of the Functional Limitations Profile (FLP)	Patrick & Peach 1989
Carer Knowledge of Dementia	Diekmann et al 1988
Neuropsychiatric Inventory-Caregiver Distress Scale	Kaufer et al 1998
Hopkins Symptom Checklist	Derogatis, Lipman, Rickels, Uhlenhult, Covi 1974
Automatic Thoughts Questionnaire	Hollon & Kendall 1980
Jalowiec Coping Scale	Jalowiec 1988
Dyadic Adjustment Scale	Spanier 1976

Amount of items	Outcome variables
30 items	The frequency with which common behavioral problems occurred and evaluated caregivers' appraisal of each problem Behavior problems
24 items	Spousal satisfaction
9 domains	Potential and actual health problems
Range from 0 to 107	Discrimination between people with dementia and normal
26 items	The extent of change of memory and intelligence over 10 years Memory and intelligence
–	Physical and communicational difficulties, apathy and social disturbance
–	Sleep and rest, alertness and emotional behavior, social interaction, recreation Psychosocial dimension score
10 items	Knowledge of dementia
12 items	Caregiver distress
45 items	Depression, anxiety, somatization, interpersonal sensitivity, obsessive-compulsive symptomatology
–	Depressive thinking: Negative self-concept, perception of maladjustment, low self-esteem, helplessness
36 items	Coping styles
–	Global perception of marital adjustment Affectional expression, satisfaction, cohesion

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Table 34.9 continued

Name of scale	Author, year*
Family Perceptions of Caregiving Role (FPCR) Family Perceptions of Care Tool (FPCT)	Maas & Buckwalter 1990
Marital Needs Satisfaction Scale	Stinnett et al 1970
Geriatric Center Morale Scale	Lawton et al 1982
Philadelphia Geriatric Center Multilevel Assessment Instrument (MAI)	Lawton et al 1982
Physical health status	Rosencranz & Pihlblad 1970
Positive and Negative Affect Scale	PANAS; Watson, Clark, Tellgren Developed by Kecher 1992
Memory and Behavior Problems Checklist (1982)	Zarit & Zarit 1982
Common Physical Symptoms Derived from the Rand MOS	Ware et al 1984
Hopkins Symptom Checklist modified by Pearlin and Lieberman	Derogatis 1974
Well-being Scale	Bradburn 1969
Affect Balance Scale (ABS)	Bradburn 1969
Modified Andersen framework	Bass et al 1992

* Specifications of references not included.

Amount of items	Outcome variables
81 items 51 items	Stress Satisfaction
–	Marital satisfaction
–	Morale
4 items	Physical health
25 items	Physical health
Range from 1 (not at all) to 5 (very much)	Subjective well-being
30 common problems	Management of problem behavior
21 items	Common somatic symptoms Headache, backache
23 items	Anxiety and depression
11 items	General well-being
5 items	Positive and negative effects
4 predictors	Cognitive impairment

***Table 34.10** Excluded intervention studies – informal caregivers.*

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Barnes et al, 1981 [100]	8		
Burgio et al, 2001 [101]	4		
Cohen, 2000 [102]	4		
Connell et al, 1996 [103]	8		
Cummings et al, 1998 [104]	4		
Done et al, 2001 [105]	4	2	
Emerson Lombardo et al, 2002 [106]	1		
Ferris et al, 1987 [107]	4		
Gallagher-Thompson et al, 2001 [108]	1		
Haley et al, 1987 [109]	4	3	
Hansen et al, 1988 [110]	3	4	
Henry et al, 1995 [111]	4		
Hepburn et al, 2003 [112]	4		
Hosaka et al, 2003 [113]	4		
Karlin et al, 1999 [114]	4		
Lazarus et al, 1981 [115]	4		
Lyman, 1989 [116]	2	4	
Martin-Cook et al, 2003 [117]	3	4	
McCurry et al, 2003 [118]	2	4	

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***Table 34.10** continued*

Author, year, reference	Exclusion reason 1	Exclusion reason 2	Exclusion reason 3
Mizuno et al, 1999 [119]	4		
Monahan et al, 1992 [120]	8		
Morano et al, 2002 [121]	4	2	
Palmer et al, 1996 [122]	4		
Tibaldi et al, 2004 [123]	2	4	
Zarit et al, 1998 [124]	4		

Explanation of reasons for exclusion:

0. Outside the research question of interest. This is not a quality level, it just means that the paper is unrelated to the question of interest. It may be a result of inadequate coding in databases or an insufficient search strategy.
1. Insufficient number of subjects/low power.
2. Inadequacies in description/selection of subjects, abstracts.
3. Inadequacies in methods/instruments to measure outcomes/effects/consequences.
4. Inadequacies in design.
5. Inadequacies in data collection/high attrition/drop out/drop in rate.
6. Inadequacies in statistical methods/calculations.
7. Inadequacies in ethics.
8. Serious conflict of interest.
9. No original data.
10. Miscellaneous.

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35. Ethnicity and Culture in Dementia Care – an Evaluation of Interventions Studies

Conclusions

Only a few studies were found that were relevant to the aim and specific question of this evaluation. Eight studies were evaluated. Due to differences in interventions and outcomes, the evidence was inconclusive. No systematic review was found. Two qualitative articles from one study showed effects from the use of the patient's native language in care situations but were insufficient in terms of evidence.

Research in the area of ethnicity and dementia, particularly descriptive and intervention studies in Europe about how different ethnic groups care for people with dementia, is badly needed. The growing mobility of various EU populations, including the elderly, makes such research even more urgent.

Introduction

The words culture and ethnicity are often used synonymously [1]. This report uses culture to refer to inherited ways of life to which a person is socialized, including value systems, beliefs and norm systems that a group of people deal with [2–4] – or the ideological phenomena that provide them with means of interpreting the world [5].

Language plays a vital role in communicating and permitting interpretation of a culture [6]. Research on bilingualism and health care has noted the loss of the more recently acquired language as a dementia disorder progresses [7–9]. Only the patient's native language remains in the final phase of the disease, leading to major problems unless caregivers happen to master it as well [10–12]. Several studies have pointed to the importance of language comprehension when employing various tests to diagnose dementia disorders. A review by Lampley-Dallas et al [13] and [14] argued that the physician's inability to communicate with a member of a minority group poses obstacles to making a correct diagnosis.

Ethnicity is a matter of group affinity and a collective sense of identity [15]. As a system that constructs meaning, people's ethnicity is meaningful to them only in contrast to that of other groups [16,17]. Important to keep in mind when reading US literature is that ethnicity is often used as a synonym for race [18].

Aim

The aim of this review is to describe and evaluate care interventions that focus on the significance of culture and language in the care of people with dementia.

Question of interest

Do linguistic and cultural considerations play any role when caring for people with dementia?

Method

Inclusion criteria

Care interventions were included that focused on patients who had been diagnosed with dementia by means of the DSM III–IV, ICD 9–10, ADRS, NINDS, NINCDS-ADRDA or Lund-Mancheter tools or the MMSE, GBS or GDS rating scales.

Exclusion criteria

Care interventions were excluded that had primarily biomedical or economic outcomes, that involved psychological or linguistic testing, or that concerned patients with dementia in connection with schizophrenia, Down's syndrome, AIDS or Parkinson's disease.

Strategy for searching the literature

We were interested in nonmedical, nonpharmacological, psychosocial interventions with evaluated effect in people with dementia that had been published from January 1, 1975 to June 30, 2004. The search terms for PubMed, Medline, Cinahl and Social Services Abstracts were Dementia or Alzheimer's disease (DE) AND ethnicity OR minority or immigrant OR bilingual/multilingual OR culture OR/AND intervention. The reference lists of studies were checked and combined with the search results.

About 500 abstracts were read, but it was difficult to exclude irrelevant studies due to the insufficient information that they yielded. Of these studies, 185 were read, given that the quality of the abstracts was so low that it was not possible to judge whether a study involved an intervention or not. Forty of these articles were not research papers and 123 were not intervention studies. Eight papers were accepted (Tables 35.1 and 35.2). Two relevant articles were excluded (Table 35.3) due to methodological problems. No Cochrane review was found. Thirteen reviews (Table 35.4) were identified, but none were systematic. Those articles lacked information about study quality and often about the level of the dementia disorder as well.

The common quality criteria, evaluation scheme and manual are the same as in Parts I and II (Interventions studies – patient perspective and formal/informal caregivers, see Chapter 34).

Results

General considerations

Our review found few studies that focused on the specific needs of various ethnic groups. Most intervention studies were conducted in the United States, usually with and for minority groups. The studies generally justified cultural considerations with reference to the aging populations – and thereby the greater number of people with dementia – among those groups. Few studies explained why a group should be regarded as ethnic or as having cultural differences that called for customized interventions. For instance, the very fact that African Americans are a minority was assumed to be sufficient reason to study them separately.

A number of studies concentrated on training professional or family caregivers. Interventions that included educational activities for professional caregivers often strove to increase their knowledge about a group's concepts and customs when it comes to dementia disorders. The assessments attempted to determine whether the caregivers had in fact become more knowledgeable or shared their new insights with others. Educational activities that targeted family caregivers frequently zeroed in on information about dementia and treatment. The assessments looked at whether they had absorbed the information and adopted more suitable adjustment strategies.

No interventions were directed at patients only. Whenever patients were involved in the interventions, caregivers participated as well.

Specific considerations

Evaluation of the interventions in which the cultural focus was on language (Table 35.1)

Ekman et al compared morning care sessions for bilingual patients who had severe dementia and a Finnish background with both monolingual and bilingual caregivers in order to analyze the relationship of the three groups in terms of promoting patient integrity [10]. The background of the study was that bilingual people with dementia encounter three kinds of communication problems, as opposed to one for monolingual patients. The patients were Finnish immigrants in Sweden, and the languages were Finnish and/or Swedish. The comparison showed that there was a positive effect on relationship in promoting integrity when the caregivers were bilingual and a negative effect if all caregivers were monolingual. In these situations, latent abilities emerged. In mixed relationships, there were both monolingual and bilingual caregivers.

Ekman et al assessed the dimensions of progress of the interaction between bilingual and monolingual caregivers and bilingual Finnish immigrants with dementia by means of Erikson's theory of the eight stages of man [11]. Morning care sessions for bilingual patients who had severe dementia and a Finnish background were compared with both monolingual and bilingual caregivers. Bilingual caregivers communicated more multi-dimensionally, and their interactions more often progressed in a positive direction.

Lombardo et al reported on an educational Train-the-Trainer model for bilingual Chinese professional caregivers of people with dementia [19]. The goals were to train them as dementia specialists so that they could improve services to the elderly, as well as to encourage them to spread their knowledge throughout their agencies and to others in the Chinese American community. Another goal was to involve the participants in creating and supporting new dementia outreach and service development efforts at the workplace. Sixteen professionals were certificated as dementia specialists, and the participants had spread the information to 300–400 other people, thereby ensuring that the institution as a whole would be able to identify and serve patients with dementia and their families. The effects of the intervention were poorly described.

A study by Eisdorfer et al was part of a large multisite research project (REACH) on efficacious interventions by family caregivers for people with Alzheimer's disease (AD) or related dementia [20]. The study quantitatively evaluated the effects of two different family caregiver therapies on depression in Spanish-speaking Cuban American and white non-Hispanic American caregivers. The aim was to examine the efficacy of the interventions for the two groups and over time. The interventions and the evaluation instruments were in both English and Spanish, but there was no evaluation of whether the instruments were culturally appropriate. The models used were: 1) the Structural Ecosystems Therapy (SET), a family therapy model to identify and restructure interactions within the family and with other systems that are linked to caregiver burden and that were developed for treating behavioral problems in Hispanic families; and 2) the Computer-Telephone Integrated System (CTIS), an arrangement that facilitates linkages of caregivers with both the family and supportive resources outside of the home. The interventions were conducted either by SET or by a combination of SET and CTIS. The effects were compared with those in a control group. A therapy model that combined SET and CTIS turned out to be the most effective for reducing depressive symptoms in both caregiver groups, as well as over time.

Evaluation of interventions with a focus on cultural aspects (Table 35.2 and 35.3)

Cox compared use and the predictors of use for the Alzheimer's Association's two types of services (support groups and information and referral) among white American and African American family caregivers [21]. The aim was to examine patterns of use of those two types of services over 12 months after initial contact with the association. According to the results, service use was similar for both groups while needs were the only significant predictor.

Gallagher-Thompson et al reported on an educational intervention for health and social care professionals treating patients with dementia in Hispanic cultural milieus [22]. The intervention included an overview of AD (types, prevalence, symptoms, course of the disease, care, support for family members and medication), Hispanic cultural and family values (demographics of Hispanic elderly, perspective on dementia, cultural characteristics such as development of trust, respect for the elderly, cultural characteristics as barriers to accepting assistance from the outside, family stress and lack of available services in Spanish). The outcomes were measured pre-intervention and post intervention and evaluated within the knowledge domain (two questionnaires about knowledge of AD and in Hispanic culture) and the behavioral domain about the use of the services and referrals for patients and their families, as well as by participants' written action plans and follow-up. A total of 39 sessions were completed, and comparison from baseline to post-intervention showed that the knowledge domain increased significantly, as did behavioral changes among the professionals.

The study by Gallagher-Thompson et al was part of the REACH project from the Palo Alto site [23]. They studied the effects of two different group therapy models. The Coping with Caregiving (CWC) model teaches a limited number of cognitive-behavioral mood management skills through reducing negative affect by learning how to relax in a stressful situation, appraise the patient's behavior and communicate assertively, emphasizing increased positive mood, developing strategies to perform more pleasant activities and learning to set self-changing goals and personal rewards. The Enhanced Support Group (ESG) model was designed as a caregiver support group according to Alzheimer's Association guidelines.

The effects of the two models were compared, and their cultural appropriateness for female Latino and Anglo family caregivers was examined. In addition, the effectiveness of the interventions was examined for the female Mexican American Latino subgroup. The study did not find any significant differences between the ethnic groups at baseline or in the 3-month follow-up and considered the interventions to be culturally appropriate for all three groups. The CWC model was found to be more effective in reducing negative interactions. The results were significant for all the ethnic groups.

Burgio et al studied the racial effects of the Skills Training Condition (STC) program with a focus on changing the coping strategies of family caregivers in a positive direction [24]. The goals were to develop short-term interventions that were culture-sensitive (or neutral) for African Americans and white Americans, as well as to standardize them. Furthermore, the goal was to compare the effectiveness of the intervention with the control group and to explore the differing impact of the intervention on the two groups of caregivers. The researchers found the intervention model to be more appropriate for the African American group. Their conclusion was that the STC reliably delivered psychosocial interventions for both groups.

Summary of the results

Effects were found in the following studies:

- Short-term service use interventions, which were culture-sensitive (or neutral), were found to be more appropriate for African American than white American family caregivers.

- A qualitative study (two papers) that allowed bilingual caregivers to create positive relationships and communication by promoting integrity. Bilingual caregivers communicated more multi-dimensionally, and interactions more often progressed in a positive direction. Latent abilities also emerged in situations with positive relationships [10,11].

- An educational intervention model for professionals in Hispanic cultural milieus who treated dementia patients showed significantly knowledge about Alzheimer's disease and about Hispanic persons' beliefs and values regarding the disease and did behavioral changes among the professionals [22].

- An educational Train-the-Trainer model for bilingual Chinese professional caregivers of people with dementia disorders (effects poorly described) [19].

- A combined therapy model with support shown to be an effective intervention for reducing depressive symptoms in both Cuban American and white non-Hispanic American family caregivers, as well as over time. No conclusion concerning cultural appropriateness was drawn [20].

- Effects of the Coping with Caregiving (CWC) and Enhanced Support Group (ESG) group therapy models were compared in terms of cultural appropriateness for female Latino and Anglo family caregivers. No significant differences between the groups were found. The interventions were considered to be culturally appropriate for both groups, as well as for a Mexican American subgroup. CWC was found to be more effective in reducing negative interactions, and the results were significant for all the groups [23].

- The racial effects of the Skills Training Condition (STC) program with a focus on changing the coping strategies of family caregivers were found to be more appropriate for African American than white American family caregivers [24].

Discussion

The differing designs of studies that focused on linguistic considerations posed serious obstacles to drawing any conclusions with respect to evidence. Two articles from one study demonstrated the advantages of using caregivers who speak the patient's native language. Language comprehension was shown to enable a deeper relationship between the patient and caregiver, as well as to bring out latent abilities (and thereby a greater sense of wellbeing) in the patient. Such research can succeed only if based on individualized interventions that include in-depth, qualitative analyses of communication and relationship [10,11]. Even if certain effects emerge, one study is insufficient to obtain conclusive evidence.

Culturally oriented interventions showed varying results. Some studies found only a small difference between the minority group and the rest of the population. Studies that took for granted that linguistic or cultural differences, which the authors deemed unnecessary to describe, led to specific dementia characteristics were vague by virtue of their lack of clear objectives. But studies that explained in detail why the particular group was in need of interventions yielded results that were easier to assess. However, they produced no conclusive evidence either.

Table 35.1 Interventions with cultural focus on language.

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients/ caregivers/ staff (n) included (attrition)	Age-groups range (SD)
Eisdorfer et al 2003 [20] USA	Intervention, comparison between white Americans and Cuban American caregivers. Quantitative evaluation, randomisation	Family caregivers living at home with the patient	Patients MMSE; ADL IADL	MMSE <24 (M = for whites 14.5; Cuban 12.67)	Caregivers to 225 patients (whites 111; Cuban 114); 25% men, 75% women	Caregivers: 68.48 (11.33), patients: 83.23 (7.7)
Lombardo et al 2002 [19] USA	Intervention for Chinese-speaking bilingual staff. Quantitative evaluation of the effects. Participants as their own controls	Community care agencies	Not relevant	Not relevant	23 professional care providers (CP)	20–61+ (not calculated)

Study period	Intervention (end)	Primary outcome measures	Results	Remarks from reviewer	Quality of study
Baseline, 6 months, 12 months, 18 months	Comparison of effects of following therapy groups compared over time and by ethnicity: a) Structural ecosystem therapy (SET) b) Structural ecosystem therapy (SET) and computer telephone integrated system (CTIS) c) Minimal support control group	Backtranslated Spanish and English evaluation instruments: 1) CES-D (depressive symptoms scale) 2) RMBPC (upset or burden with the presence of memory/behavioural problems) 3) Satisfaction with social support baseline, 6 months and 18 months follow-up	Combined SET and CTIS effective in lowering depression both for Cuban Americans and white non-Hispanic American. More research needed on influence of cultural aspects	No conclusions of cultural appropriateness of the interventions. Part of the REACH project	2
Pre- and posttests after education and 10 months post	Train-the-trainer educational program in signs and symptoms, drugs, ADL, cultural issues, coping strategies, working with families and therapeutic activities	a) Demografic information b) Program content evaluations c) Train-the-trainer monitoring tool	16 of 22 participants were certified as DS. Significant changes in knowledge about dementia diseases, 300–400 others had been educated	Effects poorly reported	1

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Table 35.1 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients/ caregivers/ staff (n) included (attrition)	Age-groups range (SD)
Ekman et al 1993 [10] Sweden	Intervention videotaped morning sessions. Qualitative methods	Nursing homes, geriatric hospital, health service centres	MMSE GDS Katz Index	3, 3, 5, 6, 7, 13, 16 5, 6, 6, 6, 6, 7, 7 B, D, D, E, E, F, F	7 patients (female), 16 caregivers (1 male)	Patients: 71–85 years (men = 74) Caregivers: 15–64 years (men = 34–35). 2 RNs, 4 LPNs, 10 Nas. Time in dementia care: 1–21 years (men = 5)
Ekman et al 1995 [11] Sweden	Intervention. Qualitative methods	Nursing homes, geriatric hospital, health service centres	MMSE GDS Katz Index	3, 3, 5, 6, 7, 13, 16 5, 6, 6, 6, 6, 7, 7 B, D, D, E, E, F, F	7 patients (female), 16 caregivers (1 male)	Patients: 71–85 years (men = 74) Caregivers: 15–64 years (men 34–35). 2 RNs, 4 LPNs, 10 Nas. Time in dementia care: 1–21 years (men = 5)

Study period	Intervention (end)	Primary outcome measures	Results	Remarks from reviewer	Quality of study
Single morning care sessions compared	Care by bilingual careproviders. Compared with monolingual caregivers	Content analysis (mislabelled phenomenological hermeneutic), 2 minutes sequences coded according to the Erikson theory “eight stages of man”	More positive (positive poles coded) and mixed relationships and negative (positive and negative poles coded) together with bilingual caregivers	Detailed description of coding	1
Single morning care sessions compared	Bilingual caregiver. Compared with monolingual care providers	Content analysis as Ekman [10], coding according to how caregivers supported positive poles. Factor analysis and graphs of progress of interaction	Bilingual care providers communicated more multidimentionally and positively than monolingual care providers	Detailed description of coding	1

Table 35.2 *Interventions studies with culture focus on cultural aspects.*

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups range (SD)
Gallagher-Thompson et al 2003 [23] USA	Intervention. Comparison between Latino (even a subgroup of Mexican Americans) and Anglo female caregivers. Quantitative evaluation, randomization	Family caregivers living at home with the patient	Patients MMSE; ADL IADL	MMSE <24 (m = for whites 14.5; Cuban 12.67)	Caregivers 257 (Anglos 147, Latinos 110); 100% women	Caregivers Latino: M = 50.99 (12.65) Anglo: M = 61.81 (13.32) Patients Latino: M = 76.00 (10.01) Anglo: M = 77.90 (9.00)
Cox 1999 [21] USA	Intervention. Comparison between African American and white American family caregivers service use and predictors for service use. Quantitative evaluation. No randomisation	Family caregivers living at home with the patient	Contacted through Alzheimer's Associations Memory/ Behavior Checklist ADL IADL	Diagnosis or severity not mentioned	Caregivers 300 (150 African Americans, 150 white Americans); gender not mentioned	Whites: M = 59 African: M = 56 No SD mentioned

Study period	Intervention (end)	Primary outcome measures	Results (end)	Remarks from reviewer	Quality of study
Baseline, 3 months	Comparison of effects of following therapy groups compared over time and by ethnicity: a) Coping with caregiving class (CWT) b) Enhanced support group (ESG) c) Minimal support control group	Backtranslated Spanish and English evaluation instruments for CGs: 1) CES-D (depressive symptoms scale) 2) RMBPC (upset or burden with the presence of memory/behavioural problems) 3) Satisfaction with social support. Baseline, 3 months follow-up	Both ethnic groups show similar results in baseline and after 3 months follow-up, CWT effective in diminishing depressive symptoms and coping skills and culturally appropriate for both groups, even for Mexican Americans	Part of the REACH project	2
6 and 12 months after baseline	Comparison of utilisation of a) Alzheimer's Associations' support groups or/and b) Information and Referral services	Statistical differences a) Burden scale: changes in activities, restrictions in leisure, feelings of stress, quality of the relationship to patient b) CES-D: depression c) Personal gain. Baseline, 6 months and 12 months follow-up	Only 1/4 in both ethnic groups had followed their intentions to use the services. Information and Referral services can play a role in the life of the CGs in both groups. Needs the only predicting factors for service use. Race in itself not a determining factor in the use of Alzheimer's services	Race as the diverting aspect without explanation why it would be that	1

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Table 35.2 continued

Author Year Reference Country	Type of study	Setting	Dementia diagnosis	Severity of dementia	Patients (n) included (attrition)	Age-groups range (SD)
Burgio et al 2003 [24] USA	Intervention. Compare effectiveness of an intervention program for skills training among white American and African American family CGs. Randomization	Family caregivers living at home with the patient	MMSE RMBPC	Whites: M = 14.53 (SD 10.30); Africans: M = 10.98 (SD 5.88)	Caregivers: 128. Whites: 70 (18 men, 52 females). Africans: 48 (15 men, 33 females)	Patients Whites: M = 78.06 (8.36) Africans: M = 79.59 (8.36) Caregivers Whites: M = 66.35 (10.30) Africans: M = 57.62 (13.78)
Gallagher-Thompson et al 2000 [22] USA	Intervention. Effects of an educational intervention on Hispanic families' culture for health and social care professionals. No randomisation, participants their own controls	16 acute care hospitals, 5 long term care facilities, 7 community agencies, 2 county psychological associations	Not relevant	Not relevant	340 participants (152 completed the tests)	Not mentioned

AD = Alzheimer's disease; ADL = Activities of daily living; CG = Caregiver; IADL = Instrumental activities of daily living; MMSE = Mini-mental state examination; RMBPC = Revised memory and behavior problems checklist; SD = Standard deviation

Study period	Intervention (end)	Primary outcome measures	Results (end)	Remarks from reviewer	Quality of study
Baseline, 6 months	Comparison of effects of a) Skills training group (STG): behaviour management, problem solving and cognitive restructuring b) Minimal support control group	Statistical differences: a) RMBPC b) NAM-powers index of occupational status c) PAC (positive aspects of caregiving) d) LSNI (Lubben social network Index) e) Leisure time satisfaction f) CES-D g) Anxiety subscale from State-Trait Personality Inventory h) Desire to institutionalize	STG benefited more African Americans than white Americans. No changes in outcomes of depression or anxiety. Significant therapeutic changes over time. Number of experienced problem behaviours, both of these diminished and activity satisfaction increased	REACH methodology	2
Baseline, post-intervention, 3 months later	Education training sessions about an overview of AD, specifics about diagnosis and screening instruments, overview of treatment options for patients and CGs, education in Hispanic cultural and family values	Statistical measures, post-intervention changes in 1) Knowledge domain: a) Alzheimer's disease knowledge test b) Hispanic knowledge 2) Behavioural domain: a) Special services use b) Behavioural changes	Small but significant changes in knowledge domain. Changed self-reported actual patient care behaviours	Tests created mainly by the research team	1

Table 35.3 *Excluded papers (interventions studies with cultural focus on language and culture).*

Author, year, reference	**Exclusion reason 1**	**Exclusion reason 2**	**Exclusion reason 3**
Chung, 2001 [25]	3	4	
Mattern et al, 1998 [26]	1		

Table 35.4 *Excluded review studies (cultural interventions).*

Author, year, reference	**Exclusion reasons**
Aranda, 2001 [27]	Not systematic review
Ayalon et al, 2001 [28]	Not systematic review
Connell et al, 1997 [29]	Missing a scheme for quality assessment as well as a list of excluded studies and the reason for exclusion
Gonzales et al, 1995 [30]	Not systematic review
Daker-White et al, 2002 [31]	Not systematic review
Espino et al, 2001 [32]	Not systematic review
Harwood et al, 2000 [33]	Not systematic review
Hinton et al 1999 [34]	Not systematic review
Janevic et al, 2001 [35]	Missing a scheme for quality assessment as well as a list of excluded studies and the reason for exclusion
Jervis et al, 2002 [36]	Not systemativ review
Kane, 2000 [37]	Not systematic review
Lampley-Dallas, 2002 [14]	Not systematic review
Lee, 1991 [38]	Not systematic review

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36. Ethical and Societal Issues in Dementia

Introduction

Dementia, which is derived from the Latin word demens (without mind), refers to an aquired, longstanding clinical situation that deteriorates with time. It was previously used as a synonym for mental illness and insanity.

Dementia is defined as an aquired, progressive global impairment of intellect, memory and personality but not consciousness. The most common causes of dementia are untreatable, although reversible forms exist. Five major syndromes are irreversible: Alzheimer's disease (AD), dementia associated with stroke, Parkinson's dementia, Lewy body dementia and frontotemporal dementia. AD is the most common, accounting for around 2/3 of all diagnosed cases of dementia. The prevalence of dementia rises sharply with age, representing a significant burden on national health services, social services and caregivers.

The progressive detoriation of brain functions is the reason for the inability to understand, to appreciate and to make decisions – functions that characterize a competent person. That inability is the major ethical issue when discussing all aspects of care for people with dementia.

Ethical issues arise in all types of contacts among healthcare professionals, caregivers and people with dementia. Some initial questions are:

- What is the attitude of society and the healthcare community toward people with dementia?
- What quality of life issues are of particular importance?
- What specific ethical issues are at stake?

- What role does competence play in relation to diagnosis, treatment, research and everyday decisions?
- What does caring for people with dementia involve?

Views toward people with dementia

Differing attitudes toward a person with dementia influence how ethical issues are discussed.

If the focus is on *organic brain* damage, options for pharmacological treatment tend to assume centre stage.

If attitudes are more *people oriented*, questions about human rights, autonomy, life experiences and earlier opinions dominate.

If the emphasis is on *the person's role as a social being*, family, caregivers and society play a central role.

The view of the society at large toward people with dementia has changed in recent decades; the main reason being the ability to provide diagnoses and prognoses, as well as interventions to alleviate matters for the patient and family. An important contribution to the understanding of AD has been literature and films about people such as Iris Murdoch [1] and the novel about Erik Hj Linder [2].

A dementia disorder affects all aspects of a human being. Thus, attitudes toward people with dementia as human beings have major implications for dementia care. The literature on ethics addresses various dimensions of attitudes toward people with dementia. The questions concern whether the personhood, selfhood and subjecthood of people with dementia are lost or maintained [3–10] (see Chapter 33).

Opinions concerning whether or how those aspect of a human being changed or are lost during the progress of the disorder are of utmost importance for decisions about, and the provision of, treatment and care. The goal of dementia care ethics is to enhance wellbeing by facilitating a sense of self-worth, agency, social confidence and basic trust or security in the environment and others [10].

The attitudes of society at large toward people with dementia are mirrored in the way that it organizes care – the availability of resources for diagnosis, treatment, home care or institutionalization.

A committee appointed by the Swedish government to examine healthcare priorities concluded that palliative care at the end of life and for people with reduced autonomy should be assigned the greatest importance. The Parliament later approved the statement [11,12].

Dementia and quality of life

Life with dementia can bring pleasant as well as painful experiences. Some people claim that only mental states matter, others that emotional states are also important [13]. Many patients with dementia are either unaware of their impairments and disabilities or unable to communicate about them, having lost the capacity to verbalize and recall the necessary information.

Due to communication difficulties with patients in the later stages of dementia, healthcare professionals are often unclear about what the experience is like. The problems involved in assessing quality of life in people with dementia, especially when it becomes severe, have been discussed [14,15]. Patients can be observed, caregivers and family members can give their opinions, and various measures can be tried. Bond reviewed measures to improve quality of life, finding that the meaning of the concept differs according to biomedical, psychological and social model of dementia [16]. The Alzheimer Disease Related Quality of Life (ADRQL) scale was developed in an attempt to quantify the concept [17]. The ADRQL is the first instrument to evaluate multiple dimensions of disease-related quality of life in people with AD. The scale asses-ses the following dimensions: relating to and being among other people, special identity and important relationships, different types of distress behavior, ordinary activities and behavior in the living environment, including caregiver views.

Diagnostics of dementia

Questions of ethical relevance

The progression of dementia in which the person gradually loses cognitive function has already started at the time of the initial symptoms. A diagnosis of dementia changes expectations about the future in a very negative way for both patients and families. That may make the physician reluctant to provide full information. Most authors who have discussed this problem agree that information on the disorder, as well as its progress and prognosis, is not only ethically justified but necessary for acceptance of the diagnosis and the prospect of reduced cognitive function [18,19].

Robinson et al demonstrated that negative information is preferable to uncertainty [20]. Knowledge about the diagnosis is also important if advanced directives are to be possible (see Chapter 33).

The ethical issues in dementia diagnosis relate both to the patient's situation and the techniques involved. The patient's situation includes type of pathology, the extent of brain lesions, their consequences for cognitive function, autonomy and awareness, as well as social and existential context. Respect for autonomy is a central ethical issue, but a patient may have restricted perceptual capacity, so that the physician has limited ability to obtain informed consent for diagnostic procedures. However, the influence exerted by awareness of the various diagnostic processes may not be particularly straightforward. For instance, awareness may depend on the context. If information is presented slowly and repeatedly in a non-stressful situation, even patients with substantial cognitive decline may be able to grasp it. Therefore, to respect autonomy, all patients should be informed in the way that is most suitable for them as individuals that they can have the opportunity for informed consent. There is a wide range of possible diagnostic methods, from fairly simple recalling of the patient's medical history to PET and functional MRI. As a result, some diagnostic interventions require full cooperation from the patient.

Another question of ethical relevance is when different diagnostic procedures should be used during the progress of the disease. Repeated invasive, painful or stressful procedures are questionable given that neither prevention nor cure is yet available.

From an ethical point of view, based on the principles of individual uniqueness and the right to know, all patients should be offered a customized diagnostic procedure. The evaluation should be based on respect for the patient's autonomy and on a reasonable selection of diagnostic methods. The diagnostic process should provide sufficient knowledge to the patient and the family while offering some basis for medical management of the clinical situation. Thus, standardized investigation programs should not be used, and patients should not be left out of the process because of age, etc. Diagnostic honesty is the necessary starting point in an ethics of "precedent autonomy" for those who wish to control their future by means of advance directives [19,20].

Genetic testing

Pre-symptomatic genetic testing has been advised for many hereditary diseases, including those for which the option of cure is not available. One is Huntington's disease, given that the individual may have a need to make decisions concerning reproduction [21]. For this particular disease, the genetic background and hereditary path are both known and a diagnosis provides a definitive prognosis. This is not the case for AD, although genetic factors are thought to contribute to the aging of the brain and to sensitivity to different environmental factors, thus contributing to the development of the disease. A recent study taken from the Swedish twin registry claims that some 80% of AD is inherited [22]. Although not all the possible genes involved in AD have been identified, one genetic factor (ApoE) has been described. But ApoE genotyping does not facilitate the diagnosis of AD or help differentiate it from other forms of dementia. Thus, several ethical analyses have concluded that it is unacceptable to include such genotyping as a screening procedure for people without symptoms. It should only be used when autosomal dominant inheritance of early onset dementia has been recognized [23]. On the other hand, the recent findings taken from the Swedish twin registry make an ethically sound case for using available clinical and/or laboratory methods to diagnose members of families with a high prevalence of the disease in order to adopt measures that may delay onset or slow progression. Ethically speaking, it is important that patients or families who request the diagnostic procedures be given accurate information so as not to encourage unrealistic hope.

Treatment of dementia

There are a number of questions with ethical implications for the drug treatment of people with dementia. Two major areas of interest are 1) autonomy and informed consent of the patient during cognitive decline, including perceptual deficiencies; 2) drugs. The loss of cognitive capacity may influence the patient's ability (ranging anywhere from excellent to virtually non-existent) to understand the treatment alternatives and make sensible decisions. That raises questions about the limits of competence. Are there definite limits? Do they fluctuate? Do they differ among dementia disorders? Are physicians – and if so, which ones – best suited to judge the patient's competence? A paper by Markson et al concluded that physicians in general, and psychiatrists in particular, are familiar with the standard for competence but may apply it incorrectly [24].

The central question is the ability of the patient to approve or reject use of the medication. Can patients make such decisions on their own? If not, who are their proxies? A study by Hirschman et al examined the reasons that patients chose to participate in decisions to use a medication that retarded the progress of AD. The study showed that understanding of the diagnosis and prognosis, having less cognitive impairment, having a female caregiver and having a spousal caregiver all increased the likelihood that the patient would participate in the decision [25].

The ethical principles of beneficence and non-maleficence come into play when the ethical issues related to drugs are discussed. Are they efficient? Do they have only symptomatic effect or do they retard progression of the disease? The scientific knowledge involved in these questions has been reviewed elsewhere in this report (see Chapter 22). Thus, only a few issues that are relevant to ethical reflections will be discussed here.

A central issue is the usefulness of the drugs. Are they effective? Do they influence quality of life? Do they induce side-effects? Are they efficient? Are they cost-effective? Is it ethical to use them even though they may have limited or no effects? When should drug treatment be stopped? Is it ethical to prolong the advanced stage of dementia with drugs?

It must be stressed that the answers to these questions are profoundly influenced by the perspective taken. This report suggests some but not substantial positive effects of certain drugs for mild to moderate AD. All drugs have side-effects. No medication has shown positive effects in severe AD. Reports on the use of anti-dementia drugs in AD rarely discuss ethical issues. Post highlighted some of them, concluding that the use of such drugs makes sense in mild to moderate stages of AD [26]. But instead of administering these morbidity-protracting drugs in the advanced stage of the disease, better therapeutic goals that focus on enhanced quality of life should be pursued [26].

Care of patients with dementia

Everyday ethics

Attitudes and experiences

Professional caregivers

Collopy et al described directions for nursing home ethics, based on a large project with many articles reviewed [27]. They stressed the difference between acute care and care in nursing homes and that acute care ethics cannot be applied at nursing homes. Being the object of care at a nursing home leads to a lack of personal control that permeates the patient's daily life. Because it is difficult for the staff to protect safety and privacy, control and modification of the behavior of other patients may be necessary. The challenge is to find benign ways to deal with the situation.

Practically every task in the daily care of people with moderate to severe dementia presents ethical challenges for caregivers. How they react depends on their attitude toward the patient. Patients who exhibit behavioral symptoms pose the most difficult care problems. They can be tranquilized with drugs or restrained physically when caregivers find no meaning in the behavior. Caregivers may also try to understand the meaning of the behavior, enter into the patient's world and act from that perspective. Classical ethical reasoning cannot answer every question that arises in the daily care of patients with dementia. Caregivers must be able to act spontaneously in an ethical way.

Empirical studies show cultural differences in the ethical principles that should be given priority.

A cross-cultural study by Norberg et al held structured interviews with registered nurses in Arizona, Australia, California, Canada, China, Finland, Israel, and Sweden concerning the feeding of patients with severe dementia who refused to eat [28]. The nurses were asked to decide whether they should use force to feed the patients or let them starve to death. The findings strongly indicated a connection between willingness to force-feed and ethical principles. The nurses who were most prone to force-feed ranked the sanctity of life highest. Those least prone to force-feed ranked autonomy highest. However, all nurses stressed the ethical principle of beneficence.

One clinical trial related the narratives of 42 staff members in different dementia day care centers [29]. An invisible boundary seemed to define acceptable behavior. Examples of unacceptable behaviors included threatening the safety and wellbeing of themselves, other participants or the staff; certain sexual conduct; walking away from the center; compelling the staff to use force; combinations of physical restraint and medication; and false accusations or abuse by family members. An ethical hierarchy of staff responses ranging from benign manipulation, pretending, white lies, chemical restraint and physical restraint to discontinuing day care was presented. When a real conflict arises, codes of ethics generally offer no clue as to how to reconcile competing principles. The values at stake are safety, respect (which may take precedence over autonomy and truth-telling) and dignity. Face-saving deception may be a means of accomplishing that.

Non-professional caregivers

In most countries, most caregivers of patients with dementia are spouses, daughters and daughters-in-law. Over the past decade, many studies have looked at how to best help family caregivers – also referred to as nonprofessional or informal caregivers [30].

The literature is scarce on the ethical problems that these caregivers encounter. Hughes et al reviewed the ethical concerns of caregivers discussed in the literature and conducted a pilot survey among a small number of volunteers from the Alzheimer's Society in the UK [31]. The results indicated that quantitative research answers some questions but only qualitative research can provide a more profound understanding of the ethical issues involved from the point of view of caregivers. Caregivers listed many different ethical issues with respect to themselves and people with dementia that needed to be resolved. Epidemiological research has continued to identify high levels of depression, psychological distress and caregiver burden [32]. Sometimes that is linked to behavior on the part of the person with dementia How difficult behavior is managed often raises ethical issues among caregivers. Wilson used "grounded theory" to examine the ways in which caregivers deal with "negative choices" [33]. That brought out ethical issues for caregivers. But despite the mention of "a keen sense of moral duty," there was no systematic consideration of the ethical nature of many of the negative choices that caregivers must make. Hughes et al concluded that "we can speculate that these ethical issues contribute to caregiver burden" and that professionals may be able to help caregivers deal with them once they have been identified. Furthermore, the lay perspective of ethical issues, as revealed by qualitative research, can inform clinical practice and assist in the provision of services [31].

Making decisions for people with dementia

People in later stages of dementia lose their ability to make rational decisions in their own best interests. When they are deemed to be unable to make their own decisions, other people must do so for them. The question is how, and the answer is related to the way in which people with dementia are viewed [9]. Ethicists differ over whether attention should be paid to the way that the patient was before the disease, “the then self” or the patient’s current situation, “the now self “ as well as the priority given to autonomy and/or beneficence [4,6,8,34,35].

Derse argues that patients with dementia should not be presumed to totally lack decision-making capacity [36]. The patient might be more capable during intermittent periods of lucidity. Thus, the patient’s decision-making capacity should be analyzed. Low-risk situations should be treated differently than high-risk situations. The main focus should be on the process of reasoning, not the results. Decisions inconsistent with the views of the staff are not always irrational [36].

Upcoming Swedish legislation focuses on key issues concerning decisions for people with dementia, as well as advance directives (see below) [37]. A new government committee has been given the task of addressing legal questions involving people with cognitive deficiencies that remain unanswered in the Swedish health care system [38]:

- How should loss of competence be confirmed?
- Which criteria should be used?
- Who should make the decision?
- What kind of safety measures and coercion should be allowed?

The recommendations of the committee will be helpful in the future care of people with dementia.

End-of-life decisions

Suffering and nutritional support

When reasoning about ethical problems in end-stage care, the caregiver evaluation of the “facts” are extremely important. In this stage of dementia, it is not possible to rely on direct communication with the patient and other means are required. Is the patient suffering? Is the patient thirsty, hungry, fearful, etc? What is the probable effect of a certain treatment? There is a paucity of scientific knowledge that highlights the ethical issues involved in treatment and care of end-stage dementia.

Whether or not to treat pneumonia is an example of an ethical dilemma in end-stage dementia. When studying more than 600 patients, van der Steen et al found that pneumonia caused suffering, particularly among patients who were not given antibiotics [39,40]. Guidelines have been developed for the treatment of pneumonia in patients at nursing homes in the Netherlands [39]. They suggest that physicians follow the ethical principles of respect for autonomy, doing good, not doing harm, and justice.

Patients with end-stage dementia often have nutritional difficulties. That has led to the use of tube feeding or percutaneous endoscopic gastrostomy (PEG). Finucane et al [41] and McNamara et al [42] reviewed the literature and concluded that no data supported the efficacy of tube feeding patients with dementia who have eating difficulties. Studies have shown that the survival of patients with PEG was considerably lower in those with dementia [43,44]. Studies of quality of life have not shown any benefit from the use of PEG [41,45,46]. Niv et al stated that PEG in dementia may prolong the process of dying [47]. Despite these data, PEG has been increasingly used for nutrition in disorders, including dementia, that involve swallowing difficulties.

Thus, there are substantial ethical problems concerning the use of PEG in dementia. Shega et al found a notable discord between physician opinion and the literature regarding PEG [48]. PEG is sometimes used to reduce stress on nurses [46,49]. Patients with dementia may view tube feeding or PEG as force-feeding [50]. Both the Roman Catholic position and Orthodox Jewish traditions suggest “that there should be an assumption in providing nutrition and hydration to all patients” [51,52]. That should be taken into account for individual patients. But the lack of evidence that the use of PEG or tube feeding prolongs longevity in people with dementia, as well as the danger that they may lead to poorer quality of life, must also be considered.

In examining studies about the effects of starvation, Winter found that nutritional support, provided by either the enteral or parenteral route, for a terminally ill patient may be both medically and ethically indefensible because it can increase suffering without improving the outcome [53].

Professionals are obligated to provide factual information to family members concerning the issues of nutrition and hydration in the end stages of dementia, thereby alleviating the guilt they may otherwise feel in forgoing treatment [26].

Withholding and withdrawing treatment

Withholding and withdrawing treatment is another area that has been discussed widely by authorities in the field of dementia care ethics. Callahan has made important contributions [7]. His suggestions concerning criteria for treatment termination stress the following:

- No one should have to live longer in an advanced state of dementia than they would have in a pre-technological era.
- The likely deterioration in a late-stage patient with dementia should lead to a shift in the usual standard, ie, treatment should be stopped rather than continued.
- There is as great an obligation to prevent a painful lingering or degrading death as there is to promote life.

Most articles on the subject, as well as major textbooks on medical ethics, reflect these views. Loewy argues that “things stand differently when terminally ill patients are burdened by our attempt to continue feeding them or infusing fluids. Our overriding duty to comfort, above all, and to refrain from causing pain would suggest that forcing nutrition and fluid under these circumstances is difficult to defend” [54].

Advance directives

Advance directives are the area that has led to the most intense discussion in the ethical literature about terminal illnesses, including dementia. The views of ethicists are colored by the legal framework and traditions of their particular societies. Advance directives are legally binding in some countries and non-existent in others.

The main arguments are related to whether an advance directive written by a healthy person in an ordinary mental state should be respected later when they are suffering from severe dementia. Vollmann argues that it is important that people who are diagnosed with probable dementia are informed about this and also about the uncertainty associated with the diagnosis, in order to have an opportunity to write an advance directive [18]. Davis believes that people who receive information about the genetic risk of a dementia disorder should be able to consider the possibility of "pre-emptive suicide" [55].

DeGrazia argues that because a person with dementia of significant severity cannot grasp the consequences of various choices, they should be regarded as largely uninformed when formulating an advanced directive. If major psychological change occurs, the individual is no longer the same person who wrote the directive [56].

A major change in values and preferences may occur during the progress of the disease. Callahan tried to devise criteria for termination of treatment. One argument for foregoing an advance directive is that it is impossible to anticipate situations before they are experienced [7]. On the other hand not honoring an advance directive may increase the terror that many people feel when thinking about the ultimate end of their disease.

Post argues that the authority of the intact self over the future self with severe dementia is based on notions of integrity and precedent autonomy. Despite criticism of this authority, he believes that the principle of precedent autonomy in the care of people with AD or other forms of progressive and irreversible dementia retains its moral significance [6].

Substituted judgment standard

According to the substituted judgment standard, family members and physicians should make decisions based on what the patient would have done if not under the influence of the dementia disorder. In other words, the patient's religious beliefs, general values and attitudes should be taken into consideration. One danger identified in the literature is that decision makers act in accordance with their own values. Some critiques argue that substituted judgment is applicable to only a limited number of issues [4].

Imagined dialog

Lynn et al proposed that decisions for someone with dementia should be made in collaboration with people that they trusted [57]. These people can have imagined dialogs with the patient. The model assumes that those people talked about values with the patient when that was still possible. The authors argue that people often do not know exactly what they think before dialoging with others. Gedge suggests some refinements of the proposal [35]. She argues that care professionals must judge the trusted people (usually the patient's family) in terms of reliability. Suggestions for combining the patient's previously stated wishes and imagined conversations are in line with the criticism of a narrow view of autonomy in dementia ethics [4,58].

Best interests standard

More objective methods include the "best interests standard", the "benefit-burden standard" and the "reasonable person standard". These standards are especially applicable when the patient's wishes and values are insufficiently known. Community norms, ie, the values of most people, are used in the decision making process. The usual benefits and burdens to be considered are pleasure, enjoyment, pain and distress. The problem with these kinds of standards is that healthy people are making decisions for sick people. There is a risk that issues of social worth and finances will influence the decisions. One example is the use of PEG to reduce staff costs instead of to promote the patient's wellbeing. Thus, there is an obvious danger of inappropriate quality of life judgments.

Dresser argues that because objective methods of decision making are preferable, it is important for society to clarify which treatment alternatives are permissible to protect people who are incompetent to make decisions [4,58]. Attitudes toward the patient's awareness of burdens and benefits are of utmost importance when making objective care choices. However, benefits and burdens for the family must also be taken into consideration.

Writers who regard sanctity of life to be a basic value assess the burdens connected with treatment and not with life itself. Others think that life itself can be a burden to the patient with dementia. Individual patients value of life must be considered apart from the question of the value that their life has for others [53].

Physician-assisted suicide and euthanasia

Countries in which physician-assisted suicide (PAS) is legal require patients to be terminally ill and likely to die within a month. There has been a discussion whether people with dementia should be allowed to make decisions about PAS before they become incompetent to do so [59]. The argument in favor of that approach is that people with dementia would otherwise be discriminated against and unable to avoid the suffering associated with severe dementia. Among the reasons for choosing PAS might be to avert intolerable suffering and loss of personal identity. Post et al warn that PAS in AD is cheaper than good palliative care and might thereby be an attractive option [59]. PAS is a middle ground between treatment limitation and euthanasia. The patient performs the last action in PAS, whereas someone else does so in euthanasia. That is obviously an obstacle in the case of patients with severe dementia.

Euthanasia is legal in only a few countries. If death is foreseen but not intended when treatment is administered, euthanasia is not involved [60]. Quill et al call that the double effect [61]. Other ethicists think that this distinction is unclear. They refer to such treatment as passive euthanasia [62].

The views of caregivers concerning euthanasia have been studied in several countries. One study involved the attitudes of 80 nurses toward active euthanasia [63]. One-hour structured interviews were conducted about their thinking and values, how they would explain their standpoints to other staff members and the impact that legalizing active euthanasia would have on their views. A content analysis showed no differences between nurses in dementia care (20% in favor) and acute care (22.5% in favor). Religious beliefs, sanctity of life, patient autonomy and the wishes of the family were among their rationales. They also referred to professional responsibility, severe suffering, terminal illness, and the principle of double effect. Arguments both for and against active euthanasia were based on the principle of beneficence and the physician's responsibility. Well over half of both groups said that the passage of legislation permitting active euthanasia would not change their views.

A Finnish survey on attitudes to PAS, active voluntary euthanasia and passive euthanasia indicated that passive euthanasia was considered acceptable in cases of severe dementia among physicians (88%), nurses (79%) and the general public (64%) Few respondents accepted the use of active voluntary euthanasia in patients with dementia [64].

Euthanasia for people with severe dementia is legal in the Netherlands if they have stated that wish in an advance directive while competent to do so and certain other criteria have been met. Rurup et al reported that about 2 200 patients with dementia who have written an advance euthanasia directive die annually in the Netherlands [65]. A questionnaire among physicians showed that physicians did not follow the directive in most cases (76%) even though they regarded the patient's suffering as unbearable and hopeless. The advance directive for euthanasia was seen either as a valid or as an unacceptable request for people with severe dementia but no other disease [65]. Another Netherlands study showed that the general public was much more in favor of actively ending the life of people with dementia than were physicians [66].

A recent report by the Health Council of the Netherlands concluded that dementia alone is an insufficient basis for terminating life or for a request for assisted suicide. Those who are unwilling to accept their dementia and who record their wish to die in the form of an advanced directive should be aware that the options for implementation are limited, given that physicians must comply with the requirement to exercise due care [67].

Ethical aspects on research of dementia

The ethical literature has intensely debated the specific situation that arises when conducting research on people with dementia. Acquiring original knowledge about a disease is generally regarded as desirable, and valuable new knowledge is often assumed to be good for both the patients and the caregiver. More than in other cases, both therapeutic and non-therapeutic research in people with dementia has to be assessed. Research on new methods for diagnosis and treatment is of value only if conducted in patients with dementia.

Current international codes and guidelines, including the Declaration of Helsinki, the latest revision adopted in 2002 [68], and the Council for International Organizations of Medical Sciences (CIOMS) guidelines [69] deal with the question of research in vulnerable populations. They make it obvious that the balance between risks and benefits is especially important when discussing non-therapeutic vs therapeutic research – only minimal risks are allowed when the research has no benefit to the subjects. International groups have put forth specific guiding principles on dementia drug development [14].

The responsibilities of research ethics committees are fundamental in these respects. A survey among members of research ethics committees in Sweden examined their attitudes toward the informed consent process [70]. Few differences emerged between experts and laypeople, different age-groups or men and women. However, women and laypeople were generally more anxious to preserve patient integrity, while experts were more willing to allow the participation of patients with dementia in placebo controlled trials. A recent publication by Rikkert et al discusses differing views among 29 European research ethics committees on a joint multinational study on dementia treatment [71]. The investigators addressed informed consent very differently, but all centers were approved. Characterizations of the study ranged from “no experimental study” to “phase IV drug trial”. The survey shows that successful implementation of the Good Clinical Practice guidelines and the harmonization of research standards throughout Europe will require serious improvements in the ethical evaluation of protocols, particularly for dementia.

The overriding question is the need for informed consent – if and when during the different stages of the disease the patient can consent, and if not, who should be able to. The literature has discussed these issues repeatedly. Kim et al concluded that even relatively mild AD significantly impairs consent-giving capacity but that the differentiation of capable from incapable subjects remains an issue despite standardized tools [72]. Post focused on research in AD associated with high risk [73]. He asked what upper threshold of potential risk should be allowed and whether proxy consent should ever be permitted in high-risk research.

In weighing the value of research against patient autonomy, the preference has been toward protecting control over your own body. Designing a doctrine of informed consent must determine who is responsible for the development of a social policy. Such policies cannot be left to the investigators. All subjects must be informed, understand the information, voluntarily consent and be competent to do so. If that is not possible, a proxy decision has to be made. Patients with dementia are likely to be very dependent on their families, physicians and caregivers. Many patients have very little social contact, and "volunteering" may be a means of changing that. Cognitive and emotional impairment, impaired vision and hearing, difficulty in resisting coercion, dependence on family and caregivers, and institutionalization all require the careful application of the doctrine of competent, voluntary, informed consent in research on elderly subjects, especially those with dementia. Research involving AD prefers patients with less severe dementia, who are more often deemed to have retained their competence, and those who are not at nursing homes. This inequality is an ethical concern in itself. It goes without saying that research is also needed in people with moderate to severe dementia.

Many countries, Sweden included, have no clear and generally accepted definition of competence for purposes of consenting to a research procedure. Legislators have not reached a consensus on who should make that decision. Family members may be favorably inclined to research based on unwarranted optimism about finding a cure, or at least providing relief to patients and themselves.

In conclusion, clinical dementia research is generally regarded as ethically defensible. However, some questions still remain to be answered. Following are some of them. What level of cognitive function is required for informed consent? Are representatives always acting in the patient's interests? Do certain forms of cognitive decline, such as language or judgment deficiency, always require the consent of representatives?

Conclusions

The word dementia comes from the Latin demens (without mind). While that is obviously misleading, dementia clearly affects expressive ability and perception. In other words, it may be regarded as a disruption of communication between the inner world, the self and the outer world. Thus, the reactions of people with dementia are typically human, albeit influenced by the disorder. For that reason, diagnosis, treatment, care and research on dementia must always include a reflection on ethical considerations.

A person with dementia loses the ability to act autonomously and must thereby rely on the decisions and support of others, not only for survival but in all areas of life. That has to be done carefully in a way that validates the person as a human being – always consoling, often alleviating suffering and sometimes curing. Ethical aspects are essential to preserving quality of life in dementia and retaining the focus of treatment goals on the whole person.

The most serious ethical problem in treating patients with dementia is their declining mental competence, eventually making it impossible to obtain informed consent to health care and research. Thus, the overriding concern must be the safety of the patient.

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