

Draft Comparative Effectiveness Review

Number XX

Comparison of Characteristics of Nursing Homes and Other Residential Long-Term Care Settings for People With Dementia

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Statement of Funding and Purpose

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Preface

The Agency for Healthcare Research and Quality (AHRQ) conducts the Effective Health Care Program as part of its mission to organize knowledge and make it available to inform decisions about health care. As part of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Congress directed AHRQ to conduct and support research on the comparative outcomes, clinical effectiveness, and appropriateness of pharmaceuticals, devices, and health care services to meet the needs of Medicare, Medicaid, and the Children's Health Insurance Program (CHIP).

AHRQ has an established network of Evidence-based Practice Centers (EPCs) that produce Evidence Reports/Technology Assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care. The EPCs now lend their expertise to the Effective Health Care Program by conducting comparative effectiveness reviews (CERs) of medications, devices, and other relevant interventions, including strategies for how these items and services can best be organized, managed, and delivered.

Systematic reviews are the building blocks underlying evidence-based practice; they focus attention on the strength and limits of evidence from research studies about the effectiveness and safety of a clinical intervention. In the context of developing recommendations for practice, systematic reviews are useful because they define the strengths and limits of the evidence, clarifying whether assertions about the value of the intervention are based on strong evidence from clinical studies. For more information about systematic reviews, see

<http://www.effectivehealthcare.ahrq.gov/reference/purpose.cfm>

AHRQ expects that CERs will be helpful to health plans, providers, purchasers, government programs, and the health care system as a whole. In addition, AHRQ is committed to presenting information in different formats so that consumers who make decisions about their own and their family's health can benefit from the evidence.

Transparency and stakeholder input from are essential to the Effective Health Care Program. Please visit the Web site (<http://www.effectivehealthcare.ahrq.gov>) to see draft research questions and reports or to join an e-mail list to learn about new program products and opportunities for input. Comparative Effectiveness Reviews will be updated regularly.

We welcome comments on this CER. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by e-mail to epc@ahrq.hhs.gov.

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The investigators deeply appreciate the considerable support, commitment, and contributions of the EPC team staff at <NAME>. We express our gratitude to the following individuals for their contributions to this project: <NAME, degrees>

Key Informants

Key Informants are the end users of research, including patients and caregivers, practicing clinicians, relevant professional and consumer organizations, purchasers of health care, and others with experience in making health care decisions. Within the EPC program, the Key Informant role is to provide input into identifying the Key Questions for research that will inform health care decisions. The EPC solicits input from Key Informants when developing questions for systematic review or when identifying high priority research gaps and needed new research. Key Informants are not involved in analyzing the evidence or writing the report and have not reviewed the report, except as given the opportunity to do so through the peer or public review mechanism.

Key Informants must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals are invited to serve as Key Informants and those who present with potential conflicts may be retained. The Task Order Officer and the EPC work to balance, manage, or mitigate any potential conflicts of interest identified.

Key Informants

To be completed after peer review.

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Technical Experts comprise a multidisciplinary group of clinical, content, and methodologic experts who provide input in defining populations, interventions, comparisons, or outcomes as well as identifying particular studies or databases to search. They are selected to provide broad expertise and perspectives specific to the topic under development. Divergent and conflicted opinions are common and perceived as healthy scientific discourse that results in a thoughtful, relevant systematic review. Therefore study questions, design and/or methodological approaches do not necessarily represent the views of individual technical and content experts. Technical Experts provide information to the EPC to identify literature search strategies and recommend approaches to specific issues as requested by the EPC. Technical Experts do not do analysis of any kind nor contribute to the writing of the report and have not reviewed the report, except as given the opportunity to do so through the peer or public review mechanism.

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Technical Expert Panel

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Peer Reviewers are invited to provide written comments on the draft report based on their clinical, content, or methodologic expertise. Peer review comments on the preliminary draft of the report are considered by the EPC in preparation of the final draft of the report. Peer Reviewers do not participate in writing or editing of the final report or other products. The synthesis of the scientific literature presented in the final report does not necessarily represent the views of individual reviewers. The dispositions of the peer review comments are documented and will, for CERs and Technical briefs, be published three months after the publication of the Evidence report.

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Peer Reviewers

To be completed after peer review

Comparison of Characteristics of Nursing Homes and Other Residential Long-Term Care Settings for People With Dementia

Structured Abstract

Objectives. To compare characteristics of nursing homes (NHs) and other residential long-term care settings for people with dementia to reduce the uncertainty of families who want to make the best decision about the setting of care for their family member with dementia.

Data Sources. We searched MEDLINE,[®] EMBASE,[®] the Cochrane Library, the Cumulative Index to Nursing and Allied Health Literature (CINAHL[®]), AgeLine,[®] and PsycINFO[®] from 1990 through July 15, 2011. We identified additional studies from reference lists and experts.

Review Methods. Two people independently selected, extracted data from, and rated the quality of relevant studies. Given that quantitative analyses were inappropriate because of clinical heterogeneity, insufficient numbers of similar studies, or insufficient or variation in outcome reporting, we synthesized the data qualitatively. Two reviewers graded the strength of evidence (SOE) using established criteria.

Results. We identified 13 studies meeting our inclusion criteria. Generally, studies examined characteristics, structures, and process of care for populations with mild to severe dementia. Ten studies addressed health outcomes (key question [KQ] 1), and nine examined psychosocial outcomes (KQ 2) for people with dementia. No eligible studies examined health or psychosocial outcomes (respectively, KQ 3 and KQ 4) for informal caregivers. The studies included three prospective cohort studies, nine randomized controlled trials (RCTs), and one non-RCT. We found moderate SOE (two studies) for the use of pleasant sensory stimulation to reduce agitation. We found low SOE for a limited number of outcomes, including protocols for individualized care to reduce pain/discomfort and agitation/aggression and functional skill training to improve function. We found largely no differences across outcomes including function, cognition, depression, pain, morbidity, behavioral symptoms, engagement, and quality of life based on residence in a NH or residential care/assisted living (RC/AL), other than increased hospitalization for people with mild dementia in RC/AL compared with NHs and increased restraint use in NHs compared with RC/AL for imminently dying residents.

Conclusions. Overall, we found low or insufficient SOE regarding the effectiveness of organizational characteristics, structures, and processes of care as related to health and psychosocial outcomes for people with dementia and no evidence for informal caregivers. Findings of moderate SOE indicate that pleasant sensory stimulation reduces agitation. Also, although the SOE is low, protocols for individualized care and to improve function relate to better outcomes. Finally, outcomes do not differ between NHs and RC/AL except when medical care is indicated. Additional research is needed to develop a sufficient evidence base to support decisionmaking.

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Executive Summary

Background

Dementia is a group of progressive, irreversible neurological conditions that lead to gradual decline in mental function. It is the most common reason for entry into long-term care settings such as nursing homes (NHs) and residential care/assisted living (RC/AL).¹ The majority of care for people with dementia is provided in the community by family members; however, increasing care needs in later stages of the illness often lead to placement in a long-term care setting. Because long-term care settings are highly varied, people with dementia and their families who must make a decision regarding placement would benefit from evidence-based guidance on how to choose from the available options. The purpose of this review is to identify and summarize the evidence regarding which long-term care setting characteristics, structures, or processes are effective for improving health and psychosocial outcomes for people with dementia and their family caregivers, so as to provide better guidance when making placement decisions.

Definition of Dementia

Dementia is a progressive, irreversible decline in mental function, marked by memory impairment and a reduction in at least one other area of cognitive function, such as reasoning, judgment, abstract thought, registration, comprehension, learning, task execution, and use of language.² The most common cause of dementia is Alzheimer's disease; other causes include vascular dementia, mixed dementia, dementia with Lewy bodies, and frontotemporal dementia. The *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR)* defines dementia as "the development of multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning. The cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning and must represent a decline from a previously higher level of functioning."

(<http://dsm.psychiatryonline.org/content.aspx?bookid=22§ionid=1889063#8455>)³

Prevalence of Dementia

More than 5 million Americans—as many as one in every eight individuals ages 65 years or older—have dementia.² This number may rise to as high as 19 million by 2050.¹ Dementia increases dramatically with age; the frequency of dementia is approximately 2 percent among people ages 65 to 70 and more than 30 percent for people over 85.⁴

Impact of Dementia

Dementia causes significant morbidity and mortality and creates a substantial burden on the people affected, caregivers, health systems, and society.² The disease gradually erodes the individual's ability to make decisions, manage personal affairs, and eventually to do even simple tasks such as dressing, toileting, and eating. Late stages of the disease are characterized by weight loss, limited mobility, and frequent infections, so that, unless some other illness is fatal sooner, people with dementia will eventually die of the disease. The course of the disease from diagnosis to death is variable but typically 8 to 12 years. Costs of dementia care, including both

medical care and informal caregiver time, are estimated at more than \$148 billion in the United States annually.⁵

Need for Evidence-Based Guidance for Family Caregivers and Others to Select a Long-Term Care Setting

Inspired by a consumer request, the U.S. Agency for Healthcare Research and Quality (AHRQ) identified a need for an unbiased, evidence-based review on factors within long-term care settings that affect the quality of care. The topic of our review—the comparison of characteristics of NHs and other residential long-term care settings for people with dementia—addresses this issue, with the goal of reducing the uncertainty of families who are trying to make the best decision regarding a setting of care for a family member with dementia.

Characteristics of Long-Term Care Settings

One relevant question to ask is whether one type of long-term care setting is superior to another for dementia overall or for certain subgroups of people with dementia. However, long-term care settings are complex and vary widely within licensure categories, as was highlighted in the 2001 report of the Institute of Medicine Committee on Improving the Quality of Long-Term Care.⁶ Therefore, an especially relevant question for family members seeking to select a site is whether certain characteristics are critical in providing quality care.

A commonly accepted model places key characteristics of long-term care settings into three categories: organizational characteristics, structures of care, and processes of care.⁷ Organizational characteristics are demographic, community, and licensure characteristics of long-term care settings; they include proprietary status, affiliation (e.g., chain, hospital, continuing care retirement community), location (urban versus rural), size, diversity, cultural fit, cost, and resident case-mix (e.g., dementia, Medicaid), as well as the overall model of care (e.g., NH, RC/AL). Structures of care consist of physical characteristics (“bricks and mortar”); these can involve material resources (e.g., private rooms, familiar homelike components, access to outdoors), human resources (e.g., level of staffing, expertise of staff), and organizational structure (e.g., hours of care per resident per day by type of worker, consistency of assignment, universal worker perspective). Processes of care are services and systems including programs and services implemented at the system/setting level in the context of care provision (e.g., assistance with activities of daily living [ADLs], involvement of informal caregivers, activity programs).

Scope and Key Questions

Scope of This Review

Considering the central role of family caregivers in decisions resulting in people with dementia entering long-term care settings, information on the current state of the science of dementia management would be very helpful. Different long-term care settings offer different care and services, and no comprehensive evidence-based guidance exists that identifies which characteristics or settings are best for which type of person based on age, disease severity, or other characteristics. The objective of this review, therefore, is to provide information that would help families who are trying to decide where to place a family member who has dementia and who can no longer be managed at home.

Key Questions

This review sought to address the following key questions (KQs):

- KQ 1. What is the effectiveness of organizational characteristics, structures, or processes of care in nursing homes and other residential long-term care settings for improving health outcomes for people with dementia?
- KQ 2. What is the effectiveness of organizational characteristics, structures, or processes of care in nursing homes and other residential long-term care settings for improving psychosocial outcomes for people with dementia?
- KQ 3. What is the effectiveness of organizational characteristics, structures, or processes of care in nursing homes and other residential long-term care settings for improving health outcomes for informal caregivers of people with dementia?
- KQ 4. What is the effectiveness of organizational characteristics, structures, or processes of care in nursing homes and other residential long-term care settings for improving psychosocial outcomes for informal caregivers of people with dementia?
- KQ 5. Does the effect of organizational characteristics, structures, or processes of care on health and psychosocial outcomes vary by the characteristics of the person with dementia (e.g., severity of dementia, functional status) or of the informal caregiver (e.g., age, relationship, health status)?

We developed an analytic framework to guide the systematic review process (Figure A).

Methods

Literature Search Strategy

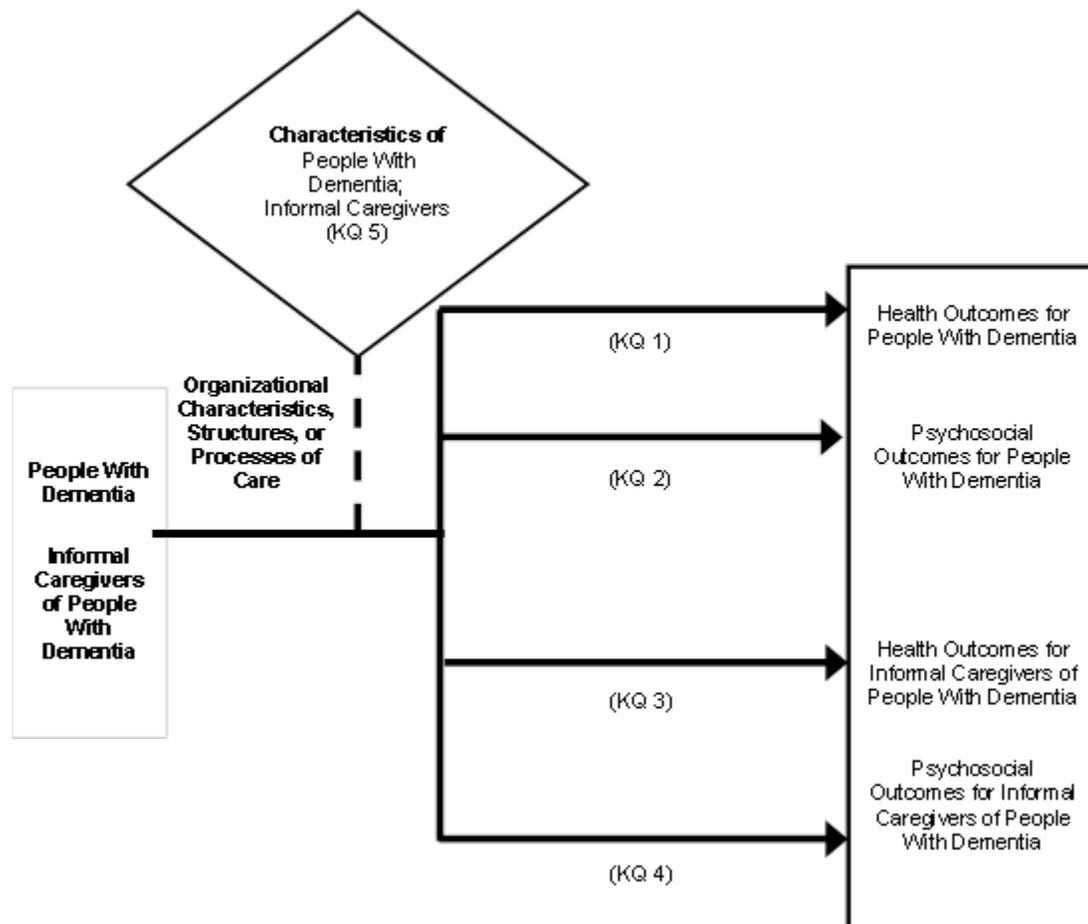
Search Strategy

To identify articles relevant to each KQ, we searched MEDLINE,[®] EMBASE,[®] the Cochrane Library, the Cumulative Index to Nursing and Allied Health Literature (CINAHL[®]), AgeLine,[®] and PsycINFO.[®] We focused our search on long-term care settings, dementia, and informal caregivers by using a variety of terms, medical subject headings (MeSH[®]), and key words. We reviewed our search strategy with the Technical Expert Panel (TEP) and incorporated their input into our search strategy.

We limited the electronic searches to English language (consistent with our focus on characteristics, structures, and processes in the United States) and humans. Sources were searched for articles published from 1990 through July 15, 2011, to reflect the changing nature and evolution of NHs and other residential long-term care settings, especially after the Omnibus Budget Reconciliation Act (OBRA) of 1987 (Public Law 100-203), which established new regulatory standards of NH care.

We manually searched reference lists of reviews, including trials and background articles to look for relevant citations that our searches might have missed and that addressed our KQs. We imported all citations into an electronic database (EndNote[®] X4).

Figure A. Analytic framework for comparisons of characteristics of nursing homes and other residential long-term care settings for people with dementia



Inclusion and Exclusion Criteria

We developed eligibility (inclusion and exclusion) criteria with respect to the PICOTS (Population, Intervention/Exposure, Comparators, Outcomes, Timing, Setting). Because many studies have not required a formal diagnosis of dementia for subject inclusion, we did not require that the dementia be specified as formally diagnosed dementia. Instead, dementia could be determined by (1) formal diagnosis, (2) signs or symptoms (e.g., cognitive status assessment), or (3) report by staff or an informal caregiver.

In consultation with the TEP, we determined that a study must have explicitly stated that (1) at least 80 percent of the population had dementia or that (2) some analyses were specific to the subgroup of those with dementia. The rationale for this decision was to ensure that the findings were relevant and applicable to the population of interest. This cut-point was determined in consultation with our TEP and, of note, no excluded studies reached even a 70 percent cut-point. In addition, we examined informal caregivers as a population of interest (in KQs 3 and 4). Informal caregivers are unpaid individuals who provide care to relatives or friends.⁸

Interventions/exposures of interest included organizational characteristics, structures of care, or processes of care as defined earlier. Organizational characteristics, structures, and processes of

care could either be those inherent to the setting to which people were exposed (e.g., NH versus RC/AL) or new interventions being implemented. Staff training interventions are not included in this review because they are a proxy for and a presumed indicator of care. Level of training in the context of staff role (e.g., certified nursing assistant [CNA], registered nurse [RN], licensed practical nurse [LPN]) was considered in this review.

We sought to compare the effectiveness of elements of interventions/exposures with one another and combinations of interventions/exposures. Comparators included various types and amounts (e.g., consistent versus rotating staffing) of the elements or combinations of certain elements as exhibited in particular models (e.g., the Green House⁹ model). We excluded studies without a comparator.

Outcomes of interest were quite broad:

- health outcomes for people with dementia, such as pain or discomfort; symptoms of depression; sleep quality; health decline/morbidities, including skin ulcers; decline in functioning, self-care, or maintenance; decline in cognitive functioning; falls; mortality; and hospitalizations;
- psychosocial outcomes for people with dementia, such as positive and negative affect, including pleasure and anxiety; behavioral symptoms; engagement, quality of life; quality of dying; spiritual well-being; control, autonomy, choice; satisfaction; use of psychoactive medications; and use of restraints;
- health outcomes for informal caregivers of people with dementia, such as symptoms of depression; sleep quality; and morbidities such as cardiovascular disease; and
- psychosocial outcomes for informal caregivers of people with dementia, such as anxiety; quality of life; caregiver burden; emotional stress, psychosocial stress; quality of relationship with person who has dementia; self-efficacy; guilt; grief reactions; perception of suffering; satisfaction; financial burden; and family conflict.

The time period of interest in choosing studies was any duration of time beginning after the admission of the person with dementia to a residential long-term care setting until either permanent transfer to another setting or death.

Settings include NHs, RC/AL, Green House homes, other small NHs, Alzheimer's/dementia special care units (SCUs), residential long-term hospice care, and continuing care retirement communities.

We confined our review to studies done in the United States so that the evidence examined would be relevant to care in this country. The health care systems and approaches to long-term care in other countries differ substantially from those here, so research from other countries will be less applicable to the United States than studies done here.

Study Selection

Two people independently reviewed article abstracts using the inclusion/exclusion criteria. If the reviewers agreed that the study did *not* meet eligibility criteria, we excluded it; otherwise, the two reviewers then independently reviewed the full-text article. If the reviewers disagreed, they resolved conflicts by discussion and consensus or by consulting a third member of the team. A reviewer who was also an author of a specific study was not permitted to make the final determination as to whether the study was included.

Data Abstraction

For studies that met our inclusion criteria, we abstracted important information into evidence tables. We designed and used structured data abstraction forms to gather pertinent information from each article, including characteristics of study populations, settings, interventions/exposure, comparators, study designs, methods, and results. Trained reviewers abstracted the relevant data from each included article into the evidence tables. A second member of the team reviewed all data abstractions against original articles for completeness and accuracy. We recorded intention-to-treat results if available. All data abstraction was performed using Microsoft Excel[®] software.

Quality Assessment of Individual Studies

To assess the quality (internal validity) of studies, we used predefined criteria based on those developed by the U.S. Preventive Services Task Force (USPSTF) (ratings: good, fair, poor)¹⁰ and the University of York Centre for Reviews and Dissemination.¹¹ Two independent reviewers assigned quality ratings to each study. Disagreements between the reviewers were resolved by discussion and consensus or by consulting a third member of the team. We gave poor quality ratings to studies that had a fatal flaw (defined as a methodological shortcoming that leads to a very high risk of bias) in one or more categories, and we excluded them from our analyses.

Data Synthesis

To determine whether quantitative analyses were appropriate, we assessed the clinical and methodological heterogeneity of the studies following established guidance.¹² We examined the PICOTS, looking for similarities and differences. Because we determined that quantitative analyses were not appropriate (owing to clinical heterogeneity, insufficient numbers of similar studies, or insufficient or variation in outcome reporting), we synthesized the data qualitatively. All synthesis was evaluated by multiple coauthors.

Strength of the Body of Evidence

We graded the strength of evidence (SOE) based on the guidance established for the Evidence-based Practice Center Program.¹³ Developed to grade the overall strength of a body of evidence, this approach incorporates four key domains: risk of bias (includes study design and aggregate quality), consistency, directness, and precision of the evidence. It also considers other optional domains that may be relevant. A grade of high SOE indicates that we have high confidence that the evidence reflects the true effect and that further research is very unlikely to change our confidence in the estimate of effect. Moderate SOE implies that we have moderate confidence that the evidence reflects the true effect. Further research may change our confidence in the estimate of the effect and may change the estimate. Low SOE suggests that we have low confidence that the evidence reflects the true effect. Further research is likely to change our confidence in the estimate of the effect and is likely to change the estimate. Insufficient SOE signifies either that evidence is completely unavailable or that it does not permit estimation of an effect.

We graded the SOE for health and psychosocial outcomes for people with dementia. Two reviewers assessed each domain for each key outcome and differences were resolved by consensus. We used a qualitative process, considering each of the domains, to determine the overall SOE grade for each outcome. Differences were resolved by discussion with the research

team until reaching consensus. Given that most outcomes had only a single study to provide evidence, consistency would be considered not applicable; when the study had estimates of effects that were not statistically significant or had wide confidence intervals, we rated that domain as imprecise. As a general proposition, therefore, for outcomes with a single study with imprecise results and for which power was not ensured, we graded the SOE as insufficient; for a single study with precise results, we graded it as low. Therefore, although effectiveness is not synonymous with precision nor with SOE, individual studies that showed an effect generally merited a rating of low SOE.

Applicability

We assessed the applicability of the evidence following guidance from the *Methods Guide for Effectiveness and Comparative Effectiveness Reviews*.¹⁴ We used the PICOTS framework to explore factors that affect applicability.

Results

This section is organized by KQ and results are then grouped by intervention/exposure category. We wanted to compare the effectiveness of organizational characteristics, structures, and processes of care in NHs and other residential long-term care settings on four sets of outcomes: health outcomes for people with dementia (KQ 1), psychosocial outcomes for people with dementia (KQ 2), health outcomes for informal caregivers of people with dementia (KQ 3), and psychosocial outcomes for informal caregivers of people with dementia (KQ 4). KQ 5 concerned whether the effect of organizational characteristics, structures, or processes of care on outcomes varied by the characteristics of the person with dementia (e.g., severity of dementia, functional status) or of the informal caregiver (e.g., age, relationship, health status); we report on relevant KQ 5 studies only in the context of KQs 1 to 4. Summary tables and evidence tables of included studies can be found in the full report.

Results of Literature Searches

A total of 5,653 articles were identified through our database searches and hand searches of relevant articles. We ultimately included 13 published articles: 9 randomized controlled trials (RCTs), 1 nonrandomized controlled trial, and 3 prospective cohort studies. We recorded the reason that each excluded full-text publication did not satisfy the eligibility criteria and compiled a comprehensive list of such studies (which is located in an appendix to the full report).

Ten studies addressed health outcomes for people with dementia (KQ 1); nine studies examined psychosocial outcomes for people with dementia (KQ 2). No eligible studies of fair or better quality examined health or psychosocial outcomes (KQ 3 and KQ 4, respectively) for informal caregivers with dementia. One study addressed whether effects of organizational characteristics differed by dementia severity, and another examined differences by resident gender (KQ 5).

Key Question 1. Health Outcomes for People With Dementia

Of the 10 studies reviewed, eight interventions showed statistically significant effects on health outcomes, with insufficient or low SOE. Process of care interventions provided more evidence than did interventions focusing on organizational characteristics or structures of care.

Organizational Characteristics

Two studies addressed organizational attributes but found few differences between RC/AL settings and NHs on a range of health outcomes; we found some differences between dementia SCUs and non-SCUs located within either RC/AL settings or NHs (insufficient or low SOE).

Mortality rates for residents in RC/AL compared with those in NHs did not differ in one study (low SOE).

Some evidence suggested higher hospitalization rates (low SOE) in RC/AL settings than in NHs but little difference in morbidity rates (low or insufficient SOE).

Evidence on dementia SCUs was inconsistent. Residents of dementia SCUs, when compared with those not in SCUs, had greater decline in functioning over time (low SOE) and lower rates of both hospitalization and new or worsening morbidity (low SOE).

Structures of Care

One RCT found no effect for lighting interventions on sleep quality (insufficient SOE), and another RCT found no effect on depression (insufficient SOE) for the overall populations studied; both trials reported some effects for some subgroups (insufficient SOE).

Processes of Care

Evidence for group activity interventions was mixed. A functional skills training intervention produced modest effect sizes for improving ADLs, with effect sizes being equivalent to moving from major to moderate or from moderate to minor assistance in performing the ADLs (low SOE). A storytelling intervention improved cognitive alertness by about 3 percentage points (low SOE). Two interventions had no benefits: validation group therapy intervention did not improve functional self-care or depression, and an attention-focusing intervention did not improve cognitive impairment.

Evidence for personalized care interventions was modest. A personalized assessment and treatment intervention reduced resident discomfort with an effect size of 0.89 (low SOE). Both personalized showering and towel bath interventions reduced resident discomfort on an Alzheimer's discomfort scale by 0.32 and 0.57 points, respectively, compared with a control group score of 2.14.

Key Question 2. Psychosocial Outcomes for People With Dementia

Nine studies (five RCTs) addressed psychosocial outcomes. All showed some statistically significant effects on outcomes (low or moderate SOE).

Organizational Characteristics

With one exception (restraint use), psychosocial outcomes did not differ between NHs and RC/AL settings. Behavioral symptoms, engagement, quality of dying, quality of life, and psychoactive medication use did not differ by setting (insufficient or low SOE). Restraints were used more often in imminently dying residents in NHs than in RC/AL settings (any restraints, 92 percent versus 66 percent; any restraints other than partial bedrails, 68 percent versus 46 percent; low SOE).

Quality of life did not differ based on proprietary status, chain affiliation, size, age, percentage of dementia beds, and resident case-mix (insufficient SOE).

Behavioral symptoms and engagement did not differ based on residence in an SCU (low SOE).

Structures of Care

With one exception, quality of life did not differ based on many structures of care: RN, LPN, and aide full-time equivalents and number of contract staff per type; administrator, RN, LPN, and aide turnover; environmental quality; consistent staffing; or use of universal workers (insufficient SOE). Quality of life was statistically but not clinically better in settings that used specialized care workers (mean raw change over 6 months was 1.7 points worse when specialized workers were not used; low SOE).

Processes of Care

A creative expression storytelling group resulted in more challenging behaviors, anxiety, and sadness (low SOE) and also less disengagement, neutral affect, and more engagement (low SOE).

A validation therapy group was superior to a social control group and/or usual care control group in regard to nurse-reported (but not observer-reported) physically and verbally aggressive behavior at 1 year (low SOE); it also resulted in more physically nonaggressive behaviors (low SOE). Validation therapy did not produce significant changes in engagement, irritability, restraint use, psychoactive medication use, or positive behaviors (insufficient SOE).

More frequent encouragement of activity participation resulted in statistically but not clinically better quality of life (mean raw change over 6 months was 0.9 times worse when activities were encouraged less than once a day; low SOE).

Pleasant sensory stimulation (evaluated in two studies) produced a clinically significant decrease in agitation (75 percent to 83 percent compared with controls in one study; moderate SOE).

Individualized assessment and management of discomfort and behavioral symptoms did not result in behavioral change but did increase return of behavior to baseline levels (70 percent versus 40 percent in the control group; low SOE).

Person-centered protocols for showering and bathing reduced behavioral symptoms (agitation and aggression) more in the intervention group than the control group (mean time agitated or aggressive 24 percent and 26 percent in the intervention groups versus 36 percent in the control group; low SOE).

Various processes of care (including policies and practices; staff involvement in care planning; assessments; treatment; use of medications; and use of stimuli such as craft or household items) did not improve quality of life (insufficient SOE).

Discussion

Key Findings and Strength of Evidence

Key Question 1. Health Outcomes for People With Dementia

Table A summarizes the SOE for health outcomes for people with dementia. Regarding organizational characteristics reviewed, NHs and RC/AL differed little on a range of health outcomes (insufficient or low SOE). Residents with mild dementia in RC/AL settings, when compared with those in NHs, had moderately higher hospitalization rates (low SOE); residents differed little in morbidity rates regardless of dementia level (low or insufficient SOE). Evidence on SCUs within these settings was inconsistent. Residents of SCUs in RC/AL settings, when compared with those in non-SCUs in those settings, had a modestly greater decline in functioning over time (low SOE). By contrast, residents of dementia SCUs in NHs, when compared with those in non-SCUs in NHs, had moderately lower rates of both hospitalization and new or worsening morbidity (low SOE).

Table A. Strength of evidence for the effect of organizational characteristics, structures, or processes of care on health outcomes for people with dementia.

Outcome	Summary of Results	Strength of Evidence
Functional impairment/decline (including self-care/maintenance)	Functional impairment/decline was worse in RC/AL settings for residents living in a dementia SCU (1 study; 1,252 subjects).	Low
	Function was clinically significantly better (equivalent to moving from major to moderate or moderate to minor need for assistance) after functional skill training (1 study; 63 subjects).	Low
Cognitive impairment/decline	Alertness was modestly better (3 percentage points) after creative expression storytelling (1 study; number of subjects not reported).	Low
Depressive symptoms	Depression/depressive symptoms were better for women but worse for men after a bright morning-light intervention (1 study; 155 subjects).	Low
Pain/discomfort	Pain/discomfort was better after individualized assessment and management of discomfort (1 study; 114 subjects) and person-centered protocols for showering and bathing (1 study; 73 subjects).	Low
Sleep quality	Sleep quality was better for only those with aberrant sleep cycle timing following morning bright light (1 study; 46 subjects).	Low
New/worsening morbidity and various discrete measures	Morbidity across multiple measures differed little in RC/AL settings compared with NHs, but was lower in SCUs than in non-SCUs in NHs (1 study; 1,252 subjects).	Low
Hospitalization	Hospitalization occurred more often for residents with mild dementia living in RC/AL settings than for residents in NHs (1 study; 1,252 subjects).	Low
	Hospitalization occurred more often for NH residents (but not RC/AL residents) not living in dementia SCUs (1 study; 1,252 subjects).	Low
Mortality	Evidence did not support a difference based on residence in a NH vs. RC/AL setting or in an SCU vs. non-SCU (1 study; 1,252 subjects).	Low

Note: No study examined the outcome of falls (insufficient SOE), and not all of the eight outcomes listed above were examined in every one of the 10 studies. Only findings with low or better SOE are reported.

Abbreviations: NH = nursing home; RC/AL = residential care/assisted living; SCU = special care unit.

Only two studies focused on structures of care. We saw no effect in the overall populations studied for lighting interventions on either sleep quality (insufficient SOE) or depression (insufficient SOE). Both studies found benefits for certain subgroups (women for depression and

those with aberrant sleep-cycle timing for sleep quality) (insufficient SOE). Therefore, lighting interventions may have more benefit on a person-by-person level as opposed to being a structural intervention throughout a setting.

Regarding processes of care, evidence for group activity interventions was mixed. A functional skills training intervention produced moderate effect sizes for improving ADLs; effect sizes were equivalent to moving from major to moderate or from moderate to minor assistance in performing ADLs (low SOE). A storytelling intervention modestly improved cognitive alertness (low SOE). An intervention involving validation therapy groups did not improve functional self-care or depression, and an attention- focusing intervention did not improve cognitive impairment or cognitive function (both insufficient SOE). A personalized assessment and treatment intervention moderately reduced resident discomfort (low SOE). Finally, personalized showering and towel bath interventions reduced resident discomfort (low SOE).

No studies examined the outcome of falls (insufficient SOE).

Key Question 2. Psychosocial Outcomes for People With Dementia

Table B summarizes the SOE for psychosocial outcomes for people with dementia. Regarding organizational characteristics, NHs and RC/AL differed little on a range of psychosocial outcomes including behavioral symptoms, engagement, quality of dying, quality of life, and psychoactive medication use (insufficient or low SOE). Restraints were used more often in imminently dying residents in NHs than in RC/AL (low SOE). The authors suggested additional study of this finding considering that the use of physical restraints in NHs has been strongly discouraged following the Nursing Home Reform Act of 1987, and there is evidence that overall use of restraints is low.¹⁵ Behavioral symptoms and engagement did not differ based on residence in an SCU (low SOE).

Regarding structures of care, quality of life did not differ based on many structures (insufficient SOE); it was statistically but not clinically significantly better when specialized workers were used (low SOE).

Regarding processes of care, evidence for group activity interventions was mixed. A storytelling intervention resulted in more challenging behaviors, anxiety, and sadness (low SOE), and also more engagement (low SOE). An intervention involving validation therapy groups resulted in less physical and verbal aggression and also more physical nonaggression, although these findings were not consistent across raters (low SOE). More frequent encouragement of activity participation resulted in statistically but not clinically better quality of life (low SOE). Pleasant sensory stimulation produced a clinically significant decrease in agitation (moderate SOE). A personalized assessment and treatment intervention of behavioral symptoms increased return of behavior to baseline levels (low SOE). Finally, both personalized showering and towel bath interventions reduced behavioral symptoms (agitation and aggression) more in the intervention group than control group (low SOE).

No studies examined the outcomes of spiritual well-being, control, autonomy, choice, or satisfaction (insufficient SOE).

Table B. Strength of evidence for the effect of organizational characteristics, structures, or processes of care on psychosocial outcomes for people with dementia.

Outcome	Summary of Results	Strength of Evidence
Behavioral symptoms	Behavioral symptoms were worse after creative expression storytelling (1 study; number of subjects not reported).	Low
	Physical and verbal aggression were better, and physical nonaggression was worse, after validation therapy (based on nurse report). Verbal aggression was worse after validation therapy (based on observer report) (1 study; 88 subjects).	Low
	Agitation was clinically significantly better after pleasant sensory stimulation (two studies; 99 subjects; agitation decreased 75% to 83% in one study).	Moderate
	Behavioral symptoms were better after individualized assessment and management of behavioral symptoms (70% vs. 40% return to baseline). (1 study; 114 subjects)	Low
	Agitation and aggression were better after person-centered protocols for showering and bathing (mean time agitated/aggressive 24% to 26% vs. 36% for control group) (1 study; 73 subjects).	Low
Affect	Anxiety and sadness were worse after creative expression storytelling (1 study; number of subjects not reported).	Low
Engagement	Engagement was better after creative expression storytelling (1 study; number of subjects not reported).	Low
Quality of life	Quality of life over 6 months was statistically but not clinically significantly better when specialized workers were used and activities were encouraged (1 study; 421 subjects).	Low
Quality of dying	Evidence did not support a difference based on residence in a NH vs. RC/AL setting (1 study; 422 subjects).	Insufficient
Psychoactive medication use	Evidence did not support a difference based on residence in a NH vs. RC/AL setting or after validation therapy (1 study; 422 subjects). ^a	Insufficient
Restraint use	Restraint use in imminently dying residents occurred more often in NHs than in RC/AL settings (66% vs. 92%) (1 study; 422 subjects).	Low

Note: No study examined the outcomes of spiritual well-being, control, autonomy, choice, or satisfaction (insufficient SOE). Not all of the outcome categories in this table were examined in every one of the nine studies. Except where indicated, only findings with low or better SOE are reported.

^a Evidence was from a single study with imprecise estimates.

Abbreviations: NH = nursing home; RC/AL = residential care/assisted living; vs., versus.

Table C summarizes the SOE for statistically significant differences in health and psychosocial outcomes according to organizational characteristics, structures, and process of care.

Table C. Strength of evidence for the effect of organizational characteristics, structures, or processes of care on health and psychosocial outcomes for people with dementia

Characteristics	Intervention/Exposure	Summary of Results	Strength of Evidence
Organizational	NH vs. RC/AL	Morbidity across multiple measures differed little in RC/AL settings compared with NHs (1 study; 1,252 subjects).	Low
		Hospitalization occurred more often for residents with mild dementia living in RC/AL settings than for residents in NHs (1 study; 1,252 subjects).	Low
		Restraint use in imminently dying residents occurred more often in NHs than in RC/AL settings (66% vs. 92%) (1 study; 422 subjects).	Low

Table C. Strength of evidence for the effect of organizational characteristics, structures, or processes of care for people on health and psychosocial outcomes with dementia (continued)

Characteristics	Intervention/Exposure	Summary of Results	Strength of Evidence
	SCU in NH vs. no SCU	Morbidity was lower in SCUs than in non-SCUs in NHs (1 study; 1,252 subjects). Hospitalization occurred more often for NH residents not living in SCUs (1 study; 1,252 subjects).	Low Low
	SCU in RC/AL vs. no SCU	Functional impairment/decline was worse in RC/AL settings for residents in SCUs (1 study; 1,252 subjects).	Low
	Specialized workers vs. not	Quality of life over 6 months was statistically but not clinically significantly better when specialized workers were used (1 study; 421 subjects).	Low
Processes of Care	Functional skill training vs. no such training	Function was clinically significantly better (equivalent to moving from major to moderate or moderate to minor need for assistance) after functional skill training (1 study; 63 subjects).	Low
	Creative expression storytelling vs. no such activity	Alertness was modestly better (3 percentage points) after creative expression storytelling (1 study; number of subjects not reported). Behavioral symptoms, anxiety, and sadness were worse after creative expression storytelling (1 study; number of subjects not reported).	Low Low
	Validation therapy vs. no such activity	Physical and verbal aggression were better, and physical nonaggression was worse, after validation therapy (based on nurse report). Verbal aggression was worse after validation therapy (based on observer report) (1 study; 88 subjects).	Low
	Encouraging activities more vs. less	Quality of life over 6 months was statistically but not clinically significantly better when activities were encouraged (1 study; 421 subjects).	Low
	Pleasant sensory stimulation vs. no such stimulation	Agitation was clinically significantly better after pleasant sensory stimulation (two studies; 99 subjects; agitation decreased 75% to 83% in one study).	Moderate
	Individualized assessment and management of discomfort and behavioral symptoms vs. no such protocols	Pain/discomfort was better after individualized assessment and management of discomfort. Behavioral symptoms were better after individualized assessment and management of behavioral symptoms (1 study; 114 subjects; 70% vs. 40% return to baseline).	Low Low
	Person-centered protocols for showering and bathing vs. no special protocols	Pain/discomfort was better after person-centered protocols for showering and bathing. Agitation and aggression were better after person-centered protocols for showering and bathing (1 study; 73 subjects; mean time agitated/aggressive 24% to 26% vs. 36% for control group).	Low Low

Note: No study examined the outcomes of falls, spiritual well-being, control, autonomy, choice, or satisfaction (insufficient SOE). Not all of the interventions in this table were examined in relation to all outcomes. Only findings with low or better SOE are reported.

Abbreviations: NH = nursing home; RC/AL = residential care/assisted living; SCU = special care unit.

Key Questions 3 and 4: Outcomes for Informal Caregivers

No studies met inclusion criteria for either of these key questions about the impact of organizational characteristics, structures of care, or processes of care on caregiver health or psychosocial outcomes. Thus, evidence is insufficient for these topics.

Applicability

This review was intended to apply to all people with dementia regardless of their level of dementia. It also was intended to examine differences in outcomes related to the extent of dementia and other characteristics, because people with mild, moderate, or severe dementia differ in the extent to which they are able to respond to interventions.

Studies varied in regard to the level of dementia represented and some did not specify the level. Two included only residents with severe dementia, making those findings applicable to that subgroup. Only one study considered the evidence in relation to the level of dementia severity. In regard to the other studies, the evidence is insufficient regarding whether effects would have differed for subgroups.

The interventions/exposures included a broad range of organizational characteristics, structures, and processes of care. We had envisioned special interest in exposure to organizational characteristics, such as NHs compared with RC/AL settings, small NHs with large NHs, and SCUs with no SCU. These are often the level at which families first make their decision regarding a setting of care. However, only three prospective cohort studies provided evidence about these options.

The outcomes examined across the 13 studies included eight broad categories of health outcomes and seven categories of psychosocial outcomes. In some cases, the strengths or limitations of a given intervention differed by outcome. In such instances, families are advised to consider which outcomes are most valued and make their decision accordingly.

The SOE for all findings reported in this review, except one, was low or insufficient. Further, although we found statistically significant effects for some organizational characteristics, structures, and processes of care, for many we found no significant effects. In addition, some statistically significant results were relatively small, meaning that their clinical importance is limited or unclear.

Finally, we found no evidence related to health or psychosocial outcomes for informal caregivers. Although understanding the benefits or harms of various organizational characteristics, structures, or processes of care for people with dementia may well promote better outcomes for informal caregivers, far more evidence is required on this topic.

Implications for Clinical and Policy Decisionmaking

Few studies met inclusion criteria, and evidence was generally of low SOE. Additional research is needed to develop a sufficient evidence base to support family decisionmaking.

The SOE regarding impact was low for all but one intervention: it was moderate for use of pleasant sensory stimulation to reduce agitation. Families, providers, policymakers, advocates, and educators may want to promote the use of pleasant sensory stimulation, and researchers may want to study its use further to strengthen the evidence and examine effects for subgroups of residents.

In addition, we found evidence of positive impacts (all low SOE) and no evidence of negative impacts for a limited number of outcomes in SCUs in NHs (but not RC/AL settings)

and for protocols for individualized care, functional skill training, use of specialized workers, and encouraging activities.

Personalized care protocols can be more accurately targeted and possibly have more of a direct effect on outcomes than group activity interventions. In particular, the person-centered showering and bathing intervention protocol that we examined¹⁶ has been widely adopted and is considered an example of culture change that strives to individualize care.¹⁷ Further, the one study that found both positive and negative outcomes related to the use of morning bright light (decreased depression for women, increased depression for men)¹⁸ suggests that lighting interventions may best be applied at the person level rather than the setting level.

Studies found both positive and negative evidence for a limited number of outcomes for residents of NHs as compared with residents of RC/AL settings. Residents with mild dementia were less likely to be hospitalized if they resided in a NH, and residents in NHs were more likely to have stable health before death. The explanation may be that NHs, as contrasted with RC/AL settings, can provide more medical care. However, we found no evidence regarding differences across these setting types in relation to numerous psychosocial outcomes. If people with dementia and their families are choosing between NHs and RC/AL settings, considering the individual's current medical needs and health stability will be helpful. In addition, taking into account the difference in costs between these two settings (annual 2011 rate \$78,000 to \$87,000 in NHs; \$42,000 in RC/AL)¹⁹ and the availability of Medicaid (should it be necessary) may also be important.

Limitations of the Comparative Effectiveness Review Process and the Evidence Base

We excluded numerous studies of potential relevance for a variety of reasons determined a priori and with the agreement of our TEP; these included studies not specifying that at least 80 percent of the study population had dementia and the analyses not being conducted specific to the subgroup of those with dementia. A total of 76 studies were excluded because they did not meet these criteria; some might have been excluded for other reasons as well. Despite the fact that a large proportion of residents in NHs and RC/AL settings have dementia,²⁰ we had to ensure that the population being studied in these investigations was specific to this review.

In addition, we dropped from our analyses any study for which our quality rating was poor. Given that the SOE of available evidence was principally low (if not insufficient), we do not believe adding poor quality studies would have improved the overall robustness or applicability of the evidence.

Moreover, this was a comparative effectiveness review concerned with outcome differences examined over time. Thus, cross-sectional studies were considered as being less directly pertinent or appropriate to include. Many cross-sectional studies that have adjusted for confounders have been conducted, and some might inform the research questions with respect to effectiveness. We found almost 30 cross-sectional studies with potential relevance.²¹⁻⁵¹ Some findings were that hospitalization is less likely when more residents with dementia are present in the NH and when Medicaid payment rates are relatively higher; also, depression and pain were higher in for-profit settings than nonprofit settings^{33, 35, 50} This type of information may be helpful when determining the optimal setting of care, but such studies might well have higher risks of bias than those we included and, therefore, would not produce findings of materially higher SOE.

Research Gaps

Assuming the overriding question for stakeholders is whether an individual with dementia is best served in a NH or RC/AL setting, or in an SCU, we found no RCTs to answer these questions and only sparse evidence from nonexperimental studies. RCTs would not be expected to inform the matter of NHs versus RC/AL, given that they would be hard to justify in ethical or feasibility terms. Trials of placement in SCUs might be possible, however. All things considered, additional high-quality prospective cohort studies would be beneficial in this area, especially because the majority of RC/AL residents have dementia⁵² and the number of RC/AL beds has almost doubled in the last 20 years.⁵³

The wide array of structural variables and process interventions that surfaced in this work reflects impressive thinking about factors that might improve outcomes. However, this diversity made it impossible for us to improve estimates of effect sizes by pooling data. We are not convinced that “one-off” studies are the best possible use of research resources. Instead, concerted emphasis on key variables may be warranted so that findings can be combined in quantitative analyses to yield stronger evidence for decisionmaking. Two examples of this type of effort include the National Institute on Aging studies examining SCUs and the Robert Wood Johnson Foundation collaborative of projects examining Green House NHs.

Another consideration about future research involves the types of outcomes to be studied. As noted, no evidence surfaced on falls or on several aspects of psychosocial well-being including spiritual well-being, control, autonomy, choice, and satisfaction. Some research effort to clarify care related to these outcomes is warranted, although they may be less salient for decisionmaking than matters such as depression, hospitalization, and quality of life.

A related matter is encouraging investigators to use established outcome measures to enhance the possibility of quantitative pooling of studies or qualitative interpretations of the same outcome information. Many studies in this review used the CMAI (the Cohen Mansfield Agitation Inventory, a measure of behavioral symptoms),⁵⁴⁻⁵⁷ and other established measures are available for other outcomes of interest.

Cutting across the matter of care and outcomes is the question of methods. Of the 13 studies included, we could rate the quality as good for only 4 studies. We excluded 13 studies because of substantial flaws that yielded quality ratings of poor, reflecting important threats to internal validity. Future research should attempt to overcome the risk of bias, such as by attending more closely to masking raters and maintaining consistent raters over time, ensuring similar representation of subjects across arms, focusing on fidelity, and accounting for missing data in analyses. Also, studies with larger samples would provide more precise estimates of differential effects. Finally, more attention to the heterogeneity of people with dementia will better inform the matter of applicability.

Conclusions

Overall, we generally found low or insufficient SOE about the effectiveness of organizational characteristics, structures, and processes of care for people with dementia. This is true about both their health and their psychosocial outcomes. Virtually no good or fair evidence meeting our inclusion criteria exists about outcomes for informal caregivers of people with dementia.

Even with those caveats, we can state some conclusions. Findings of moderate SOE indicate that pleasant sensory stimulation reduces resident agitation. Even though the SOE was low, protocols for individualized care can reduce pain/discomfort and agitation/aggression, and

functional skill training can improve function. Further, if people with dementia and their families are choosing between NHs and RC/AL settings, considering the individual's current medical needs and health stability is important, because these settings do not differ much in outcomes other than those relating to people for whom medical care is indicated or for whom NHs may be better suited on other grounds.

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Introduction

Background

Dementia is a group of progressive, irreversible neurological conditions that lead to gradual decline in mental function. It is the most common reason for entry into long-term care settings such as nursing homes (NHs) and residential care/assisted living (RC/AL).¹ The majority of care for people with dementia is provided in the community by family members; however, increasing care needs in later stages of the illness often lead to placement in a long-term care setting. Because long-term care settings are highly varied, people with dementia and their families who must make a decision regarding placement would benefit from evidence-based guidance on how to choose from the available options. The purpose of this review is to identify and summarize the current evidence regarding which long-term care setting characteristics, structures, or processes are effective for improving health and psychosocial outcomes both for people with dementia and for their family caregivers, so as to provide better guidance to families making placement decisions.

Definition of Dementia

Dementia is a progressive, irreversible decline in mental function, marked by memory impairment and a reduction in at least one or more other areas of cognitive function, such as reasoning, judgment, abstract thought, registration, comprehension, learning, task execution, or use of language.² The most common cause of dementia is Alzheimer's disease; other causes include vascular dementia, mixed dementia, dementia with Lewy bodies, and frontotemporal dementia. The *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR)* provides a commonly accepted definition of dementia (Table 1).

Table 1. Definition of dementia

Definition

Dementia: "The development of multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia,^a agnosia,^b or a disturbance in executive functioning.^c The cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning and must represent a decline from a previously higher level of functioning."

(<http://dsm.psychiatryonline.org/content.aspx?bookid=22§ionid=1889063#8455>)³

^a Apraxia is defined as the "impaired ability to execute motor activities despite intact motor abilities, sensory function, and comprehension of the required task."³

^b Agnosia is defined as the "failure to recognize or identify objects despite intact sensory function."³

^c Executive functioning, "involves the ability to think abstractly and to plan, initiate, sequence, monitor, and stop complex behavior."³

Prevalence of Dementia

More than 5 million Americans—as many as one in every eight individuals ages 65 years or older—have dementia.² This number may rise to as high as 19 million by 2050.¹ Dementia increases dramatically with age; the frequency of dementia among people ages 65 to 70 is approximately 2 percent, whereas for people older than 85 it is more than 30 percent.⁴

Impact of Dementia

Dementia causes significant morbidity and mortality and creates a substantial burden on the people affected, caregivers, health systems, and society.² The disease gradually takes away the individual's ability to make decisions, manage personal affairs, and eventually to do even simple tasks such as dressing, toileting, and eating. Late stages of the disease are characterized by weight loss, limited mobility, and frequent infections, so that, unless some other illness is fatal sooner, people with dementia will eventually die of the disease. The course of the disease from diagnosis to death is variable but is typically from 8 to 12 years. This longevity places a tremendous burden on family caregivers, on personal savings, and on the health care system.² Costs of dementia care, including both medical care and informal caregiver time, are estimated at more than \$148 billion in the United States annually.⁵

Dementia in Long-Term Care Settings

Although about 70 percent of people with dementia are cared for at home, the duration and intensity of care needs cause many families to place people affected with dementia into residential long-term care settings as care needs increase.² Residential settings that provide care for people with dementia are numerous and differ in their organizational characteristics, structures, and processes of care. The four principal categories include the following:^{2, 6}

- Nursing homes. NH settings are federally licensed and regulated settings that provide room, board, 24-hour oversight, health monitoring, assistance with activities of daily living (ADLs), health services, recreational activities, and skilled nursing services. In June 2008, 47 percent of all NH residents had a diagnosis of dementia in their NH record;² however, many more have dementia without a recorded diagnosis, so the true proportion of residents with dementia may be as high as 80 percent.
- Residential care/assisted living. RC/AL settings are residences that provide room, board, 24-hour oversight, and assistance with ADLs. They vary widely in size, structure, and services, and are licensed by the States under a multiplicity of names, including sheltered housing, domiciliary care, intermediate care housing, adult foster care, assisted living, congregate care, and other labels. Estimates indicate that, depending on the type of RC/AL setting, between 45 percent and 67 percent of residents have dementia.⁷
- Alzheimer's (or dementia) special care units (SCUs) in RC/AL settings and NHs. During the past 2 decades, specialized dementia care units have become increasingly common in NHs and RC/AL settings. As of June 2008, NHs had a total of 86,669 beds in SCUs, accounting for 5 percent of all NH beds. More recently, the growth in SCUs has been largely in RC/AL settings; however, as of 2010 only 11 percent of RC/AL settings had a distinct dementia unit, wing, or floor; of these, the majority had less than 40 percent of their residents in the dementia unit.⁸ Given that more than 50 percent of residents in both settings have dementia, the majority of NH and RC/AL residents with dementia are clearly not in SCUs.⁹
- Continuing care retirement communities (CCRCs). CCRCs are retirement communities with different housing and level-of-care options. The area in which a person lives depends on the level of care that he or she needs at a given time. Residents may move from one area to another depending on care needs but stay within the same CCRC. Most CCRCs have both NH and RC/AL beds.

Nationally, 2.25 million older adults reside in long-term care settings. Almost two-thirds (1.5 million) are in one of the country's 16,100 NHs, and the remainder (750,000) are in one of 40,000 RC/AL residences.^{8, 10, 11} As noted above, more than half of these are people with dementia.

Critical Role of Family Caregivers in Dementia

People with dementia typically need an increasing amount of assistance as the disease progresses, and these care needs extend over many years. Families, not long-term care settings, provide the majority of care to individuals with Alzheimer's disease and related dementias (<http://www.caregiver.org>).¹² Relatives or friends who provide unpaid care are known as informal caregivers.¹³

When someone with dementia enters a long-term care setting, family caregivers tend to be intimately involved in the placement decision and remain active after placement.¹⁴⁻¹⁶ Families visit long-term care residents an average of 1.9 times a week, for approximately 4.0 to 4.2 hours a week. They are important to the resident to maintain emotional connectedness and psychosocial health. Also, they constitute an important resource to staff because they have knowledge of the resident's history and provide support for ADLs, thereby augmenting the care provided by staff.¹⁴⁻¹⁶ Indeed, family presence improves resident psychological and psychosocial well-being, the accuracy of diagnosis, and the resultant care.¹⁷ Family members are called on to make decisions regarding care for cognitively impaired residents and to provide continuity that may otherwise be lacking because of staff turnover.^{18, 19}

Need for Evidence-Based Guidance for Consumers Who Wish to Select a Long-Term Care Setting

Numerous consumer/patient guides are available to help the public choose the type of long-term care setting that may be best for their family member. However, it is unclear whether any of these guides are based on evidence. Instead, most guides focus on geographic factors (such as proximity to family), regulatory criteria (such as level of care needed), financial issues (such as whether a long-term care setting accepts Medicaid, or the overall cost per month for residents who pay privately), or some combination of these considerations. Furthermore, many guides have been developed by one or more organizations with a financial interest in a certain long-term care product.

For these reasons, and inspired by a consumer request, the U.S. Agency for Healthcare Research and Quality (AHRQ) identified a need for an unbiased, evidence-based review on factors in long-term care settings themselves that affect the quality of care for individuals with dementia. The topic of our review—the comparison of characteristics of NHs and other residential long-term care settings for people with dementia—addresses this issue, with the goal of reducing the uncertainty of families who are trying to make the best decision regarding a setting of care for a family member with dementia.

Characteristics of Long-Term Care Settings

One relevant question to ask is whether one type of long-term care setting is superior to another for dementia overall or for certain subgroups of people with dementia. Long-term care settings are complex and vary widely within licensure categories, as was highlighted in the 2001 report of the Institute of Medicine Committee on Improving the Quality of Long-Term Care.²⁰

Therefore, an especially relevant question for family members seeking to select a site for a family member is whether certain characteristics are critical in providing quality care for all people with dementia or certain subgroups.

A commonly accepted model places key characteristics of long-term care settings in three categories: organizational characteristics, structures of care, and processes of care.²¹ Table 2 displays definitions and provides examples of each of these key categories of setting characteristics.

Table 2. Organizational characteristics, structures of care, and processes of care

Characteristics	Definitions and Examples
Organizational	Demographic, community, and licensure characteristics of long-term care settings. Includes proprietary status, affiliation (e.g., chain, hospital, CCRC), location (urban vs. rural), size of setting or unit, diversity, cultural fit, cost, and resident case-mix (e.g., dementia, Medicaid), as well as the overall model of care (e.g., NH, assisted living)
Structures of Care	Physical characteristics (“bricks and mortar”) of long-term care settings. Includes material resources (e.g., private rooms, familiar homelike components, access to outdoors), human resources (e.g., level of staffing, expertise of staff), and organizational structure (e.g., hours of care per resident per day by type of worker, consistency of assignment, universal worker perspective)
Processes of Care	Services and systems in place within long-term care settings. Includes programs and services implemented at the system/setting level in the context of care provision (e.g., assistance with ADLs, involvement of informal caregivers, activity programs)

Abbreviations: ADL = activities of daily living; CCRC = continuing care retirement center; NH = nursing home.

Numerous organizational characteristics, structures, and processes of care have been identified as potentially affecting quality of life of persons in residential long-term care settings.²² Among those most commonly suggested are the following:

- Organizational characteristics: residence type, age, profit status, affiliation with another level of care, number of beds, presence of a dementia special care unit, and resident case-mix (related to dementia diagnosis).
- Structures of care: aspects of staffing, including the following: stability of care provider-resident assignment, universal worker perspective (where staff fill multiple roles) and/or a specialized worker perspective (where staff have specialized roles), the number of nurses and nursing or personal care aides, staff turnover, previous experience in dementia care, and physical structure (e.g., lighting, cleanliness).
- Processes of care: care planning (professional staff involvement and aide involvement), policies and practices (admission, discharge, acceptance of behavioral symptoms, policy choice), assessments and treatments conducted, and activities.

Scope and Key Questions

Scope of This Review

Considering the central role of family caregivers in decisions resulting in people with dementia entering long-term care settings, information on the current state of the science of dementia management would be very helpful. The above settings offer different levels of care and different services, and to date no comprehensive evidence-based guidance exists that identifies which characteristics or settings are best for which type of resident based on age, disease severity, or other characteristics. The objective of this review, therefore, is to provide

information that would help families who are trying to decide where to place a family member who has dementia and who can no longer be managed at home.

Key Questions

This review sought to address the following five key questions (KQ):

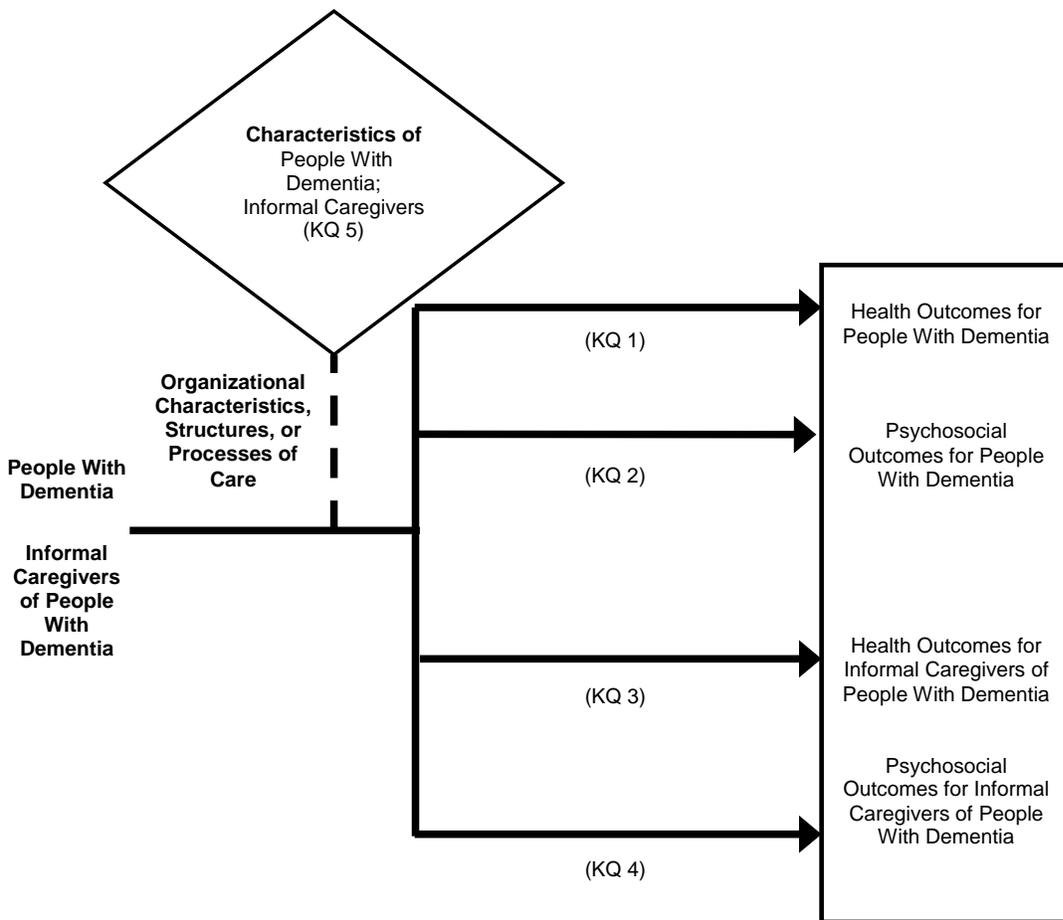
- KQ 1. What is the effectiveness of organizational characteristics, structures, or processes of care in nursing homes and other residential long-term care settings for improving health outcomes for people with dementia?
- KQ 2. What is the effectiveness of organizational characteristics, structures, or processes of care in nursing homes and other residential long-term care settings for improving psychosocial outcomes for people with dementia?
- KQ 3. What is the effectiveness of organizational characteristics, structures, or processes of care in nursing homes and other residential long-term care settings for improving health outcomes for informal caregivers of people with dementia?
- KQ 4. What is the effectiveness of organizational characteristics, structures, or processes of care in nursing homes and other residential long-term care settings for improving psychosocial outcomes for informal caregivers of people with dementia?
- KQ 5. Does the effect of organizational characteristics, structures, or processes of care on health and psychosocial outcomes vary by the characteristics of the person with dementia (e.g., severity of dementia, functional status) or of the informal caregiver (e.g., age, relationship, health status)?

The population of interest for KQs 1, 2, and 5 included people with dementia (i.e., Alzheimer's disease or a related disorder). The population of interest for KQs 3, 4, and 5 included informal caregivers of people with dementia of any age, sex, or relationship to the person with dementia. Intervention/exposure elements of interest included organizational characteristics, structures, and processes of care in NHs and other residential long-term care settings for people with dementia. In addition, combinations of certain organizational characteristics, structures, and processes of care as exhibited in particular models of care (e.g., traditional NHs, "Green House" NHs,²³ RC/AL settings) were also of interest.

Some examples of comparisons of organizational characteristics, structures, and processes of care include not-for-profit versus for-profit, smaller size versus larger size (setting or unit), consistent staffing versus rotating staffing, larger proportion of care paid by Medicaid versus private pay, urban versus rural location, specialized dementia care versus nondementia care, more versus fewer hours of care per resident per day by type of worker, private versus nonprivate rooms and/or bathrooms, neighborhood versus non-neighborhood designs, centralized versus noncentralized nursing desk, and access to outdoors versus no access to outdoors. Examples of comparisons of combinations of organizational characteristics, structures, and processes of care with other combinations include NH versus RC/AL settings, and Green House NHs versus traditional NHs.

We developed an analytic framework to guide the systematic review process (Figure 1).

Figure 1. Analytic framework for comparisons of characteristics of nursing homes and other residential long-term care settings for people with dementia



Outcome measures for each KQ included health and psychosocial outcomes for people with dementia (KQ 1 and KQ 2, respectively) and informal caregivers (KQ 3 and KQ 4, respectively). This review focused on residential long-term care—that is, settings that provide room and board, 24-hour oversight, health monitoring, and support for ADLs and are licensed by the Federal government and/or the States as NHs, RC/AL settings, or other similar names that are subsumed within these categories.

Methods

The methods for this comparative effectiveness review (CER) follow the methods suggested in the *ARHQ Methods Guide for Effectiveness and Comparative Effectiveness Reviews* (available at <http://www.effectivehealthcare.ahrq.gov/methodsguide.cfm>). The main sections in this chapter reflect the elements of the protocol established for the CER; certain methods map to the PRISMA checklist.²⁴ All methods and analyses were determined a priori.

Topic Refinement and Review Protocol

The topic of this report arose through a public process involving the public, the Scientific Resource Center (SRC), and various stakeholder groups (www.effectivehealthcare.ahrq.gov/aboutUs/stakeholder.cfm). Investigators from the <NAME> Evidence-based Practice Center then generated an analytic framework, preliminary Key Questions (KQs), and preliminary inclusion/exclusion criteria in the form of PICOTS (Population, Intervention/Exposure, Comparator, Outcome, Timing, Setting) and study design. The processes were guided by the information provided by the topic nominator, a scan of the literature, methods and content experts, and Key Informants. We worked with eight Key Informants during the topic refinement, and nine additional individuals participated in the Technical Expert Panel (listed in the front matter of this report). Key Informants and the Technical Expert Panel (TEP) members participated in conference calls and discussions through email to review the analytic framework, KQs, and PICOTS at the beginning of the project. Disciplines represented by the Key Informants and TEP included clinicians and researchers in long-term care settings, policy, caregiver advocacy, health care provision, palliative and end-of-life care, minority health issues, dementia care, and consumer advocacy.

TEP members suggested specifically including sleep quality, activity engagement, positive and negative affect, pleasure, use of psychoactive medications, and use of restraints as outcomes of interest for people with dementia. They also suggested specifically including emotional stress, psychosocial stress, family conflict, and self-efficacy as outcomes for informal caregivers.

Our KQs were posted for public comment on AHRQ's Effective Health Care Web site from June 27, 2011 to July 25, 2011; the EPC put them into final form after review of the comments and discussion with the TEP.

Literature Search Strategy

Search Strategy

To identify articles relevant to each KQ, we searched MEDLINE,[®] EMBASE,[®] the Cochrane Library, the Cumulative Index to Nursing and Allied Health Literature (CINAHL[®]), AgeLine,[®] and PsycINFO.[®] We focused our search on long-term care settings, dementia, and informal caregivers by using a variety of terms, medical subject headings (MeSH[®]), and key words. The full search strategy is presented in Appendix A. We reviewed our search strategy with the TEP and incorporated their input into our search strategy.

We limited the electronic searches to English language (consistent with our focus on characteristics, structures, and processes in the United States) and humans. Sources were searched for articles published from 1990 through July 15, 2011, to reflect the changing nature and evolution of nursing homes (NHs) and other residential long-term care settings, especially after the Omnibus Budget Reconciliation Act (OBRA) of 1987 (Public Law 100-203), which

established new regulatory standards of NH care. The landmark Nursing Home Reform Act (amendment to Public Law 100-203), which introduced sweeping change in the way NHs were operated and regulated, was passed by the U.S. Congress as part of OBRA 1987; most of its provisions were implemented under regulations promulgated in 1991-1992 (http://www.access.gpo.gov/nara/cfr/waisidx_02/42cfr483_02.html). Therefore, the investigative team chose 1990 as the beginning date for its literature review, because publications before that date would reflect pre-OBRA status and be of limited relevance to today's long-term care settings.

We manually searched reference lists of reviews, including trials and background articles on this topic, to look for any relevant citations that our searches might have missed and that addressed our KQs. We imported all citations into an electronic database (EndNote[®] X4).

We will conduct an updated literature search (of the same databases searched initially) concurrent with the peer review process. Any literature suggested by peer reviewers or the public will be investigated and, if appropriate, incorporated into the final review. We will determine the appropriateness by the same methods described in this chapter.

Inclusion and Exclusion Criteria

We developed eligibility (inclusion and exclusion) criteria with respect to the PICOTS (Table 3). Because many studies have not required a formal diagnosis of dementia for subject inclusion, we did not require that the dementia be specified as formally diagnosed dementia. Instead, dementia could be determined by (a) formal diagnosis, (b) signs or symptoms (e.g., cognitive status assessment), or (c) report by staff or an informal caregiver.

In consultation with the TEP and through an iterative process, we determined that a study must have explicitly stated that (a) at least 80 percent of the population had dementia or that (b) some analyses were specific to the subgroup of those with dementia. The rationale for this decision was to ensure that the findings were relevant and applicable to the population of interest. This cut-point was determined in consultation with our TEP and, of note, no excluded studies reached even a 70 percent cut-point. In addition, we examined informal caregivers as a population of interest (in KQs 3 and 4).

Interventions/exposures of interest included organizational characteristics, structures of care, or processes of care as defined in the Introduction. Organizational characteristics, structures, and processes of care could either be those inherent to the setting to which people were exposed (e.g., NH versus RC/AL) or new interventions being implemented. Staff training interventions are not included in this review because they are a proxy for and a presumed indicator of care. Level of training in the context of staff role (i.e., certified nursing assistant, registered nurse, licensed practical nurse, licensed vocational nurse, medical technologist, and other direct-care workers) was considered in this review.

We sought to compare the effectiveness of elements of interventions/exposures with one another and combinations of interventions/exposures. Comparators included various types and amounts (e.g., consistent versus rotating staffing) of the elements or combinations of certain elements, as exhibited in particular models (e.g., the Green House model). Studies without a comparator were not included in this review.

The research team determined the categorization of outcomes with input from TEP members. We considered symptoms of depression as health outcomes but other components of affect (e.g., anxiety, pleasure) as psychosocial outcomes. Quality of life could be considered as either a psychosocial outcome or a health outcome. For the purpose of this review, we have categorized

it within the psychosocial outcomes (KQ 2 and KQ 4). Caregiver burden, a psychosocial outcome, is defined as “the strain or load borne by a person who cares for an elderly, chronically ill, or disabled family member or other person. It is a multidimensional response to physical,

Table 3. Study eligibility criteria

Category	Inclusion Criteria	Exclusion Criteria
Population	<ul style="list-style-type: none"> • People with dementia residing within a long-term residential setting with or without coexisting disease • Informal caregivers of people with dementia 	<ul style="list-style-type: none"> • No indication of dementia • Persons with mild cognitive impairment • Studies in which the case-mix proportion of the population with dementia is unspecified or <80% or in which analyses have not been conducted specific to the subgroup of people with dementia
Interventions/ exposures (described in the Introduction)	<ul style="list-style-type: none"> • Organizational characteristics • Structures of care • Processes of care 	<ul style="list-style-type: none"> • Interventions/exposures delivered at the person level^a • Prescribed therapies (e.g., medication trials, nutritional supplements) • Staff training interventions • In-home care • Community services • Interventions/exposures that require the individual to leave the long-term care setting to receive the intervention
Comparators	<ul style="list-style-type: none"> • Various types or amounts of the intervention/exposure element • Combination of certain intervention/exposure elements 	<ul style="list-style-type: none"> • Studies with no comparator
Outcomes	<ul style="list-style-type: none"> • Health outcomes for people with dementia: Pain or discomfort; symptoms of depression; sleep quality; health decline/morbidities (including skin ulcers); decline in functioning, self-care or maintenance; decline in cognitive functioning; falls; mortality; hospitalizations. • Psychosocial outcomes for people with dementia: Positive and negative affect (e.g., pleasure, anxiety); behavioral symptoms; engagement, quality of life; quality of dying; spiritual well-being; control, autonomy, choice; satisfaction; use of psychoactive medications, use of restraints. • Health outcomes for informal caregivers of people with dementia: Symptoms of depression; sleep quality; morbidities (e.g., cardiovascular disease). • Psychosocial outcomes for informal caregivers of people with dementia: Anxiety; quality of life; caregiver burden; emotional stress, psychosocial stress; quality of relationship with person who has dementia; self-efficacy; guilt; grief reactions; perception of suffering; satisfaction; financial burden; family conflict. 	<ul style="list-style-type: none"> • Biomarkers
Timing	<ul style="list-style-type: none"> • No minimum study duration limit 	

Table 3. Study eligibility criteria (continued)

Category	Inclusion Criteria	Exclusion Criteria
Settings	<ul style="list-style-type: none"> • Nursing homes • Residential care / assisted living (and similar settings of a different name, such as board and care homes) • Green House homes • Alzheimer's special care units • Residential long-term hospice care • Continuing care retirement communities 	<ul style="list-style-type: none"> • Adult day centers • PACE • In-home • Accessory dwelling units • Hospital
Geography	<ul style="list-style-type: none"> • United States 	<ul style="list-style-type: none"> • All other countries
Sample size	<ul style="list-style-type: none"> • Trials with an N\geq30 • Observational studies with an N\geq100 	<ul style="list-style-type: none"> • Trials with an N$<$30 • Observational studies with an N$<$100
Time period	<ul style="list-style-type: none"> • 1990 to July 15, 2011; searches to be updated after draft report is submitted for peer review 	<ul style="list-style-type: none"> • Articles published before 1990
Publication language	<ul style="list-style-type: none"> • English 	<ul style="list-style-type: none"> • All other languages
Admissible evidence (study design and other criteria)	<ul style="list-style-type: none"> • Eligible study designs include the following: <ul style="list-style-type: none"> ○ Randomized controlled trials ○ Nonrandomized controlled trials with concurrent eligible controls ○ Systematic reviews with or without meta-analyses ○ Subgroup and/or post-hoc analyses of data from relevant controlled trials ○ Case-control studies ○ Prospective-cohort studies 	<ul style="list-style-type: none"> • Case series • Case reports • Nonsystematic/narrative reviews • Editorials • Letters to the editor • Pre-post designs without a comparison group • Focus groups • Qualitative interviews • Cross-sectional designs • Articles rated as poor quality (a high risk of bias)

^a Given the intent of this comparison to inform the selection of a setting for individuals with dementia based on organizational characteristics, structures, and processes of care, we restricted interventions to those at the setting/system level (e.g., dementia care unit, something to which all persons are exposed) rather than at the person level (e.g., tube feeding, something to which not every one is exposed).

Abbreviations: N = number; PACE = Program of All-Inclusive Care for the Elderly.

psychological, emotional, social, and financial stressors associated with the caregiving experience.²⁵

The time period of interest in choosing studies to review was any duration of time beginning after the admission of the person with dementia to a residential long-term care setting until permanent transfer to another setting or death.

We confined our review to studies done in the United States so that the evidence examined would be relevant to care in this country. The health care systems and approaches to long-term care in other countries differ substantially from those here (and from each other), so that research from other countries will be less applicable to the United States than studies done in this country.

Study Selection

Two persons independently reviewed article abstracts using the inclusion/exclusion criteria presented in Table 3. If both reviewers agreed that the study did *not* meet eligibility criteria, we excluded it; otherwise, two reviewers then independently reviewed the full-text article. If the reviewers disagreed, they resolved conflicts by discussion and consensus or by consulting a third member of the review team. A reviewer who was also an author of a specific study was not

permitted to make the final determination as to whether the study was included or excluded. Studies excluded at the full-text stage, along with reasons for exclusion, are listed in Appendix B.

Data Abstraction

For studies that met our inclusion criteria, we abstracted important information into evidence tables. We designed and used structured data abstraction forms to gather pertinent information from each article, including characteristics of study populations, settings, interventions/exposures, comparators, study designs, methods, and results. Trained reviewers abstracted the relevant data from each included article into the evidence tables. A second member of the team reviewed all data abstractions against original articles for completeness and accuracy. We recorded intention-to-treat results if available. All data abstraction was performed using Microsoft Excel[®] software. Evidence tables containing all abstracted data of included studies are presented in Appendix C. Evidence tables are organized by study characteristics, study population characteristics, intervention/exposure components, and outcomes.

Quality Assessment of Individual Studies

To assess the quality (internal validity) of studies, we used predefined criteria based on those developed by the U.S. Preventive Services Task Force (USPSTF) (ratings: good, fair, poor)²⁶ and the University of York Centre for Reviews and Dissemination.²⁷ In general terms, a “good” study has the least risk of bias and its results are considered to be valid. To be rated “good” for the purpose of this review, a trial must have fulfilled all of the following criteria: adequate randomization of patients; adequate allocation concealment; blinded outcome assessors; similar baseline characteristics across treatment arms; overall attrition less than 20 percent; differential attrition less than 15 percent (i.e., there is less than a 15 percentage point difference between attrition in one group and attrition in another); intention-to-treat analysis; and use of equal (across comparison groups), valid, and reliable outcome measures. An observational study receiving the quality rating of “good” must have fulfilled all of the following criteria: prospective design; recruitment from the same source population and during the same time period for the control and intervention subjects; similar inclusion and exclusion criteria across treatment arms; similar length of follow-up; adequate accounting for confounding in statistical analyses or study design; overall attrition less than 20 percent; differential attrition less than 15 percent; and the use of equal, valid, and reliable outcome measures. A “fair” study is susceptible to some bias but probably not sufficient to invalidate its results. A “poor” study has significant risk of bias (e.g., stemming from serious errors in design or analysis) that may invalidate its results.

Two independent reviewers assigned quality ratings for each study. Disagreements between the two reviewers were resolved by discussion and consensus or by consulting a third member of the team. We gave poor quality ratings to studies that had a fatal flaw (defined as a methodological shortcoming that leads to a very high risk of bias) in one or more categories, and we excluded them from our analyses. Appendix D details the criteria used for evaluating the quality of all included studies. Articles excluded because of a quality rating of poor can be found in Appendix D along with an explanation for the poor quality rating. A reviewer who was also an author on an included study was not permitted to rate the quality of the study in question.

Data Synthesis

To determine whether quantitative analyses were appropriate, we assessed the clinical and methodological heterogeneity of the studies under consideration following established guidance.²⁸ We examined the PICOTS of the included studies, looking for similarities and differences. Because we determined that quantitative analyses were not appropriate (because of clinical heterogeneity, insufficient numbers of similar studies, or insufficiency or variation in outcome reporting), we synthesized the data qualitatively. All syntheses were evaluated by multiple coauthors of this report.

More specifically, we individually reviewed all articles of good or fair quality to articulate clearly whether the intervention/exposure under study was an organizational characteristic, structure of care, and/or process of care; whether the population under study was people with dementia and/or their informal caregivers; and whether the intervention/exposure was examined in the context of health and/or psychosocial outcomes. Then, the research team evaluated articles in terms of their bias, design, quality, directness, precision, and strength of evidence.

Strength of the Body of Evidence

We graded the strength of evidence (SOE) based on the guidance established for the Evidence-based Practice Center Program.²⁹ Developed to grade the overall strength of a body of evidence, this approach incorporates four key domains: risk of bias (includes study design and aggregate quality), consistency, directness, and precision of the evidence. It also considers other optional domains that may be relevant for some scenarios, such as a dose-response association, plausible confounding that would decrease the observed effect, strength of association (magnitude of effect), and publication bias.

Table 4 describes the grades of evidence that can be assigned. We graded the SOE for a wide array of outcomes relating to KQ 1 and KQ 2:

- Health outcomes for people with dementia, such as pain or discomfort; symptoms of depression; sleep quality; health decline/morbidities including skin ulcers; decline in functioning, self-care, or maintenance; decline in cognitive functioning; falls; mortality; and hospitalizations;
- Psychosocial outcomes for people with dementia, such as positive and negative affect including pleasure and anxiety; behavioral symptoms; engagement; quality of life; quality of dying; spiritual well-being; control; autonomy; choice; satisfaction; use of psychoactive medications, and use of restraints.

Table 4. Definitions of the grades of overall strength of evidence

Grade	Definition*
High	High confidence that the evidence reflects the true effect. Further research is very unlikely to change our confidence in the estimate of effect.
Moderate	Moderate confidence that the evidence reflects the true effect. Further research may change our confidence in the estimate of the effect and may change the estimate.
Low	Low confidence that the evidence reflects the true effect. Further research is likely to change our confidence in the estimate of the effect and is likely to change the estimate.
Insufficient	Evidence either is unavailable or does not permit estimation of an effect.

*Owens et al., 2010²⁹

Two reviewers assessed each domain for each key outcome and resolved any differences by consensus. We used a qualitative process, considering each of the domains, to determine the

overall SOE grade for each relevant outcome. Differences in overall strength of grades were resolved by discussion with the research team until reaching consensus. Given that most outcomes had only a single study to provide evidence, consistency would be considered not applicable; when the study had estimates of effects that were not statistically significant or had wide confidence intervals, we rated that domain as imprecise. As a general proposition, therefore, for outcomes with a single study with imprecise results and for which power was not ensured, we graded the SOE as insufficient; for a single study with precise results, we graded it as low. Therefore, although effectiveness is not synonymous with precision nor with SOE, individual studies that showed an effect generally merited a rating of low SOE.

Applicability

We assessed the applicability of the evidence following guidance from the *Methods Guide for Effectiveness and Comparative Effectiveness Reviews*.³⁰ We used the PICOTS framework to explore factors that affect applicability. Some factors identified a priori that may limit the applicability of evidence included the following: differences between study resident populations and general resident populations with respect to race, ethnicity, sex, comorbidity, extent of cognitive impairment, and functional status; intensity and delivery of interventions; years in which the studies were performed; and standards of care that differ markedly from settings of interest (e.g., practice standards that vary from state to state).

Peer Review and Public Commentary

Experts in the field and individuals representing stakeholder and user communities were invited to provide external peer review of this CER. They were charged with commenting on the content, structure, and format of the evidence report, providing additional relevant citations, and pointing out issues related to how we conceptualized the topic and analyzed the evidence. Our peer reviewers (listed in the front matter) gave us permission to acknowledge their review of the draft. AHRQ staff and an associate editor also provided comments. In addition, the Scientific Resource Center posted the draft report on the AHRQ Web site (<http://effectivehealthcare.ahrq.gov/>) for 4 weeks to elicit public comment. We addressed all reviewer comments, revising the text as appropriate, and documented everything in a “disposition of comments report” that will be made available 3 months after the Agency posts the final CER on the AHRQ Web site.

Results

Introduction

This chapter is organized by Key Question (KQ) and then grouped by intervention/exposure category. Briefly, we wanted to compare the effectiveness of organizational characteristics, structures, and processes of care in nursing homes (NHs) and other residential long-term care settings on four types of outcomes: health outcomes for people with dementia (KQ 1), psychosocial outcomes for people with dementia (KQ 2), health outcomes for informal caregivers of people with dementia (KQ 3), and psychosocial outcomes for informal caregivers of people with dementia (KQ 4). KQ 5 concerned whether the effect of organizational characteristics, structures, or processes of care on health and psychosocial outcomes varied by the characteristics of the person with dementia (e.g., severity of dementia, functional status) or of the informal caregiver (e.g., age, relationship, health status); we report on relevant KQ 5 studies only in the context of KQs 1 to 4.

People who reside in long-term care settings are often referred to as residents; generally speaking, the term “residents” refers to people who do and do not have dementia. For the ease of reading, we refer to people with dementia as residents; unless otherwise noted, however, our comments are relevant only to those residents who have dementia.

Results of Literature Searches

Results of our literature searches appear in Figure 2. We ultimately included 13 published articles: 9 randomized controlled trials (RCTs), 1 nonrandomized controlled trial, and 3 prospective cohort studies. We recorded the reason that each excluded full-text publication did not satisfy the eligibility criteria and compiled a comprehensive list of such studies (Appendix B). Evidence tables for included studies can be found in Appendix C.

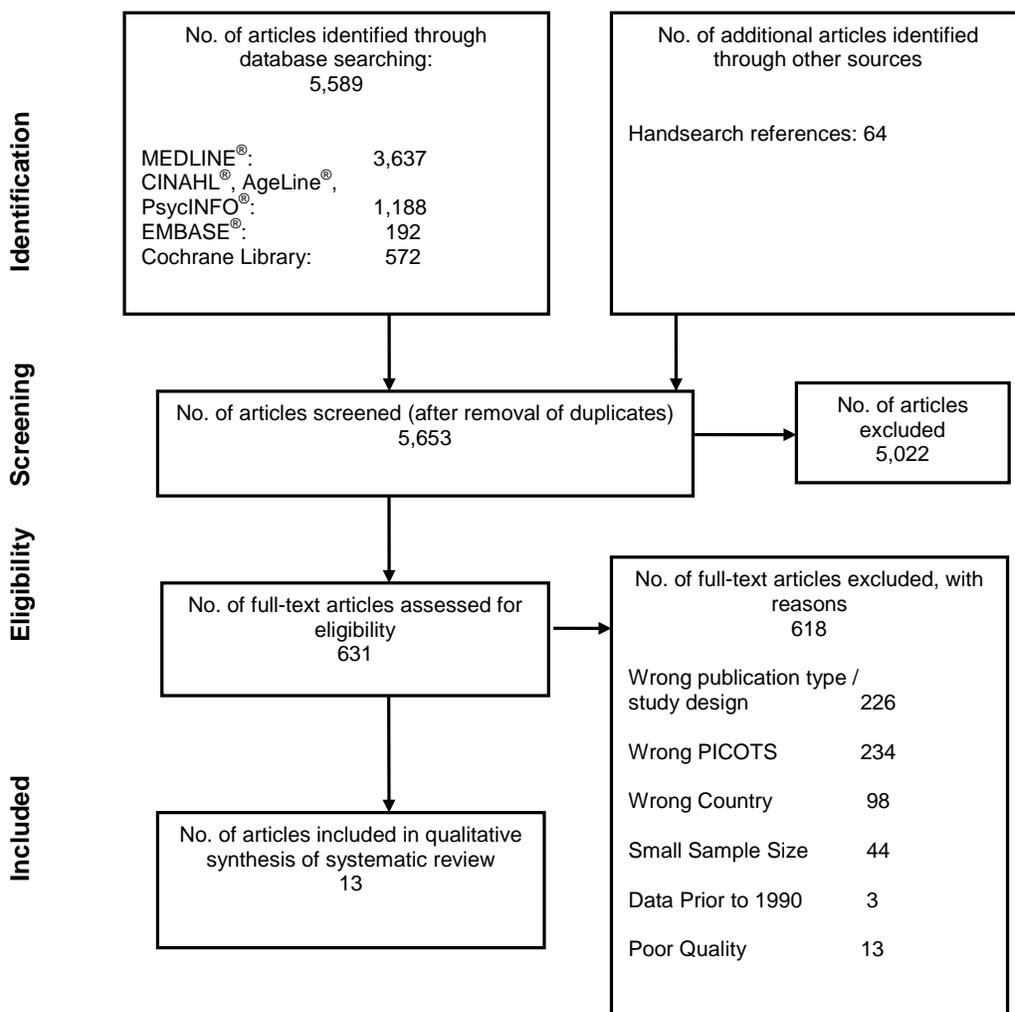
Description of Included Studies

Table 5 outlines the characteristics of the 13 included studies. About half the studies examined the effectiveness of an intervention/exposure among a population ranging in dementia severity from mild to severe.^{22,31-35} One study included a population with moderate to severe dementia severity³⁶ and two studies focused on populations with severe dementia.^{37, 38} A few studies did not report enough information (e.g., range on the Mini-Mental State Examination, Minimum Data Set Cognition Scale, or Global Deterioration Scale) to determine the extent of cognitive impairment or dementia severity of the population.³⁹⁻⁴²

Ten studies addressed health outcomes for people with dementia (KQ 1);^{31, 32, 34-37, 39-42} nine studies examined psychosocial outcomes for people with dementia (KQ 2).^{22, 33, 35-40, 42} No eligible studies of fair or better quality examined either health or psychosocial outcomes (respectively, KQ 3 and KQ 4) for informal caregivers of people with dementia. Thus, we do not comment on those two questions further in this chapter. One study addressed whether effects of organizational characteristics differed by dementia severity but not by other characteristics (KQ 5),³⁵ and one study examined whether effects of a structure of care differed by sociodemographic characteristics (i.e., sex).³²

Two studies took place in a dementia care unit within a NH.^{32, 39} Three additional studies occurred in RC/AL settings and NHs.^{22, 35, 40} The remaining eight studies examined characteristics within NHs.^{31, 33, 34, 36-38, 41, 42}

Figure 2. Disposition of articles



Abbreviations: CINAHL = Cumulative Index to Nursing and Allied Health Literature; PICOTS = population, intervention/exposure, comparator, outcome, timing, setting; No. = number.

Three prospective cohort studies examined the effectiveness of organizational characteristics.^{22, 35, 40} Two RCTs and one prospective cohort study assessed the effectiveness of structures of care.^{22, 31, 32} The remaining studies examined processes of care. Five of these process of care studies (four RCTs and one prospective cohort) assessed group activity interventions,^{22, 34, 39, 41, 42} two trials related to pleasant sensory stimulation,^{33, 38} and two RCTs were protocols for individualized care.^{36, 37}

We rated four studies as good quality^{34, 35, 37, 40} and the remaining nine studies as fair quality.^{22, 31-33, 36, 38, 39, 41, 42} We excluded studies that we rated poor quality from further analyses; they are listed in Appendix D.

Table 5. Characteristics of all included studies

Characteristics	Author, Year, Design Duration Quality	Dementia Severity^a	Baseline Cognitive Impairment	Sample Size	Setting	Interventions/Exposures
Organizational	Sloane et al., 2005 ³⁵ Prospective cohort 12 months Good	Mild to severe	MDS-COGS G1: 5.3 G2: 5.7	G1: 773 G2: 479 G3: 164 G4: 607 G5: 94 G6: 385	RC/AL, NH	G1: RC/AL G2: NH G3: SCU within RC/AL G4: Non-SCU within RC/AL G5: SCU within NH G6: Non-SCU within NH
	Sloane et al., 2008 ⁴⁰ Prospective cohort 1 month Good	NR	NR	G1: 175 G2: 247	RC/AL, NH	G1: RC/AL G2: NH
	Zimmerman et al., 2005 ^{22b} Prospective cohort 6 months Fair	Mild to severe	MMSE or MDS-COGS Mild to moderate: 152 Severe to very severe: 259	G1: 48 G2: 101 G3: 135 G4: 137 G5: NR G6: NR G7: NR G8: NR	RC/AL, NH	G1: RC/AL – settings with <16 beds G2: RC/AL traditional – settings with ≥ 16 beds, not meeting new-model criteria G3: New-Model: RC/AL settings with ≥ 16 beds of the “new-model” type G4: NH G5: Use of specialized workers (staff fill specialized roles) G6: No use of specialized workers G7: Encourage activities ^d ≥ once a day G8: Encourage activities ^d < once a day
Structures of Care	Dowling et al., 2005 ³¹ RCT 10 weeks Fair	Mild to severe	MMSE Overall: 6.7; range 0 to 23	G1: 29 G2: 17	NH	G1: Morning bright light exposure (9:30–10:30 a.m., >2,500 lux in gaze direction) G2: Control - Usual indoor light levels (150–200 lux)
	Hickman et al., 2007 ³² RCT 3 weeks Fair	Mild to very severe	MDS-COGS ^c Mild to Moderate Men: 34.3% Women: 29.0 % Severe Men: 42.9% Women: 51.6% Very Severe: Men: 22.9% Women: 19.4%	G1: 32 G2: 46 G3: 47 G4: 48	Geriatric unit and SCU	G1: Morning bright light (7 a.m.–11 a.m.) G2: Evening bright light (4 p.m.–8 p.m.) G3: All-day bright light (7 a.m.–8 p. m.) G4: Standard light (7 a.m.–8 p. m.)

Table 5. Characteristics of all included studies (continued)

Characteristics	Author, Year, Design Duration Quality	Dementia Severity^a	Baseline Cognitive Impairment	Sample Size	Setting	Interventions/Exposures
Structures of Care (continued)	Zimmerman et al., 2005 ^{22b} Prospective cohort 6 months Fair	Mild to severe	MMSE or MDS-COGS Mild to moderate: 152 Severe to very severe: 259	G1: 48 G2: 101 G3: 135 G4: 137 G5: NR G6: NR G7: NR G8: NR	RC/AL, NH	G1: RC/AL – settings with <16 beds G2: RC/AL traditional – settings with ≥ 16 beds, not meeting new-model criteria G3: New-Model – RC/AL settings with ≥ 16 beds of the “new-model” type G4: NH G5: Use of specialized workers (staff fill specialized roles) G6: No use of specialized workers G7: Encourage activities ^d ≥ once a day G8: Encourage activities ^d <once a day
Processes of Care	Fritsch et al., 2009 ³⁹ RCT 10 weeks Fair	NR	NR	G1: 10 SCUs G2: 10 SCUs	SCU in NHs	G1: TimeSlips – group storytelling program that encourages creative expression among persons with dementia G2: Control – No intervention
	Kovach et al., 2006 ³⁷ RCT 4 weeks Good	Severe	MMSE G1: 7.35 G2: 8.26 Overall: 7.81	G1: 57 G2: 57	NH	G1: Serial trial intervention – multistep clinical protocol for assessment and management of unmet needs in people with late-stage dementia G2: Control – curricula informed of common misconceptions about aging, reversible and irreversible causes of dementia, stages of AD, approaches to treating behaviors and physical conditions associated with dementia
	Remington, 2002 ³³ RCT 10 minutes Fair	Mild to severe	NR	G1: 17 G2: 17 G3: 17 G4: 17	NH	G1: Calm music (10 minutes) G2: Hand massage (10 minutes) G3: Calm music and hand massage (10 minutes simultaneously) G4: Control – no intervention
	Rosswurm, 1990 ³⁴ RCT 3 weeks Good	Mild to severe	MMSE G1: 9.86 G2: 11.1	G1: 15 G2: 15	NH	G1: Attention-focusing group – welcoming and relaxation exercises; perceptual-matching exercises; reinforcement with refreshments G2: Control – refreshments and the opportunity for social interaction

Table 5. Characteristics of all included studies (continued)

Characteristics	Author, Year, Design Duration Quality	Dementia Severity^a	Baseline Cognitive Impairment	Sample Size	Setting	Interventions/Exposures
Processes of Care (continued)	Sloane et al., 2004 ³⁶ RCT 2 weeks Fair	Moderate to severe	MDS-COGS G1 and G2: 7.7 G3: 6.5	G1: 24 G2: 25 G3: 24	NH	G1: Patient-centered showering – patient-centered techniques: providing choices, covering with towels to maintain warmth, distracting attention, using family- or staff-recommended bathing products, using no-rinse soap, modifying shower spray G2: Towel bath – patient-centered techniques: using two bath blankets, two bath towels, a no-rinse soap, and 2 quarts of warm water; keeping the resident covered at all times; cleansing the body using gentle massage G3: Control – showering without patient-centered training
	Tappen, 1994 ⁴¹ RCT 20 weeks Fair	NR	MMSE Overall: 6.4	G1: 21 G2: 21 G3: 21	NH	G1: Functional skill training – regain function in basic activities of daily living through repeated practice; group setting 5 days/week for 2.5 hours per day G2: General stimulation – recreationall oriented group activities provided for dementia patients in therapeutically oriented settings; 5 days/week for 2.5 hours per day G3: Control – regular care
	Toseland et al., 1997 ⁴² RCT 52 weeks Fair	NR	SPMSQ G1: 7.43 G2: 7.46 G3: 7.15	G1: 31 G2: 29 G3: 28	NH	G1: Validation group therapy – encourage residents with dementia to continue communicating using memory fragments and other aspects of cognitive, affective, and motoric functioning G2: Social contact – one activity each meeting in the eight categories of music, art, literature and writing, dance/exercise, games/trivia, holiday and event planning, discussion, and other activities G3: Usual care – participation in regular social and recreational programming offered by each NH
	Whall et al., 1997 ³⁸ Non-RCT 1 week Fair	Severe	NR	G1: 15 G2: 16	NH	G1: Shower room – recorded songs of birds, sounds of babbling brooks, and sounds of other small animals; large bright pictures coordinated with audio; offering foods such as banana pudding and/or soda G2: Usual care

Table 5. Characteristics of all included studies (continued)

Characteristics	Author, Year, Design Duration Quality	Dementia Severity^a	Baseline Cognitive Impairment	Sample Size	Setting	Interventions/Exposures
Processes of Care (continued)	Zimmerman et al., 2005 ^{22b} Prospective cohort 6 months Fair	Mild to severe	MMSE or MDS-COGS Mild to moderate: 152 Severe to very severe: 259	G1: 48 G2: 101 G3: 135 G4: 137 G5: NR G6: NR G7: NR G8: NR	RC/AL, NH	G1: RC/AL – settings with <16 beds G2: RC/AL traditional – settings with ≥ 16 beds, not meeting new-model criteria G3: New-Model – RC/AL settings with ≥ 16 beds of the “new-model” type G4: NH G5: Use of specialized workers (staff fill specialized roles) G6: No use of specialized workers G7: Encourage activities ^d ≥ once a day G8: Encourage activities ^d <once a day

^a Investigators used the following scales and measurement to determine the level of dementia severity: mild, scores of 17-23 on the Mini-Mental State Examination, 0-1 on the Minimum Data Set Cognition Scale, or stage 4 on the Global Deterioration Scale; moderate, scores of 11-16 on the Mini-Mental State Examination, 2-4 on the Minimum Data Set Cognition Scale, or stage 5 on the Global Deterioration Scale; and severe, scores of ≤ 10 on the Mini-Mental State Examination, ≥ 5 on the Minimum Data Set Cognition Scale, or stage 6 and stage 7 on the Global Deterioration Scale.

^b Zimmerman et al.²² examined interventions/exposures within all three categories – organizational characteristics, structures of care, and processes of care. It has thus been listed three times in Table 5.

^c For four residents missing MDS-COGS scores, dementia severity was based on MMSE, education, and activities of daily living score.

^d Activities included exercise, personal care, social activities, housekeeping, meal preparation, crafts/handiwork, special event, sensory activities, and/or intellectual activities.

Abbreviations: AD = Alzheimer’s disease; G = group; MDS-COGS = Minimum Data Set Cognition Scale; MMSE = Mini-Mental State Examination; NH = nursing home; NR = not reported; OC = organizational characteristic; PC = process of care; RC/AL = residential care/assisted living; RCT = randomized controlled trial; SC = structure of care; SCU = special care unit; SPM.SQ = Short Portable Mental Status Questionnaire.

Key Question 1. Health Outcomes for People With Dementia

KQ 1 compares the effectiveness of organizational characteristics, structures, or processes of care in NHs and other residential long-term care settings for improving health outcomes for people with dementia. Health outcomes measured in at least one included study include discomfort from pain, functional decline, cognitive decline, symptoms of depression, morbidities (e.g., skin ulcers), hospitalization, mortality, and sleep quality. Another health outcome on which we sought but did not identify evidence from included studies was falls. We also assessed whether effects differed by dementia severity and other characteristics of the person with dementia.

Of the 10 studies reviewed, eight interventions showed statistically significant effects on health outcomes, with insufficient to low SOE. Process of care interventions provided more evidence than did interventions focusing on organizational characteristics or structures of care. Only one study addressed whether effects differed by dementia severity (but not by other characteristics) and found hospitalization was more likely in RC/AL settings than in NHs for residents with mild dementia (low SOE). Another found the effects of a lighting intervention differed by sex.

Key Points of Organizational Characteristics

- Two studies addressed organizational attributes but found few differences between RC/AL settings and NHs on a range of health outcomes, with some differences occurring between dementia special care units (SCUs) and non-SCUs located within either RC/AL settings or NHs (insufficient or low SOE).
- Evidence from one study did not show a difference in mortality rates for residents in RC/AL compared with those in NHs (low SOE).
- Some evidence suggested higher hospitalization rates (low SOE) but little difference in morbidity rates (low to insufficient SOE) in RC/AL settings than in NHs.
- Evidence on dementia SCUs was inconsistent. Residents of dementia SCUs, when compared with no SCU, had greater decline in functioning over time (low SOE), and lower rates of both hospitalization and new or worsening morbidity (low SOE).

Key Points of Structures of Care

- One RCT found no effect for lighting interventions on sleep quality (insufficient SOE) and another RCT found no effect on depression (insufficient SOE) for the overall populations studied, but benefit in both trials for some subgroups (insufficient SOE).

Key Points of Processes of Care

Evidence for group activity interventions was mixed:

- A functional skills training intervention produced modest effect sizes for improving ADLs, with effect sizes being equivalent to moving from major to moderate or from moderate to minor assistance in performing the ADLs (low SOE).
- A storytelling intervention improved cognitive alertness by about 3 percentage points (low SOE).

- Two interventions had no benefits. A validation group therapy intervention did not improve functional self-care or depression. An attention focusing intervention did not improve cognitive impairment.

Evidence for personalized care interventions was modest:

- A personalized assessment and treatment intervention reduced resident discomfort with an effect size of 0.89 (low SOE).
- Both personalized showering and towel bath interventions reduced resident discomfort on an Alzheimer's discomfort scale by 0.32 and 0.57 points respectively compared with a control group score of 2.14.

Detailed Synthesis of Organizational Characteristics

Two studies considered organizational characteristics and their effects on health outcomes (Tables 6 and 7).^{35,40} Both studies^{35, 40} evaluated the effects of care in RC/AL settings versus NHs. The first study also analyzed a second exposure of interest, separately testing whether dementia SCUs within each setting improved health outcomes when compared with no SCU within each setting.³⁵ These results from this one study are provided separately. The second study focused on outcomes for people who died.

Both cohort studies reported few differences between RC/AL settings versus NHs on a range of outcomes for which study authors controlled for differences in resident baseline demographic, health and cognitive characteristics. In the first study, RC/AL settings had a slightly higher hospitalization rate than NHs for residents with mild dementia.³⁵ In addition, residents on dementia SCUs versus no SCU within each setting differed on some measures. First, residents of dementia SCUs within RC/AL settings had more decline in ADL functioning over time than residents who were not in SCUs.

Second, residents in dementia SCUs within NHs had lower rates of hospitalization and new or worsening morbidity than those who were not in SCUs. All differences reported were small in magnitude. This study found no differences across either settings or dementia SCUs on outcome measures for discomfort, depression, cognitive impairment, or mortality.

In the second study, morbidity differed little between RC/AL settings and NHs.⁴⁰ When compared with NHs on five different morbidity measures, RC/AL settings differed only by having a much larger proportion of residents who experienced a disease course reflecting a series of ups and downs in resident health compared with a steady decline in the last months of life. The rate of hospitalization did not differ between settings.

Taken together, these two studies suggest that residents in RC/AL settings and NHs differ little on the health outcomes measured (low to insufficient SOE; Table 8). Evidence is insufficient on falls and sleep quality.

For KQ 5, only one study³⁵ addressed whether effects differed by dementia severity (but not by other characteristics) and found no differences in health outcomes based on residence in a NH versus RC/AL (low SOE).

Detailed Synthesis of Structures of Care

Two RCTs considered structures of care, specifically lighting interventions, and their effects on two health outcomes (sleep quality and depression) (Table 9).^{31,32} One intervention was conducted in NHs either outdoors or in an indoor space with expansive surrounding windows.³¹

Table 6. Effect of organizational characteristics on functioning, discomfort, depression, cognitive impairment, mortality, and hospitalization

Author, Year Design	Interventions/ Exposures	Change in ADL Functioning ^a	Discomfort	Increase in Depressive Symptoms ^b	Cognitive Impairment	Mortality ^c	Hospitalization ^c	Life-sustaining Hospitalization in Last Month of Life	
Sloane et al., 2005 ³⁵ Prospective Cohort	G1: RC/AL G2: NH	Mild dementia	Pain not effectively treated during last month of life^d	Mild dementia	Mild dementia	Mild dementia	Mild dementia	NR	
		G1: 4.29 G2: 5.80 p=0.059		G1: 1.33 G2: 1.53 p=0.753	G1: 0.41 G2: 0.71 p=0.181	G1: 3.2 G2: 4.2 p=0.409	G1: 14.2 G2: 8.4 p=0.009		
	G3: SCU in RC/AL G4: Non-SCU in RC/AL G5: SCU in NH G6: Non-SCU in NH	G3 vs. G4: p=0.029 G5 vs. G6: p=0.886	Moderate to severe dementia	Moderate to severe dementia	Moderate to severe dementia	Moderate or severe dementia	Moderate or severe dementia	Moderate or severe dementia	
			G1: 0.87 G2: 1.13 p=0.807	G1: 10.2 % G2: 5.5 % p= 0.186	G1: 1.52 G2: 0.85 p=0.409	G1: -0.13 G2: 0.45 p=0.93	G1: 3.7 G2: 4.2 p=0.682	G1: 14.2 G2: 10.0 p=0.115	
			Any dementia	Any dementia	Any dementia	Any dementia	Any dementia	Any dementia	NR
			G3: 5.64 G4: 2.91 G5: 3.00 G6: 3.19	G3: 1.59 G4: 1.32 G5: 0.89 G6: 1.25	G3: 0.33 G4: 0.30 G5: 0.58 G6: 0.61	G3: 7.0 G4: 4.0 G5: 3.4 G6: 4.0	G3: 17.3 G4: 14.4 G5: 3.9 G6: 9.6		
		G3 vs. G4: p=0.823 G5 vs. G6: p=0.630	G3 vs. G4: p=0.943 G5 vs. G6: p=0.903	G3 vs. G4: p=0.116 G5 vs. G6: p=0.540	G3 vs. G4: p=0.430 G5 vs. G6: p=0.006				
Sloane et al., 2008 ⁴⁰ Prospective Cohort	G1: RC/AL G2: NH	NR	NR	NR	NR	NR	NR	Any dementia G1: 39.7 % G2: 23.6 % p=0.149	

^a Mean change in ADL dependency per 12 months using the MDS-ADL scale

^b Measured by Cornell Scale for Depression in Dementia (CSDD) scale

^c Incidence rate per 100 participants per quarter

^d Study also reported pain never an issue during the last month of life, G1: 48.5 percent vs. G2: 38.7 percent, p = 0.249

Abbreviations: ADL, Activities of Daily Living; CSDD, Cornell Scale for Depression in Dementia; MDS-ADL, Minimum Data Set – Activities of Daily Living; NH, nursing home; NR, not reported; RC/AL, residential care/assisted living; SCU, special care unit.

Table 7. Effect of organizational characteristics on morbidity

Author, Year Design	Interventions/ Exposures	New or Worsening Morbidity ^{a,b}	Stable Health ^c	Steady Decline in Health ^c	Series of Ups and Downs in Health ^c	One or More Skin Ulcers ^c
Sloane et al., 2005 ³⁵ Prospective Cohort	G1: RC/AL G2: NH	Mild dementia G1: 23.5 G2: 21.8 p=0.574	NR	NR	NR	NR
		Moderate to severe dementia G1: 21.1 G2: 21.7 p=0.865				
	G3: SCU in RC/AL G4: Non-SCU in RC/AL G5: SCU in NH G6: Non-SCU in NH	Any dementia G3: 26.7 G4: 25.3 G5: 15.0 G6: 22.0 G3 vs. G4: p=0.772 G5 vs. G6: p=0.043	NR	NR	NR	NR
Sloane et al., 2008 ⁴⁰ Prospective Cohort	G1: RC/AL G2: NH	NR	Any dementia, % G1: 12.6 G2: 8.1 p=0.136	Any dementia, % G1: 53.4 G2: 71.7 p=NR	Any dementia, % G1: 33.9 G2: 20.2 p<0.001	Any dementia, % G1: 26.9 G2: 22.6 p=0.566

^a Incidence rate per 100 participants per quarter.

^b New or worsening morbidity defined as the incidence or worsening of fracture, infection, stroke or paralysis, bleeding from the stomach or bowel, diabetes, heart condition, or skin ulcer

^c Health change in last 12 months of life

Abbreviations: NH = nursing home; NR = not reported; RC/AL = residential care/assisted living; SCU = special care unit.

Table 8. Effect of organizational characteristics comparing residential care/assisted living settings versus nursing homes on health outcomes: strength of evidence

Outcomes	Number of Studies; Number of Subjects	Risk of Bias; Design; Quality	Consistency	Directness	Precision	Results	Strength of Evidence
Change in ADL functioning	1; 1,252	Low; Prospective Cohort; Good	NA	Direct	Precise	Favors non-SCU vs. SCU in RC/AL	Low
Discomfort	1; 1,252	Low; Prospective Cohort; Good	NA	Direct	Precise	RC/AL vs. NH no difference	Low
Change in depressive symptoms	1; 1,252	Low; Prospective Cohort; Good	NA	Direct	Precise	RC/AL vs. NH and SCU vs. non-SCU no difference	Low
Cognitive impairment	1; 1,252	Low; Prospective Cohort; Good	NA	Direct	Precise	RC/AL vs. NH and SCU vs. non-SCU no difference	Low
Mortality	1; 1,252	Low; Prospective Cohort; Good	NA	Direct	Precise	RC/AL vs. NH and SCU vs. non-SCU no difference	Low
Hospitalization	1; 1,252	Low; Prospective Cohort; Good	NA	Direct	Precise	Favors NH vs. RC/AL; favors NH SCU vs. NH non-SCU	Low
Life-sustaining hospitalization in last month of life	1; 422	Low; Prospective Cohort; Good	NA	Direct	Imprecise	RC/AL vs. NH no difference	Insufficient ^a
New or worsening morbidity	1; 1,252	Low; Prospective Cohort; Good	NA	Direct	Precise	Favors NH SCU vs. NH non-SCU	Low
Stable health	1; 422	Low; Prospective Cohort; Good	NA	Direct	Imprecise	RC/AL vs. NH no difference	Insufficient ^a
Steady decline in health	1; 422	Low; Prospective Cohort; Good	NA	Direct	Imprecise	RC/AL vs. NH no difference	Insufficient ^a
Series of ups and downs in health	1; 422	Low; Prospective Cohort; Good	NA	Direct	Precise	Favors NH vs. RC/AL	Low

Table 8. Effect of organizational characteristics comparing residential care/assisted living settings versus nursing homes on health outcomes: strength of evidence (continued)

Outcomes	Number of Studies; Number of Subjects	Risk of Bias; Design; Quality	Consistency	Directness	Precision	Results	Strength of Evidence
One or more skin ulcers	1; 422	Low; Prospective Cohort; Good	NA	Direct	Imprecise	RC/AL vs .NH no difference	Insufficient ^a

^a No power calculations provided to justify sample size.

Abbreviations: ADL = activities of daily living; NA = not applicable; NH = nursing home; RC/AL = residential care/assisted living; SCU = special care unit.

Table 9. Effect of lighting interventions on depression and sleep quality

Author, Year	Design	Interventions	Depression ^a	Sleep Time	Awake Time
Dowling et al., 2005 ³¹	RCT	G1: Morning bright light exposure G2: Control - Usual indoor light levels	NR	Proportion of night asleep,% G1: 66.64 G2: 71.14 p=NR ^b	Night wake time, hours: minutes G1: 3:59 G2: 3:27 p=NR ^b
				Sleep time, hours: minutes G1: 7:59 G2: 8:32 p=NR ^b	Number of awakenings at night when asleep G1: 42.88 G2: 37.99 p=NR ^b
					Day wake time, hours: minutes G1 6:24 G2: 6.34 p=NR ^b
Hickman et al., 2007 ³²	RCT	G1: Morning bright light G2: Evening bright light G3: Standard light G4: All-day light	Subanalyses by men G1 vs.G3: 2.62, p=0.007 G2 vs.G3: 1.13, p=0.23 G4 vs.G3: 1.64, p=0.08 G1 vs.G2: 1.50, p= 0.16 G1 vs.G4: 0.98, p=0.33 G2 vs. G4: -0.52, p=0.60 Subanalyses by women G1 vs.G3: -1.61, p=0.09 G2 vs.G3: 0.09, p=0.94 G4 vs. G3: 1.41, p=0.16 G1 vs. G2: -1.70, p=0.08 G1 vs. G4: -3.02, p=0.01 G2 vs. G4: -1.32, p=0.24	NR	NR

^a Cornell Scale for Depression in Dementia (negative change scores mean less depressed).

^b Analysis of Variance was not significant.

Abbreviations: NR = not reported; RCT = randomized controlled trial.

The other intervention was conducted in a state-operated psychiatric hospital or a dementia-specific residential care setting in both the activity and dining areas of both sites.³²

These trials did not find an overall effect of either morning bright light on sleep³¹ or morning, evening, or all-day light on depression.³² One trial found that bright morning light improved the start of the sleep and wake cycles of those persons with aberrant cycle timing; it found no effect on residents with nonaberrant sleep/wake cycle timing. No other effects were found on persons with aberrant sleep/wake cycle timing. Subgroup analyses in the other trial found better depression scores for women for morning bright light compared with all-day light. Neither study assessed measures for functioning, discomfort, cognitive impairment, morbidity, mortality, or hospitalization.

Taken together, these studies provide insufficient SOE that lighting interventions improve sleep quality and depression (Table 10).

Table 10. Effect of lighting interventions on health outcomes: strength of evidence

Outcome	Number of Studies; Number of Subjects	Risk of Bias; Design/Quality	Consistency	Directness	Precision	Results	Strength of Evidence
Sleep Quality	1; 46	Medium; RCT; Fair	NA	Direct	Imprecise	No difference	Insufficient ^a
Depression	1; 155	Medium; RCT; Fair	NA	Direct	Imprecise	No difference	Insufficient ^a

^a No power calculations provided to justify sample size

Abbreviations: NA, not applicable; RCT, randomized controlled trial.

For KQ 5, one study on structures of care related to health outcomes for people with dementia differentiated findings by dementia severity or other characteristics of the person with dementia (insufficient SOE).³² This study found that the lighting intervention produced better depression outcomes for women exposed to morning bright light compared with all-day light but worse outcomes for men exposed to morning bright light compared with standard light.

Detailed Synthesis of Processes of Care

Six RCTs evaluated the effects of process of care interventions on five health outcomes. Four studies evaluated the effects of various group activity interventions on functioning, self-care, depression, and cognitive impairment.^{34, 39, 41, 42} Two studies assessed effects of personalized care interventions on discomfort.^{36, 37} The interventions in these studies were dissimilar so evidence on each intervention is graded separately. All trials were conducted in NHs, although one was conducted on a dementia SCU within a NH.³⁹

Group Activity Interventions

Four trials employed group activity interventions. Tappen⁴¹ used functional skill training to improve basic ADLs; Toseland et al.,⁴² used validation group therapy to improve self-care and depression (Table 11). Fritsch et al.³⁹ employed a storytelling intervention designed to improve cognition, while Rosswurm³⁴ sought to improve cognition through an attention-focusing intervention (Table 12).

Table 11. Effect of group activity interventions on ADL functioning, self-care, and depression

Author, Year	Interventions	ADL Goal Attainment ^a	ADL Test ^b	Self-care ^c	Depression ^c
Tappen, 1994 ⁴¹	G1: Functional Skill Training	Adjusted post-test means score	Within group mean change	NR	NR
RCT	G2: General Stimulation G3: Control Group	G1: 26.17 G2: 24.10 G3: 22.63 G1 vs. G3 p=0.01 G2 vs. G1 or G3: p=NS Mean achieved score G1: 1.75 G2: 1.43 G3: 1.10 G1 vs. G3, p=0.05 G2 vs. G1 or G3: p=NS	G1: -3.01 G2: -0.86 G3: +1.14 p=0.12		
Toseland et al., 1997 ⁴²	G1: Validation Group Therapy G2: Social Contact G3: Usual Care	NR	NR	Change at endpoint G1: 0.02 G2: -0.59 G3: -1.07	Change at endpoint G1: 1.45 G2: -2.56 G3: 0.6 p=NR, stated difference NS

^a Physical Self Maintenance Scale (higher scores show greater goal attainment)

^b Performance Test of Activities of Daily Living

^c Multidimensional Observation Scale for Elderly Subjects Self-care Subscale

Abbreviations: ADL = activities of daily living; NR = not reported; NS = not significant; RCT = randomized controlled trial.

Table 12. Effect of group activity interventions on cognitive impairment

Author, Year	Interventions	Cognitive Alertness ^a	Cognitive Improvement ^b	Cognitive Function ^b
Fritsch et al., 2009 ³⁹	G1: TimeSlips G2: Control	G1: 1512/1647 G2: 1111/1245 G1 vs. G2: 1.028 times greater number of general alertness events p<0.05	NR	NR
RCT				
Rosswurm, 1990 ³⁴	G1: Attention-focusing group G2: Control group	NR	Mean gain score at endpoint G1: 1.33 G2: -0.33 t value=1.36, NS	Mean gain score at endpoint G1: 0.33 G2: -0.33 t value=0.32, NS
RCT				

^a General Alertness Subscale

^b Mini Mental State Examination

Abbreviations: NR = not reported; NS = not significant; RCT = randomized controlled trial.

These four RCTs produced mixed results. A functional skills training intervention comprising repeated practice of five ADLs in a group setting 5 days per week for 2.5 hours per day over 20 weeks versus a control group provided usual nursing care produced a strong effect on both a scale measure of functional performance and a personal goal attainment measure.⁴¹ The effect size was reported to be the equivalent of moving from major to moderate or from

moderate to minor assistance in performing ADLs. A third group participating in recreationally oriented group activities in a therapeutic setting with the same intensity and performance period experienced no effect.

Another trial found a modest (approximately 3 percentage point) effect of a 10-week storytelling intervention designed to improve general alertness as a measure of cognitive impairment.³⁹ Residents were asked to comment on a picture, and staff then wove resident contributions into a story that was retold frequently. The intervention group was more alert in a larger proportion of events than the control group receiving usual care.

Two other interventions found no effect. An attention-focusing group using perceptual-matching exercises for 30 minutes three times weekly over 4 weeks produced no improvement on two measures of cognitive status.³⁴ A validation group therapy intervention versus a social interaction intervention for four 30-minute weekly sessions over 1 year versus usual care yielded no effect on measures of functioning and depression.⁴²

Half of the RCTs assessed yielded some benefits across a variety of outcomes (Table 13). For all interventions/exposures, we found no evidence for the following health outcomes: falls, discomfort, hospitalization, morbidity, mortality, and sleep quality. We found no evidence for depression except for validation group therapy, no evidence for functional decline except for functional skill training, and no evidence for cognitive impairment measures except for a storytelling intervention and an attention focusing intervention. We graded SOE for interventions that did not measure or report on the outcomes below as insufficient.

Table 13. Effect of processes of care on health outcomes: strength of evidence

Process of Care	Outcome	Number of Studies; Number of Subjects	Risk of Bias; Design/Quality	Consistency	Directness	Precision	Results	Strength of Evidence
Functional Skill Training	Goal Attainment	1; 63	Low; RCT; Fair	NA	Direct	Precise	Favors functional skill training	Low
	Activities of Daily Living	1; 63	Low; RCT; Fair	NA	Direct	Imprecise	No difference	Insufficient ^a
Validation Group Therapy	Self-Care	1; 63	Low; RCT; Fair	NA	Direct	Precise	No difference	Insufficient ^a
	Depression	1; 88	Medium; RCT; Fair	NA	Direct	Imprecise	No difference	Insufficient ^a
Storytelling Intervention	Cognitive Alertness	1; NR – 20 NHs	Medium; RCT; Fair	NA	Direct	Precise	Favors storytelling	Low
Attention-focusing Group	Cognitive Improvement	1; 30	Low; RCT; Good	NA	Direct	Imprecise	No difference	Insufficient ^a
	Cognitive Function	1; 30	Low; RCT; Good	NA	Direct	Imprecise	No difference	Insufficient ^a

^aNo power calculations provided to justify sample size.

Abbreviations: NA = not applicable; NH = nursing home, NR = not reported; RCT = randomized controlled trial

For KQ 5, none of the four studies on group activity interventions related to health outcomes for people with dementia differentiated findings by dementia severity or other characteristics of the person with dementia (insufficient SOE).

Personalized Care Interventions

Two trials designed to reduce discomfort were individualized to each resident (Table 14). Kovach et al.³⁷ provided assessment and treatment customized to each resident in the experimental group. Sloane et al.³⁶ used a patient-centered showering protocol for one intervention group and a towel bath protocol for a second intervention group.

Kovach et al.³⁷ evaluated a clinical protocol called the Serial Trial Intervention for assessment and management of unmet needs over a 4-week period designed to create a customized care plan for each resident. Intervention group members were compared with residents whose care staff received general instruction on how to care for all residents but not an individualized care plan for each resident. Residents receiving Serial Trial Intervention had 0.89 times lower discomfort score than the control group.

Sloane et al.³⁶ evaluated two different showering/bathing interventions to reduce discomfort. The first intervention employed person-centered showering using a wide variety of techniques to calm residents. The second intervention used a towel bath, which encloses and covers the resident while care staff use massage and a no-rinse soap to bathe the resident. A third group received non-person-centered showering. The towel bath and person-centered showering intervention reduced resident discomfort by 26 percent and 14 percent, respectively.

Table 14. Effect of personalized care interventions on discomfort

Author, Year, Design	Interventions	Change in Discomfort ^a
Kovach et al., 2006 ³⁷ RCT	G1: Serial Trial Intervention	Change at endpoint G1: 40.74
	G2: Control	G2: -39.53
		G1 vs. G2: p<0.001
Sloane et al., 2004 ³⁶ RCT	G1: Patient-centered showering	Change at endpoint G1: 0.32
	G2: Towel Bath	G2: 0.57
	G3: Showering without patient-centeredness	G3: -0.02
		G1 vs. G3: p<0.001 G2 vs. G3: p=0.001 G1 vs. G2: p=0.003

^a Modified Discomfort Scale for dementia of the Alzheimer type. Possible scores ranged from 0 to 900, with higher scores indicating more discomfort.

Abbreviations: RCT = randomized controlled trial; vs. = versus.

These two trials showed substantial improvements on measures of discomfort (Table 15; low SOE). We found no evidence for the following health outcomes: falls, functioning, pain, depression, hospitalization, morbidity, mortality, and sleep quality. We graded SOE for interventions that did not measure or report on these outcomes as insufficient.

Table 15. Effect of personalized care interventions on health outcomes: strength of evidence

Process of Care	Outcome	Number of Studies; Number of Subjects	Risk of Bias; Design/Quality	Consistency	Directness	Precision	Results	Strength of Evidence
Serial Trial Intervention	Change in Discomfort	1;114	Low; RCT; Good	NA	Direct	Precise	Favors STI	Low
Bathing	Change in Discomfort	1;73	Low; RCT; Fair	NA	Direct	Precise	Favors both showering and towel bath	Low

Abbreviations: NA = not applicable; RCT = randomized controlled trial; STI = Serial Trial Intervention.

For KQ 5, neither study using personalized care interventions differentiated findings by dementia severity or other characteristics of the person with dementia (insufficient SOE).

Key Question 2. Psychosocial Outcomes for People With Dementia

KQ 2 compares the effectiveness of organizational characteristics, structures, or processes of care in NHs and other residential long-term care settings for improving psychosocial outcomes for people with dementia. Psychosocial outcomes measured in at least one included study include behavioral symptoms (e.g., agitation, aggression), engagement (e.g., social function, withdrawal), affect other than depression (e.g., anxiety, pleasure), quality of life in Alzheimer’s disease, quality of dying, use of restraints, and use of psychoactive medications. Other psychosocial outcomes on which we sought but did not identify evidence from included studies were spiritual well-being, control, autonomy, choice, and satisfaction. We also assessed whether effects differed by dementia severity and other characteristics of the person with dementia.

Nine studies (five RCTs) addressed psychosocial outcomes, all showing some statistically significant effects on outcomes (low to moderate SOE). Only one study addressed whether effects differed by dementia severity (but not by other characteristics) and found no differences in behavioral symptoms or engagement based on residence in a NH versus RC/AL (low SOE).

Key Points of Organizational Characteristics

- Two studies found that, with one exception (restraint use), psychosocial outcomes did not differ between NHs and RC/AL settings.
 - Behavioral symptoms, engagement, quality of dying, quality of life, and psychoactive medication use did not differ by setting (insufficient and low SOE).
 - Restraints were used more often in imminently dying residents in NHs than in RC/AL settings (any restraints, 92 percent versus 66 percent; any restraints other than partial bedrails, 68 percent versus 46 percent; low SOE).
- One study found that quality of life did not differ based on proprietary status, chain affiliation, size, age, percentage of dementia beds, and resident case-mix (insufficient SOE).

- One study found that behavioral symptoms and engagement did not differ based on residence in an SCU (low SOE).

Key Points of Structures of Care

- Based on one study, with one exception, quality of life did not differ based on many structures of care.
 - Quality of life did not differ based on the following structures: registered nurse (RN), licensed practical nurse (LPN), and aide full-time equivalents (FTEs) and number of contract staff per type; administrator, RN, LPN, and aide turnover; environmental quality; consistent staffing; or use of universal workers (insufficient SOE).
 - Quality of life was statistically but not clinically better in settings that used specialized care workers (mean raw change over 6 months was 1.7 points worse when specialized workers were not used; low SOE).

Key Points of Processes of Care

- Group activity:
 - A creative expression storytelling group resulted in more challenging behaviors, anxiety, and sadness, and also less disengagement, neutral affect, and more engagement (low SOE).
 - A validation therapy group was superior to a social control and/or usual care control groups in regard to nurse-reported (but not observer reported) physically and verbally aggressive behavior at 1 year, and also resulted in more physically nonaggressive behaviors (low SOE). Validation therapy did not produce significant changes in engagement, irritability, restraint use, psychoactive medication use, or positive behaviors (insufficient SOE).
 - More frequent encouragement of activity participation resulted in statistically but not clinically better quality of life (mean raw change over 6 months was 0.9 times worse when activities were encouraged less than once a day; low SOE).
- Based on two studies, pleasant sensory stimulation produced a clinically significant decrease in agitation (75 percent to 83 percent compared with control in one study; moderate SOE).
- Protocols for individualized care:
 - Individualized assessment and management of discomfort and behavioral symptoms did not result in behavioral change but did increase return of behavior to baseline levels (70 percent versus 40 percent in the control group; low SOE).
 - Person-centered protocols for showering and bathing reduced behavioral symptoms (agitation and aggression) more in the intervention group than control group (mean time agitated or aggressive 24 percent and 26 percent in the intervention groups versus 36 percent in the control group; low SOE).
- In one study various processes of care (including policies and practices; staff involvement in care planning; assessments; treatment; use of medications; and use of stimuli such as craft or household items) did not improve quality of life (insufficient SOE).

Detailed Synthesis of Organizational Characteristics

Three prospective cohort studies examined organizational characteristics and their effect on psychosocial outcomes, comparing NHs to RC/AL.^{22, 35, 40} One study³⁵ (1,252 residents across 146 settings) differentiated 1-year outcomes by degree of dementia severity and residence on an SCU (Table 16);³⁵ it examined the effect of these organizational characteristics on behavioral symptoms and engagement, using standardized measures administered by interview to nursing staff. Another study, of 422 residents who died in 230 settings, investigated whether four components of the death experience (appeared to be at peace, received compassionate touch daily, maintained dignity, and had close attachment to staff) and the use of restraints and sedative medications differed by residence in a NH or RC/AL based on interviews with staff (Table 17).⁴⁰ The third study²² focused on change in quality of life over 6 months (Table 17), examining outcomes for 421 residents across 45 NHs and RC/AL settings using a standardized measure of quality of life in Alzheimer's disease administered to staff; it additionally examined proprietary status and chain affiliation in relation to change in quality of life.²²

With one exception for one outcome, none of the three studies found differences in outcomes (i.e., behavioral symptoms, engagement, quality of dying, quality of life, psychoactive medication use) according to residence in a NH or RC/AL (low and insufficient SOE; Table 18). However, use of restraints in imminently dying residents were more frequent in NHs than in RC/AL (any restraints used, 92 percent versus 66 percent; $p < 0.001$; any restraints other than partial bedrails, 68 percent versus 46 percent, $p = 0.031$; low SOE).⁴⁰

Quality of life over 6 months also did not differ by different types of RC/AL settings (smaller, traditional, new-model) or by other variables (not shown in Table 17 because no statistics were provided) including proprietary status, chain affiliation, size, age, percentage of dementia beds, and resident case-mix (insufficient SOE).²²

Behavior and engagement outcomes did not differ by residence on an SCU within a NH or RC/AL (low SOE).³⁵

Taken together, most residents' outcomes did not differ by organizational characteristics of settings, except for use of restraints (all insufficient or low SOE). Evidence about effects of organizational characteristics was insufficient on numerous other outcomes not included in the studies (e.g., affect, spiritual well-being, control, autonomy, choice, satisfaction).

For KQ 5, only one study³⁵ addressed whether effects differed by dementia severity (but not by other characteristics); it found no differences in behavioral symptoms or engagement based on residence in a NH versus RC/AL (low SOE).

Detailed Synthesis of Structures of Care

One prospective cohort study described above examined change in quality of life over 6 months for 421 residents across 45 NHs and RC/AL settings in relation to the following structures of care: FTEs for RN, LPN, and aides; number of contract staff per type; administrator, RN, LPN, and aide turnover; environmental quality; and use of universal and specialized workers (i.e., staff who fill specialized roles; Table 19).²²

The mean raw change in quality of life over 6 months was 1.7 points worse when specialized workers were not used (adjusted change $p < 0.05$; low SOE) (Tables 19 and 20),²² a difference not considered to be clinically significant.⁴³ Other than use of specialized workers, the structure of care variables and change in quality of life were not related, and because the authors did not provide the related data, this information is not shown in Table 19 (insufficient SOE). Also,

evidence about effects of structures of care was insufficient for numerous other outcomes not included in the studies (e.g., behavioral symptoms, engagement, affect, quality of dying, spiritual well-being, control, autonomy, choice, satisfaction, use of restraints, use of psychoactive medications).

For KQ 5, one study conducted of structures of care related to psychosocial outcomes for people with dementia did not differentiate findings by dementia severity or other characteristics of the person with dementia (insufficient SOE).

Detailed Synthesis of Processes of Care

Seven studies examined processes of care and their effect on psychosocial outcomes. Three studies related to group activity interventions, two studied pleasant sensory stimulation, and two studied individualized care. One of the seven additionally examined other processes of care.

Group Activity Interventions

Three studies examined group activity interventions. Two were RCTs that examined behavioral symptoms and engagement (Table 21). One trial (in dementia care units) employed a creative expression storytelling intervention;³⁹ the other trial examined the effects of validation group therapy in NHs compared with a social contact comparison group and a usual care group.⁴² In the first trial, research staff coded outcomes for 2,088 10-minute observations of staff-resident interactions. In the second, behavior was assessed through a standardized measure completed by blinded nursing staff and nonparticipant observers (the Cohen-Mansfield Agitation Inventory-Nursing Staff Derived [CMAI-N] and the Cohen-Mansfield Agitation Inventory-Observer Derived [CMAI-O]), respectively, in Table 21), and engagement was assessed through interviews with nursing staff using a standardized measure.

These two RCTs also examined results related to affect (Table 22). One used observations coded according to an established affect rating scale,³⁹ and the other used nurse interview with a standardized measure.⁴² The latter trial additionally examined restraint and psychoactive medication use.

Finally, one prospective cohort study examined the extent to which encouraging participation in activities related to quality of life.²² It also investigated numerous other processes of care, including policies and practices, professional and paraprofessional involvement in care planning, assessments conducted (professional or standardized), treatment provided (professional or informal), use of antipsychotic or sedative hypnotic medications, and use of stimuli such as craft or household items.

The creative expression group activity³⁹ resulted in more challenging behaviors (9 versus 1 event in more than 1,000 observations per group; $p=0.034$), anxiety (39 versus 11 events; $p=0.002$), and sadness (7 versus 0 events; $p=0.021$);³⁹ it also produced less disengagement (68 versus 107 events; $p<0.001$); more engagement (1,400 versus 1,007 events, $p=0.003$), and less neutral affect (30 versus 75 events; $p<0.001$) (low SOE) (Table 23). Effects related to nonsocial engagement, anger, or pleasure were not statistically significant.

A validation therapy group⁴² was superior to the social control and/or usual care in regard to blinded nurse report of physically aggressive behavior ($p<0.001$) and verbally aggressive behavior ($p<0.01$) at 1 year, but it resulted in more physically nonaggressive behaviors ($p=0.034$)

Table 16. Effect of organizational characteristics on behavioral symptoms and engagement

Author, Year, Design	Interventions/ Exposures	CMAI Mild Dementia ^a	CMAI Moderate or Severe Dementia ^a	CMAI ^a	Decrease in Social Function Mild Dementia ^a	Decrease in Social Function Moderate or Severe Dementia ^a	Decrease in Social Function ^a	MOSES Increased Withdrawal from Activities Mild Dementia ^a	MOSES Increased Withdrawal from Activities Moderate or Severe Dementia ^a	MOSES Increased Withdrawal from Activities ^a
Sloane et al., 2005 ³⁵ Prospective Cohort	G1: RC/AL	G1: 1.08	G1: 1.72	G3: -1.53	G1: 1.55	G1: 0.91	G3: 1.58	G1: 2.84	G1: 2.55	G3: 3.48
	G2: NH	G2: 0.69	G2: 1.49	G4: -1.14	G2: 1.76	G2: 1.44	G4: 1.34	G2: 2.24	G2: 1.78	G4: 2.58
	G3: SCU in RC/AL	p=0.604	p=0.809	p=0.763	p=0.568	p=0.110	p=0.681	p=0.364	p=0.307	p=0.409
	G4: Non-SCU in RC/AL			G5: -2.18			G5: 1.88			G5: 2.22
	G5: SCU in NH			G6: -0.72			G6: 1.46			G6: 1.77
	G6: Non-SCU in NH			p=0.168			p=0.303			p=0.604

^a Outcomes are adjusted for baseline age, gender, race, education, marital status, length of stay, cognition, and number of comorbid conditions

Abbreviations: CMAI = Cohen-Mansfield Agitation Inventory; MOSES = Multidimensional Observation Scale for Elderly Subjects; NH = nursing home; RC/AL = residential care/assisted living; SCU = special care unit

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Table 17. Effect of organizational characteristics on quality of dying, quality of life, restraint use, and psychoactive medication use

Author, Year, Design	Interventions/ Exposures	Appeared to be at Peace ^a	Received Compassionate Touch Daily ^a	Dignity Maintained ^a	One Staff Had Close Attachment to Resident ^a	QOL-AD Adjusted Change	Any Restraints Used	Any Restraints Other Than Partial Bed Rails	Sedative Used Frequently	Sedative Used at Least Sometime
Sloane et al., 2008 ⁴⁰	G1: RC/AL	G1: 70.1%	G1: 96.6%	G1: 90.2%	G1: 82.8%	NR	G1: 65.7%	G1: 46.3%	G1: 21.0%	G1: 29.9%
	G2: NH	G2: 64.2%	G2: 95.1%	G2: 89.4%	G2: 72.1%		G2: 91.5%	G2: 67.6%	G2: 29.2%	G2: 37.3%
Prospective Cohort		p=0.304	p=0.399	p=0.847	p=0.528		p<0.001	p=0.031	p=0.592	p=0.792
Zimmerman et al., 2005 ²²	G1: RC/AL: <16 Beds G2: RC/AL traditional: ≥ 16 beds G3: RC/AL new model: ≥ 16 beds G4: NH	NR	NR	NR	NR	G1: +0.54 G2: +0.48 G3: -0.38 G4: -0.18 p=0.206	NR	NR	NR	NR

^a The outcome is a variable related to quality of dying during the last month of life.

Abbreviations: NH = nursing home; NR = not reported; QOL-AD = Quality of Life in Alzheimer's disease; RC/AL = residential care/assisted living.

Table 18. Effect of organizational characteristics on psychosocial outcomes: strength of evidence

Outcomes	Number of Studies; Number of Subjects	Risk of Bias; Design/ Quality	Consistency	Directness	Precision	Results	Strength of Evidence
Behavioral Symptoms	1; 1,252	Low; Prospective Cohort; Good	NA	Direct	Precise	RC/AL vs. NH no difference SCU vs. non-SCU no difference	Low
Engagement	1; 1,252	Low; Prospective Cohort; Good	NA	Direct	Precise	RC/AL vs. NH no difference SCU vs. non-SCU no difference	Low
Quality of Dying	1; 422	Low; Prospective Cohort; Good	NA	Direct	Imprecise	RC/AL vs. NH no difference	Insufficient ^a
Quality of Life	1; 421	Low; Prospective Cohort; Fair	NA	Direct	Imprecise	RC/AL vs. NH no difference	Insufficient ^a
Restraint Use (before death)	1; 422	Low; Prospective Cohort; Good	NA	Direct	Precise	Favors RC/AL vs. NH	Low
Psychoactive Medication Use	1; 422	Low; Prospective Cohort; Good	NA	Direct	Imprecise	RC/AL vs. NH no difference	Insufficient ^a

^a No power calculations provided to justify sample size.

Abbreviations: NA = not applicable; NH = Nursing Home; RC/AL = residential care/assisted living; SCU = special care unit.

Table 19. Effect of structures of care on quality of life

Author, Year	Design	Interventions	QOL-AD Mean raw change
Zimmerman et al., 2005 ²²	Prospective Cohort	G5: Use specialized workers (staff fill specialized roles) G6: No use of specialized workers	G5: -1.3 G6: -3.0 p=0.036

Abbreviations: QOL-AD = Quality of Life in Alzheimer's Disease.

Table 20. Effect of structures of care on psychosocial outcomes: strength of evidence

Outcomes	Number of Studies; Number of Subjects	Risk of Bias; Design/ Quality	Consistency	Directness	Precision	Results	Strength of Evidence
Quality of Life	1; 421	Medium; Prospective Cohort; Fair	NA	Direct	Precise	Favors specialized workers vs. not	Low

Abbreviations: NA = not applicable

Table 21. Effect of group activity interventions on behavioral symptoms and engagement

Author, Year, Design	Interventions	Challenging Behaviors # of Observations	CMAI-N	CMAI-O	Types of Engagement # of Observations	MOSES Withdrawal Subscale
Fritsch et al., 2009 ³⁹	G1: TimeSlips G2: Control	G1: 9/1,651 G2: 1/1,250 6.80 times more for G1 p=0.034	NR	NR	Disengaged G1: 68/1,651 G2:107/1,250 0.481 times less disengaged for G1 p<0.001 Nonsocial engagement G1: 174/1,651 G2:135/1,250 0.976 times less nonsocial engagement for G1 p=0.822 Engagement G1: 1,400/1,651 G2:1,007/1,250 1.053 times more engaged for G1 p=0.003	NR

Table 21. Effect of group activity interventions on behavioral symptoms and engagement (continued)

Author, Year, Design	Interventions	Challenging Behaviors # of Observations	CMAI-N	CMAI-O	Types of Engagement # of Observations	MOSES Withdrawal Subscale
Toseland et al., 1997 ⁴²	G1: Validation Group Therapy G2: Social Contact Group G3: Usual Care	NR	Physically Aggressive Behavior $\chi^2=14.90$ $p=0.001$ G1 vs. G2 and G3 showed significant reduction in physically aggressive behaviors	Physically Aggressive Behavior $\chi^2=1.41$ $p=0.590$	NR	Baseline^a G1: 14.05 G2: 13.05 G3: 14.43
RCT			Verbally Aggressive Behavior $\chi^2=5.88$ $p=0.053$ G1 and G2 vs. G3 showed significant reduction in verbally aggressive behaviors	Verbally Aggressive Behavior $\chi^2=12.46$ $p=0.002$ G2 vs. G1 and G3 showed significantly lower scores in verbally aggressive behaviors		Endpoint G1: 13.95 G2: 13.67 G3: 14.91
			Physically Nonaggressive Behaviors $\chi^2=6.76$ $p=0.034$ G2 and G3 reduced	Physically Nonaggressive Behaviors $\chi^2 =1.52$ $p=0.47$		

^a No effect by Condition X Time

Note: Toseland, 1997⁴² found among the Geriatric Indices of Positive Behavior— no significant changes in positive social interactions with family, staff, or other residents.

Abbreviations: CMAI-N = Nurse-derived Cohen-Mansfield Agitation Inventory; CMAI-O = Observer-derived Cohen-Mansfield Agitation Inventory score; MOSES = Multidimensional Observation Scale for Elderly Subjects; NR = not reported; RCT = randomized controlled trial; χ^2 = chi-square statistic.

Table 22. Effect of group activity interventions on affect, quality of life, restraint use and psychoactive medication use

Author, Year, Design	Interventions	PGCARS Other Subscale (Neutral Affect)	PGCARS Anxiety Subscale # of Observations	PGCARS Anger Subscale # of Observations	PGCARS Sadness Subscale # of Observations	PGCARS Pleasure Subscale # of Observations	MOSES Irritability Subscale	QOL-AD Mean raw change	Restraint Use	Psychoactive Medication Use
Fritsch et al., 2009 ³⁹	G1:Time-Slips G2: Control	G1: 30/1,647 G2: 75/1,245 0.302 times less neutral for G1 p=0.001	G1: 39/1,647 G2: 11/1,245 2.68 times more events for G1 p=0.002	G1: 6/1,647 G2: 1/1,245 4.54 times more events for G1 p=0.124	G1: 7/1,647 G2: 0/1,245 >7 times more events for G1 p=0.021	G1: 54/1,647 G2: 47/1,245 0.869 times less pleasure for G1 p=0.472	NR	NR	NR	NR
Toseland et al., 1997 ⁴²	G1: Validation Group G2: Social Contact Group G3: Usual Care	NR	NR	NR	NR	NR	Baseline ^a G1: 5.36 G2: 5.64 G3:5.22 Endpoint G1: 4.81 G2: 6.10 G3: 5.36	NR	No significant changes in frequency of restraint use in the three groups.	No significant differences in the three groups with regard to use of antipsychotic, antianxiety, or antidepressant medications
Zimmerman et al., 2005 ²²	G7: Encourage activities ≥ once a day G8: Encourage activities <once a day	NR	NR	NR	NR	NR	NR	G1: -1.9 G2: -2.6 p=0.043	NR	NR

^aNo effect by condition X time

Abbreviations: MOSES = Multidimensional Observation Scale for Elderly Subjects; NR = not reported; PGCARS = Philadelphia Geriatric Center Affect Rating Scale; QOL-AD = Quality of Life in Alzheimer’s Disease; RCT = randomized controlled trial.

Table 23. Effect of group activity interventions on psychosocial outcomes: strength of evidence

Process of Care	Outcomes	Number of Studies; Number of Subjects	Risk of Bias; Design/Quality	Consistency	Directness	Precision	Results	Strength of Evidence
Creative Expression Storytelling Intervention	Behavioral Symptoms	1; NR	Medium; RCT; Fair	NA	Direct	Precise	Favors control vs. storytelling	Low
	Engagement	1; NR	Medium; RCT; Fair	NA	Direct	Precise	Favors storytelling vs. control for engagement Storytelling vs. control no difference for nonsocial engagement	Low
	Affect	1; NR	Medium; RCT; Fair	NA	Direct	Precise	Favors control vs. storytelling for anxiety and sadness; Storytelling vs. control no difference for anger or pleasure	Low
Validation Group Therapy	Behavioral Symptoms	1; 88	Medium; RCT; Fair	NA	Direct	Precise	Nurse rating: Favors validation vs. control for physical and verbal aggression; favors control vs. validation for physical nonaggression Observer rating: Favors comparison vs. validation for verbal aggression; validation vs. control no difference for physical aggression or physical nonaggression	Low
	Engagement	1; 88	Medium; RCT; Fair	NA	Direct	Imprecise	Validation vs. control no difference	Insufficient ^a
	Affect	1; 88	Medium; RCT; Fair	NA	Direct	Imprecise	Validation vs. control no difference	Insufficient ^a
	Restraint Use	1; 88	Medium; RCT; Fair	NA	Direct	Imprecise	Validation vs. control no difference	Insufficient ^a
	Psychoactive Medication Use	1; 88	Medium; RCT; Fair	NA	Direct	Imprecise	Validation vs. control no difference	Insufficient ^a
Encouragement of Activities	Quality of Life	1; 421	Medium; Prospective Cohort; Fair	NA	Direct	Precise	Favors encouragement vs. not	Low

^a No power calculations provided to justify sample size.

Abbreviations: NA = not applicable; NR = not reported; RCT = randomized controlled trial; vs. = versus.

(low SOE; Table 23).⁴² Blinded observers did not favor validation therapy, and rated social contact as superior in relation to verbally aggressive behavior. Validation group therapy did not produce significant changes in engagement or positive social interactions, irritability, restraint use, or psychoactive medication use (insufficient SOE).

In the prospective cohort study, the mean raw change in quality of life over 6 months was 0.9 points worse when activities were encouraged less than once a day ($p=.043$; adjusted change $p<0.05$)²² (low SOE), a difference not considered to be clinically significant.⁴³ No other processes of care (policies and practices, staff involvement in care planning, assessments, treatment, medications, and use of stimuli) had a statistically significant relationship to change in quality of life (data not reported by authors and so not included in Table 22).

These studies indicate that group activity interventions may have both positive and negative effects on psychosocial outcomes (low SOE). Evidence about effects of group activity interventions was insufficient on numerous other outcomes not included in the studies (e.g., spiritual well-being, control, autonomy, choice, quality of dying, or satisfaction).

For KQ 5, the three studies of group activity interventions related to psychosocial outcomes for people with dementia did not differentiate findings by dementia severity or other characteristics of the person with dementia (insufficient SOE).

Pleasant Sensory Stimulation Interventions

Two studies were related to the use of pleasant sensory stimulation to reduce agitation and aggression in NH residents who displayed agitated behavior (Table 24). One RCT compared outcomes of calm music, hand massage, and a combination of the two with those of a control group in terms of agitated behavior displayed over 1 hour.³³ The other, a nonrandomized controlled trial, administered pleasant sensory stimulation during shower-bath time and measured agitation over 1 and 2 weeks (i.e., time one and time two).³⁸ Both sets of investigators measured agitation using an existing observational instrument completed by research staff.

Table 24. Effect of pleasant sensory stimulation interventions on behavioral symptoms

Author, Year, Design	Interventions	CMAI–Agitation (Mean Difference in Score)	CMAI–Aggression
Remington, 2002 ³³ RCT	G1: Calm Music G2: Hand Massage G3: Calm Music and Hand Massage G4: Control	G1: 13.76 (75% change) ^a G2: 13.41 (81% change) ^a G3: 18.24 (83% change) ^a G4: 1.29 (0.06% change) ^a $p<0.01$ ^b	Physically aggressive behaviors: G1: NR G2: NR G3: NR G4: NR $p=0.09$ ^c
Whall et al., 1997 ³⁸ Non-RCT	G1: Pleasant Sensory Stimulation Shower Room G2: Usual Care	Mean baseline to time two: -6.73 ^d $p<0.004$	Mean baseline to time two: -1.47 $p<0.19$

^a These are measures of the within-group mean reduction in score. Mean baseline scores: G1: 18.41; G2: 16.47; G3: 22.00; G4: 21.76

^b Repeated measures analysis of variance yielded significant difference among the four groups.

^c Repeated measures ANOVA yielded no significant differences in physically aggressive behavior among the four groups.

^d T-test mean difference scores between G1 and G2

Abbreviations: CMAI, Cohen-Mansfield Agitation Inventory; NR, not reported; RCT, randomized controlled trial.

Both pleasant sensory stimulation interventions resulted in a decrease in agitation. Specifically, the study of music and hand massage found a decrease in agitation 1 hour after the intervention to be between 12.12 points (hand massage) and 16.95 (music plus hand massage) greater than the control group ($p < 0.01$),³³ compared with their own baseline values, the decrease in agitation for the three intervention groups ranged from 75 percent to 83 percent. The pleasant sensory stimulation during the shower-bath found a decrease in agitation over 2 weeks to be 6.73 points greater in the intervention group.³⁸ Because a 30 percent reduction in agitation has been determined to be of clinical significance,⁴⁴ we graded the SOE that pleasant sensory stimulation interventions may reduce agitation as moderate (Table 25).

Table 25. Effect of pleasant sensory stimulation interventions on psychosocial outcomes: strength of evidence

Outcome	Number of Studies; Number of Subjects	Risk of Bias; Design/Quality	Consistency	Directness	Precision	Results	Strength of Evidence
Behavioral Symptoms: Agitation	2;99	Medium; One RCT, one non-RCT; both fair	Consistent	Direct	Precise	Favors stimulation vs. control	Moderate
Behavioral Symptoms: Aggression	2;99	Medium; One RCT, one non-RCT; both fair	Consistent	Direct	Imprecise	Stimulation vs. control no difference	Insufficient ^a

^a No power calculations provided to justify sample size.

Abbreviations: RCT = randomized controlled trial; vs. = versus.

Neither of the pleasant sensory stimulation interventions resulted in a statistically significant decrease in physical aggression (insufficient SOE). The authors of both studies commented that the lack of significance was likely the result of either measurement error or low levels of aggressive behaviors overall. Also, evidence about effects of pleasant sensory stimulation was insufficient on numerous other outcomes not included in the studies (e.g., engagement, affect, quality of life, quality of dying, spiritual well-being, control, autonomy, choice, satisfaction, use of restraints, use of psychoactive medications).

For KQ 5, the two studies of pleasant sensory stimulation related to psychosocial outcomes for people with dementia did not differentiate findings by dementia severity or other characteristics of the person with dementia (insufficient SOE). One study commented on the distribution of residents by level of dementia (mild, 4 percent; moderate, 43 percent; severe, 53 percent); the other noted that all residents had late-stage Alzheimer’s disease or Alzheimer’s disease with multi-infarct dementia.

Protocols for Individualized Care Interventions

Two trials tested protocols for individualized care (Table 26). One focused on assessment and management of discomfort and behavioral symptoms for NH residents with late-stage dementia; staff used a standardized scale of behavioral symptoms at baseline and over 4 weeks and also recorded return of behavioral symptoms to baseline by marking a visual analog scale.³⁷ The other trial focused on agitation and aggression during bathing for NH residents with moderate or severe cognitive impairment who demonstrated these types of behaviors during bathing.³⁶ Research staff masked to the intervention coded behavioral observations 2 weeks after the intervention and noted the percentage of time residents displayed agitation or aggression using a coding tool (the Care Recipient Behavior Assessment) based on the CMAI.³⁶

Table 26. Effect of protocols for individualized care interventions on behavioral symptoms

Author, Year Design	Interventions	BEHAVE-AD (Within-Group Mean Change) ^a	Return of Behavior to Baseline: Number of Subjects (%)	CAREBA (Endpoint Scores, Percent Time)
Kovach et al., 2006 ³⁷	G1: Serial Trial Intervention G2: Control	G1: 2.75 G2: 1.84 p=0.50 ^b	G1: 40/57 (70%) G2: 23/57 (40%) p=0.002	NR
RCT				
Sloane et al., 2004 ³⁶	G1: Person-Centered Showering G2: Towel Bath G3: Control	NR	NR	G1: 25.84 G2: 23.51 G3: 35.65 G1 vs.G3: p=0.02 G2 vs.G3: p=0.01 G1 vs.G2 Change from Baseline: p=0.4
RCT				

^a Baseline scores were as follows, G1:7.43, G2:6.80

^b Measures the Time X Group Interaction

Abbreviations: BEHAVE-AD = Behavioral Pathology in Alzheimer’s Disease Rating Scale; CAREBA = Care Recipient Behavior Assessment; NR = not reported; RCT = randomized controlled trial.

The trial that individualized assessment and management of discomfort and behavioral symptoms found no change in behaviors compared with those for the control group using the standardized measure of behavioral symptoms, but found a significant difference in return of behavior to baseline levels for residents in the intervention group (70% versus 40% in the control group; p=0.002) (low SOE; Table 27).³⁷

Table 27. Effect of protocols for individualized care interventions on psychosocial outcomes: strength of evidence

Process of Care	Outcome	Number of Studies; Number of Subjects	Risk of Bias; Design/ Quality	Consistency	Directness	Precision	Results	Strength of Evidence
Serial Trial Intervention	Behavioral Symptoms	1;114	Medium; RCT; Good	NA	Direct	Precise	Individualized care vs. control no difference	Low
	Behavioral Symptoms: Return to Baseline	1;114	Medium; RCT; Good	NA	Direct	Precise	Favors individualized care vs. control	Low
Bathing	Behavioral Symptoms	1;73	Medium; RCT: Fair	NA	Direct	Precise	Favors individualized care vs. control	Low

Abbreviations: NA = not applicable; RCT = randomized controlled trial.

The trial of protocols for showering and bathing found a significant reduction in overall agitation and aggression for both groups compared with outcomes in the control group condition (mean time agitated or aggressive 24 to 26 percent in the intervention groups compared with 36 percent in the control group; p=0.01 and p=0.02, respectively; low SOE).³⁶

Evidence about effects of protocols for individualized care interventions was insufficient on numerous other outcomes not included in the studies (e.g., engagement, affect, quality of life, quality of dying, spiritual well-being, control, autonomy, choice, satisfaction, use of restraints, use of psychoactive medications).

For KQ 5, the two studies of protocols for individualized care related to psychosocial outcomes for people with dementia did not differentiate findings by dementia severity or other characteristics of the person with dementia (insufficient SOE).

Key Question 3. Health Outcomes for Informal Caregivers of People With Dementia

No studies met inclusion criteria for KQ 3 about the impact of organizational characteristics, structures of care, or processes of care on caregiver health outcomes.

Key Question 4. Psychosocial Outcomes for Informal Caregivers of People With Dementia

No studies met inclusion criteria for KQ 4 about the impact of organizational characteristics, structures of care, or processes of care on caregiver psychosocial outcomes.

Key Question 5. Dementia Severity and Other Characteristics of the Person With Dementia

Key Question 5 concerned whether the effect of organizational characteristics, structures, or processes of care on health and psychosocial outcomes varied by the characteristics of the person with dementia (e.g., severity of dementia, functional status) or of the informal caregiver (e.g., age, relationship, health status); we report on relevant KQ 5 studies in the context of KQs 1 to 4.

Discussion

This report addressed a question commonly posed when an older adult with dementia requires long-term care beyond what can be provided by the family: What is the best care setting for an older adult with dementia who can no longer be managed at home? Numerous options are available when this need arises, including traditional nursing homes (NHs), specific models of NHs (e.g., Green House homes), and residential care/assisted living (RC/AL). Because these options differ considerably in various attributes (e.g., settings are of different sizes, have different policies, and offer different services), we assembled and reviewed evidence on specific components of the organizational structure and care and their effects on a range of outcomes for residents who live in such settings. We sought similar information about the effects of interventions on informal caregivers (i.e., family members of long-term care residents), but we identified no eligible studies.

We broadly defined the scope of our review to include all organizational characteristics, structures, and processes of care as they exist in the United States; the substantial differences in health care systems and approaches to long-term care in other countries make studies from other countries less applicable to the United States. Also, we focused on articles published after 1990 to reflect the changing nature and evolution of NH and other residential long-term care settings, especially after the Omnibus Budget Reconciliation Act (OBRA) of 1987 (Public Law 100-203), which established new regulatory standards for NH care (http://www.access.gpo.gov/nara/cfr/waisidx_02/42cfr483_02.html).

Our review focused on four key questions (KQs), differentiated by two types of outcomes relevant to people with dementia and their informal caregivers: health outcomes (KQ 1 and KQ 3, respectively) and psychosocial outcomes (KQ 2 and KQ 4, respectively). We also examined the extent to which outcomes differed according to dementia severity and other characteristics of the person with dementia (KQ 5); these findings are subsumed under KQ 1 and KQ 2.

Below we summarize the main findings and strength of evidence (SOE) for each KQ. In the summary section that follows, we first present findings on outcomes by specific organizational characteristics, structures of care, or processes of care that the included studies had examined.

Key Findings and Strength of Evidence: Outcomes

Key Question 1: Health Outcomes for People With Dementia

Ten studies examined organizational characteristics (two prospective cohort studies), structures of care (two randomized controlled trials [RCTs]), or processes of care (six RCTs) related to health outcomes for people with dementia. Table 28 presents key findings and the related SOE grades. Across these 10 studies, the health outcomes assessed included functional impairment or decline (including self-care/maintenance), cognitive impairment or decline, depression and depressive symptoms, pain or discomfort, sleep quality, morbidities (e.g., skin ulcers), hospitalization, and mortality. SOE grades are given for all major outcomes and comparisons. For many outcomes such as falls, no evidence was available at all, so SOE was insufficient (these are not noted in the table).

Table 28. Strength of evidence for the effect of organizational characteristics, structures, or processes of care for people with dementia on health outcomes

Outcome	Summary of Results	Strength of Evidence
Functional impairment/decline (including self-care/maintenance)	Functional impairment/decline was worse in RC/AL settings for residents living in a dementia SCU (1 study; 1,252 subjects). Function was clinically significantly better (equivalent to moving from major to moderate or moderate to minor need for assistance) after functional skill training (1 study; 63 subjects).	Low
Cognitive impairment/decline	Alertness was modestly better (3 percentage points) after creative expression storytelling (1 study; number of subjects not reported).	Low
Depressive symptoms	Depression/depressive symptoms were better for women but worse for men after a bright morning light intervention (1 study; 155 subjects).	Low
Pain/discomfort	Pain/discomfort was better after individualized assessment and management of discomfort (1 study; 114 subjects) and person-centered protocols for showering and bathing (1 study; 73 subjects).	Low
Sleep quality	Sleep quality was better for only those with aberrant sleep cycle timing following morning bright light (1 study; 46 subjects).	Low
New/worsening morbidity and various discrete measures	Morbidity across multiple measures differed little in RC/AL settings compared with NHs, but was lower in SCUs than in non-SCUs in NHs (1 study; 1,252 subjects).	Low
Hospitalization	Hospitalization occurred more often for residents with mild dementia living in RC/AL settings than for residents in NHs (1 study; 1,252 subjects). Hospitalization occurred more often for NH residents (but not RC/AL residents) not living in dementia SCUs (1 study; 1,252 subjects).	Low
Mortality	Evidence did not support a difference based on residence in a NH vs. RC/AL setting or in an SCU vs. non-SCU (1 study; 1,252 subjects).	Low

Note: No study examined the outcomes of falls (insufficient SOE). Not all of the outcome categories in this table were examined in every one of the 10 studies. Only findings with low or better SOE are reported.

Abbreviations: NH = nursing home; RC/AL = residential care/assisted living; SCU = special care unit.

Regarding organizational characteristics reviewed, NHs and RC/AL differed little on a range of health outcomes (insufficient or low SOE). Residents with mild dementia in RC/AL, when compared with NHs, had moderately higher hospitalization rates (low SOE) but little difference in morbidity rates regardless of dementia level (low to insufficient SOE). Evidence on SCUs within these settings was inconsistent. Residents of SCUs in RC/AL, when compared with non-SCUs in those settings, had a modestly greater decline in functioning over time (low SOE). On the other hand, residents of dementia SCUs in NHs, when compared with non-SCUs in those settings, had moderately lower rates of both hospitalization and new or worsening morbidity (low SOE).

Only two studies focused on structures of care, finding no effect in the overall populations studied for lighting interventions on sleep quality (insufficient SOE) and depression (insufficient SOE). Both studies found benefits for certain subgroups (women for depression and those with aberrant sleep cycle timing for sleep quality) (insufficient SOE). Therefore, lighting interventions may have more benefit on a person-by-person level as opposed to being a structural intervention throughout a setting.

Regarding processes of care, evidence for group activity interventions was mixed. A functional skills training intervention produced moderate effect sizes for improving activities of daily living (ADLs), with effect sizes being equivalent to moving from major to moderate or from moderate to minor assistance in performing ADLs (low SOE). A storytelling intervention modestly improved cognitive alertness (low SOE). An intervention involving validation therapy

groups did not improve functional self-care or depression, and an attention focusing intervention did not improve cognitive impairment or dementia behavior. A personalized assessment and treatment intervention moderately reduced resident discomfort. Finally, personalized showering and towel bath interventions reduced resident discomfort.

Key Question 2: Psychosocial Outcomes for People With Dementia

Nine studies examined organizational characteristics (three prospective cohort studies), structures of care (one prospective cohort study), and/or processes of care (five RCTs, one non-RCT, and one prospective cohort study) related to psychosocial outcomes for people with dementia. Table 29 presents key findings and the related SOE grades. Across these nine studies, the psychosocial outcomes assessed included behavioral symptoms (e.g., agitation, aggression), engagement (e.g., social function, withdrawal), affect other than depression (e.g., anxiety, pleasure), quality of life in Alzheimer’s disease, quality of dying, use of restraints, and use of psychoactive medications. SOE grades are given for all major outcomes and comparisons. For many outcomes such as spiritual well-being, control, autonomy, choice, or satisfaction, no evidence was available at all, so the strength of evidence was insufficient (these are not noted in the table).

Table 29. Strength of evidence for the effect of organizational characteristics, structures, or processes of care for people with dementia on psychosocial outcomes

Outcome	Summary of Results	Strength of Evidence
Behavioral symptoms	Behavioral symptoms were worse after creative expression storytelling (1 study; number of subjects not reported).	Low
	Physical and verbal aggression were better, and physical nonaggression was worse, after validation therapy (based on nurse report). Verbal aggression was worse after validation therapy (based on observer report) (1 study; 88 subjects).	Moderate
	Agitation was clinically significantly better after pleasant sensory stimulation (2 studies; 99 subjects; decreased 75% to 83% in one study).	Low
	Behavioral symptoms were better after individualized assessment and management of behavioral symptoms (70% vs. 40% return to baseline) (1 study; 114 subjects). Agitation and aggression were better after person-centered protocols for showering and bathing (mean time agitated/aggressive 24% to 26% vs. 36% for control group) (1 study; 73 subjects).	Low
Affect	Anxiety and sadness were worse after creative expression storytelling (1 study; number of subjects not reported).	Low
Engagement	Engagement was better after creative expression storytelling (1 study; number of subjects not reported).	Low
Quality of life	Quality of life over 6 months was statistically but not clinically significantly better when specialized workers were used and activities were encouraged (1 study; 421 subjects).	Low
Quality of dying	Evidence did not support a difference based on residence in a NH vs. RC/AL setting (1 study; 422 subjects).	Insufficient
Psychoactive medication use	Evidence did not support a difference based on residence in a NH vs. RC/AL setting or after validation therapy (1 study; 422 subjects).	Insufficient
Restraint use	Restraint use in imminently dying residents occurred more often in NHs than in RC/AL settings (66% vs. 92%) (1 study; 422 subjects).	Low

Note: No study examined the outcomes of spiritual well-being, control, autonomy, choice, or satisfaction (insufficient SOE). Not all of the outcome categories in this table were examined in every one of the nine studies. Except where indicated, only findings with low or better SOE are reported.

Abbreviations: NH = nursing home; RC/AL = residential care/assisted living; vs., versus.

Regarding organizational characteristics, NHs and RC/AL differed little on a range of psychosocial outcomes including behavioral symptoms, engagement, quality of dying, quality of life, and psychoactive medication use (insufficient or low SOE). Restraints were used more often in imminently dying residents in NHs than in RC/AL (low SOE). The authors suggested additional study of this finding considering that the use of physical restraints in NHs has been strongly discouraged following the Nursing Home Reform Act of 1987 and there is evidence that overall use of restraints is low.⁴⁰ Behavioral symptoms and engagement did not differ based on residence in an SCU (low SOE).

Regarding structures of care, quality of life did not differ based on many structures (insufficient SOE), but was statistically but not clinically significantly better when specialized workers were used (low SOE).

Regarding processes of care, evidence for group activity interventions was again mixed. A storytelling intervention resulted in more challenging behaviors, anxiety, and sadness, and also more engagement (low SOE). An intervention involving validation therapy groups resulted in less physical and verbal aggression, and also more physical nonaggression, although these findings were not consistent across raters (low SOE). More frequent encouragement of activity participation resulted in statistically but not clinically better quality of life (low SOE). Pleasant sensory stimulation produced a clinically significant decrease in agitation (moderate SOE). A personalized assessment and treatment intervention of behavioral symptoms increased return of behavior to baseline levels (low SOE). Finally, both personalized showering and towel bath interventions reduced behavioral symptoms (agitation and aggression) more in the intervention group than control group (low SOE).

Key Questions 3 and 4: Outcomes for Informal Caregivers

No studies met inclusion criteria for either of these key questions about the impact of organizational characteristics, structures of care, or processes of care on caregiver health or psychosocial outcomes. Thus, evidence is insufficient for these topics.

Key Question 5: Variation by Characteristics of People With Dementia

Two studies examined outcomes of residents with dementia in terms of dementia severity or sociodemographic variables. In one, hospitalization (but not other outcomes) for persons in RC/AL settings was more likely for those with mild dementia than for those with moderate to severe dementia. Hospitalization rates did not differ by dementia severity for NH residents. In a second study, a lighting intervention produced better depression outcomes for women exposed to morning bright light compared with all-day light, but worse outcomes for men exposed to morning bright light compared with standard light.

Key Findings and Strength of Evidence: Organizational Characteristics, Structures of Care, and Processes of Care

Table 30 summarizes the SOE we found for statistically significant differences in health and psychosocial outcomes according to organizational characteristics, structures, and process of care.

Table 30. Strength of evidence for the effect of organizational characteristics, structures, or processes of care for people with dementia on health and psychosocial outcomes

Characteristics	Intervention/Exposure	Summary of Results	Strength of Evidence
Organizational	NH vs. RC/AL	Morbidity across multiple measures differed little in RC/AL settings compared with NHs (1 study; 1,252 subjects).	Low
		Hospitalization occurred more often for residents with mild dementia living in RC/AL settings than for residents in NHs (1 study; 1,252 subjects).	Low
		Restraint use in imminently dying residents occurred more often in NHs than in RC/AL settings (66% vs. 92%) (1 study; 422 subjects).	Low
	SCU in NH vs. no SCU	Morbidity was lower in SCUs than in non-SCUs in NHs (1 study; 1,252 subjects). Hospitalization occurred more often for NH residents not living in SCUs (1 study; 1,252 subjects).	Low Low
	SCU in RC/AL vs. no SCU	Functional impairment/decline was worse in RC/AL settings for residents in SCUs (1 study; 1,252 subjects).	Low
Structures of Care	Morning bright light vs. all-day light/control	Depression/depressive symptoms were better for women but worse for men after bright morning light (1 study; 155 subjects). Sleep quality was better for only those with aberrant sleep cycle timing following morning bright light (1 study; 46 subjects).	Low Low
		Specialized workers vs. not	Quality of life over 6 months was statistically but not clinically significantly better when specialized workers were used (1 study; 421 subjects).
Processes of Care	Functional skill training vs. no such training	Function was clinically significantly better (equivalent to moving from major to moderate or moderate to minor need for assistance) after functional skill training (1 study; 63 subjects).	Low
	Creative expression storytelling vs. no such activity	Alertness was modestly better (3 percentage points) after creative expression storytelling (1 study; number of subjects not reported). Behavioral symptoms, anxiety, and sadness were worse after creative expression storytelling (1 study; number of subjects not reported).	Low Low
	Validation therapy vs. no such activity	Physical and verbal aggression were better, and physical nonaggression was worse, after validation therapy (based on nurse report). Verbal aggression was worse after validation therapy (based on observer report) (1 study; 88 subjects).	Low
	Encourage activities more vs. less	Quality of life over 6 months was statistically but not clinically significantly better when activities were encouraged (1 study; 421 subjects).	Low
	Pleasant sensory stimulation vs. no such stimulation	Agitation was clinically significantly better after pleasant sensory stimulation (2 studies; 99 subjects; decreased 75% to 83% in one study).	Moderate
	Individualized assessment and management of discomfort and behavioral symptoms vs. no such protocols	Pain/discomfort was better after individualized assessment and management of discomfort. Behavioral symptoms were better after individualized assessment and management of behavioral symptoms (1 study; 114 subjects; 70% vs. 40% return to baseline).	Low Low
	Person-centered protocols for showering and bathing vs. no special protocols	Pain/discomfort was better after person-centered protocols for showering and bathing. Agitation and aggression were better after person-centered protocols for showering and bathing (1 study; 73 subjects; mean time agitated/aggressive 24% to 26% vs. 36% for control group).	Low Low

Note: No study examined the outcomes of falls, spiritual well-being, control, autonomy, choice, or satisfaction (insufficient SOE). Not all of the interventions/exposures in this table were examined in relation to all outcomes. Only findings with low or better SOE are reported.

Abbreviations: NH = nursing home; RC/AL = residential care/assisted living; SCU = special care unit, vs., versus.

Findings in Relation to What Is Already Known

This systematic review is the first to examine these specific questions in this way. Therefore, we could not compare evidence reported here with any established knowledge base.

Applicability

This review was intended to apply to all people with dementia regardless of their level of dementia. It also was intended to examine differences in outcomes related to the extent of dementia and other characteristics of the person with dementia, because people with mild, moderate, or severe dementia vary in the extent to which they are able to respond to interventions.

Studies varied in regard to the level of dementia represented. Some included residents only with severe dementia,^{37, 38} one with moderate to severe dementia,³⁶ some with mild through severe dementia,^{22, 31-35} and some did not specify the level of dementia.³⁹⁻⁴² Those that included only residents with severe dementia were one of the pleasant sensory stimulation studies and the study of individualized assessment and management of discomfort and behavioral symptoms; the findings from these studies are generally applicable to residents with severe dementia. Only one study considered the evidence in relation to the level of dementia severity, examining differences between NHs and RC/AL settings based on dementia severity for several outcomes: mortality, hospitalization, new or worsening morbidity, and changes in function, cognition, depressive symptoms, behavioral problems, and engagement. It found no differences except an increased risk of hospitalization for residents with mild dementia in RC/AL.³⁵ These findings, which generally did not favor either NHs or RC/AL and were of insufficient or low SOE, nevertheless are broadly applicable to people with all levels of dementia severity. There is no evidence whether findings from the other studies differed in relation to the level of dementia severity.

Only one other characteristic of the person with dementia was examined in any study. It found (with low SOE) that the effects of a lighting intervention differed for women and men, with depression improved for women but worsened for men, making its implications specific to those subgroups.³²

The evidence is therefore insufficient regarding whether the effects of some of the interventions/exposures under study would have been different for different subgroups of the populations. Other than for the small number of findings noted above, we cannot say whether they are the same or different for people at different stages of disease severity or by other characteristics.

The interventions/exposures under study included a broad range of organizational characteristics, structures, and processes of care. We had envisioned special interest in exposure to organizational characteristics, such as NH versus RC/AL, small NH versus large NH, and SCU versus no SCU. These are often the level at which families first make their decision regarding a setting of care. However, only three prospective cohort studies (one focused on care for imminently dying residents) provided evidence about these options. Thus, although the evidence is informative, our confidence in whether these effects will hold up over time is low, and future research could either confirm or change them.

The outcomes examined across these 13 studies included eight broad categories of health outcomes and seven categories of psychosocial outcomes. Not all were examined in all studies, and in some cases, the strengths or limitations of a given intervention differed by outcome. For example, creative expression storytelling resulted in better alertness and more engagement but

worse behavioral symptoms, anxiety, and sadness. In such instances, families are advised to consider which outcomes they and the person with dementia most value and make their decision accordingly.

The SOE for all findings reported in this review, except one, was low or insufficient. Furthermore, although we found statistically significant effects for some organizational characteristics, structures, and processes of care, for many we found no significant effects. In addition, some statistically significant results were relatively small, meaning that their clinical importance is limited or unclear. Also, it is important to note that not all outcomes were examined in these studies, including falls, spiritual well-being, control, autonomy, choice, and satisfaction. Thus, even though these studies covered a wide array of outcomes, a substantial set of outcomes of interest was never examined.

Finally, we found no evidence related to health or psychosocial outcomes for informal caregivers of people with dementia. Thus, this review is not directly applicable to such family members or other caregivers, although understanding the benefits or harms of various organizational characteristics, structures, or processes of care for people with dementia may well promote better outcomes for informal caregivers; still, far more evidence is required on this point.

Implications for Clinical and Policy Decisionmaking

Few studies met the evidence criteria; those that did provided information with only generally low SOE. We found limited evidence related to health and psychosocial outcomes for people with dementia, and none for informal caregivers. Additional research is needed to develop a sufficient evidence base to support family decisionmaking.

As documented in the preceding discussion and tables, the SOE was low for any impact of all but one of the organizational characteristics, structures, and processes of care we examined. The one exception is that SOE was moderate for use of pleasant sensory stimulation to reduce agitation, and we found no evidence that pleasant sensory stimulation resulted in negative outcomes. Therefore, families, providers, policy makers, advocates, and educators may want to promote the use of pleasant sensory stimulation, and researchers may want to study further the use of pleasant sensory stimulation to strengthen the available evidence.

In addition, we found evidence of positive impacts (all low SOE) and no evidence of any negative impacts for a limited number of outcomes in SCUs in NHs (but not RC/AL settings); protocols for individualized care including person-centered showering/bathing and assessment/management of discomfort and behavioral symptoms; functional skill training, use of specialized workers, and encouraging activities.

Apart from our review, other reviews focused on SCUs have shown mixed results on various outcomes. A Cochrane review identified no RCTs investigating the effects of SCUs on behavioral symptoms in dementia; in addition, it found no strong evidence of benefit from available non-RCTs.⁴⁵ The Cochrane study authors suggested that implementing “best practices” may be more important for resident outcomes than providing a specialized care environment.⁴⁵ Other specific studies (not included in our review) provide some evidence that SCU residents are at lower risk for hospitalization and more often receive better care, but also that they have greater use of antipsychotic medications.⁴⁶⁻⁴⁸ Conflicting results may in part reflect the fact that SCU residents may have different baseline characteristics from those not residing in SCUs.⁴⁹

Personalized care protocols may have potential effectiveness in that they can be more accurately targeted and possibly have more of a direct effect on outcomes than group activity

interventions. In particular, the person-centered showering and bathing intervention protocol that we examined in this review³⁶ has been widely adopted by practitioners; it is broadly considered an example of culture change that strives to deinstitutionalize NHs and individualize care.⁵⁰ More generally, both in the United States and overseas, person-centered care has received broad support.^{51, 52} A wide range of personalized care interventions related to organizational characteristics, structures, and processes of care fit within this broader effort, including care provision in smaller, home-like settings.⁵⁰ Further, the one study we reviewed that found both positive and negative outcomes related to the use of morning bright light (decreased depression for women, increased depression for men)³² suggests that lighting interventions may best be applied at the person level rather than the setting level.

Functional skill training in ADLs has also had mixed effects, including short-term but not long-term functional benefits.⁵³ The functional skill training examined in this review,⁴¹ as well as a behavioral rehabilitation intervention for improving the performance of morning care activities⁵⁴ both found some success. Given the challenges of improving function in this population and the limited research available, additional study is needed to test new interventions.

Studies found both positive and negative evidence for a limited number of outcomes for residents of NHs as compared with residents of RC/AL settings. Residents with mild dementia were less likely to be hospitalized if they resided in NHs, and residents in NHs were more likely to have stable health before death. The explanation may be that NHs, as contrasted with RC/AL settings, can provide more medical care and have more nursing staff. However, we found no evidence regarding differences across these setting types in relation to behavioral symptoms, engagement, quality of life, quality of dying, and for imminently dying residents, psychoactive medication use. If people with dementia and their families are choosing between NHs and RC/AL settings, considering the individual's current medical needs and health stability will be helpful. In addition, taking into account the difference in costs between these two settings (annual 2011 rate \$78,000 to \$87,000 in NHs and \$42,000 in RC/AL settings)⁵⁵ and the availability of Medicaid (should it be necessary) may also be important.

Limitations of the Comparative Effectiveness Review Process and the Evidence Base

We excluded numerous studies of potential relevance conducted in NHs and RC/AL settings for a variety of reasons determined a priori and with the agreement of our TEP. Particularly relevant were two criteria: (1) that the studies did not specify that at least 80 percent of the study population had dementia and (2) that analyses had not been conducted specific to the subgroup of those with dementia. A total of 76 studies were excluded because they did not meet these criteria; some might have been excluded for other reasons as well and in none did at least 70 percent of the population have dementia. Despite the fact that a large proportion of residents in NHs and RC/AL settings have dementia,²² we still had to ensure that the populations under study included articles were specific to this review.

In addition, we dropped from our analyses any study for which our quality rating was poor; we retained only trials or prospective cohort studies assessed as either good or fair. Given the fact that the SOE was principally low (if not insufficient), we do not believe that adding poor quality studies, which may have involved yet other organizational characteristics, structures of care, or processes of care, would have improved the overall robustness or applicability of this body of evidence.

Moreover, this was a comparative effectiveness review concerned with outcome differences examined over time. Thus, cross-sectional studies were considered as not as directly pertinent or appropriate to include. Many cross-sectional studies that have adjusted for confounders have been conducted over the years, and some might inform the research questions with respect to effectiveness.

We found almost 30 cross-sectional studies with potential relevance.^{46-48, 56-83} For example, evidence from cross-sectional studies has indicated that hospitalization is less likely in NH SCUs (compared with NHs with no SCU), when more residents with dementia are present in the NH, and when Medicaid payment rates are relatively higher. In addition, depression and pain were higher in for-profit settings than nonprofit settings.^{47, 68, 82} This type of information may be helpful for family members when determining the optimal setting of care for relatives with dementia, but such studies might well have higher risks of bias than the studies we included and, therefore, would not produce findings of materially higher SOE.

Research Gaps

Assuming that the overriding (or first) question for stakeholders is whether an individual with dementia is best served in a NH or RC/AL setting, or in an SCU, we reiterate that we found no RCTs to answer these questions and only quite sparse evidence from nonexperimental studies. RCTs would not be expected to inform the matter of NHs versus RC/AL settings, given that they would be hard to justify in ethical or feasibility terms. Trials of placement in SCUs might be possible, however. All things considered, additional high-quality prospective cohort studies would be beneficial in clarifying the advantages and disadvantages of residence in different types of settings, especially because the majority of RC/AL residents have dementia⁷ and the number of RC/AL beds almost doubled in the last 20 years.⁸⁴

The wide array of structural variables and process interventions/exposures that surfaced in this work reflects impressive thinking about all the factors that either experience or theory suggests might improve the quality of life and outcomes of people with dementia. This diversity did, however, make it impossible for us to improve estimates of effect sizes of any one characteristic, structure, or process by pooling data. We are not convinced that continued “one-off” studies are the best possible use of research resources. Instead, concerted emphasis on key structural variables or types of specialized services may be warranted in coming years, so that findings can be combined in quantitative analyses to yield stronger evidence for decisionmaking by all stakeholders. Two examples of this type of effort include the National Institute on Aging studies examining SCUs (launched in 1991), and The Robert Wood Johnson Foundation collaborative of research projects examining Green House NHs (launched in 2011).

Of special concern might be efforts to maintain or improve physical function and to decrease pain/discomfort and behavioral symptoms in this population. Thus, we emphasize that additional studies are warranted to test interventions that show some promise, including functional skill training⁴¹, pleasant sensory stimulation,^{33, 38} and individualized protocols for care,^{36, 37} in addition to exploring the impact of enhanced or completely new interventions in this area. Of particular importance is to build on the existing empirical work and also on robust conceptual frameworks and clinical or behavioral theories about what might “work best” for these individuals.

Another consideration about future research involves the types of outcomes to be studied. As noted, we and our TEP had identified a considerable array of health and psychosocial outcomes about which we believed clinicians, people with dementia and their families, and other interested parties would want to know more. Of these, no evidence at all surfaced on several important

matters, including falls and several aspects of psychosocial well-being including spiritual well-being, control, autonomy, choice, and satisfaction. Some research effort to clarify care related to these outcomes is warranted, although they may be less salient for decisionmaking than matters such as depression, hospitalization, and quality of life. Falls are especially important insofar as they constitute a significant threat to safety and cost to the health care system, which is a matter of concern for residents and families, staff, administrators, and policymakers.

A related matter may be encouraging investigators to use established outcome measures that have proven reliability and validity. Consolidation on some types of measures might enhance the possibility of quantitative pooling of studies (other things equal) or at least of some qualitative interpretations of the same (or very similar) outcome information. Many studies in this review used the Cohen-Mansfield Agitation Inventory (CMAI, a measure of behavioral symptoms),^{33, 35, 38, 42} and other established measures are available for numerous other outcomes of interest.

Cutting across components of care and outcomes is the question of methods. As noted, of the 13 studies finally included, we could rate the quality of the investigation as good for only four studies. We excluded 13 studies because of substantial flaws that yielded quality ratings of poor (Appendix D). The principal problems of these studies, which hinge on threats to internal validity (substantial risks of bias), were performance bias (e.g., care providers provided care in both arms of the study),⁸⁵⁻⁸⁷ selection bias (e.g., groups were not similar at baseline),⁸⁸⁻⁹¹ detection bias (e.g., raters were not blind to the group to which the resident belonged),^{92, 93} and attrition bias (e.g., greater than 20 percent).⁹⁴⁻⁹⁷ Thus, we conclude that future research should attempt to overcome at least the primary deficits of this entire body of work. For example, investigators should attend more closely to masking raters and maintaining consistent raters over time, assuring similar representation of subjects across arms, focusing on fidelity, and accounting for missing data in their analyses.

Moreover, most studies were relatively small. Larger sample sizes might allow investigators to gain more precision in estimates of differential effects or changes over time. Then, they will be in a better position to say more about the superiority (or inferiority) of various organizational characteristics and interventions. Similarly, more attention to the heterogeneity of people with dementia, and examining how different levels of dementia and other differences (measured in consistent ways) relate to outcomes, will better inform the matter of applicability.

Finally, the number of people with dementia who reside in traditional and emerging settings can only rise in future. Finding answers to the numerous questions and concerns that people today might have about dementia care (for themselves and for family members) is crucial. Focusing on *truly* critical choices and questions, and improving the quality of studies, are crucial steps for providing actionable information for such difficult decisions.

Conclusions

Overall, we generally found low or insufficient SOE about the effectiveness or comparative effectiveness of organizational characteristics, structures, and processes of care for people with dementia. This is true about both their health and their psychosocial outcomes. Virtually no good or fair evidence meeting our inclusion criteria exists about health and psychosocial outcomes for informal caregivers of people with dementia.

Even with those caveats, we can state some conclusions about interventions. In particular, findings of moderate SOE indicate that pleasant sensory stimulation reduces resident agitation. In addition, even though the SOE was only low, protocols for individualized care can reduce resident pain/discomfort and agitation/aggression, and functional skill training of people with

dementia can improve their functioning. Further, if people with dementia and their families are making a choice between NHs and RC/AL settings, considering the individual's current medical needs and health stability is important because these settings do not differ much in outcomes other than those relating to people for whom medical care is indicated or for whom NHs may be better suited on other grounds.

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