



Effective Health Care Program

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

Executive Summary

Background

Dementia is a group of 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 what to choose from the available options.

Definition of Dementia

Dementia is a syndrome with multiple causes characterized by a decline in mental function, marked most commonly 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 type of dementia is Alzheimer's disease; other types include vascular dementia, mixed dementia, dementia with Lewy bodies, and frontotemporal dementia.

Effective Health Care Program

The Effective Health Care Program was initiated in 2005 to provide valid evidence about the comparative effectiveness of different medical interventions. The object is to help consumers, health care providers, and others in making informed choices among treatment alternatives. Through its Comparative Effectiveness Reviews, the program supports systematic appraisals of existing scientific evidence regarding treatments for high-priority health conditions. It also promotes and generates new scientific evidence by identifying gaps in existing scientific evidence and supporting new research. The program puts special emphasis on translating findings into a variety of useful formats for different stakeholders, including consumers.

The full report and this summary are available at www.effectivehealthcare.ahrq.gov/reports/final.cfm.

Prevalence of Dementia

More than 5 million Americans—as many as one in every eight individuals age 65 years or older—have dementia.² This number may rise to as high as 13 million



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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 85.³ The prevalence of dementia differs according to stage, such that by 2050 approximately 7 million people will have mild dementia, and 6 million will have moderate to severe dementia.¹ The impact of dementia relates to its stage.

Impact of Dementia

Dementia causes significant morbidity and mortality and creates a substantial burden on the people affected, as well as on caregivers, health systems, and society.² Dementia gradually erodes the individual's ability to make decisions; manage personal affairs; and eventually do even simple tasks such as dressing, toileting, and eating. Late stages of dementia are characterized by weight loss, limited mobility, and frequent infections so that, unless some other illness is fatal sooner, dementia will lead to death. The course of dementia 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.⁴

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, such as those with mild, moderate, or severe 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.⁵ Therefore, an especially relevant question is whether certain characteristics are critical in providing quality care.

Key characteristics of long-term care settings can be conceptualized in three categories: organizational characteristics, structures of care, and processes of care. Conceptually, good characteristics and structures increase the likelihood of good processes, which increase the likelihood of good outcomes.⁶ 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 vs. rural), size, cost, and resident case-mix (e.g., dementia, Medicaid, race/ethnicity), as well as the overall model of care (e.g., NH, RC/AL, Alzheimer's/dementia special care units [SCUs]). Structures of care are attributes of the

setting, including 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 their operation (e.g., hours of care per resident per day by type of worker, consistency of assignment, universal worker perspective). Processes of care refer to what is actually done in giving and receiving care, and include 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). For additional examples, see Table 2 in the full report.

Scope and Key Questions

Considering the central role of family caregivers in deciding which NH or other residential long-term care setting to choose when home care is no longer feasible, information on which components of these settings relate to better outcomes 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, symptom severity, or other characteristics. Further, settings that are better for the person with dementia may also be better for the family caregiver, such as by bringing the family peace of mind. The objective of this review 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 cared for at home.

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

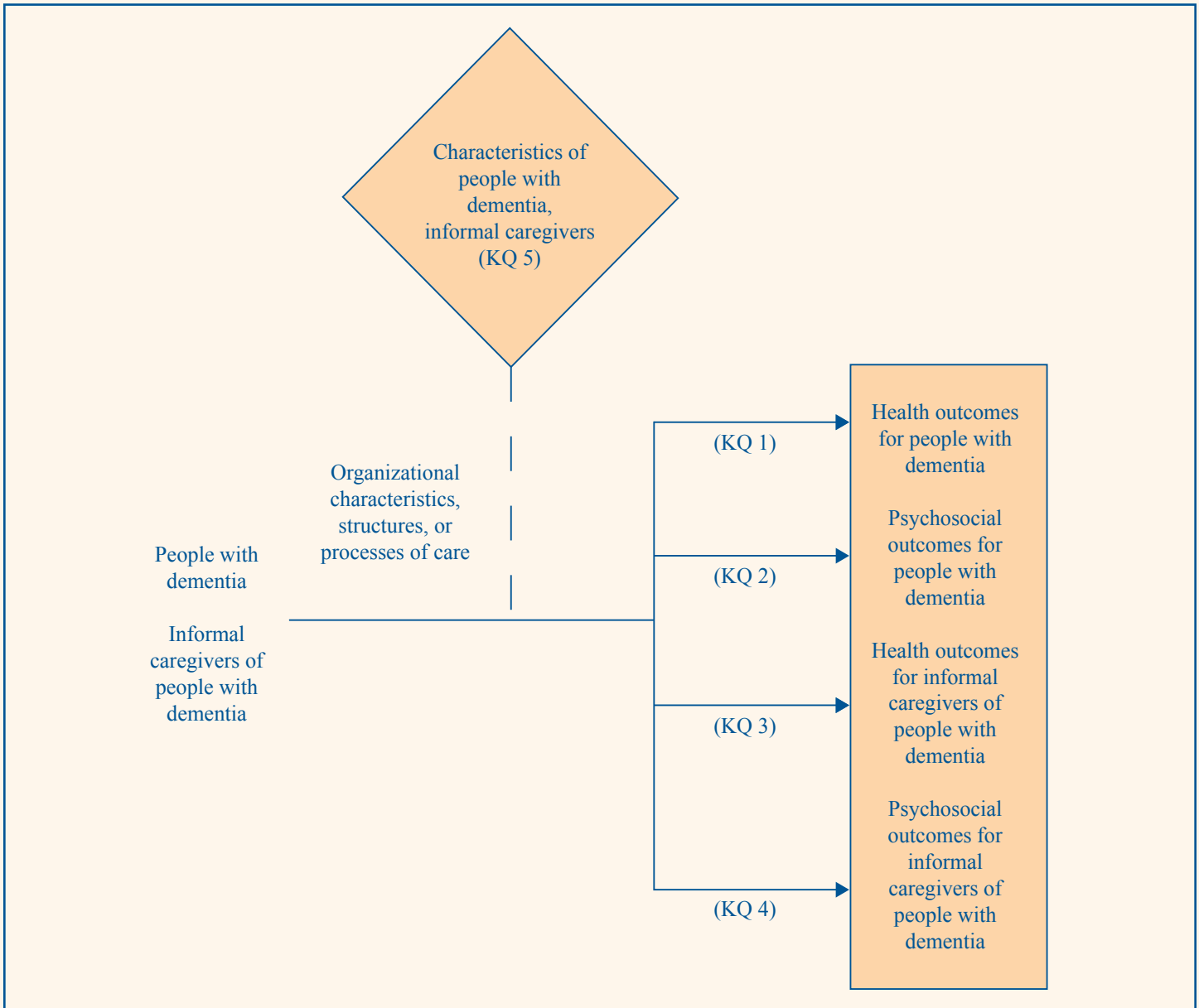
homes and other residential long-term care settings for improving psychosocial outcomes for informal caregivers of people with dementia?

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)?

Wording KQ 1 and KQ 2 in terms of “improving” outcomes for people with dementia recognizes that improvement may be relative; it includes change to a better state of well-being, maintenance of the current state of well-being rather than decline, and also less decline, as opposed to more, in the current state of well-being.

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

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



KQ = Key Question

Methods

Literature Search Strategy

Search Strategy

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 and incorporated the panel's 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 March 23, 2012, 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).

Inclusion and Exclusion Criteria

We developed inclusion and exclusion criteria with respect to the PICOTS (populations, interventions/exposures, comparators, outcomes, timing, settings) framework. 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 formal diagnosis, signs or symptoms (e.g., cognitive status assessment), or report by staff or an informal caregiver.

We required that a study must have explicitly stated that at least 80 percent of the population had dementia or that 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. 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.⁷

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 vs. RC/AL) or new interventions being implemented.

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 vs. rotating staffing) of the elements or combinations of certain elements as exhibited in particular models (e.g., the Green House⁸ model). We excluded studies without a comparator. We excluded studies judged to be of poor quality.

Outcomes of interest were quite broad:

- Health outcomes for people with dementia, such as pain or discomfort; depressive symptoms; 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 depressive symptoms; sleep quality; and morbidities such as cardiovascular disease.
- 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 admission 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 SCUs, residential long-term hospice care, and continuing care retirement communities.

We confined our review to studies done in the United States so the evidence examined would be relevant to care in this country.

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/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.

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)⁹ and the University of York Centre for Reviews and Dissemination.¹⁰ 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. We excluded poor-quality studies from our analyses, which could in turn affect the strength of the body of evidence.

Data Synthesis

To determine whether quantitative analyses were appropriate, we assessed the clinical and methodological heterogeneity of the studies following established

guidance.¹¹ 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 syntheses were 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.¹² This approach incorporates four key domains: risk of bias (including study design and aggregate quality), consistency, directness, and precision of the evidence. A grade of high SOE indicates we have high confidence that the evidence reflects the true effect. Further research is very unlikely to change our confidence in the estimate of effect. Moderate SOE implies 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 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 all included studies. Two reviewers assessed each domain for each key outcome; differences were resolved by 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. For outcomes with a single study with imprecise results and for which power was not ensured, we generally graded the SOE as insufficient; for a single study with precise results, we graded it as low. Therefore, although effectiveness is neither 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 AHRQ's Methods Guide for Effectiveness and Comparative Effectiveness Reviews.¹³ 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. Summary tables and evidence tables of included studies can be found in the full report.

Results of Literature Searches

A total of 6,209 articles were identified through our database searches and hand searches of relevant articles. Results of our literature searches appear in Figure B. We included 14 published articles: 9 randomized controlled trials (RCTs), 1 nonrandomized controlled trial, and 4 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 of the full report).

KQ 1. Health Outcomes for People With Dementia

Of the 10 studies reviewed, 8 interventions showed statistically significant effects on health outcomes,

with either insufficient or low SOE. Process of care interventions provided more evidence than did interventions focusing on organizational characteristics or structures of care.

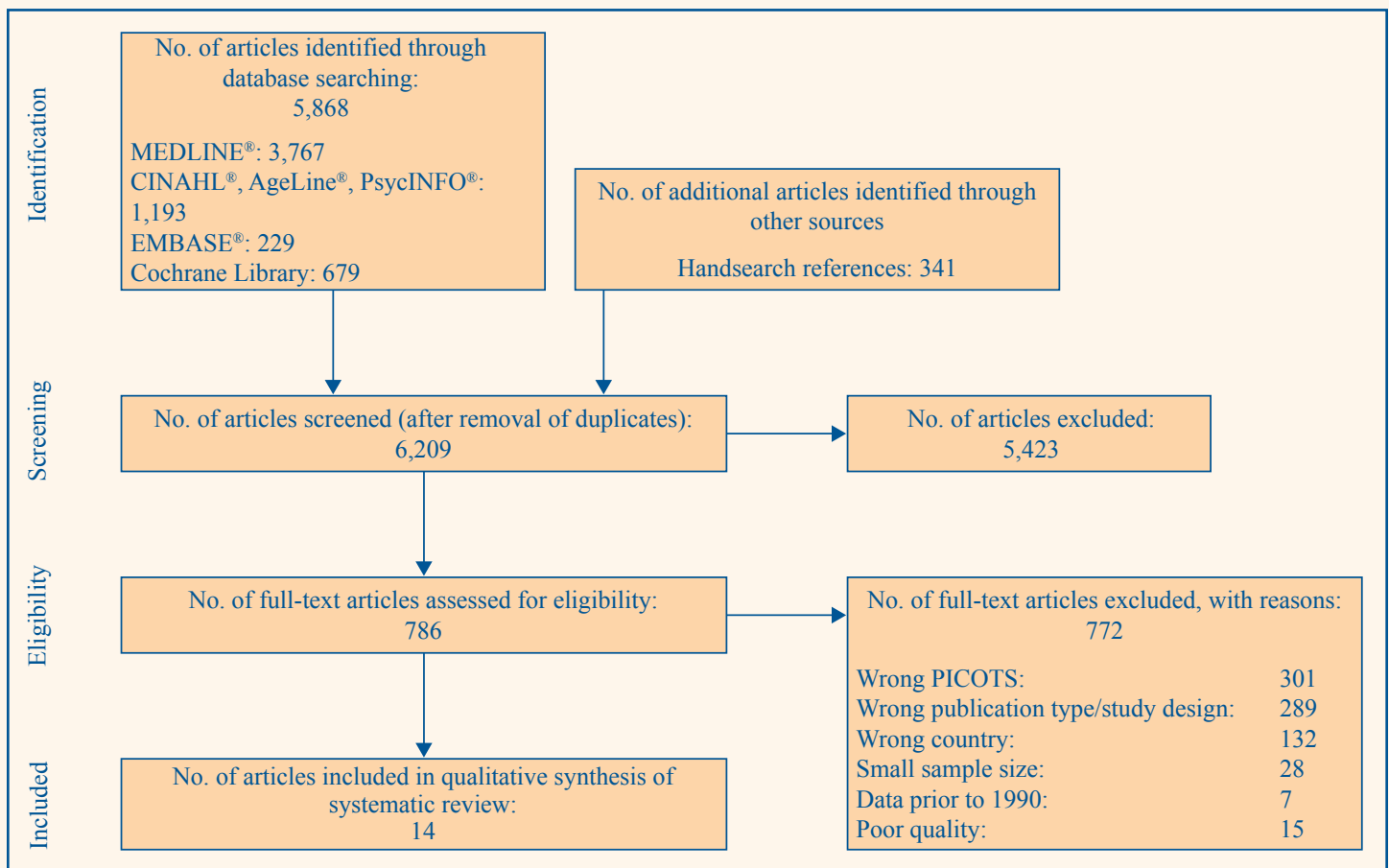
Organizational Characteristics

Two studies addressed organizational attributes but found few differences between RC/AL settings and NH settings on a range of health outcomes; we found some differences between dementia SCUs and non-SCUs located within either RC/AL settings or NH settings (either 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 NH settings but little difference in new or worsening morbidity (low SOE). Among four other morbidity measures the evidence was insufficient.

Figure B. Disposition of articles



CINAHL = Cumulative Index to Nursing and Allied Health Literature; No. = number; PICOTS = populations, interventions/exposures, comparators, outcomes, timing, settings

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, and another RCT found no effect on depressive symptoms for the overall populations studied; both trials reported some effects for some subgroups. However, evidence was insufficient regarding the effects of lighting interventions on these outcomes and for subgroup analyses; these were single studies with imprecise results for which power was not ensured.

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 three percentage points (low SOE). Two interventions had no benefits: validation group therapy intervention did not improve functional self-care or depressive symptoms, and an attention-focusing intervention did not improve cognitive impairment. However, evidence was insufficient for these two single studies regarding these specific outcomes due to imprecise results and no reported power calculations to justify sample size.

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.

KQ 2. Psychosocial Outcomes for People With Dementia

Ten studies (five RCTs) addressed psychosocial outcomes. Almost all showed some statistically significant effects on outcomes (either low or moderate SOE).

Organizational Characteristics

With one exception (restraint use), psychosocial outcomes did not differ between NH settings and RC/AL settings.

Behavioral symptoms and engagement did not differ by setting (low SOE). Quality of dying, quality of life, and psychoactive medication use also did not differ by setting although evidence is insufficient in these single studies that had imprecise results and no power calculations. Restraints were used more often in imminently dying residents in NH settings than in RC/AL settings (any restraints, 92% vs. 66%; any restraints other than partial bedrails, 68% vs. 46%; low SOE).

Quality of life did not differ based on proprietary status, chain affiliation, size, age, percentage of dementia beds, and resident case-mix. Evidence was insufficient on the effect of these organizational characteristics on quality of life in this single study that had imprecise results and no reported power calculations.

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. Evidence was insufficient on the effect of these structures of care on quality of life in this single study that had imprecise results and no reported power calculations. 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. Evidence was insufficient for the effect of validation group therapy on these outcomes due to imprecise results in this single study that did not reported power calculations.

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% to 83% 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% vs. 40% 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% and 26% in the intervention groups vs. 36% in the control group; low SOE).

In one prospective cohort 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. However, evidence was insufficient for the effects of these processes of care in this single study that had imprecise results and no reported power calculations.

KQ 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.

KQ 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.

KQ 5. Dementia Severity and Other Characteristics of the Person With Dementia

Two studies examined outcomes of residents with dementia in terms of dementia severity or socio-demographic variables. In one, hospitalization (but not other outcomes) for people 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 depressive

symptoms 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.

Discussion

Key Findings and Strength of Evidence

KQ 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. Residents with mild dementia in RC/AL settings, when compared with those in NH settings, had moderately higher hospitalization rates (low SOE); residents differed little in morbidity rates regardless of dementia level (low 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).

Only two studies focused on structures of care. Those two studies reported no effect in the overall populations studied for lighting interventions on either sleep quality or depressive symptoms. Both studies found benefits for certain subgroups (women for depressive symptoms and those with aberrant sleep-cycle timing for sleep quality). Although these studies suggest that lighting interventions may have more benefit on a person-by-person level as opposed to being a structural intervention throughout a setting, we judge the current evidence as insufficient based on these single studies with imprecise results that did not report power calculations.

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). A single study of validation therapy groups did not find improvement of functional self-care or depressive symptoms. A single study of attention focusing did not find any improvement of cognitive impairment cognitive function. However, the evidence was insufficient

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	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 NH settings, 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 NH settings (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 an NH setting vs. RC/AL setting or in an SCU vs. non-SCU (1 study; 1,252 subjects).	Low

NH = nursing home; RC/AL = residential care/assisted living; SCU = special care unit; SOE = strength of evidence; vs. = versus

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.

regarding the effects of validation group therapy for self-care and depressive symptoms and of an attention-focusing intervention for cognitive impairment and cognitive function due to imprecise results in these single studies that did not report power calculations to justify sample size. 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).

KQ 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. Behavioral symptoms and

engagement did not differ by setting (low SOE). Quality of dying, quality of life, and psychoactive medication use also did not differ by setting although evidence was insufficient in these single studies that had imprecise results and no reported power calculations. 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.¹⁴ Behavioral symptoms and engagement did not differ based on residence in an SCU (low SOE), although the two studies reviewed were prospective cohort studies in which risk adjustment potentially may not have been sufficient.

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

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 (2 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	One study did not find a difference based on residence in an NH setting vs. RC/AL setting (1 study; 422 subjects).	Insufficient ^a
Psychoactive medication use	One study did not find a difference based on residence in an NH setting vs. RC/AL setting (1 study; 422 subjects) or after validation therapy (1 study; 88 subjects) studies; 510 subjects).	Insufficient ^a
Restraint use	Restraint use in imminently dying residents occurred more often in NH settings than in RC/AL settings (66% vs. 92%) (1 study; 422 subjects).	Low

NH = nursing home; RC/AL = residential care/assisted living; SOE = strength of evidence; vs. = versus

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 10 studies. Except where indicated, only findings with low or better SOE are reported.

^aEvidence was from a single study with imprecise estimates.

based on many structures although the evidence was insufficient in this single study that had imprecise results and no reported power calculations.

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 physically nonaggressive behaviors (e.g., restlessness, repetitious mannerisms, pacing), 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, such as calm

music and hand massage, 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 the control group (low SOE).

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

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 NH settings (1 study; 1,252 subjects).	Low
	NH vs. RC/AL	Hospitalization occurred more often for residents with mild dementia living in RC/AL settings than for residents in NH settings (1 study; 1,252 subjects).	Low
	NH vs. RC/AL	Restraint use in imminently dying residents occurred more often in NH settings 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).	Low
	SCU in NH vs. no SCU	Hospitalization occurred more often for NH residents not living in SCUs (1 study; 1,252 subjects).	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).	Low
	Morning bright light vs. all-day light/control	Sleep quality was better only for those with aberrant sleep-cycle timing following morning bright light (1 study; 46 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	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).	Low
	Creative expression storytelling vs. no such activity	Behavioral symptoms, anxiety, and sadness were worse after creative expression storytelling (1 study; number of subjects not reported).	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 (2 studies; 99 subjects; agitation decreased 75% to 83% in 1 study).	Moderate

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 (continued)

Characteristics	Intervention/Exposure	Summary of Results	Strength of Evidence
Processes of Care (continued)	Individualized assessment and management of discomfort and behavioral symptoms vs. no such protocols	Pain/discomfort was better after individualized assessment and management of discomfort (1 study; 114 subjects; discomfort score 0.89 times lower than control).	Low
	Individualized assessment and management of discomfort and behavioral symptoms vs. no such protocols	Behavioral symptoms were better after individualized assessment and management of behavioral symptoms (1 study; 114 subjects; 70% vs. 40% return to baseline).	Low
	Person-centered protocols for showering and bathing vs. no special protocols	Pain/discomfort was better after person-centered protocols for showering and bathing (1 study; 73 subjects; reduced discomfort by 26% for towel bath and 14% for person-centered showering).	Low
	Person-centered protocols for showering and bathing vs. no special protocols	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

NH = nursing home; RC/AL = residential care/assisted living; SCU = special care unit; SOE = strength of evidence; vs. = versus

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.

KQs 3 and 4: Outcomes for Informal Caregivers

No studies met inclusion criteria for either of these KQs 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.

Three potential studies¹⁵⁻¹⁷ were identified in this review, each addressing encouragement of family involvement in care as a means to promote improved family/staff relationships and thus improve resident care. While these studies were excluded for methodological shortcomings (e.g., selection bias, high attrition, inadequate randomization), this literature is evolving and represents an increasingly important aspect of NH and residential care for residents with and without dementia.

KQ 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 people 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 depressive symptoms 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.

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. This is a serious omission, as what may be helpful at one time (such as to reduce wandering)

may not be needed at a later time (if the person becomes bedridden), and what is needed at a later time may not be necessary earlier.

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 NH settings 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 four prospective cohort studies provided evidence about these options.

The outcomes examined across the 14 studies included 8 broad categories of health outcomes and 7 categories of psychosocial outcomes. In some cases, a given intervention had both desired and undesired outcomes. In such instances, families are advised to consider which outcomes are most relevant and which 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. Further, although we found statistically significant effects for some organizational characteristics, structures, and processes of care, for many we found none. In addition, some statistically significant results were relatively small, meaning 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.

Research Gaps

Assuming the overriding question for stakeholders is whether an individual with dementia is best served in an NH setting 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 dementia,¹⁸ and the number of RC/AL beds has almost doubled in the past 20 years.¹⁹

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 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. Related to this strategy is the suggestion that all studies conducted in NHs and other residential long-term care settings indicate the number and percentage of residents with dementia who composed the sample, and analyze data specific to these individuals.

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 depressive symptoms, 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),²⁰⁻²³ 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 14 studies included, we could rate the quality as good for only 4 studies. We excluded 15 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.

To summarize, we suggest the following guidance for future research:

- Examine differences between NH settings versus RC/AL settings, and between SCUs and settings without SCUs as related to outcomes for people with dementia and their caregivers.
- Conduct studies with concerted emphasis on key organizational characteristics, structures, and processes of care as opposed to one-of studies.
- Indicate the number and percentage of residents with dementia who composed the sample, and analyze data specific to these individuals.
- Examine how results differ according to characteristics of the person with dementia, especially the degree of dementia.
- Continue studying outcomes of depressive symptoms, hospitalization, and quality of life, but also consider the relevance of outcomes including falls, spiritual well-being, control, autonomy, choice, and satisfaction.
- Use established outcome measures to enable the pooling of data or qualitative interpretations.
- Employ rigorous methodologies that overcome bias, and use samples of sufficient size to provide precise estimates.

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 NH settings 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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Full Report

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