

Care Interventions for People Living With Dementia (PLWD) and Their Caregivers

Minnesota Evidence-based Practice Center
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1

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2

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3

What We Will Cover Today:

- Purpose of report and Key Questions
- VERY brief highlights of methods
- Results
- Discussion and thoughts for future research
- Questions



4

Report Objective

To assess the evidence for care interventions for PLWD and their informal and formal caregivers for potential for broad dissemination and implementation.



5

Key Questions

KQ 1-2: Care Interventions for Behavioral and Psychological Symptoms of Dementia (BPSD) in **People Living With Dementia (PLWD)**

KQ 3-4: Care Interventions for Quality of Life, Function, or Non-BPSD Symptoms in **PLWD**

KQ 5-8: Care Interventions for Quality of Life and Health Outcomes for **Informal** and **Formal** PLWD Caregivers

KQ 9-10: Interventions for How Care Is Delivered



6

Data Sources and Outcomes of Interest

- Ovid Medline, Ovid Embase, Ovid PsycINFO, and the Cochrane Central Register of Controlled Trials (CENTRAL) from inception **through March 2020**
- Wide array of outcomes from individual to system-level
 - Always captured both PLWD and caregiver outcomes if available within a single study.

7

What Studies Were Included

- Trials with comparator arms or single arm studies with appropriate methods (e.g., intermittent time series)
- Excluded higher education-based training programs
- Otherwise, all non-pharmacologic interventions.

8

Interventions



9

Categorizing Interventions



[Insert Program /Unit Title or Delete]

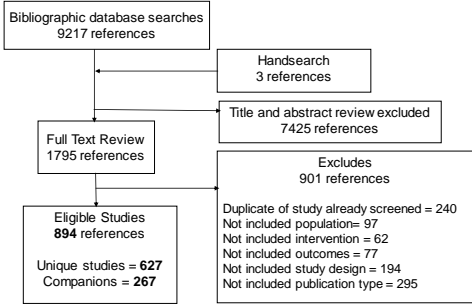
10

How The Review Was Conducted

- Followed AHRQ EPC program systematic review guidelines
- Focused on studies best positioned to answer “what is ready for broad dissemination”
 - Pilot, feasibility, small sample size, and high risk of bias studies were catalogued in an evidence map but not analyzed

11

Results - Eligible Studies



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    graph TD
      A[Bibliographic database searches  
9217 references] --> B[Full Text Review  
1795 references]
      C[Handsearch  
3 references] --> B
      B --> D[Eligible Studies  
894 references  
Unique studies = 627  
Comparisons = 267]
      B --> E[Excludes  
901 references  
Duplicate of study already screened = 240  
Not included population= 97  
Not included intervention = 62  
Not included outcomes = 77  
Not included study design = 194  
Not included publication type = 295]
      F[Title and abstract review excluded  
7425 references] --> E
  
```

12

Results - Eligible Studies (continued)

100 studies in the **analytic set**

- the set of studies not judged to be pilots or have a high potential for bias that might have interfered with the ability of the study to answer its research question.

527 studies in the **evidence map**

- the set of studies that did not undergo synthesis. Summarizes what has been studied and facilitates identifying future research needs.



13

Clarification

An assessment of insufficient evidence does not mean that the intervention is determined to be of no value. Rather, it means that due to the uncertainty of the evidence we could not draw meaningful conclusions at this time.



14

Managing Behavioral and Psychological Symptoms of Dementia (BPSD) (Ch 4)

Location	Intervention	Total Unique Studies	# Analytic Set	# Evidence map	# non-U.S.
Chapter 4 Managing PLWD BPSD	Assisted Therapy	16	1	15	15
	Multi-Sensory Stimulation/Snoezelen	9	2	7	6
	Complementary and Alternative Medicine (CAM) Therapies	21	5	16	19
	Bright Light Therapy	9	0	9	4
	Psychosocial Therapies for BPSD	6	0	6	1
	Multicomponent Interventions for BPSD	9	0	9	5
	Chapter 4 TOTAL	70	8	62	50



15

Managing BPSD in PWD

Evidence was insufficient to draw conclusions

- Robot-assisted therapy
- Multi-sensory stimulation/Snoezelen
- Aromatherapy or foot massage interventions (CAM)

Evidence that did not advance to analysis

- Live animal- or doll-assisted therapy
- Bright light therapy
- Psychosocial therapies
- Multicomponent interventions



16

Care Interventions for PLWD Well-being (Ch 5)

Location	Intervention	Total Unique Studies	# Analytic Set	# Evidence map	# non-U.S.	
Chapter 5 PLWD Wellbeing	Exercise	53	10	43	48	
	Music	35	5	30	26	
	Reminiscence Therapy	25	4	21	22	
	Cognitive Rehabilitation	23	3	20	19	
	Cognitive Training	18	5	13	15	
	Cognitive Stimulation Therapy	12	2	10	11	
	Recreation Therapy	14	3	11	11	
	Psychosocial Interventions for PLWD well-being	7	0	7	4	
	Creative Expression Therapy	5	0	5	2	
	Multicomponent Interventions	24	3	21	14	
	Assistive Technology	4	0	4	2	
	Electrostimulation	14	0	11	12	
	Other Interventions for PLWD well-being	7	0	7	4	
	Chapter 5 TOTAL		241	35	207	190



17

Care Interventions for PLWD Well-being

Evidence was insufficient to draw conclusions

- Exercise
- Music
- Reminiscence
- Cognitive rehabilitation
- Cognitive training
- Cognitive stimulation therapy
- Recreation therapy
- Multicomponent interventions



18

PLWD Well-being (cont.)

Evidence that did not advance to analysis

- Psychosocial therapy
- Creative expression therapy
- Assistive technology
- Electrostimulation
- Other interventions

19

Interventions for Informal Caregiver (CG/P, or caregiver/partner) Well-being (Ch 6)

Location	Intervention	Total Unique Studies	# Analytic Set	# Evidence map	# non-U.S.
Chapter 6 Informal Caregivers	Psychosocial Interventions for Informal Caregiver Wellbeing	122	29	93	74
	Social Support	13	2	11	10
	Lifestyle Interventions	19	1	18	10
	Respite Care	3	0	3	0
	Multicomponent for Informal Caregivers	22	7	15	13
	Other Interventions for Informal Caregiver Wellbeing	6	0	6	4
	Chapter 6 TOTAL		185	39	146

20

Interventions for CG/P Well-being

Low-strength evidence

- Intensive multicomponent intervention with education, group discussion, in-home and phone support sessions, and caregiver feedback for informal caregiver support (REACH II), improved informal caregiver depression at 6 months.

21

CG/P Well-being (cont.)

Evidence was insufficient to draw conclusions

- Psychosocial interventions
- In-person social support
- Mindfulness, meditation, spiritually-focused activities
- Most forms of multicomponent interventions



22

CG/P Well-being (cont.)

Evidence that did not advance to analysis

- Phone-based social support
- Physical activity or other lifestyle interventions
- Respite care
- Other interventions



23

Interventions for Formal Caregivers (Ch 7)

Intervention	Total Unique Studies	# Analytic Set	# Evidence map	# non-U.S.
Formal Caregiver Wellbeing	3	0	3	3
Chapter 7 TOTAL	3	0	3	3



24

Care Interventions for Formal Caregivers

Evidence that did not advance to analysis

- Support such as peer support, stress management, and relaxation techniques

25

Care Delivery (Ch 8)

Location	Intervention	Total Unique Studies	# Analytic Set	# Evidence map	# non-U.S.
Chapter 8 Care Delivery	Care Service Provision	50	6	44	29
	Consultation Services	5	1	4	4
	Case Management	9	3	6	6
	Care Protocols for PLWD	17	0	17	11
	Advance Care Planning	9	1	8	3
	Palliative Care	5	0	5	3
	Other Service Provision Interventions	5	1	4	2
	Care Delivery Models or Programs	31	12	18	18
	Care Delivery Staff Education and Support Needs	46	1	45	27
	Caregiver Staff Training	22	0	22	18
	Informal Caregiver Staff Training	12	0	12	6
	Family Education and Partnering	5	0	5	1
	Multitier Training	7	1	6	2
	Chapter 8 TOTAL	127	19	107	74

26

Care Delivery Models

Low-strength evidence

- Collaborative care models may improve PWD quality of life. This improvement may be very small to small, or it may be larger but concentrated in some not yet identified subgroup of people.
- Collaborative care models may improve system-level markers, including guideline-based quality indicators and reduction in emergency department visits.

27

Care Service Provision

Evidence was insufficient to draw conclusions

- Consultation services
- Case management
- Advance care planning
- Other service provision (decision aid)

Evidence that did not advance to analysis

- Care protocols for PWD
- Palliative care



28

Care Staff Education and Support

Evidence was insufficient to draw conclusions

- Multi-tier training

Evidence that did not advance to analysis

- Formal caregiver staff training
- Informal caregiver staff training
- Family education and partnering



29

Discussion

- Despite a lot of work and often compelling rationales, current available evidence cannot yet provide clear answers about which interventions (or interventions components) offer consistent benefits.
 - Low-strength evidence for collaborative care models
 - Low-strength evidence for REACH II
- On-going research funded post-2015 under stronger rigor/reporting requirements may help resolve some questions.



30

Thoughts for Future Research

- Weaknesses of the current evidence base can be addressed through attention to study design and conduct
 - Small studies biased toward showing larger effect sizes that are reduced or eliminated with later larger studies.
 - Risk of bias largely due to problems with
 - Selection
 - Attrition
 - Fidelity



31

Thoughts for Future Research

- Many populations and outcomes of interest were not represented in the literature.
- Lack of consensus on intervention taxonomies and terms hampers aggregation.
- Fidelity to interventions is a particular challenge.
- Quality of life still often lacking as outcome, as were harms



32

Bigger Thoughts for Future Research


- Research questions related to dissemination and implementation at the outset of intervention design may help prepare dementia care and caregiver interventions for rapid implementation in real-world settings.
- Complex interventions for complex systems are hard to do. Initiatives to creatively redesign research processes in other fields may provide opportunities to learn from and experiment with other ways of doing this science.



33

Questions?


Complete report materials:
<https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>



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34

Supplemental Materials



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35

Study selection criteria - Population

Element	PWD	PWD Caregiver
Population	<p>PWD, including individuals with possible or diagnosed AD/ADRD.</p> <p>PWD Subgroups: Age, sex, sexual orientation/gender identity, race/ethnicity, education, socioeconomic status, prior disability, age at diagnosis, dementia type, dementia severity (e.g. stage of dementia (early stage, moderate, or severe), level of cognitive impairment rate of cognitive decline), family/household characteristics, health insurance, geographic location (e.g. urban, rural), setting type</p>	<p>Informal PWD Caregivers, such as spouses, family, friends, and volunteers</p> <p>Informal PWD Caregiver Subgroups, including age, sex, sexual orientation/gender identity, race/ethnicity, family history of dementia, education, socioeconomic status, employment status, relationship with PWD, living distance from PWD, dementia care training, general health status, caregiving networks, setting type</p> <p>Formal PWD Caregivers, such as certified nursing assistants (CNAs), home health aides, auxiliary workers, personal care aides, hospice aides, promoters or promotores, and community health workers</p> <p>Formal PWD Caregiver Subgroups, including age, sex, race/ethnicity, education, job position, skill, training, general health status, setting type</p>

36

Study selection criteria - Interventions

Element	PWD	PWD Caregiver
Intervention	<p>KQ 1-4. Any nondrug care intervention intended to benefit PWD patients interventions to treat conditions other than dementia, including but not limited to CPOD, and those that use supplements/natural products.</p> <p>(See list of example intervention types in Appendix A.)</p> <p>Guiding Question: Any quality improvement or implementation science study that informs the dissemination or implementation of a care intervention at least low-strength evidence for "test it out" benefits and harms (i.e., NIH Stage Model for Behavioral Intervention Development Stages 3-5)</p>	<p>KQ 5-6. Any care intervention intended to support informal PWD caregivers' well-being except interventions to treat health conditions unrelated to providing care to PWD.</p> <p>KQ 7-8. Any care intervention intended to support formal PWD caregivers' well-being except interventions to treat health conditions unrelated to providing care to PWD.</p> <p>KQ 9-10. Any care delivery intervention to improve how care is delivered. If the training intervention is incorporated as on-going operational procedures into the structure or processes of the organization, interventions carried out by higher education organizations or professional organizations to provide training to and licensed professionals, and continuing education for degraded health professionals are also excluded.</p> <p>(See list of example intervention types in Appendix A.)</p> <p>Guiding Question: Any quality improvement or implementation science study that informs the dissemination or implementation of a care intervention at least low-strength evidence for "test it out" benefits and harms (i.e., NIH Stage Model for Behavioral Intervention Development 3-5)</p>

10/28/2020

37

Study selection criteria - Outcomes

Element	PWD	PWD Caregiver
Outcomes (Generalizability, applicability, management)	Quality of life and subjective well-being	Quality of life and subjective well-being
Figure 1 Framework	<p>Number of care</p> <p>Satisfaction with care</p> <p>Perceived Support</p> <p>Expanded/unexpanded burden (formal caregiver)</p> <p>Health-related outcomes: Psychosocial health (e.g., depression, anxiety), cognition, and cognition (including memory), Function (e.g., ADL, IADL, ability to care for one's self, ability to manage medication)</p> <p>Drug utilization</p> <p>Use of medicines</p> <p>Use of services/resources</p> <p>Harm reduction (e.g. driving, firearms)</p> <p>Palliative care/hospice outcomes</p> <p>Completion of advanced directives</p> <p>Control using emergency</p> <p>Concordance with preferred location of death</p> <p>Social/Community level outcomes</p> <p>Engagement in community activities, Personal inclusion</p> <p>Self-rated quality</p> <p>Utilization of healthcare services/outcomes</p> <p>Admissions to emergency</p> <p>Access to care and services</p> <p>Use of social support</p> <p>Household admission and readmission</p> <p>Primary, Secondary caregiver/ Care usage</p> <p>Quality of care and services (e.g., overall/evaluation of effectiveness, antibiotic, other quality care metrics.)</p> <p>Several costs, including caregiver/time/expense spent on activities</p> <p>Harms, including isolation, loneliness, perceived stigma, social exclusion or stigma, older abuse (e.g., physical harm, abuse, neglect, caregiver/ family distress)</p>	<p>Number of care</p> <p>Satisfaction with care for PWD (informal caregiver)</p> <p>Perceived Support</p> <p>Expanded/unexpanded burden (informal caregiver)</p> <p>Health-related outcomes: Psychosocial health (e.g., depression, anxiety), cognitive function (e.g., informant or cutoff), Sleep problems (e.g., informant or cutoff), Sleep health issues</p> <p>Health behaviors (e.g., exercise, substance use)</p> <p>Emergency use of services</p> <p>Costs/denial to manage caregiver needs</p> <p>Social/Community level outcomes (informal caregiver): Engagement in community activities, Perceived inclusion, Safety perceived safety</p> <p>Tumor and infection (formal caregiver)</p> <p>Utilization of healthcare services (e.g., physician visits, antidepressant or antipsychotic medication usage)</p> <p>Several costs including caregiver/time/expense spent on activities</p> <p>Harms, including isolation, loneliness, perceived stigma, caregiver PTSD</p>

10/28/2020

38

Study selection criteria - Timing and Settings

Element	PWD	PWD Caregiver
Timing	No minimum duration or follow up	No minimum duration or follow up
Setting	Any setting, no exclusion based on geographic location or setting. Includes home, home health care, adult day care, acute care settings, social service agencies, nursing homes, assisted living, memory care units, hospice, rehabilitation centers/skilled nursing facilities, long-distance caregiving, and nonplace-based settings.	Any setting, no exclusion based on geographic locations or setting. Includes home, home health care, adult day care, acute care settings, social service agencies, nursing homes, assisted living, memory care units, hospice, rehabilitation centers/skilled nursing facilities, long-distance caregiving, and nonplace-based settings.

10/28/2020

39

Study Selection Criteria - other

Category	Criteria for Inclusion
Study Enrollment	Adults with possible or diagnosed AD/ADRD. No age requirement is made, that is, early onset disease that may be experienced by people with Down syndrome or other genetic risk factors are included. Study populations may include adults with mild cognitive impairment (MCI) if 15% or less of total sample, or must report results for dementia population separately.
Study Objective	KG 1-2: Evaluate benefits and harms of care interventions for BPSD symptoms in PWD KG 3-4: Evaluate benefits and harms of care interventions for quality of life, function, or non-BPSD symptoms in PWD KG 5-6: Evaluate benefits and harms of care interventions for quality of life and health outcomes of informal caregivers for PWD KG 7-8: Evaluate benefits and harms of care interventions for quality of life and health outcomes of formal caregivers for PWD KG 9-10: Evaluate benefits and harms of care delivery interventions that address how care is delivered KG subquestions: Evaluate possible effect modifiers of intervention, benefits and harms
Study Design	RCTs, and prospective studies with concurrent comparator arms, and at least 10 participants per arm at study analysis.* Interrupted time series with at least 3 measures both pre- and post-intervention.
Outcomes	Outcomes listed in Table 1. Actual outcome measures will be defined by study authors. Common measures are provided in Appendix A. We will only include studies with immune function, turnover, or retention of caregivers. If the study also includes another PWD or quality outcomes, that is, we will not include the study if it only examines turnover or retention as an intermediate outcome in isolation.
Publication type	Published in peer-reviewed journals and grey literature with full text available (if sufficient information to assess eligibility and risk of bias are provided). Letters and abstracts are excluded due to the inability of such short publications to provide the information needed to fully describe the interventions.
Language of Publication	English only, due to resource limitations

40

#1

Risk of Bias of Individual Studies

- Overall confidence that the results were believable given the study limitations – low, moderate or high
- Relevant components included:
 - Participant selection
 - Method of randomization or selection
 - Blinding/Independent outcome assessors
 - Allocation concealment
 - Attrition
 - Fidelity to intervention
- Dual, independent assessment

41

#2

Strength of Evidence

- Confidence that the findings will not change with further research – insufficient, low, moderate, or high
- Domains:
 - Study limitations (overall risk of bias of the body of evidence)
 - Directness (single, direct link between intervention and outcome)
 - Consistency (similarity of effect direction and size)
 - Precision (degree of certainty around an estimate)
 - Reporting bias
- Strength of evidence assessed cautiously
 - Inability to pool due to heterogeneity in populations, interventions, outcomes, and settings
 - large number of comparisons with findings where intervention and comparison results not statistically significant.

42

Disposition of Comments Table

- We responded to all public and peer comments in the Disposition of Comments Table.
- <https://effectivehealthcare.ahrq.gov/sites/default/files/cer-231-dementia-care-interventions-comments.pdf>



43

Disposition of Comments Table Supplement

- Supplement provides full, unedited pdfs of letters submitted
- Several included policy recommendations that were beyond the scope of the EPC report.
- <https://effectivehealthcare.ahrq.gov/sites/default/files/care-interventions-pwd-comments-suppl.pdf>



44
