Caregiver Intervention Research: Now and into the Future

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Objectives

• Key frameworks
• Progress to date
• Emerging recommendations
Key Frameworks
Direct and Indirect Pathways for Nonpharmacological Interventions Supporting Family Caregivers and Persons Living with Dementia

Person with Dementia
- Etiology
- Disease Stage
- Physical Health
- Cognitive functioning
- Preferences

Caregiver
- Relationship
- Closeness
- Gender/Race/ethnicity/culture
- Employment
- Life course
- Readiness, Style, Hours caregiving

Care setting

Non-pharmacological Interventions

Family Caregiver Outcomes
- Mood
- Quality of life
- Efficacy
- Skills
- Upset/burden
- Physical health

Person with Dementia Outcomes
- Mood
- Behaviors
- Quality of life
- Function
- Engagement
- Physical health
- Aging in place

Caregiver
- Behavioral, Cognitive, Mood, Skills, Health, Resources, Financial

Person with Dementia
- Physical, cognitive, emotional, engagement

Environment
- Safety
- Under/over Stimulation
- Wayfinding

Direct and Indirect Pathways for Supporting Family Caregivers and Persons Living with Dementia

Person with Dementia
- Etiology
- Disease Stage
- Physical Health
- Cognitive functioning
- Preferences

Caregiver
- Relationship
  - Closeness
- Gender/Race/ethnicity/culture
- Employment
- Life course
- Readiness, Style, Hours caregiving

Care setting

Pharmacological Interventions (and/or Combined with non-pharmacological)

Family Caregiver Outcomes
- Mood
- Quality of life
- Efficacy
- Skills
- Upset/burden
- Physical health

Person with Dementia Outcomes
- Mood
- Behaviors
- Quality of life
- Function
- Engagement
- Physical health
- Aging in place

Pathway for Supporting Formal Caregivers

**Person with Dementia**
- Etiology
- Disease Stage
- Physical Health
- Cognitive functioning
- Preferences

**Caregiver**
- Double and Triple caregivers

**Care setting**

**Caregiver Training**
- Knowledge
- Skills
- Communications
- Acceptability & feasibility

**Intervention**
- Targets

**Formal Caregivers Outcomes**
- Knowledge
- Skills
- Efficacy
- Job satisfaction
- Retention
- Mood/affect

**Person with Dementia Outcomes**
- Mood
- Behaviors
- Quality of life
- Function
- Engagement
- Physical health
Categories of Searches

1. Meta analyses and systematic reviews of efficacy trials concerning nonpharmacological intervention effects for:
   - Formal caregivers
   - Family caregivers

2. Meta analyses and systematic reviews concerning impact of dementia drugs on caregivers

3. Individual studies of translation, effectiveness and pragmatic trials

4. Published protocols of trials to understand near future interventions and their outcomes

5. Global perspective
   - Asia
   - Latin America
   - Europe

6. Reports:
   - National research summit recommendations
   - NASEM Family caregiver report

**CONSIDERATIONS**
- Setting
- Disease stage
- Type of intervention
- Intervention characteristics
Non-pharmacological Interventions for Family Caregivers


Formal Providers
- >60 studies (feasibility, pilot, efficacy)

Pragmatic Trials
Hybrid Designs (in progress)

Stage I: Intervention Generation/Refinement

Stage II: Efficacy (Research Clinics)

Stage III: Effectiveness

Stage IV: Implementation & Dissemination

Stage V: Basic research

*Stage 0: Basic research

>200 Efficacy Trials
> 28 meta analyses & systematic reviews of trials

Asia
- 30 Efficacy Trials
  - in progress

Latin America
- in progress

Europe
- in progress

Translational phase

Formal Providers

Translational studies

About 16 Translational studies

Caution

Formal Providers

Pragmatic Trials
Hybrid Designs (in progress)
Emerging Recommendations
## Emerging Areas for Research Recommendations

<table>
<thead>
<tr>
<th>Domain</th>
<th>Example</th>
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<tr>
<td>Improve clinical relevance of trials</td>
<td>• Examine mechanisms or why interventions have positive effects</td>
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<td>• Evaluate dose-response relationships and long term effects</td>
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<td>• Link intervention to disease stage</td>
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<td>• Evaluate cost and willingness to pay</td>
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<td>• Determine and report clinical significance</td>
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<td>Adequately describe interventions to enable reproducibility, replication, adaptation, widespread adoption</td>
<td>• Identify theory base guiding intervention</td>
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<td>• Describe interventionist characteristics</td>
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<td>• Detail number of sessions, duration and length of intervention</td>
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<td>• Describe role of family caregiver in delivering intervention or supporting use of strategies for person with dementia</td>
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<td>• Describe treatment fidelity plan and adherence rates</td>
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<td>• Describe type of blinding applied to trial</td>
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<td>Examine outcomes of relevance to different stakeholders</td>
<td>Derive consensus in the field as to set of outcome measures for cross-study comparisons</td>
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<td>Consider use of objective (performance-based), biological and subjective measures</td>
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<td>Enhance study designs</td>
<td>• Locate design to stage model</td>
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<td>• Mediation (mechanisms of action)</td>
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<td>• Use pragmatic trial designs, hybrid designs and/or mixed methods for effectiveness and implementation</td>
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<td>• Standardize attention control groups used across studies to address attention, attrition</td>
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<td>• Examine long-term treatments and treatment effects</td>
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<td>Target &amp; tailor to caregiver needs, lived experience, readiness, style, dementia stage, persons needs, and families from different race/ethnic groups</td>
<td>• Address broader range of needs and for different stages, preferences, values</td>
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<td>• Examine dyadic relationships and which types of interventions impact carer and person;</td>
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<td>• Move beyond isolating primary caregiver and examine informal networks, family decision-making</td>
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<td>Engage in implementation science</td>
<td>• Move evidence to real world settings using hybrid and pragmatic trial designs</td>
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<td>• Test implementation strategies for wide scale implementation/dissemination</td>
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<td>• Examine issues related to sustainability and scalability</td>
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<td>• Identify barriers to access for race/ethnic groups</td>
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