Supporting Family Caregivers Effectively: Lessons Learned from Research

Linda Olivia Nichols, PhD
Caregiver Center, VA Memphis
Preventive and Internal Medicine, University of Tennessee Health Science Center

How we know

• 7 meta-analyses and 17 systematic reviews of randomized clinical trials (RCTs) published 1966-2013
• 200 interventions tested with randomized designs
• Interventions
  - care coordination
  - behavioral management
  - professional support
  - respite
  - skills training
  - counseling/psychotherapy
  - multi-component approaches
  - psycho-education
  - self-care/relaxation


What we know – the evidence

• Outcomes and interventions that impact*
  – Knowledge – psycho-education
  – Well-being – psycho-education, multi-component, skills training, counseling, care coordination
  – Anxiety – relaxation
  – Confidence/self-efficacy – psycho-education, skills training, multi-component
  – Time to institutionalization – multi-component, counseling
  – Behavioral symptoms# – multi-component, skills training, care coordination

• Costs
  – Tailored Activity Program (8 sessions, 4 months) - $941, $2.37 per day
  – REACH II (12 individual and 5 telephone support group sessions, 6 months) - $1,214, $4.96 per day
  – REACH VA (12 sessions, 6 months) - $2.93 per day (travel not included) patient care costs were 33.6% lower during year following intervention

*Small to medium effect sizes
#Similar to or greater than those for AD drugs

What works – the evidence

• Tailoring – adjust dose, intensity, and focus based on risk/need profile
  – Assess caregiver’s risks, needs, and preferences

• Address multiple areas of identified need or risk

• Multi-component approaches vs. single approaches
  – Education, support, skills building (e.g., problem solving, cognitive reframing, stress management, communication)

• Active involvement in learning skills vs. provision of information or instructions

• Longer or episodic/booster support over duration of caregiving
What is missing – the gaps

- Translation and implementation – 6/200 interventions translated
- Not evaluated in real-world and delivery settings
  - Subject to funding/payment constraints
  - Cost and cost effectiveness
- Lack of data on broader caregiving experience
  - Long term outcomes
  - Outcomes across the spectrum of dementia and cognitive impairment levels
  - Co-morbid chronic diseases, complex medical conditions
  - Multiple caregivers
  - Healthcare use of dyad
  - Financial/employment strain
- Limited data on diverse caregivers – race, ethnicity, economic level, rural/low resource settings, LGBT, non-family, long-distance
- Not clear why interventions work or who might benefit most from a certain intervention

What are implementation steps

Implementation model steps*

- Exploration and adoption
  - Determine if intervention needed, assess match between it and organization
- Program installation
  - Install structural supports, training, funding
- Initial implementation
  - Changes in practice, education, time vs. status quo, fear of change, inertia
- Full operation
  - Program works, organization supportive
- Innovation
  - Refine and expand, how to use with fidelity, evaluate
- Sustainability
  - Funding, intervention remain a priority as organization changes

REACH VA example

- Identified national and local partners and sites, developed implementation manual, secured funding for translation pilot
- Funded as a clinical program, refined webinar training and certification, increased coaching
- VA staff wanted changes to fit their needs and those of the facility and caregivers – fewer sessions, more delivery modes
- Modified per staff and caregiver comments, workload capture, CPT codes, CEUs for training
- EMR templates, evaluated – caregiver outcomes similar to RCT and pilot translation
- Caregiver Center funding, SCI/D, PTSD, ALS, MS, expanded to other models of delivery – Caregiver Center staff and national clinical staff

*Fixsen, et al., 2005
What is needed – recommendations

- **Increase implementation research** – HHS, VA, private funders, health care and social service systems
  - Embed into real world settings – clinical sites, healthcare systems, community
  - Build in sustainability – make interventions subject to funding/payment constraints
  - Examine cost and cost effectiveness
  - Explore how intervention could fit into existing staffing levels and whether staff can be re-trained
- **Expand outcomes** that reflect caregiver, person with dementia, professional, and funder interests – HHS, VA, private funders, researchers
  - Clinically meaningful
  - Healthcare use for dyad
  - Long term outcomes
  - Outcomes across spectrum of dementia types and cognitive impairment levels
  - Financial distress, employment strain
- **Determine effectiveness** for different subgroups of caregivers – federal and private funders, researchers, communities
  - Men, minority populations, rural, long distance, multiple, non-family, LGBT

What is needed – recommendations

- **Increase implementation research** – HHS, VA, private funders, health care and social service systems
  - Embed into real world settings – clinical sites, healthcare systems, community
  - Build in sustainability – make interventions subject to funding/payment constraints
  - Examine cost and cost effectiveness
  - Explore how intervention could fit into existing staffing levels and whether staff can be re-trained
- **Expand outcomes** that reflect caregiver, person with dementia, professional, and funder interests – HHS, VA, private funders, researchers
  - Clinically meaningful
  - Healthcare use for dyad
  - Long term outcomes
  - Outcomes across spectrum of dementia types and cognitive impairment levels
  - Financial distress, employment strain
- **Determine effectiveness** for different subgroups of caregivers – federal and private funders, researchers, communities
  - Men, minority populations, rural, long distance, multiple, non-family, LGBT
Final thoughts

• Funding of dementia care must be a societal priority
  – Science is there – magnitude of benefit and quality of evidence exceed those of pharmacologic therapies

• How to accomplish
  – Grass-roots demand
  – Prioritization
  – Medicalize dementia care

“If these interventions were drugs, it is hard to believe that they would not be on the fast track to approval.”
Covinsky, 2006