Accelerating Translation of Knowledge to Community Practices for Older Adults Workshop Series

Family Caregiving to Persons with Dementia

November 19-20, 2013
Sheraton New Orleans / New Orleans Marriot
New Orleans, Louisiana

A pre-conference workshop in conjunction with
The Gerontological Society of America
Annual Scientific Meeting

Funding for this conference was made possible in part by R13 AG044930-01 from the National Institute on Aging. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute on Aging or the National Institutes of Health. The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services; nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S Government.
Accelerating Translation of Knowledge to Community Practices for Older Adults Workshop Series 2013-2014

Objectives of the Workshop Series

- Clarify the state of translational research and identify next steps in intervention development, adaptation, implementation, and dissemination on a selected topic;
- Identify opportunities and challenges for translational work from the perspective of community partners; and
- Explore interdisciplinary and agency partnerships to move this work forward.

Focuses for the 2-year program are:

- 2012 Family Caregiving to Persons with Dementia
- 2013 Disability and Aging
Thanks to our Sponsors

National Center on Gerontological Social Work Excellence
Friedman Center for Aging, Washington University
National Institute on Aging (R13 AG044930-01)
Accelerating Translation of Knowledge to Community Practices for Older Adults Workshop Series

Family Caregiving to Persons with Dementia

November 19-20, 2013

PROGRAM AGENDA

Accelerating Translation of Knowledge to Community Practices for Older Adults:
Family Caregiving to Persons with Dementia

The Gerontological Society of America and the National Center on Gerontological Social Work Excellence aim to energize and focus applied researchers to translate knowledge into widespread and sustainable practices in community-based organizations serving older adults. The first workshop in this series focuses on family caregiving to persons with dementia.

Support is provided by a grant from NIA (R13 AG044930-01), the John A. Hartford Foundation, and the Friedman Center for Aging at Washington University.

TUESDAY, NOVEMBER 19, 2013   Marriott Salon G-H

5:00pm to 7:00pm   Welcome and overview
Linda Harootyan, Deputy Executive Director, GSA
Nancy Morrow-Howell, Director, Friedman Center for Aging, Washington University

Keynote address
Dissemination and implementation research: Where we are and where we are going
Enola Proctor, Director of Center for Dissemination and Implementation Research, Washington University, St. Louis, MO

Reception and poster session
Barbara Berkman, Chair, National Advisory Board, National Center on Gerontological Social Work Excellence

WEDNESDAY, NOVEMBER 20, 2013   Marriott Salon G-H

9:00am   Welcome and introductions
Nancy Morrow-Howell, Washington University
9:05am- 9:45am  Assessing the state of translation work in caregiving: Have we been successful and where do we go from here?
Laura Gitlin, PhD, Professor, Johns Hopkins School of Nursing
Director, Center for Innovative Care in Aging, Johns Hopkins School of Nursing

9:45am-10:30am  What makes an intervention evidence-based? Criteria and definitions for advancing dementia caregiver interventions
Brent Mausbach, PhD, Associate Professor, Department of Psychiatry, University of California, San Diego

10:30am-10:45am  Break

10:45am-11:30am  REACH Primary Care: Translation of REACH II into healthcare
Alan Stevens, PhD, Professor, Texas A&M Health Science Center Director, Aging and Care Research Program, Scott & White Memorial Hospital

11:30am-12:15pm  Implementation of Effective Dementia Caregiver Treatments in Ethnically Diverse Populations
Veronica Cardenas, PhD, Assistant Clinical Professor, University of California, San Diego; Cultural Consultant, Southern Caregiver Resource Center

12:30pm-1:30pm  Lunch and networking (lunch provided)

1:30-3:15PM  Community-based perspectives on implementation and dissemination research
Moderator: Laura Gitlin
Panelists: Kurt Buske, MS, Associate Director, Southern Caregiver Resource Center
          Cathy Piersol, PhD, MS, OTR/L Clinical Director, Jefferson Elder Care
          Laura Bauer, MPA, Director of National Initiatives, Rosalynn Carter Institute for Caregiving, Georgia Southwestern State University

Questions that the panelists will address:
- What are key considerations and challenges in implementing an evidence-based program?
- How are programs sustained after grant funding ends?
- How do you evaluate fidelity or determine that you are implementing the program the way it was originally tested or intended?
- How do you evaluate program reach to the community you are targeting as well as the program effectiveness?
- How can we create an easier path for more community-based organizations to implement evidence-based practices?
- What needs do caregivers have that programs are not addressing?
- What advice would you give researchers seeking to develop new interventions for family caregivers?

3:15pm-3:30pm  Break

3:30pm-5:00pm  Small and large group discussions to develop next steps in translational work and explore opportunities for interdisciplinary collaborations, community partners and funding mechanisms

Evaluation and Wrap Up
Nancy Morrow-Howell, MSW, PhD, has been on the faculty at the George Warren Brown School of Social Work since 1987 and was named the Ralph and Muriel Pumphrey Professor of Social Work in 2003. In January, 2012, she was appointed Director of the Harvey A. Friedman Center for Aging at Washington University. Dr. Morrow-Howell is a national leader in gerontology, widely known for her work on productive and civic engagement of older adults. She is editor of the book Productive Aging, published by Johns Hopkins University Press. With support from private foundations and the National Institute on Aging, she explores strategies to maximize the engagement of older adults in productive roles. She has organized international conferences on productive aging and continues to collaborate with gerontology colleagues in Asia. Dr. Morrow-Howell is a fellow of the Gerontological Society of America (GSA), past vice president of the Association for Gerontological Education in Social Work (AGE-SW), and was actively involved with the John A. Hartford Geriatric Social Work Initiative. She was the recipient of the 2011 Career Achievement Award from the Association for Gerontology Education in Social Work, the 2012 Author Holly Compton Faculty Award from Washington University, and the 2013 Distinguished Career Achievement Award from the Society for Social Work and Research.

Enola Proctor, PhD, is the Frank J. Bruno Professor of Social Work Research and Associate Dean for Faculty at the George Warren Brown School of Social Work at Washington University in St. Louis, MO. Her research to improve service quality in mental health and in publicly funded settings has been supported by grants from the National Institute of Mental Health, the National Institute of Aging, and the Agency for Healthcare Research and Quality. Dr. Proctor leads several initiatives to advance the science of dissemination and implementation research, including the Implementation Research Institute (IRI), which trains mental health implementation researchers. At Washington University, she directs the Dissemination and Implementation Research Core (DIRC) of Washington University’s Institute for Clinical and Translational Science, the Center for Dissemination and Implementation for the Institute for Public Health, and dissemination and implementation research cores for two NIH funded centers. Her books include Dissemination and Implementation Research in Health: Translating Science to Practice, published in 2012, by Oxford University Press, and Developing Practice Guidelines for Social Work Interventions: Issues, Methods, and Research Agenda published in 2003 by Columbia University Press. She served as Editor in Chief for Social Work Research published by the National Association of Social Workers (NASW). She was a member of the National Advisory Council for the NIMH (2006-2010) and is a member of the Editorial Board for Implementation Science. She has received numerous awards including the Lifetime Achievement Award from the Society for Social Work and Research (2002) and Knee-Wittman Award for Lifetime Achievement in Health and Mental Health Practice (2011) from the National Association of Social Workers, and Washington University’s highest faculty honor, the Compton Award (2009). In 2010, she was elected to the inaugural class of the American Academy of Social Work and Social Welfare and its Board of Directors (2010-11).

Laura N. Gitlin, PhD, is an applied research sociologist, recently joined the Johns Hopkins University as Professor in the Department of Community Public Health, School of Nursing, with joint appointments in the Department of Psychiatry, and Division of Geriatrics and Gerontology, School of Medicine. She is the director of a new initiative, the Center for Innovative Care in Aging, which focuses on developing, testing and implementing health promoting interventions and models of care for older adults and their families. Dr. Gitlin is internationally and nationally recognized for her research programs on nonpharmacologic approaches in dementia care, family caregiving, functional disability, and mental health.
In recognition of the great level of distress associated with being a dementia caregiver, research on interventions to improve well-being, and also present data from a survey of community agencies in San Diego on who provides the “evidence-based” interventions for caregivers. We will present information on a variety of these interventions (e.g., what they involve; barriers to implementing interventions in the field, and design trials to test methods of improving the implementation and dissemination of evidence-based practices for caregivers.

Brent T Mausbach, PhD, is an Associate Professor in the Department of Psychiatry at the University of California San Diego (UCSD). For the past 10 years he has studied the effects of Alzheimer’s caregiver stress on both mental and physical health outcomes. Some of his most notable work in this area involves studying how resiliency factors prevent the effects of stress on biological markers of cardiovascular disease risk and immune system function. Based on this preliminary work, he designed and tested the efficacy of a brief behavioral activation psychotherapy for improving overall caregiver well-being, including overall caregiver mood and the biomarkers D-dimer (a measure of blood coagulation) and Interleukin-6 (a measure of inflammation). Results of this trial were recently accepted for publication and showed that in addition to reducing depressive symptoms, a brief (4-session) intervention also significantly improved IL-6 relative to a support-and-information intervention. Based on his work with efficacy trials, Dr Mausbach recently became interested in translating his interventions into the “real world”, where community agencies and caregivers can take advantage of interventions that “work.” His long-term goals with caregiver research are to examine barriers to implementing interventions in the field, and design trials to test methods of improving the implementation and dissemination of evidence-based practices for caregivers.

In recognition of the great level of distress associated with being a dementia caregiver, research on interventions to improve well-being in dementia caregivers has been ongoing for more than 2 decades. The purpose of this intervention research has been to establish interventions that work well to reduce distress in dementia caregivers. The sum of these findings is that there are a number of “evidence-based” interventions for caregivers. We will present information on a variety of these interventions (e.g., what they involve; how they work), and also present data from a survey of community agencies in San Diego on who provides the interventions.

Veronica Cardenas, Ph.D., is a bilingual licensed Clinical Psychologist and Assistant Professor at the University of California, San Diego. Her areas of research expertise are in the development and evaluation of behavioral skills training treatment interventions aimed at reducing physical and psychological distress in underserved community-dwelling older adults. Much of her work has focused specifically on the experience of U.S. older adult Latinos struggling with a severe mental illness along with the impact this has on family members involved in their care. She is currently a Co-Investigator and Cultural Consultant on a large scale San Diego County grant evaluating the implementation of a Spanish language evidenced-based treatment designed to reduce symptomatology and increase quality of life in Latino dementia caregivers.

Kurt Buske, MSW, holds a Bachelor’s degree in Human Resources Management and a Master’s degree in Social Work from San Diego State University. Kurt has over 15 years of management experience in the non-profit, social services field and is currently the Associate Director at Southern Caregiver Resource Center, a position he has held for 10 years. Southern Caregiver Resource Center, a private, independent non-profit agency, was established in 1987 and provides a full range of free support services to family caregivers in San Diego County. In his role at Southern Caregiver Resource Center, Kurt is responsible for numerous functions including strategic planning, staff management, program implementation, program management and program evaluation. Kurt has been responsible for implementing and managing a nationally recognized version of the evidence-based REACH (Resources for Enhancing Alzheimer’s Caregiver Health) intervention at Southern Caregiver Resource Center, exclusively intended to serve Latino caregivers.

Catherine (Cathy) Verrier Piersol, PhD, OTR/L, is assistant professor in the Department of Occupational Therapy and clinical director of Jefferson Elder Care, in the Jefferson School of Health Professions. Jefferson Elder Care was established to develop and implement evidence-based non-pharmacologic clinical services and professional training programs in the areas of dementia care and aging in place. Dr. Piersol is a practicing occupational therapist with over 30 years of experience including program administration, education, and training. She recently completed her dissertation which examined caregiver appraisal of functional capacity in family members with dementia. She served as an interventionist on several randomized trials conducted at Thomas Jefferson University testing non-pharmacological approaches to dementia care, under the direction of Dr. Laura Gitlin. Currently Dr. Piersol is implementing a program for low income elders with dementia, funded by the Pew Charitable Trust. She has presented extensively on a variety of topics including dementia care, community practice, and professional development. Her publications include a health home textbook, which is widely used by students and practitioners.
Laura J. Bauer, MPA, is Director of National Initiatives for the Rosalynn Carter Institute for Caregiving (RCI) at Georgia Southwestern State University (GSW) in Americus, Georgia. She is Co-author of the RCI’s signature training program, *Caring for You, Caring for Me – Education and Support for Family and Professional Caregivers, 2nd Edition*; Laura has co-authored journal articles in *Health & Social Work* (2006), *Educational Gerontology* (2004), *Generations* (2010), and *Aging Today* (2012) and contributed chapters to *Voices of Caregiving* (LaChance Publishing, 2008) and *Re-Creating Neighborhoods for Successful Aging* (Health Professions Press, 2008). Laura is a Certified Trainer in 5 evidence-based caregiving interventions: Savvy Caregiver, The Future is Now, RCI REACH, Care Consultation, and Operation Family Caregiver (Problem-Solving Training for Family Caregivers of Returning Service Members). She also teaches 3 courses in the RCI’s Certificate in Caregiving Program at Georgia Southwestern. Ms. Bauer has previously worked as a counselor for at-risk youth at an outdoor therapeutic program and as a child abuse investigator. She holds a Bachelor of Science in Psychology and a Master of Public Administration from Columbus State University in Columbus, Georgia and also holds a Certificate in Gerontology from GSW. Laura sits on the Board of Governors for the We Are Family Foundation in NYC and on the Board of Directors for the Mattie J. T. Stepanek Foundation. She is a member of Phi Kappa Phi, Pi Alpha Alpha, and the American Association of University Women. An advocate for social justice, the environment, caregiving issues, and peace; Laura enjoys hiking, camping, fishing, photography, bird-watching, dancing, and music of all genres. She and her dog Katie are a certified Pet Partner animal therapy team; regularly volunteering their services at local elementary schools, hospices, hospitals and nursing homes.
Accelerating Translation of Knowledge to Community Practices for Older Adults: Family Caregiving to Persons with Dementia

Junior Investigator Travel Awardees

Jung Kwak, PhD
Helen Bader School of Social Welfare
University of Wisconsin, Milwaukee
Poster Title: Results of a randomized trial of an innovative care management protocol for family caregivers

Shahrzad Mavandadi, PhD
Mental Illness Research, Education, and Clinical Center
Philadelphia VA Medical Center &
Department of Psychiatry
Perelman School of Medicine, University of Pennsylvania
(not able to attend)

Heehyul Moon, PhD, MSW
Postdoctoral Fellow
Carolina Program for Health and Aging Research
Institute on Aging
University of North Carolina Chapel Hill
Poster Title: Predictors of Discrepancy Between Care Recipients with Early-Stage Dementia and Their Family Caregivers on Perceptions of the Care Recipients' Quality of Life

Becky Brott Powers, MD
Geriatrics Research Fellow
Poster Title: Geriatric Research Education and Clinical Center VA Pittsburgh, Pennsylvania Poster Title: Clinical Video Telehealth for Dementia Assessment: Creation of a TeleDEMENTIA Clinic

Sunshine Rote, PhD
Sealy Center on Aging
The University of Texas Medical Branch, Galveston
Poster Title: The influence of Mother’s Health on Daughter’s Distress: Caregiving among Mexican American Adults

Mindi Spencer, PhD
Department of Health Promotion, Education, and Behavior
University of South Carolina
Poster Title: “The Influence of Subjective U.S. and Community Social Status on Depressive Symptomatology among African American and White Caregivers.”

Fei Sun, PhD
School of Social Work
Arizona State University
Poster Title: Influence of Cultural Factors on Coping with Behavioral Problems of Alzheimer’s Patients: Experience of Chinese American Caregivers in Phoenix and Their Counterparts in Shanghai

Tracy Wharton, PhD, LCSW
NIMH Research Fellow
Department of Psychiatry, University of Michigan
VA Ann Arbor Center for Clinical Management Research
Poster Title: What is known about dementia care recipient violence and aggression against caregivers?

Andrea Yevchak, PhD, GCNS-BC, RN
Duquesne University School of Nursing
Poster Title: Informal Caregiver Recognition, Detection, and Reporting of Symptoms of Delirium in Hospitalized Older Adults with Dementia
Optimal Aging Through Research

New Orleans • Louisiana

GSA Annual Scientific Meeting

NOVEMBER 20–24, 2013
Sheraton New Orleans • New Orleans Marriott

Accelerating Translation of Knowledge to Community Practices for Older Adults

2013 Family Caregiving to Persons with Dementia
Thanks to funders and sponsors

- The Gerontological Society of America
- National Center on Gerontological Social Work Excellence
- Friedman Center for Aging, Washington University

National Institute on Aging (R13 AG044930-01)
PIs: Linda Harootyan and Nancy Morrow-Howell
Senior consultant: Barbara Berkman

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1) Clarify the state of translational research and identify next steps in intervention development, adaptation, implementation, and dissemination on a selected topic;

2) Identify opportunities and challenges for translational work from the perspective of community partners;

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Family Caregiving to Persons with Dementia

Laura Gitlin, Chair

Brent Mausbach
Alan Stevens
Veronica Cardenas

Cathy Piersol
Kurt Buske
Laura Bauer

Dissemination and Implementation Research: Where we are and where we are going

Enola Proctor
Director of Center for Dissemination and Implementation Research, Washington University in St. Louis
Dissemination and Implementation Research: Where are we and where are we going?

Enola Proctor
GSA and NCGSW
November 19, 2013

Session overview

1. What is D&I research and what does it take?

2. Where are we?
   - Available tools, state of the science,
   - state of the practice

3. Where are we going?
Part one: what is D&I research?

NIH Definitions*

Dissemination Research:
– study of how & when research evidence spreads throughout agencies, organizations, and front line workers.

Implementation Research:
– scientific study of how to move evidence-based interventions into healthcare practice and policy

**PAR13-055

What is implementation research?

“Research to inform how to make the right thing to do the easy thing to do.”

-Carolyn Clancy, Agency for Healthcare Research and Quality
Implementation is about improving care

The care that “could be” vs The care that “is”

What quality gaps are of concern?

The translational continuum

T1 = basic research science translated to humans
T2 = research translated into clinical practice; knowledge translating to patients
T3 = effectiveness, cost effectiveness, CER
T4 = research on translating effective healthcare practices into new sites; dissemination research & implementation research
Implementation Outcomes: Key Concepts

- Acceptability
- Adoption
- Appropriateness
- Feasibility
- Fidelity
- Implementation cost
- Penetration
- Sustainability

Proctor et al 2009 Admin. & Pol. in Mental Health Services
Implementation research studies...

**Key variables:**
- behavior of healthcare professionals and support staff
- healthcare organizations (culture/ context)
- healthcare consumers and family members
- policymakers in context as key variables

**Key outcomes:**
- sustainable adoption, implementation and uptake of evidence-based interventions

Part two: Where are we? What do we know?

- The need: Service quality
- Evidence-based interventions
- Implementation strategies
- The “where:” Context, receptivity, capability
- Theory
- Research Methods
The need: Quality gaps abound

US mental health care: “D grade” (NAMI)

AHRQ: Physical healthcare is improving, but no improvement in depression care (AHRQ’s 2010 Health Care Quality Report)

Household data: <10% of the U.S. population with a serious mental disorder receives adequate care (Kessler et al, 2005)

Racial disparities in care

Quality of service in caregiving?

How big is the gap? Where are the gaps?

Knowledge of service quality

The quality chasm reflected by:

\[
\% = \frac{\text{number receiving EB care}}{\text{total service recipients}}
\]

What is the quality of service in family caregiving?
Evidence-based interventions

• What is the supply of EB interventions?
• How strong is the evidence?
• How relevant is the evidence?

Sources of evidence reviews

• The Cochrane Collaboration (standard setter)
• Rosalyn Carter Institute for Caregiving
• National Registry of Evidence-based Programs & Practices (SAMHSA rating & classification system)
• AHRQ Evidence-based Practice Centers
Repertoire of EB interventions

Are interventions ready for D&I?
Balancing Tx discovery v Tx roll out

When we have effective interventions, it’s time to delivery them
Implementation Strategies:
Definition

*Systematic intervention process to adopt and integrate evidence-based healthcare innovations into usual care*

Active ingredient in processes for moving EST’s and QI’s into usual care

*Powell, McMillen, Proctor et al., Medical Care Research and Review, 2012

Strategies Definitions:
A Compilation or “Menu”

68 implementation strategies and definitions, grouped by six key processes

– Planning
– Educating
– Financing
– Restructuring
– Managing quality
– Attending to policy context

* Powell, McMillen, Proctor et al., Medical Care Research and Review, 2012
Implementation Strategies: Complexity*

**Discrete**
- involve one process or action, such as “meetings,” “reminders”

**Multifaceted**
- uses two or more discrete strategies, such as “training + technical assistance”

**Blended**
- several discrete strategies are interwoven & packaged as protocolized or branded strategies, such as “ARC,” IHI Framework fro Spread”

*Powell, McMillen, Proctor et al., 2012
**Grimshaw et al., 2001, Grol & Grimshaw, 2003

Strategies: What do we know?

- Passive dissemination is ineffective (publishing articles, issuing a memo, “edict”)
- Training is most frequently used strategy
- Multi-component, multilevel are more effective
Context: what do we know?

Context matters
“It’s all about context...”

Practice change needs to aligned with
- Priorities and trends in policy ecology*
- Agency infrastructure, system antecedents **

Barriers are documented at every level

*Raghavan, 2009
** Emmons, 2013

Context: Need for an implementation imperative

Which stakeholders care about, demand EB services?
- Payers, Policy makers
- Administrators
- Researchers
- Clients/ Patients , Families
- Providers (clinicians, counselors, M.D.’s, nurses, OT, PT, SW)
- Support staff (units, labs, medical records)
- Supervisors, training teams

How invested, and how powerful?

What is the imperative to improve outcomes?
Context: Consolidated Framework for Implementation Research (CFIR)

- Composed of 5 major domains:
  - Intervention characteristics
  - Outer setting
  - Inner setting
  - Characteristics of the individuals involved
  - Process of implementation


Where are we?
The D&I tool kit

- Theories

- Research designs for IR

- Designs for implementation
Theories

Root: Rogers’ Diffusion of Innovation

Now: Many models!!!

109 identified models
How to choose?


Research Designs for D&I

Design challenges:
- Premium on external generalizability
- RCT alternatives & variations
  - Pragmatic trials, time variants
- Single site, small “n” studies of organizations

Resources:
Curran, Bauer, Mittman, Pyne, & stetler (2012). Effectiveness-implementation hybrid designs. Medical Care, 50 (3), 217-
Implementation Outcomes

Outcomes are distinct from clinical outcomes

- Could have an effective intervention, poorly implemented
- Could have an ineffective treatment, successfully implemented

Implementation outcomes: what do we know?

- Fidelity = most frequently measured outcome
- Provider attitudes frequently assessed
- Implementation outcomes are interactive:
  - Effectiveness → greater acceptability
  - Cost → feasibility
- We don’t know much about:
  - Sustainability
  - Scale up and spread
Part three: Where are we going?
Challenges and opportunities in implementation science

Priority area #1: Implementation Strategies
Build the evidence
Empirical tests of strategies
  CER
  Cost effectiveness
Understanding what strategies work, for which EST’s, in which settings
Developing more parsimonious strategies:
  which components have which effects?
Which strategies for which implementation outcomes?
Implementation Strategies: Specification & reporting*

Implementation strategies carry same demands as interventions
• Operational definitions
• Protocols & manuals
  • Undeveloped with few exceptions (ARC)*
• Fidelity
  • Few tools and fidelity measurement procedures

*Glisson & Schoenwald, Mental Health Services Research, 2005

Define strategies conceptually, operationally
• Specify, report dose, target, actors
  * Proctor, McMillen, Powell, in press. Implementation Science

Priority area II: Implementation Outcomes

Multiple stakeholders & multiple perspectives
• Which outcomes matter most to whom?
• Question from the field: How much will this cost and what kind of havoc will it wreak?

Priority outcomes:
• incremental cost
• scale up & spread
• sustainability
Measurement: Toward Standardization & Harmonization

- Seattle Implementation Research Conference (SIRC) Measures Project

- Grid-Enabled Measures developed by the National Cancer Institute

Program Sustainability Assessment Tool
Priority Area # 3: Implementation Context

Better measurement of context

Understanding leadership for implementation

Implementing EB services in resource-limited settings

What strategies work for what kinds of context?

Summary

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<th>Implementation Research Assumptions</th>
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<td>Public health focus</td>
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<td>Presumes intervention effectiveness</td>
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<td>IR = about change, very complex change</td>
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<td>Multiple stakeholders in practice &amp; practice change</td>
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<td>Contexts vary, and affect</td>
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Support:
National Institute of Mental Health
  P30 MH068579
  R25 MH080916
  P30 DK092950
  U54 CA155496
  UL1 RR024992 (Clinical and Translational Science Award, CTSA)

Washington University
  Institute for Public Health
  Brown School of Social Work

Conflicts: none

Questions...
  ....????????

Enola Proctor
  ekp@wustl.edu
ASSESSING THE STATE OF TRANSLATION WORK IN CAREGIVING:
HAVE WE BEEN SUCCESSFUL AND WHERE DO WE GO FROM HERE?

Laura N. Gitlin, PhD
Professor, Director
Center for Innovative Care in Aging
The Johns Hopkins University
lgitlin1@jhu.edu
www.nursing.jhu.edu/agingcenter

Gerontological Society of America – New Orleans, LA - November 2013

Objectives

• What is the evidence?
• What is our reach in translation?
• What are barriers to going to scale?
• What should we do next to enable more rapid translation and implementation of caregiver programs?
Funding Sources

- Research relevant to presentation funded by:
  - NIA
  - Alzheimer’s Association
  - PA Dept. of Health, Tobacco Funds
  - Rosalynn Carter Caregiver Institute/Johnson & Johnson Institute
  - Administration on Aging

- No disclosures/no sources of conflict relevant to presentation

Case Vignette:

Mr. Smith cares for his wife at home in West Virginia. She was diagnosed with dementia 4 years ago. He learned of the Alzheimer’s Association from a neighbor (by chance) and received some helpful information from national and local chapters. Mr. Smith stopped working to care for his wife. He is becoming increasingly isolated and depressed. He is having difficulty managing Mrs. Smith’s increasing dependence and behavioral symptoms. Mr. Smith does not receive any in-home help, he does not find support groups helpful, and Mrs. Smith’s physician has not provided any help except for anticholinesterase medications that are not effective.

Mr. Smith does not have access to a proven caregiver program – none exist in W. Virginia.

Male caregivers are not well represented in existing caregiver interventions and this group has higher study attrition.
What constitutes success in translation and implementation of caregiver programs?

- Every Mr. and Mrs. Smith (>20 million people) in USA has access to proven caregiver programs.
- At least one proven caregiver program is accessible in a practice and clinical setting that Mr. and Mrs. Smith encounter.
- Every health and human service provider knows is aware of evidence-based caregiver programs and has been certified to implement at least one program.

How can we make this happen?

THE EVIDENCE
GOOD NEWS!

- 6 meta-analyses and 14 systematic reviews of RCTs published between 1966 and 2010
- Sample sizes across reviews ranged from 4 to 8,095 families (average = 50 per study)
- Classified interventions into six broad types:
  - Professional support
  - Psycho-education
  - Behavior management/skills training
  - Counseling/psychotherapy
  - Self-care/relaxation training
  - Multi-component interventions
- Outcome measures: caregiver’s knowledge, burden, self-efficacy, psychological morbidity (anxiety/depression), for person with dementia, behavioral symptoms and time to institutionalization.

Average Pooled Effect Sizes (d) of Caregiver Interventions

- **Reducing caregiver burden**: range of .01 to .52, with multi-component interventions showing the largest effect for this outcome.
- **Improving caregiver knowledge**: range of .05 to .51 with interventions providing caregiver education showing the largest effect.
- **Reducing caregiver anxiety**: range of .16 to .50 with relaxation training showing the largest benefit.
- **Reducing caregiver depression**: range of .31 to .68 with psycho-education approaches demonstrating the largest benefit.
- **Delaying time to institutionalization**: average effect (OR) was in the range of 0.43 to 0.99 (Mean OR = 0.66) with multi-component interventions and those involving individual and family counseling having the largest benefit.
- No conclusions can be drawn from these reviews for other outcomes such as improving caregiver self-efficacy due to mixed results.

Gitlin and Hodgson, in press, Caregivers as Therapeutic Agents in Dementia Care: The Evidence-base for Interventions Supporting Their Role in 2nd Edition of Evidence-based Dementia Practice, Brodaty et al.,
**REACH I STUDIES:**

**Meta-analysis (active vs control) on 6-month Revised Memory and Behavior Problems Checklist (RMBPC) Burden scores (n=909)**

A. Site  
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<tr>
<td>Miami – FSMMI+CTIS</td>
<td></td>
</tr>
<tr>
<td>Palo Alto – Coping (Kauai)</td>
<td></td>
</tr>
<tr>
<td>Palo Alto – Coping (Hispanic)</td>
<td></td>
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<tr>
<td>Palo Alto – Enhanced (Kauai)</td>
<td></td>
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<tr>
<td>Palo Alto – Enhanced (Hispanic)</td>
<td></td>
</tr>
<tr>
<td>Philadelphia</td>
<td></td>
</tr>
</tbody>
</table>

Key:  
- X Parameter Estimate  
- ** 95% Confidence Interval

* Excludes 2 caregivers due to missing baseline data and 1 caregiver due to missing data on race in Memphis.

Gitlin et al. (2003) *Psychology and Aging*

---

**REACH I STUDIES:**

**Meta-analysis (active vs control) on 6-month Center for Epidemiologic Studies—Depression (CES–D) scores (n=1,086)**

B. Site  
<table>
<thead>
<tr>
<th>Active &gt; Control</th>
<th>Control &gt; Active</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pooled</td>
<td></td>
</tr>
<tr>
<td>Birmingham</td>
<td></td>
</tr>
<tr>
<td>Boston</td>
<td></td>
</tr>
<tr>
<td>Memphis – Behavior</td>
<td></td>
</tr>
<tr>
<td>Memphis – Enhanced</td>
<td></td>
</tr>
<tr>
<td>Miami – FSMMI</td>
<td></td>
</tr>
<tr>
<td>Miami – FSMMI+CTIS</td>
<td></td>
</tr>
<tr>
<td>Palo Alto – Coping (Kauai)</td>
<td></td>
</tr>
<tr>
<td>Palo Alto – Coping (Hispanic)</td>
<td></td>
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<td>Palo Alto – Enhanced (Hispanic)</td>
<td></td>
</tr>
<tr>
<td>Philadelphia</td>
<td></td>
</tr>
</tbody>
</table>

Key:  
- X Parameter Estimate  
- ** 95% Confidence Interval

* Excludes 1 caregiver due to missing data on race in Memphis.

Gitlin et al. (2003) *Psychology and Aging*
FIGURE 3. Efficacy of Interventions for Behavioral and Psychological Symptoms of Dementia

FIGURE 4. Efficacy of Interventions for Caregiver Outcomes Related to Behavioral and Psychological Symptoms of Dementia

Brodaty & Arasaratnam (2012) AJP; Gitlin, (2012, AJP, editorial)
Maslow, White Paper (September 2012)

- Response to: **National Plan to Address Alzheimer's Disease** (May 2012)
  - Review non-pharm tx’s for PwD and their caregivers
  - Reviewed published studies from 2002-2012 in USA
  - **Efficacy:** 44 RCTs that show positive outcomes
  - **Translational studies:** 10/44 (23%) treatments tested in 50 studies across 24 (48%) states

Limitations of the Evidence

- Tested outside of existing systems of care
- Interventions address limited range of family needs
- Poor link to person with dementia (etiology, disease stage)
- Limited outcomes on cost and cost savings, health care utilization and health care savings, financial distress, physical disease burden
- Limited evidence for certain subgroups (e.g., men, Asian populations, rural, long-distance carers, multiple carers, minority populations)
- Unclear which intervention to use and when and for which populations; how do interventions relate to each other, is one program all we need?
Consequences for and Needs of Caregivers along the Clinical Trajectory of Dementia

Exemplars of Caregiver Interventions

- Emotional distress (Anxiety, stress, burden, depression)
- Missed days at work
- Financial strain
- Physical strain
- Social isolation
- Decline in protective health behaviors and health

Garand et al., in press
Lu et al., 2013

Whitlach et al.,

Hodgson et al., in press

HOW ARE WE DOING?

TRANSLATION OF CAREGIVER PROGRAMS
HOW DO WE KNOW ABOUT TRANSLATIONAL EFFORTS?

- No single registry, source of data, or basic information available
- Very limited number of publications available on translation
- Sources of information about translational efforts
  - VA system (Dr. Linda Nichols; personal communications, 1 publication)
  - Administration on Aging - Alzheimer’s Disease Supportive Services Program (ADSSP; website updates)
  - Maslow’s White paper 2012 (available online)
  - Rosalynn Carter Caregiver Institute (Laura Bauer; personal communications, website)
  - Individual researchers engaged in translational and/or implementation research

Funding Mechanisms for Translational Studies

- U.S. Administration on Aging (AoA)
  - Primarily through the Alzheimer’s Disease Supportive Services Program (ADSSP)
    - Separate category for translational studies developed in 2008
- Joint NIA/AoA research grant program
  - Translational Research to Help Older Adults Maintain their Health and Independence in the Community
- U.S. Department of Veterans Affairs
- New programs mandated by the 2010 health reform law
- Rosalynn Carter Institute for Caregiving
  - With support from Johnson & Johnson
Translational Efforts of VA-REACH

32 (64%) states, 114 sites, 355 staff trained; unclear # of Caregivers; in 2011 N=127
Have now moved to an adapted version of REACH involving 4 sessions

Nichols et al., Arch Intern Med. 2011;171(4):353-359

US States/Territories Receiving ADSSP Grant Funding

36 states and territories have received AoA ADSSP grant funding since 2007.

Total People Served by Operational ADSSP Programs (National Total): 37,783

Source: http://www.adrc-tae.acl.gov
10 Translational Studies of Evidence-Based Caregiver Studies 2002-2012

10 programs tested in 50 translational studies in 24 (48%) states

Number of studies:
- 1
- 2
- 3
- 4

No studies

Maslow, 2012
Alliance for Aging Research and AoA

Translational Studies of Caregiver Programs in the United States, 2002-2012

= REACH VA

Number of overall translational studies:
- 1
- 2
- 3
- 4

Adapted from Alliance for Aging Research and AoA (2012)
Rosalynn Carter Caregiver Institute and Johnson and Johnson Initiative

- From 2007 to 2009, 9 translational efforts supported to move programs from RCT to real life settings:
  - Skills2Care
  - REACH Out/REACH adapted for Hospital/REACH II
  - NYC caregiver support program
  - Benjamin Rose Care Consultation

- Unclear number of caregivers served
- Most efforts discontinued or elements of program have become embedded in individual practices

Examples of Settings Where Caregiver Interventions have been Translated

<table>
<thead>
<tr>
<th>Setting</th>
<th>Hospital</th>
<th>Homecare</th>
<th>Adult Day Services</th>
<th>Home and community agencies</th>
<th>Assisted Living, Primary care, Memory clinics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptation of REACH II</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Skills2Care</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADS Plus</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>NYC program</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>VA REACH II</td>
<td>X (VA system)</td>
<td></td>
<td></td>
<td></td>
<td>NONE</td>
</tr>
</tbody>
</table>
Are we reaching everyone?

- 15 million caregivers in the United States
  - ADSSP
    - $37,783/15\text{ million} = .00025\%$ have received an evidence-based caregiver program
  - VA – similar prevalence rates

- Translational studies tested in up to 36 states but within each state, only in one region or location.
- Impossible to determine REACH in each state
- 5 million caregivers in the US live in areas in which translational studies of evidence-based non-pharmacologic treatments and care practices have not yet occurred

Limitations

- With few exceptions, translational efforts dependent on grant funding
  - What happens when funding ends?
- No infrastructure for reimbursement for programs
- No infrastructure in place to:
  - Reach caregivers in whatever setting they are identified
  - Train staff, health providers, community workers in proven programs
    - Train the trainers programs?
    - Who can train and what happens if the investigator/institution no longer supports training
- What interventions to select? Is one enough?
- Select elements of programs live on versus entire program
  - Do we need a different strategy of developing, testing, translating?
Barriers to Translation-Implementation-Maintenance

- Time commitment of investigators, providers
- Training/preparation needs of workforce is extensive
- Funding/reimbursement in current care systems
- Lack of guidelines (when to use which intervention and why)
- Needs of families are complex, needs are a moving target, stressors change over time with disease progression
- Lack of comprehensive dementia care in which to embed caregiver interventions

Where do we go from here?

FROM MASLOW WHITE PAPER:

- Develop a classification system to describe existing treatments and care practices
- Publish results of translational studies, both those that succeed and those that “fail”
- Further research needed among different groups (e.g., early and late stages of the conditions, racial and ethnic minorities, people under 65y, people who have non-AD dementias)
- Research specific problems (e.g., behavioral symptoms, under-recognition and under-diagnosis of AD and related dementias, connecting people to right tx’s and care practices)
Where do we go from here?

- Create a central clearing house for:
  - Sharing/storing evidence-based programs
  - Providing information on and possible training in programs
  - Reporting translation and implementation outcomes

- Hold conference to develop white paper on recommendations concerning burning questions:
  - How to go to scale? Continue training in programs? Pay for translation of programs? Pay for or reimburse for programs?
  - Identify common elements across programs and diffusion plan (versus any one evidence-based program)

How do we get there?

- Workforce preparation in basic competences:
  - Dementia knowledge
  - Caregiver assessment and effective involvement
  - Basic competencies in working with families and dementia

- More translational efforts with attention to cost, types of modifications

- Identify active ingredients of programs and provide them to agencies, clinical settings (versus adherence to entire program) and engage in practice evaluation or practice-based research

- Central clearing house for evidence-based programs

- Train the trainer models
### SUMMARY

<table>
<thead>
<tr>
<th>Good News</th>
<th>Bad News</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Many interventions tested using RCT with important outcomes</td>
<td>□ RCTs typically limited to geographic location with one subgroup of caregivers on a limited range of outcomes, and most target one disease stage (moderate)</td>
</tr>
<tr>
<td>□ Impressive array of translational efforts that have or are being conducted</td>
<td>□ Interventions tested outside health care and human service systems</td>
</tr>
</tbody>
</table>

- No centralized system for accounting for these efforts in the aggregate, determining reach, quality of implementation, outcomes or sustainability; few translational efforts are published
- Maintenance after grant funding is unclear
- Still not reaching enough caregivers
- 25% of states have not had any translational studies
- Most caregivers have never had access to a caregiver program
- After translation — then what??

### WHAT IS THE SOCIETAL COMMITMENT?

"Caregiver multi-component interventions (comprising education, training, support and respite) maintain caregiver mood and morale, and reduce caregiver strain. .......

Nevertheless, we are aware of no governments that have invested in this intervention to scale-up provision throughout the dementia care system, and hence coverage is minimal.\text{"}
REACH Primary Care: Translation of REACH II into Healthcare

Alan B. Stevens, PhD
Professor | Centennial Chair in Gerontology
Director, Center for Applied Health Research
Scott & White Healthcare | Texas A&M Health Science Center

Research has produced evidence-based interventions that partially address the negative consequences of family caregiving.

**Caregiver Interventions**
- Multi-Component, Skills-Training
  - Problem Behaviors
  - Mood Management
- Cognitive Behavioral Therapy
- Physical Activity

*REACH II is one example*
REACH I was a collaborative of research projects of dementia caregiver interventions sponsored by the National Institute on Aging and the National Institute of Nursing Research.

**REACH I Specific Aims**

1. Test Multiple Theory-Driven Interventions
2. Evaluate How Interventions Produce Positive Health Outcomes
3. Develop Standardized Treatment & Assessment Protocols

**REACH I Sites & Interventions**

- **Birmingham, AL**: Skills Training
- **Boston, MA**: Telephone-Linked Computer
- **Memphis, TN**: Behavior & Advanced Care
- **Miami, FL**: Family Based Multisystem In-Home
- **Palo Alto, CA**: Enhanced Support Group
- **Philadelphia, PA**: Environmental Skill Building
Findings from REACH I studies were used to develop a single standardized caregiving intervention guided by a caregiving stress-health process model, REACH II.

**REACH II Intervention**

- Structured, Multi-Component Intervention
- 9 Home Visits, 3 Phone Calls

<table>
<thead>
<tr>
<th>Safety Issues</th>
<th>Social Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>Problem Behaviors</td>
</tr>
<tr>
<td>Health &amp; Self-Care</td>
<td>Caregiver Burden</td>
</tr>
</tbody>
</table>

The REACH II intervention had a meaningful impact on quality of life & rates of caregiver depression were halved.

**REACH II Outcomes**

- Randomized Control Trial
- 642 Informal Caregivers
- Quality of Life Assessment
“The REACH study offered a level of caregiver support that few clinicians will be equipped to offer to their patients.”

Editorial Reply in *Annals of Internal Medicine*, Covinsky and Johnson


A strong foundation of evidence for the efficacy of an intervention is necessary but not sufficient to support its widespread implementation.

**Evidence**

Does a given set of intervention techniques and protocols achieve desired outcomes in a rigorously controlled clinical trial?

**Implementation**

How can an effective intervention fit within real-world setting? How can we adapt elements of the intervention to fit better?
A strong foundation of evidence for the efficacy of an intervention is necessary but not sufficient to support its widespread implementation.

Evidence
REACH II Clinical Trial

Implementation
REACH Primary Care

The mission of Scott & White is to provide the most personalized, comprehensive, highest quality healthcare enhanced by medical education and research.

Scott & White Memorial Hospital
- Top 100 Hospital
- Top 15 Teaching Hospital
- Only Level I Trauma Center between Dallas & Austin
- More than 65 Primary Care & Specialty Clinics
REACH Primary Care was designed to remediate the negative outcomes of caregiving through the implementation of REACH II within an integrated healthcare system.

- Contact with healthcare
  - Patient & Caregiver Identification
  - Provider Identification Client
  - Screening Questions in EMR
- Office Embedded within a Healthcare Clinic
- Community Partnership:
  - Area Agency on Aging (AAA)
  - Aging & Disability Resource Center (ADRC)

Phase I of REACH Primary Care translated REACH II materials into user-friendly products that were more typical of health promotion materials used in healthcare.

- REACH Primary Care
  - Family Profile
  - A Caregiver's Notebook

- Project supported by Rosalynn Carter Institute/Johnson & Johnson
**REACH Primary Care Phase I Results**

- Large Number of Referrals and Case Finds were Necessary to Identify and Enroll Caregivers Desiring Services
- 68% Enrollees Completed All Contacts
- Significant Reduction in RAM Risk Score

- **3,295** Alzheimer/dementia patients
- **734** Eligible
- **469** Presented Materials
- **164** Enrolled
- **72** Completed

**Additional implementation research methods were used to strengthen the approach used in Phase I.**

- Caregiver Identification
  - Comprehensive Outreach to Providers
  - Provider Sent Referral to Email Account with Patient MRN

- Outcome Measures
  - Quality of Life Composite Measure from REACH II Clinical Trial

- Cluster Assignment Used to Create Intervention and Comparison Groups
Cluster assignment of clinics by Scott & White Healthcare regions was used to create Intervention and Education- Only target areas.

• Intervention Condition
  – All Received 4-6 Home Visits
  – Content Covered Based on Caregiver's Particular Needs
  – Family Profile and A Caregiver's Notebook used in delivery

• Education- Only Condition
  – Participants were Mailed a Copy of the NIH Publication Caring for a Person with Alzheimer's Disease
  – Two Check-in Phone Calls Made Over 6 Months

Two conditions tested in our REACH Primary Care spanned 32 clinics in 27 counties in Central Texas
Three specific research questions shaped the evaluation of REACH *Primary Care* as an element of care with an integrated healthcare system.

- What is the impact of using cluster assignment of clinics to intervention or comparison conditions on the feasibility of engaging clinic staff and delivering a family caregiver intervention?
- What is the impact of REACH *Primary Care* on caregiver quality of life domains established by the REACH II Clinical Trial?
- What are the specific REACH *Primary Care* cost components, fixed and variable? (Methods and Findings not included in this presentation.)

Clinical staff at the targeted facilities were the crucial link to potential participants, so multiple recruitment strategies were used to engage busy clinical staff in referring family caregivers.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Brochures</strong> – exam rooms, hallways, lobbies</td>
<td>Program brochures were put on display in exam or treatment rooms, hallways alcoves, and waiting areas.</td>
</tr>
<tr>
<td><strong>Poster</strong> – exam rooms and lobbies</td>
<td>A program mini-poster was put on display in at least one exam or treatment room, and waiting areas.</td>
</tr>
<tr>
<td><strong>Informational materials</strong> for providers</td>
<td>Program information folders were supplied to providers. Folders were provided during a formal information session or during a site visit.</td>
</tr>
<tr>
<td><strong>Informational email to providers</strong></td>
<td>Information about the program was provided in an email to providers who were unable to attend an information session.</td>
</tr>
</tbody>
</table>
Clinical staff at the targeted facilities were the crucial link to potential participants so multiple recruitment strategies were used to engage busy clinical staff in referring family caregivers.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information session – medical director</td>
<td>Information about the program was provided during a face-to-face meeting with the senior leadership of a facility.</td>
</tr>
<tr>
<td>Information session – nurses/allied health staff</td>
<td>Information about the program was provided during a face-to-face meeting with the nurses and/or allied health staff of a facility.</td>
</tr>
<tr>
<td>Information session – physicians</td>
<td>Information about the program was provided during a face-to-face meeting with the physicians of a facility. A PowerPoint presentation and/or handouts were used to communicate program information. Lunch was provided.</td>
</tr>
<tr>
<td>Ongoing contact</td>
<td>Ongoing contact with providers included impromptu visits, periodic emails to providers thanking them for contributing to the success of the program, and checking with staff to see if brochure supplies needed to be replenished.</td>
</tr>
</tbody>
</table>

Clinical staff at the targeted facilities were the crucial link to potential participants so multiple recruitment strategies were used to engage busy clinical staff in referring family caregivers.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral incentives</td>
<td>Providers were given a $5 gift card for a coffee shop or department store for each referral. Incentives were offered for the first several months after the program was introduced at a given facility.</td>
</tr>
<tr>
<td>Tokens of appreciation</td>
<td>Refreshments were brought for providers and staff during an impromptu visit. Table tents containing expressions of gratitude for referrals and program contact information were displayed alongside the refreshments.</td>
</tr>
</tbody>
</table>
## REACH Primary Care Enrollment

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Education- Only</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>804</strong></td>
<td><strong>223</strong></td>
</tr>
<tr>
<td>Referrals</td>
<td>Referrals</td>
</tr>
<tr>
<td><strong>286</strong></td>
<td><strong>90</strong></td>
</tr>
<tr>
<td>Eligible</td>
<td>Eligible</td>
</tr>
<tr>
<td><strong>118</strong></td>
<td><strong>40</strong></td>
</tr>
<tr>
<td>Enrolled</td>
<td>Enrolled</td>
</tr>
<tr>
<td><strong>69</strong></td>
<td><strong>49</strong></td>
</tr>
<tr>
<td>Completed</td>
<td>Non Completers</td>
</tr>
<tr>
<td><strong>223</strong></td>
<td><strong>18</strong></td>
</tr>
<tr>
<td>Referrals</td>
<td>Non Completers</td>
</tr>
<tr>
<td><strong>22</strong></td>
<td><strong>18</strong></td>
</tr>
<tr>
<td>Completed</td>
<td>Non Completers</td>
</tr>
</tbody>
</table>

### Steps of REACH Primary Care

<table>
<thead>
<tr>
<th>Caregivers identified based on referral from Primary Care Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Contacts occurring 1-3 weeks from time of referral</strong></td>
</tr>
<tr>
<td>Assess &amp; Connect - Dementia Care Specialist (DCS) obtains consent and conducts Baseline Questionnaire, including demographic survey, RAM, and REACH II Quality of Life</td>
</tr>
</tbody>
</table>

| **Contacts occurring the 6 month intervention phase**        |
| Engage – 1 in-person contact to review information in Family Profile & A Caregiver’s Notebook; est. priority areas for skill training |
| Coach – 3 in-person contacts to coach caregiver to enact in skill building and provision of support |
| Telephone Contact – As needed to support caregiver’s needs |
| **6 Month Follow-up Assessment**                             |

| Assess & Connect - Dementia Care Specialist (DCS) obtains consent and conducts Baseline Questionnaire, including demographic survey, RAM, and REACH II Quality of Life |

| Link - Phone Call from DCS to family caregivers occurring approximately three and five months after Assess & Connect interaction |

1/6/2013
Our ability to deliver each condition of REACH Primary Care within healthcare settings was a primary question.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intervention</th>
<th>Education- Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants completing program</td>
<td>69</td>
<td>22</td>
</tr>
<tr>
<td>Median (range) number of scheduled therapeutic contacts that were delivered</td>
<td>4.0 (1-6)</td>
<td>2.0 (2-2)</td>
</tr>
<tr>
<td>Median (range) number of unscheduled office/home visit contacts that occurred</td>
<td>1.0 (1-2)</td>
<td>-</td>
</tr>
<tr>
<td>Median (range) number of intervention-related therapeutic contacts (Referrals to Adult Protective Services, CG contacts)</td>
<td>1.0 (1-12)</td>
<td>1.0 (1-2)</td>
</tr>
</tbody>
</table>

The five domain REACH II quality of life assessment approach was used as the study’s primary outcome. The REACH II Risk Appraisal Measure (RAM) was also used.

<table>
<thead>
<tr>
<th>REACH II Quality of Life Domains &amp; RAM</th>
<th>Intervention (N=70) Mean (SD)</th>
<th>Education- Only (N=22) Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
</tr>
<tr>
<td>Burden</td>
<td>18.8 (8.7)</td>
<td>17.1 (4.5)</td>
</tr>
<tr>
<td>Depression</td>
<td>8.9 (5.7)</td>
<td>8.1 (6.3)</td>
</tr>
<tr>
<td>Problem Behavior</td>
<td>0.68 (1.04)</td>
<td>0.84 (1.1)</td>
</tr>
<tr>
<td>Social Support</td>
<td>17.2 (4.5)</td>
<td>17.6 (5.1)</td>
</tr>
<tr>
<td>Self-Care</td>
<td>6.6 (1.9)</td>
<td>6.7 (1.9)</td>
</tr>
<tr>
<td>RAM</td>
<td>13.9 (4.6)</td>
<td>11.4 (4.4)</td>
</tr>
</tbody>
</table>
In order to realize the full potential of REACH *Primary Care* in healthcare settings, modernization of intervention practices is needed to match current healthcare and technology practices.

**Project Delivery**
Increase caregiver engagement and decrease costs associated with delivery with new treatment delivery techniques

**System Integration**
Integrate programs with Electronic Health Records

**Project Outcomes**
Adopt new assessments & participant screening tools to measure healthcare utilization & economic impact

**Funding Structure**
Investigate alternative funding structures such as Accountable Care Organizations

---

**Are community-based organizations better positioned to deliver caregiver interventions like REACH II?**

- The United Way of Tarrant County, Texas has committed 18 million dollars to a Healthy Aging and Independent Living (HAIL) Initiative

- United Way has partnered with key community-based organizations to provide health interventions that address:
  - Immediate needs of individuals at risk of poor health outcomes
  - Health promotion activities that engage adults in self-management techniques and healthy behaviors

- Overall goal: Lead to better health and, long term, lower healthcare costs (e.g., fewer hospitalizations, less need for nursing home care)
The Alzheimer’s Association of North Central Texas began a community-based translation of REACH II with funding by the Tarrant County United Way’s Healthy Aging & Independent Living (HAIL) Initiative.

- Community Resource since 1982
- Partnered with Community Research Center for Senior Health
  - Used REACH Primary Care materials
  - Independent Evaluators for HAIL
- **1053 Caregivers Enrolled** in a REACH II Program Adapted for Community Implementation from July 2010 – June 2013

The Alzheimer’s Association of North Central Texas began a community-based translation of REACH II with funding by the Tarrant County United Way’s Healthy Aging & Independent Living (HAIL) Initiative.

- HAIL REACH II Program will be highlighted in a symposium: *Practical Strategies that Impact Translation of Caregiver Interventions*
  - The Role of Technology to Augment Implementation and Delivery of the REACH II Intervention
  - November 23, 2013
  - 3:00 PM - 4:30 PM
We are currently working on two additional products to facilitate the translation of REACH II into community services.

- Training Programs to Support Community-Based Adaption of REACH II Intervention Components Supported by the Texas Department of Aging and Disability Services (DADS)
- Toolkit on Evidence-Based Programming for Seniors

The user friendly *Toolkit on Evidence-Based Programming for Seniors* will build capacity of community organizations to promote senior health and well-being.

- Community-based organizations (CBOs) are increasingly interested in evidence-based programs (EBPs)
- There is a significant amount of information available regarding evidence-based programming; however, this information is incomplete and much of it is fragmented across sources
- Toolkit will build the capacity of community organizations as a “one stop shop” that guides CBOs through the selection, implementation, and evaluation of EBPs
The user friendly Toolkit on Evidence-Based Programming for Seniors will build capacity of community organizations to promote senior health and well-being.

- Toolkit Development Process
  - Determine which topics to address (Sept-Oct ‘12)
  - Scan existing materials to identify resource gaps and materials to reference (Sept-Nov ‘12)
  - Develop the Toolkit content (Nov ‘12-June ‘13)
  - Refine the Toolkit with adjustments suggested by a team of reviewers representing multiple sectors (July-Aug ‘13)
  - Create a user-friendly website to feature the Toolkit (underway)

- The Toolkit website should be fully operational by February 2014

Special thanks to our partners!
Alan B. Stevens, PhD
astevens@sw.org
What Makes an Intervention Evidence-Based? Criteria and Definitions for Advancing Dementia Caregiver Interventions

Brent T Mausbach
Department of Psychiatry
University of California San Diego

Evidence-Based Treatments (EBTs)

- What is an EBT?
- Why is it important to identify EBTs?
- What interventions meet EBT criteria for caregivers?
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Definition of EBT

- Evidenced Based Treatment:
  - Intervention programs that meet specific criteria established by the American Psychological Association
  - Details on these criteria can be found in the coding manual developed and updated by the Society for Clinical Psychology (Weisz & Hawley, 2001*).

Criteria for EBT

1. There must be at least two peer-reviewed between-group, within-group, single-case design studies (or a combination) with:
   a. A minimum of 30 participants across studies
   b. The same age group
   c. The same psychologically-based treatment
   d. The same target problem
   e. Prospective design
   f. Random assignment


Criteria for EBT

2. Treatment must be:
   a. Better than the control or comparison condition, or
   b. Equivalent to an already-established evidence-based treatment

3. The majority of applicable studies must support the treatment

4. The treatment procedures must show acceptable adherence to the treatment manual

Evidence-Based Treatments (EBTs)

- What is an EBT?
- Why is it important to identify EBTs?
- What interventions meet EBT criteria for caregivers?

Importance of Identifying EBTs

- Family caregiver distress is a relatively prevalent problem with public health significance (REACH II, 2007; Scogin et al., 2005; 2007).
- Equips the public with knowledge to be an informed consumer of psychological services
- Guides professionals in their choice of treatment dependent upon the client’s presenting problem
- Influences future research designed to fill the gaps
Empirically Based Treatments (EBTs)

- What is an EBT?
- Why is it important to identify EBTs?
- What interventions meet EBT criteria for caregivers?


Methods Overview (Coon & Gallagher-Thompson, 2007)

- Focused on intervention studies to alleviate distress among caregivers assisting older adults with cognitive impairment and/or frailty.


- More than 350 articles were identified as candidates, of which 155 were rated.

- Using two coders per study, 59 studies were able to be coded; only 19 studies met full EBT criteria (i.e., adequate design, adequate sample, adequate results).
What’s Successful? Implementing Caregiver Interventions

- Education alone.
- Care Management.
- Respite.
- Support Groups.
- Environmental.
- Technological.
- Education & Skill Training (CR, CG, both).
- Psychotherapy/Counseling.
- Multi-component.

Summary of Results

Three categories of treatments met EBT criteria in this review:

- Psychoeducational Programs (n=14)
- Psychotherapy (n=3) (CBT)
- Multi-component Interventions (n=2)
Psychoeducational -- Skill Training Programs

Focus on:

- Behavior management of care receiver
- Depression or anger management for caregiver
- Progressively Lowered threshold model

Typically offered in a small group format
- Usually 6-10 caregivers who commit to attending weekly

Always time-limited (e.g. 6-12 sessions)

Focus on education & skill training of the caregiver
- Focus on improving adaptive coping skills and reducing the use of avoidant coping strategies.

Detailed agendas with specific goals; a structured treatment manual is followed
- Active in-class participation to learn skills (e.g. role plays)
- Extensive use of homework assignments
Behavior Log

Please use this log to write down the things your relative does (or that you do) that upset you.

<table>
<thead>
<tr>
<th>Date/Day of week</th>
<th>Time</th>
<th>Person Present</th>
<th>Trigger</th>
<th>Behavior</th>
<th>Reaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Everyday</td>
<td>In the AM</td>
<td>Myself and Husband</td>
<td>He wakes up in the morning and knows that it is time to get dressed.</td>
<td>When he dresses himself, he insists on wearing the same outfit he has worn for the past five days.</td>
<td>I feel angry because he does not want to look and smell clean.</td>
</tr>
</tbody>
</table>

Strategies Caregiver Can Use to Prevent the Problem Behavior

1. Set out fresh clothes for him and reward him when he wears them; give him a compliment on how nice he looks or make him his favorite breakfast.

2. Hide the outfit he really likes where he cannot find it.

3. Buy him several pairs of the same pants and shirt so that he thinks he is wearing his favorite outfit.

4. When he goes to bed, take his clothes and put them in the laundry machine. Set the machine on the soak cycle so that if he looks for them and notices they are wet, he will need to find something else to wear.
Psychoeducational -- Skill Training Programs

- **Why use this approach?**
  - Theory-driven: CBT (e.g., Beck’s & Lewinsohn’s focus on increasing pleasant activities) in which feelings, thoughts, and behaviors are seen as interrelated
  - Outreach: less shame
  - Less time-consuming
  - More economical

Psychotherapy Treatments

- Successful programs derived primarily from CBT theories and techniques
- Typically involve 10-20 individual sessions
- Indicated for caregivers with significant emotional problems, such as diagnosed depression, severe anxiety, or extreme emotional stress
- Requires skilled clinicians with specialized training/experience
Behavior Therapy for Caregivers – Attacking Activity Restriction

- Theoretical Model – Gayle Williamson

- People in stressful circumstances often forego meeting their own needs, particularly their need to engage in social and recreational activities.

- Without meeting social and recreational needs, people become depressed.

- This has become known as the “Activity Restriction” model of depression.
### Behavior Therapy for Caregivers – Attacking Activity Restriction

- Caregiving Stress
- Restriction of Hobbies & Activities
- Symptoms of Depression

### Identifying Pleasant Events

- **What counts as a Pleasant Event?**
  - Anything caregivers would find pleasure doing.
  - Start Small.
  - Keep it Simple.
  - Daily engagement is key.
Pleasant Events

- Identify & Schedule.
  - Material.
  - Time/Location.
  - Steps needed for success.

- Home Practice & Potential Barriers.

Pleasant Events: Events for CR & CG

- Develop list.

  Our list of Pleasant Events

  1. Look at family photo album.
  2. Take a walk in the park.
  3. Listen to music.
  4. Garden.
Tracking Pleasant Events: Learning To Put Pleasure into One’s Life

<table>
<thead>
<tr>
<th>Pleasant Events</th>
<th>Days</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>1. Working on Computer</td>
<td>✓</td>
</tr>
<tr>
<td>2. Reading Religious Books</td>
<td>✓</td>
</tr>
<tr>
<td>3. Attending a Good Movie</td>
<td></td>
</tr>
<tr>
<td>4. Going for Walks</td>
<td></td>
</tr>
<tr>
<td>5. Browsing in Library</td>
<td></td>
</tr>
<tr>
<td>6. Listening to Car-Talk</td>
<td></td>
</tr>
<tr>
<td>7. Listening to Music</td>
<td>✓</td>
</tr>
<tr>
<td>8. Doing Physical Exercises</td>
<td>✓</td>
</tr>
<tr>
<td>9. Meeting with Friends</td>
<td>✓</td>
</tr>
<tr>
<td>10. Getting out for a Drive</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
</tr>
</tbody>
</table>

Four Pleasant Events a Day Keep the Blues Away

- They don’t have to be huge pleasant events.
- But they must be **Consciously Chosen**, and **Deliberately Done** to experience control.
  
  - Events Control Mood.
  - To some extent you can control events.
  - Therefore, you can control mood.
Multi-component Interventions

- Refers to programs using a combination of at least two distinct theoretical approaches.
- Combination of approaches does not require clear prioritization
  - Telephone counseling
  - Family meetings
  - Behavioral management
  - Attendance at a support group

Interventions Needing Additional Support

- Support Groups
  - Self-efficacy as moderator (Rabinowitz et al., 2006)

- Care Management & Memory Clinics
  - The “Box”

- Respite
  - Effective use of “down time”
What interventions are being used in the community?

- We surveyed 40 agencies in San Diego County that indicated they served “seniors.”
  - 10 agencies reported they did not serve caregivers at all.
  - 6 reported they only served professional caregivers
  - Remaining 24 reported serving family caregivers

What services are being provided in the community?

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  - Remaining 24 reported serving family caregivers
What services are being provided in the community?

• Of the 24 agencies serving family caregivers:
  
  • 14 (58.3%) reported providing informational brochures to caregivers
  • 13 (54.2%) reported providing respite care
  • 10 (41.7%) reporting providing support groups
  • 6 (25%) reported providing informational talks to the public

What services are being provided in the community?

• Other answers provided:
  
  • In-home care (e.g., housework, meal prep, etc)
  • CGs can call director to "vent"
  • In-home and hospice care; daycare, and overnight respite
  • Individual therapy
  • Assessments, referrals, phone support
  • REACH intervention (n = 1)
  • Group counseling
Concluding Thoughts

- Three key categories of interventions met EBT criteria:
  - Psychoeducational skill-building programs
  - Psychotherapy (CBT based)
  - Multi-component interventions

- Challenges:
  - Plethora of intervention approaches, outcomes and measures
  - Samples often lack ethnic and racial diversity despite the opposite trend in our aging society
  - The need for effective translation

Next Steps

- Transferability into everyday practice settings
  - Help health care and social service organizations identify appropriate staff, as well as provide relevant training and supervision activities.
  - How can interventions be tailored to be practical/cost effective in community settings
GSA 2014
ANNUAL SCIENTIFIC MEETING

Note earlier dates this year!
NOVEMBER 5–9, 2014
WASHINGTON, DC

Making Connections: From Cells to Societies

Gerontologists make connections and study connections in many aging-related areas. We assess unstable molecular bonds in cells and study enduring human ones in families. We test for relationships among variables and examine them among retirement community residents. Our research generates alliances that improve community services and policies for older adults and their families.

The 2014 conference theme challenges researchers to present their best evidence on aging-related connections they investigate. The call for abstracts will be available mid-December, start planning now.

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