Research on Respite Outcomes and Access

Joseph E. Gaugler, PhD
Robert L. Kane Endowed Chair in Long-Term Care and Aging
Director, Center for Healthy Aging and Innovation
Professor, Division of Health Policy and Management
Objective

• Reflecting on the 2015 *A Research Agenda for Respite Care* report from ARCH

• Aligning with current research recommendations and initiatives emerging from multiple reports and summits on dementia care science
  - As well as our own work; e.g., Gaugler, Jutkowitz, & Gitlin, 2020, NASEM Decadal Project
6 Key Areas

1. Improved research methodologies
2. Individual, family, and societal outcomes
3. Cost-benefit and cost-effectiveness research
4. Systems change that improves respite access
5. Improved respite provider competence
6. Translate research findings into best-practice models

ARCH Respite Network (2015), p. 3
The Challenge of Researching Respite: Who Benefits

• “The most important researchable questions about respite is whether to take into account the needs of all family members when determining eligibility, or when designing and delivering services“ (ARCH Respite Network, 2015)

• The traditional methodology utilized to conduct research with caregivers/care partners
The Challenge of Researching Respite: Defining and Categorizing Alongside Other Service Types

- “Respite is planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system” (ARCH Respite Network, 2015)
  - Appended definition
- The challenges of categorizing these and other non-pharmacological interventions (Gaugler et al., 2017)
• “Three systematic reviews (SRs) utilized similar definitions when grouping and synthesizing results of respite for dementia caregivers (Cooper et al., 2007; Olazarán et al., 2010; Maayan et al., 2014). Olazarán and colleagues included two studies of respite, while Maayan et al. included four and Cooper and colleagues included three. Only one study was consistent across the three reviews. In contrast, four studies were included in at least one review but not the others. Furthermore, one study was included in two of the reviews, but was classified as respite in one and not the other.” (Gaugler et al., 2017; p. 22)

• Improved reporting of the components/elements of respite in studies and evaluations (Gaugler et al., 2020; Schulz et al., 2010)
Respite Outcome Measures

• Over-reliance on deficit oriented outcomes, in keep with biomedical perspectives
• Strengths-based measures, as applied in dementia care science (and other areas as well) (Gaugler et al., 2019)
  - Resilience
  - Successful aging domains
  - Goal attainment scaling (Jennings et al., 2018; Reuben & Jennings, 2019)
  - Social health per European research in optimal dementia care measures
  - LINC-AD
Conceptualizing

- What are the “essential ingredients” of respite
- Core to dissemination and implementation success
- Evans, 2013; Gaugler, 2014
Exploring the concept of respite

Respite for older people conceptual model

Provider

Partnership

Family Carer  Care-Recipient

Service

Assistance  Engagement

Respite

Freedom

Support  Connection
Designing Respite Studies

• Are RCTs even possible in respite? Does it matter?
• Viewing respite less as a general “intervention” to be evaluated and instead as a context for innovation
• The ADS Plus Study (Gitlin et al. 2019; Roth et al., 2020; https://nursing.jhu.edu/faculty_research/research/projects/ADS/index.html)
What is the Adult Day Plus Research Study?

• Does augmenting adult day services with systematic, evidence-based caregiver support, education and skill building (ADS Plus), enhances wellbeing for persons with dementia and family caregivers?

• We will compare usual care at 23 adult day services to 26 adult day services providing usual care and ADS Plus on these outcomes:
  • Family caregiver depressive symptoms
  • Family caregiver overall well-being
  • Number of days adult day services are used
  • Nursing home placement
What is the Adult Day Plus Intervention?

- Provision of on-going caregiver support to families using adult day services using a protocol tested in previous and ongoing pilot work
- Five intervention components:
  - Assessment of care needs
  - Referral and linkage
  - Education about disease, behavioral symptoms, caregiving, resources
  - Skills training in problem solving, managing behaviors,
  - Taking care of self
- Novelty of approach:
  - Standard yet tailored to unique needs
  - Caregiver-centered - caregivers identify top 3 challenges they want to address
  - Program integrated into ADS work follow as much as possible
  - Use of indigenous staff to deliver intervention
  - Minimal staff training
  - Families participate at times convenient to them upon pick up, drop off or another time to minimize burden
Two Primary Study Aims

• Evaluate effectiveness of ADS Plus to improve caregiver well-being and reduce depressive symptoms compared to routine ADS use at 6 months
• Evaluate long-term maintenance effects of ADS Plus at 12 months on caregiver well-being and depressive symptoms
Hybrid Design Effectiveness-Implementation

30 ADS Randomize to ADS Plus or Usual Care

300 family caregivers
Baseline Interview

ADS Usual Care Only
ADS + ADS Plus

6 month Trial outcomes
Caregiver burden and depression
ADS Plus Cost

3-month check in

12 month outcomes
Caregiver burden and depression
Older Adult Client use of ADS
Nursing home placement

6 month process evaluation of ADS Plus Participants
Open-ended and close-ended survey

12 months Stratified Purposive ADS Plus Sample
N=24 family caregivers
15 ADS Plus Staff

Thematic Analysis
Semi-structured interviews with Caregivers and ADS Staff to determine Mechanisms of ADS Plus benefits, ADS site adoption and barriers and challenges to implementation

Point of interface between Quantitative/Qualitative Findings Mixed Methods
Integration of findings from randomized controlled evaluation with embedded components to examine points of convergence or divergence as to why ADS Plus is effective in ADS
Leadership Core

Director
Joseph E. Gaugler, PhD

Associate Director
Gary Epstein-Lubow, MD

Health Equity Task Force
- Jason Resendez, ADDEN
- Lauren Parker, PhD, NADSA
- Jenna McDavid, Diverse Elders Coalition

Associate Directors
Sam Fazio, PhD
Matthew Baumgart, PhD
The Alzheimer’s Association

Center Coordination/Support
Kate Heckathorn
Elma Johnson, MPH, CRC

Executive Committee

AGS/GWEP
Nancy Lundjeberg

Benjamin Rose Institute
David Bass, PhD

John A. Hartford Foundation
Rani Snyder

LeadingAge
Kathy Kelly

NADSA
Donna Hale

Rand
Lori Frank, PhD
Regina Shih, PhD

UCLA ADC
David Reuben, MD

Other State/Local/Tribal

(\(n = 20\))

- MN-ND Alzheimer’s Association
- Washington DSHS
- Univ. of Minnesota GWEP

Family Caregiver Alliance
Kathy Kelly

People Living with Dementia
(\(n = 12\))
Members to be identified in Year 1

Other Stakeholder Engagement Advisory Boards

E-3: Increase messaging for dementia caregiving

W-3: Educate public health professionals about best available evidence

P-1: Promote the use of effective interventions and best practices

M-3: Use data to inform public health program and policy responses

E-6: Strengthen knowledge about, and greater use of, care planning

W-2: Ensure that interventions include messaging for healthcare providers

M-4: Embed evaluation into support programs

Stakeholder Engagement Advisory Boards

Executive Committee

AHCA/NCAL
Lindsay B. Schwartz, PhD

Family Caregiver Alliance
Kathy Kelly

LeadingAge
Robyn Stone, PhD

n4A
Meredith Hanley
Sandy Markwood

GSA
Patricia D’Antonio, MS, MBA, BCGP

NIA IMPACT Collaboratory
Rosa Baier, MS
Laura Gitlin, PhD
Eric Jutkowitz, PhD
Katie Maslow, MSW, FGSA

UW HPRC
Basia Belza, PhD, RN, FAAN

UCLA ADC
David Reuben, MD

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Others (to be identified in Year 1)

Innovative Partnerships
To be cultivated, Years 1-5

Figure 1. PHCOE-DC
Joseph E. Gaugler, PhD
Robert L. Kane Endowed Chair in Long-Term Care and Aging
Director, Center for Healthy Aging & Innovation
Twitter: @UMNCHAI
Email: gaug0015@umn.edu
Phone: 612-626-2485
References


References


