The Families and LTC Projects

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Specific Aims

• My educational trajectory
  – “How did you get interested in this?”
• Mission and goals
  – Alignment
• Projects
  – Research
  – Outreach/Education
  – Service
• New and future initiatives

The Families and LTC Projects Team

• Mark Reese, MA, LMFT (2008-present), Study/Family Counselor
• Mary Boldischar, MSW, (2007-2013), Research Coordinator
• Past Research Assistants
  – Katie Wocken/Louwagie
  – Kristen Sarkinen/Williamson
  – Kaitlyn Dykes
  – Vanessa Berglund
  – Mary Dang
  – Melissa Webster
  – Tai Sims
  – Aimee Hamel
  – Allison Garlinghouse
  – Shaina Rud
  – Bonnie Bata-Jones (dearly departed)

The Families and LTC Projects New(er) Team Members

• Research Coordinators
  – Amanda Weinstein, M.S.
  – Ann Emery, M.S.
• Graduate Research Assistants
  – Lauren Mitchell, M.S.
  – Colleen Peterson, M.S.
  – Shaina Rud, B.A.
• Study Counselor
  – Tamara Statz, MA, LMFT
• Other Research Assistants
  – Emily Westphal
  – Manisha, Aneri, and Ayush Shah

My Educational Path
Public Health Context

• 18.9%, or 43.5 million Americans, care for someone 50 years of age or older
• 66% of family caregivers in the United States are women
• 72% of family caregivers in the United States are white, 13% are African-American, 2% are Hispanic, and 2% are Asian American
• 85% of help provided to all older adults in the United States is from family members

From NAC/AARP, 2009; Gitlin & Schulz, 2012; Gaugler, Potter, & Prunell, 2014

Public Health Context

• The average amount of family care provided on a weekly basis is 20.4 hours
• On average, family members have been providing care for 4.6 years
• 100%, or all respondents in the 2009 NAC/AARP survey, provided help to an adult care recipient with at least 1 instrumental ADL
• 58% of family caregivers provide help to an adult care recipient on at least 1 ADL
• The economic value of care provided by family and other unpaid caregivers of people with Alzheimer’s disease or a related dementia was $217.7 billion in 2014
• This is approximately 46 percent of the net value of Walmart sales in 2013 and nearly eight times the total revenue of McDonald’s in 2013

From NAC/AARP, 2009; Gaugler, Potter, & Prunell, 2014; The Alzheimer’s Association, 2015

Families and LTC Projects

• Mission
  – To generate and disseminate relevant, useful scientific knowledge about families who care for persons with memory loss or other conditions with the objective of determining the most effective ways in which to support these families and their relatives.

• Aims
  – Longitudinal implications of family caregiving
  – Effectiveness of psychosocial and community-based long-term care services for caregiving families
  – Alzheimer’s disease and long-term care
  – Longitudinal, mixed, and person-centered methods
Aligning the Mission

• Land-Grant Mission (from the Association of Public & Land-Grant Universities):
  – “The original mission of (land-grant) institutions, as set forth in the first Morrill Act (of 1862), was to teach agriculture, military tactics, and the mechanic arts as well as classical studies so members of the working classes could obtain a liberal, practical education.”
  – “…higher education was still widely unavailable to many agricultural and industrial workers. The Morrill Act was intended to provide a broad segment of the population with a practical education that had direct relevance to their daily lives.”

From http://www.aplu.org/about-us/history-of-aplu/what-is-a-land-grant-university/

Aligning the Mission

• University of Minnesota: “We are Minnesota's research university. We change lives—through research, education, and outreach.
  – Research
    • We seek new knowledge that can change how we all work and live.
  – Education
    • We prepare students to meet the great challenges facing our state, our nation, and our world.
  – Outreach
    • We apply our expertise to meet the needs of Minnesota, our nation, and the world.
    • We partner with communities across Minnesota to engage our students, faculty, and staff in addressing society's most pressing issues.”

Families and LTC Projects: Completed Research as PI

<table>
<thead>
<tr>
<th>Project Title</th>
<th>University</th>
<th>Funding Source</th>
<th>Duration</th>
<th>Specific Aims</th>
</tr>
</thead>
</table>
| Comprehensive Support for Alzheimer's Disease Caregivers | University of Minnesota Clinical and Translational Science Institute (CTSI) | National Institutes of Health/National Institute on Aging | 2005-2011 | 1) Testing the benefits of the NYU Caregiver Intervention-Adult Child (NYUCI-AC) for Alzheimer's caregivers
  • Nursing home admission/residential long-term care entry, caregiver depression/quality of life, caregiver subjective stress
  • Gaugler et al., 2013, 2015, 2016 |

Procedure

– This prospective, single-blind, randomized controlled study included 107 adult children of persons with a physician diagnosis of ADRD in the seven-county Minneapolis/St. Paul urban and suburban area as well as outlying regions.
– Adult child caregiver eligibility criteria:
  • Self-identify as a primary caregiver;
  • Visit the care recipient at least once a week;
  • Not have received professional counseling for problems arising from being a caregiver in the year prior to enrollment; and
  • The person with ADRD had to be living at home in the community at the time of the baseline interview.
– Adult child caregivers were randomly assigned to the NYUCI-AC treatment condition (n = 54) or the control contact group (n = 53) following consent and completion of a baseline interview.
Procedure

• Baseline and follow-up assessments administered by a rater blinded to assignment.
• Quarterly follow-up assessments during the first 12 months of participation and every 6 months thereafter for a minimum of 2 years.
• Follow-up assessments were administered in person, or if that was not possible, via a telephone interview or mail.
• Participation in the evaluation continued until the study ended, the caregiver died, the caregiver refused to participate, or 2 years after the death of the parent with dementia.
• The maximum time of participation was 3.79 years after enrollment.

NYUCI-AC

• The two NYUCI-AC counselors were master’s-level psychotherapists.
• The NYUCI-AC consisted of three components: individual and family counseling, support group participation, and ad hoc counseling.
• During the initial 4-month intervention period, adult child caregivers were asked to participate in six individual and family sessions with a trained study counselor.
  – Two individual sessions, three with the adult child caregiver and one or more family members, and a final individual session.

NYUCI-AC

The clinical content of the counseling sessions was individualized to meet the needs of each caregiver by providing education and psychosocial support. Support was enhanced through improving interactions among family members and enhancing the understanding of each other’s needs.

– After the first follow-up assessment, caregivers were referred to local support groups or to an adult child-specific support group moderated by the NYUCI-AC counselors.
– Ad hoc counseling was available in person, over the phone, or via e-mail to address crises, concerns, or information needs.
– Participants in the control group were provided with a biannual project newsletter and quarterly “check-in” calls by the counselors.
  – If an immediate or a critical need was raised, counselors could provide ad hoc consultation to caregivers in the control group.

Table 2: Residential Care Placement Outcomes and Related Comparisons, New York University/NUC I Caregiver Intervention Adult Child NYUCI-AC: Treatment and Control (n = 81)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Total (n = 170)</th>
<th>Control (n = 85)</th>
<th>Treatment (n = 85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care recipient %</td>
<td>55.5</td>
<td>50.2</td>
<td>60.7</td>
</tr>
<tr>
<td>Care recipient maternal care</td>
<td>37.5</td>
<td>37.5</td>
<td>37.5</td>
</tr>
<tr>
<td>Care recipient nursing home care</td>
<td>29.0</td>
<td>29.0</td>
<td>29.0</td>
</tr>
<tr>
<td>Residential care (full-time living)</td>
<td>22.4</td>
<td>22.4</td>
<td>22.4</td>
</tr>
</tbody>
</table>

Note: Prior to unblinding, decisions were made to code three cases as unknown: placement (3) or participant withdrew (2) or was lost to follow-up (1). In the final analysis, participants who were lost to follow-up were coded as 37.5% care recipient, 37.5% maternal care, 29.0% nursing home care, 22.4% residential care, and 22.4% unknown.

Table 3: Logistic Regression Results: Effect of the New York University/NYUCI Caregiver Intervention Adult Child NYUCI-AC on Care Recipient Residential Care Placement

<table>
<thead>
<tr>
<th>Variables</th>
<th>OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care recipient</td>
<td>1.48 (1.15–1.80)</td>
</tr>
<tr>
<td>Maternal care</td>
<td>1.50 (1.09–2.04)</td>
</tr>
<tr>
<td>Nursing home care</td>
<td>1.79 (1.09–2.91)</td>
</tr>
<tr>
<td>Residential care</td>
<td>1.34 (0.62–2.90)</td>
</tr>
</tbody>
</table>

Multinomial logistic regression: Those in the control group were more than 4 times as likely to enter an assisted living or similar residential care setting than those in the NYUCI-AC treatment group (β = 1.48, SE = 0.49, Wald = 9.03, odds ratio = 4.41, 95% CI = 1.08–17.60).

• There was a trend toward the NYUCI-AC treatment leading to lower nursing home placement compared with the control group, but this difference did not achieve statistical significance (p = .08).

• Average days of study participation was 644.37 days (SD = 371.04; range = 28–1,384 days, from intake to final assessment).

From Gaugler, Reese, & Mittelman, 2013

• B = −0.64, SE = 0.32, Wald = 3.99, RR = 0.53, 95% CI = 0.28–0.99; p < .05

• The mean time from baseline to residential care admission in the NYUCI-AC treatment condition was 971.60 days (SE = 72.27) compared with 743.24 days for those in the control group (SE = 68.49) (log-rank p = .03; Breslow p = .07; Tarone–Ware p = .047).

From Gaugler, Reese, & Mittelman, 2013
Discussion

- The delay in residential care placement among parents of adult child caregivers who received the NYUCI-AC suggests the efficacy of this multi-component model.
- One of the goals of the NYUCI-AC counseling was to provide emotional support to:
  - Help NYUCI-AC participants cope with the relationship changes.
  - Enable participants understand their parents’ behaviors were due to an underlying disease process.
- The counseling sessions also offered caregivers the opportunity to develop effective solutions to emotionally challenging issues.

Limitations

- Small sample size
- Sample is largely Caucasian, well-educated, and female
- The variation in protocol delivery requires a comprehensive process evaluation (forthcoming)

Implications

- The average annual rate for assisted living memory care was $55,428 per year 2012.
- Nearly half (46%) of parents with ADRD in this sample who were admitted to assisted living were recorded as entering a memory care unit.
- It could be argued that delaying or preventing the use of assisted living as in this evaluation is a potentially positive fiscal outcome for families as well as federal and state governments.

Families and LTC Projects: Current Research as PI

- R01 AG049692 (with Gitlin), 2016-2021
- R01 AG048931, 2016-2021
- R18 HS022836, 2014-2019
- R21 NR013737, 2014-2017
- MNBoA, 2016-2017
Randomized Controlled Evaluation

Procedure
1. Baseline interview
2. Random assignment
3. Bi-annual follow-up over 12 months
4. Key outcomes:
   a) Caregiver stress and mental health
   b) Caregiver efficacy and competence
   c) Residential care stress
5. Secondary outcomes:
   a) Transitions out of RLTC

Product
- Growth curve models
- Cox proportional hazards

Embedded Process Evaluation
Quan - Biannual open-ended and close-ended survey items
Qual - Semi-structured interviews to determine mechanisms of RCTM benefit

Stratified purpose sample
Rate of change:
- n = 15 increase
- n = 15 decrease

Point of Interface/Mixed Methods Analysis
- Integration of findings from randomized controlled evaluation with embedded components to examine points of convergence or divergence as to how and why the RCTM is effective.
- Matrices and cross tabulations of empirical results and identified categories and themes.

Questions?

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