



The Families and LTC Projects

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Specific Aims 3

- 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 4

- 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 5 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, LAMFT
- Other Research Assistants
 - Emily Westphal
 - Manisha, Aneri, and Ayush Shah



My Educational Path 6




Public Health Context 7

- 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, & Pruneiri, 2014

Public Health Context 8

- 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, & Pruneiri, 2014; The Alzheimer's Association, 2015

Table 1 Syntheses that describe family caregiving for older adults and its outcomes	
Disease Context	Family Caregiving Outcomes and Correlates
<p>General^{1,5,11,26,27-30}</p> <p>Family caregivers indicate significantly higher rates of depression and stress when compared to noncaregivers</p> <p>The amount of care provided and care recipient's physical impairments are associated with caregiver burden and depression</p> <p>Uplifts, or perceived positive aspects of caregiving, are possibly associated with the well-being of family caregivers, whereas caregiving stress is linked to depressive symptoms</p> <p>Depressive signs and symptoms are associated with negative perceptions of health on the part of family caregivers. Behavior problems on the part of care recipients are also associated with poorer health of family caregivers, as is older age, lower socioeconomic status, and less social support</p> <p>When compared to noncaregivers, family caregivers suffer from greater overall and clinical depression and anxiety, less social support, greater physical impairments and disabilities, poorer self-rated health, and acute and chronic conditions than do noncaregivers</p> <p>Ethnically and racially diverse family caregivers are more likely to be of lower socioeconomic status, younger, less likely to be a spouse, more likely to receive informal support, have stronger filial obligation beliefs, are more depressed, and experience worse physical health</p> <p>There is substantial diversity in caregiving experience and outcomes across various racial and ethnic groups; more attention to acculturation, theory development, and cultural beliefs, values, and norms is needed</p>	<p>Alzheimer disease^{1,23,24,31,32}</p> <p>Family caregivers of persons with Alzheimer disease or a related dementia experience greater emotional, psychological, financial, and physiologic distress when compared to other caregivers or noncaregivers</p> <p>Lower current relationship quality is associated with increased depression and strain and decreased self-efficacy; lower previous relationship quality is related to depression, burden, and emotional reactivity</p> <p>Personal mastery, self-efficacy, and positive coping strategies can serve to protect dementia caregivers from negative outcomes</p> <p>Spouses provide more support but report more depressive symptoms, greater physical and financial burden, and lower levels of psychological well-being than children and children-in-law</p> <p>Dementia caregivers show a slightly greater risk for health problems than noncaregivers</p>

From Table 1, Gaugler, Potter, & Pruneiri, 2014

From Table 1, Gaugler, Potter, & Pruneiri, 2014

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- **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

Research ↔ Education

Research ↔ Clinical

Education ↔ Clinical

Land-Grant Mission

Aligning the Mission 13

- 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 14

- 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.”

<https://win-cities.umn.edu/about-us/anchor-our-mission/>

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Longitudinal Ramifications	CBLTC and Interventions for Family Caregivers/AD and LTC	Methods
Eli Lilly 2011-2012	R03 HS020948 (2012-2014)	K18 HS022445 (2013-2016)
Eli Lilly 2009-2010	R01 AG022066 (2006-2011)	K02 AG029480 (2008-2013)
University of Minnesota Cancer Center 2006-2007	R21 AG026525 (2007-2011)	
	UMN/CTSI 2013-2014 CTSI 2012-2014	

Project Details

- **Title:** Comprehensive Support for Alzheimer’s Disease Caregivers (R01 AG 022066; PI: Gaugler; University of Minnesota Clinical and Translational Science Institute (CTSI))
- **Key Personnel:** Joseph E. Gaugler, PhD; Mary Mittelman, DrPH (Co-Investigator)
- **Funding source:** National Institutes of Health/National Institute on Aging
- **Duration:** 2005-2011
- **Specific Aims:**
 - 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 AD/DR 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 AD/DR 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 contact control group (n = 53) following consent and completion of a baseline interview.

Procedure

- Participant recruitment was initiated in January 2006 and adult child caregivers were enrolled from January 2006 to August 2009.
 - As this study was not affiliated with a memory clinic, study recruitment was primarily community-based.
- Participants were initially identified and enrolled from a variety of sources including flyers posted on the Minnesota–North Dakota Alzheimer’s Association’s Regional Office web page and community presentations.

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 Bivariate Comparisons, New York University (NYU) Caregiver Intervention-Adult Child (NYUCI-AC) Treatment and Control Groups (N = 107).

Variables	Total (N = 107)	Control (n = 53)	Treatment (n = 54)
Care recipient died (%)	35.5	30.2	40.7
Care recipient entered residential care ^a			
Any residential care setting ^a (%)	51.4	66.0	37.0
Residential care (assisted living/family care home) ^a (%)	28.0	39.6	16.7
Nursing home (%)	23.4	26.4	20.4

Note. ^aPrior to unblinding, decisions were made to code three cases as residential care placement: (1) one participant, several months following her final interview, reported her parent was in assisted living; (2) one participant confirmed an impending nursing home admission prior to her final follow-up interview but did not complete the final interview; and (3) one participant reported using a nursing home for her parent between 6-month follow-up interviews but then arranged to have her parent return to the community.

*p < .05. **p < .01. ***p < .001.

- 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



Table 3. Logistic Regression Results: Effects of the New York University (NYU) Caregiver Intervention-Adult Child (NYUCI-AC) on Care Recipient Residential Care Placement

Variables	B	SE	Wald	OR	95% CI
Caregiver is female	-0.25	1.01	0.06	0.78	0.11–5.60
Caregiver subjective health	0.38	0.40	0.92	1.47	0.67–3.20
Stokes Social Network: number of close friends	-0.10	0.07	1.79	0.91	0.78–1.05
Overall satisfaction with social network	-0.27	0.17	2.41	0.77	0.55–1.07
NYUCI-AC treatment	-1.16*	0.46	6.53	0.31	0.13–0.76

Note. SE = standard error; OR = odds ratio; CI = confidence interval.
*p < .05. **p < .01. ***p < .001.

- **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 (B = 1.48, SE = 0.49, Wald = 9.03, odds ratio = 4.41, 95% CI = 1.68–11.60).
- 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).

From Gaugler, Reese, & Mittelman, 2013

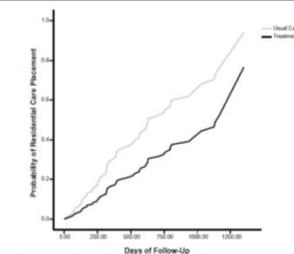


Figure 2. Cox proportional hazards survival curves: Probability of residential care placement (1 = survival probability) at the time of care entry, New York University Caregiver Intervention-Adult Child (NYUCI-AC) (N = 107).

- 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 = 66.49) (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

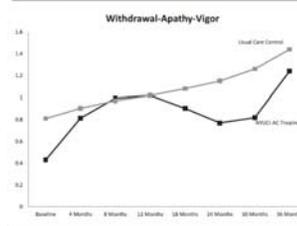
- The average annual rate for assisted living memory care was \$55,428 per year 2012.
- Nearly half (46%) of parents with ADRD in this sample who were admitted to assisted living were recorded as entering a memory care unit.
- It could be argued that delaying or preventing the use of assisted living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

Alzheimer's Association, 2012; Mollica, 2009



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FIGURE 2. Significant growth curve trajectories: Withdrawal-Apathy-Vigor subscale of the Geriatric Depression Scale.

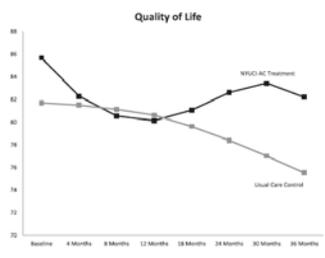


From Gaugler, Reese, & Mittelman, 2015



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FIGURE 3. Significant growth curve trajectories: Cantril Quality of Life ladder.



From Gaugler, Reese, & Mittelman, 2015

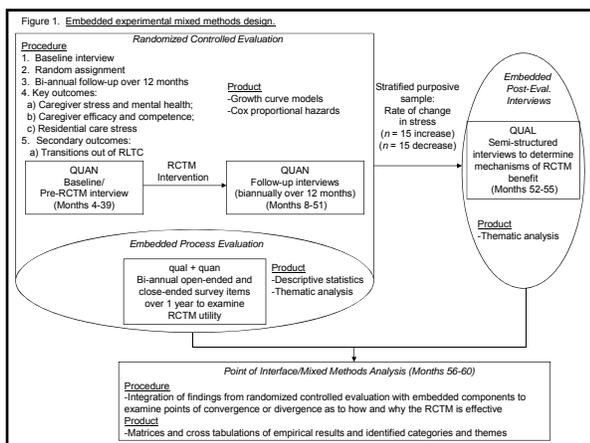


Families and LTC Projects: Current Research as PI

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





Families and LTC Projects: Future Research Directions

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- R01: MMCMC
- T32/P-Level Grant
 - Dementia-friendly communities/healthcare systems
- Care to Plan, PHR grants

Questions?

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