



Gender Differences in Dementia Caregiving: Implications for Intervention

**DATA FROM NYU PSYCHOSOCIAL INTERVENTION
RESEARCH AND SUPPORT SERVICES**

Mary S. Mittelman, DrPH
Research Professor
Psychiatry and Rehabilitative Medicine
NYU School of Medicine

Background

The First Study of the NYU Caregiver Intervention enrolled 406 spouse caregivers

The NYU Alzheimer's Disease and Related Dementias Family Support Program has provided services to 946 family caregivers since January 2016

The NYU Caregiver Intervention (NYUCI)

- **A multi-component intervention including counseling, support and education**
- **Individualized to the needs of each family**
- **Emphasizes support for the primary family caregiver**
- **Includes the caregiver and other family members**
- **Available when needed and as long as needed**
- **Geared to the stage of dementia and the strengths and limitations of the person with dementia and the family caregivers.**

Design of the NYU Caregiver Intervention

- Comprehensive intake assessment and regular follow-up assessments
- Scheduled individual and family counseling sessions within four months of enrollment
 - One individual counseling session
 - 4 family counseling sessions
 - A second individual counseling session
- Recommendation for continuous participation in a support group
- Ad hoc counseling - telephone consultation on request of caregiver or family member over the entire course of the disease.

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Results of RCT of NYUCI (1987-2010; n=406 spouse caregivers)

- *Improved support* for caregiver for at least 5 years
- *Reduced caregiver depression* for at least 3 years
- *Reduced caregiver stress reaction* to behavior of person with dementia for at least 4 years
- *Improved caregiver self rated health* for at least 4 years
- *Postponed nursing home placement of person with dementia 557 days*
- *Reduced caregiver depressive symptoms and burden during the transition to a nursing home*
- *Effects persist through bereavement*
- **Mediator of all other outcomes is social support**

* Note: Fewer than 5% dropped out while the person with dementia was still living at home..

NYU Family Support Program

- Consultation and support personalized to the needs of each caregiver
 - Individual consultation
 - Family consultation
- Ongoing support in person, by telephone and video conferencing and email
- Consistent access to care team throughout the course of caregiving
- Education about caregiving and dementia
- Referral to community services that can address the often complex needs of caregivers
- Unique features: A Buddy Program for people with dementia, peer mentoring for caregivers, workshops in music, creative writing and weaving for caregivers, “A Place for Us” – a community program for people in the early stage of dementia, a photo class for people with dementia, a musical ensemble for people with dementia and students in the School of Music at NYU.
- No cost, except for reimbursable outside service referrals.

What Have we Learned from Our Research and Services at NYU?

Older Spouse Caregivers Played Traditional Gender Roles in Marriage (Results of Baseline Assessments of 406 NYUCI Study Participants)

- Many of the female caregivers in the NYUCI were homemakers before their husbands became ill,
- Almost all the male caregivers were either still employed, or retired.
- More male caregivers reported that they had given up paid work when their spouses became ill.
- Role Changes with Caregiving
 - More than half the male caregivers had taken over tasks traditionally performed by their wives, such as cooking, housekeeping and food shopping; the majority of the men who took over these tasks were retired.
 - Female caregivers took over tasks traditionally viewed as belonging to men, such as management of finances, decision-making and management of a business.

Formal and Informal Support

(Results of Baseline Assessments of 406 NYUCI Study Participants)

- Female spouse caregivers reported having less help from family and friends than male caregivers.
- Many more female caregivers than male caregivers reported that they received help from no one at all.
- Male caregivers are more likely to receive tangible caregiving support than females and use support for household chores
- More wives than husbands were dissatisfied with the assistance they received.

Assistance Provided by Adult Children Depended on whether their Mothers or Fathers were the Primary Caregivers

(Results of Baseline Assessments of 406 NYUCI Study Participants)

- 44.4% of male caregivers had help from their daughters, compared to 23.8% of female caregivers.
- There was no difference in the amount of help male and female caregivers received from their sons.
- Daughters, appear to be more concerned with helping their fathers than their mothers.
- Many more female caregivers than male caregivers reported that they received help from no one at. More wives than husbands were dissatisfied with the assistance they received.

Consequences of Less Support for Women

(Results of Baseline Assessments of 406 NYUCI Study Participants)

- Female spouse caregivers had curtailed their other activities more than male caregivers, especially discretionary activities such as spending time with friends and family members.
- Women were significantly more likely than men to have curtailed caring for themselves, which may ultimately have an impact on their physical health
- Female spousal caregivers reported feeling isolated, suffering from lack of sleep
- Female caregivers reported lack of privacy, being embarrassed by their spouse and feeling rejected by their spouse more frequently than male caregivers.

Comparison of Same-gender Spousal Support Groups (NYU Family Support Program)

Women's Spousal Group

9 members (inconsistent attendance)

Meeting weekly 6+ months

All are caring for spouses at home.

As a group, reluctant to hire help (HHA or companion)

As a group, angry, anxious, dissatisfied with assistance from family

Miss being cared for and feel alone

Men's Spousal Group

7 members (consistent attendance)

Meeting bimonthly 6+ months

5 of 7 members have placed spouse in a SNF or are in process.

Decisions to hire help supported by adult children

As a group, sad, yet philosophical about situation

Capable of, and strongly believe in, self-care to avoid depletion

Miss companionship and intimacy

How Does Gender Affect Design of Interventions?

Who utilizes psychosocial interventions?

How can we find out about people of either gender who don't use services, to see if they would prefer something we aren't offering?

Men are Less Likely to Participate in Caregiver Research than Women

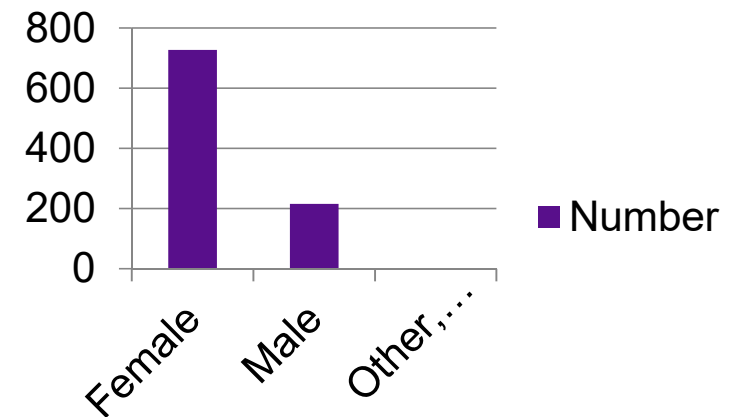
- In all our studies of psychosocial interventions for caregivers there are fewer men than women
 - ❑ In the original NYUCI study, 40% of spouse caregivers were men
 - ❑ In the adult-child variant of the NYUCI, there were only 3 men and 100 women.
- Are the men who use services and participate in research different (less supported, more flexible) than those who don't?
- What does this mean about inferences we draw about gender differences?
- Is there the same gender difference in caregivers accessing support services?

Caregivers Served by NYU Family Support Program

Total Caregivers and Family Members Receiving Services

April 2016 to July 2018	946
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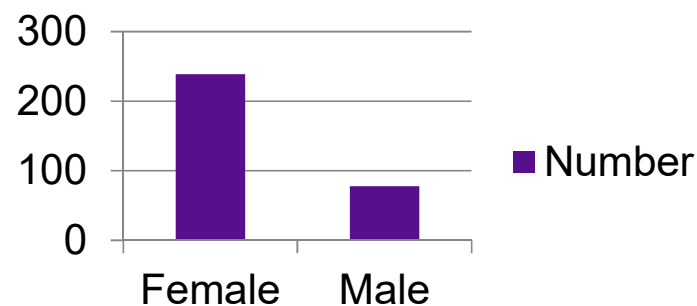
Gender	Count; Percentage
Female	n=728; 77%
Male	n=216; 22.8%
Other, Transgender	n=2; .2%



Family Support Program: Gender Breakdown for Spouses/Partners and Adult Child Caregivers

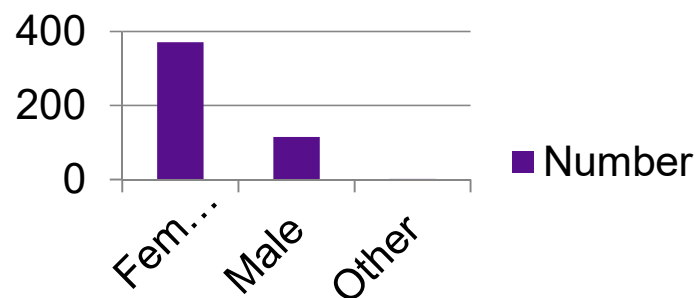
Spousal/Partner Caregivers by Gender

Gender	Count; Percentage
Female	n=239; 75.4%
Male	n=78; 24.6%
Total	n=317



Adult Child (and Step-Child) Caregivers by Gender

Gender	Count; Percentage
Female	n=371; 76.02%
Male	n=115; 23.57%
Other; Transgender	n=2; 0.41%
Total	n=488



NYU Family Support Program Service Use by Gender

Care Consultations

Gender	Count; Percentage
Female	n=3,013; 78.06%
Male	n=835; 21.63%
Other, Trans, Data Not Collected	n=12; .31%

Special Respite Programs at NYU

Gender	Count; Percentage
Female	n=254; 86%
Male	n=42; 14%

Arts Programs for People with Dementia and Caregivers

Gender	Count; Percentage
Female	Limited data but all female caregivers.

Education (2017 to present)

Gender	Count; Percentage
Female	n=46; 83.6%
Male	n=8; 14.5%
Other, Trans, Data Not Collected	n=1; 1.8%

Caregiver Wellness

Gender	Count; Percentage
Female	n=185; 96%
Male	n=8; 4%

Support Groups at NYU

Gender	Count; Percentage
Female	n=95; 70.4%
Male	n=39; 29.1%



Thank you for your attention.

To contact

Mary Mittelman

E-Mail: mary.mittelman@nyumc.org