Wisconsin Public Psychiatry Network Teleconference (WPPNT)

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Counseling and Support for Family Caregivers

Rationale and Research Results

Excerpts from a presentation by:
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The Burden of Care for People with AD

- Worldwide costs of dementia exceeded 1 percent of global GDP in 2010, at $604 billion, US.*
- The value of informal care for people with dementia worldwide is estimated at $251.89 billion US.*
- Caregivers of people with AD provide many hours of care**
  - an average of 21.9 hours of care per caregiver per week
  - 15%-40% of caregivers provided more than 40 hours a week

* World Alzheimer Report 2010, prepared by Alzheimer’s Disease International
** Alzheimer’s Association. 2012 Alzheimer’s Disease Facts and Figures

NYU Caregiver Intervention Study: 1987-2010

A Randomized Controlled Trial to Test the Efficacy of Counseling and Support for Spouse Caregivers

Special Challenges Faced by Alzheimer’s Disease Caregivers

- Alzheimer’s disease typically lasts for 5-15 years
- Increasing cognitive and functional impairments ultimately lead to complete dependence on others for survival
- The symptoms change over time
  - Early: memory problems
  - Middle: troublesome behavior
  - Late: Activities of daily living
NYU Caregiver Intervention Study Participants

- 406 spouse-caregivers of people with Alzheimer’s disease
- Enrolled from August 1987 to February 1997
- Followed for up to 18 years
- Living with the person with AD at intake
- At least 1 close relative in the area.


NYU Caregiver Intervention Original Study Design

- Comprehensive baseline interview
- Random assignment to treatment or usual care control group
- Regular comprehensive follow-up interviews
- All participating caregivers receive the services routinely available at the NYU Aging and Dementia Research Center.


Components of NYU Caregiver Intervention

- Scheduled individual and family counseling sessions within a fixed period of time
  - One individual counseling session
  - 4 family counseling sessions
  - A second individual counseling session
- 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.


Why is Individual Counseling Helpful to Family Caregivers?

- Counselor can tailor treatment to needs of individual caregiver
- Counseling can occur in a time and place convenient for caregiver
- Caregiver can establish a relationship with counselor that makes it possible to seek further advice and support when needed
- Caregiver becomes aware of need to involve other family members in patient care

Why is Family Counseling Helpful to Caregivers?

- Family members understand that person with dementia is ill
- Family members understand that person with dementia is no longer a sufficient source of social support for caregiver
- Family members learn about the needs of the primary caregiver
- The primary caregiver learns what kind of support other family members would like to give.
Why is Family Counseling Helpful to Caregivers?

- Family members can talk objectively about current problems
- Family conflict about caregiving can be resolved
- Communication among family members improves
- Family members are aware of counseling services.

Why are Support Groups Helpful to Caregivers?

- Caregivers can provide each other with ongoing emotional support
- Caregivers benefit from talking to others who have gone through similar experiences
- Caregivers can get information about how to solve the problems they are currently facing.

Why is Ad Hoc Counseling Helpful to Caregivers?

- Caregivers know that a counselor will be available when needed
- Caregivers can receive help without leaving home
- Effects of dementia change over course of illness; when a new problem arises, help is available
- In a crisis, there is someone to call.

Results of NYU Caregiver Intervention Study

NYU Caregiver Intervention Improves Caregiver Satisfaction with Support from Social Network


The Effect of NYU Caregiver Intervention on Satisfaction with Support Continues for at Least 5 Years

Covariate-adjusted trajectories for average satisfaction with social support over the first 5 years of intervention. Drentea, P; Clay, OJ; Roth, DL & Mittelman, M.S, Social Science in Medicine, 2006
NYU Intervention Reduces Caregiver Symptoms of Depression


NYU Intervention Reduces Caregiver Symptoms of Depression Continues for at Least 3 Years


Caregiver Reaction to Problem Behavior Improves with NYU Caregiver Intervention

Mittelman MS, Roth DL, Haley WE, Zarit SH: *Journals of Gerontology, Psychological Sciences* 2004; 59B:27-34

NYU Caregiver Intervention Has No Effect On Frequency of Problem Patient Behaviors

Mittelman MS., Roth, DL, Clay, OJ and Haley, WE. *AJGP, 2007; 780-789*

How Does the NYU Intervention Achieve its Effects on Caregiver Depression and Reaction to Problem Behaviors?

By increasing:
- Number of friends and relatives the caregiver considers to be “close”
- Satisfaction with emotional support from friends and relatives
- Satisfaction with assistance from friends and relatives

Counseling and Support Improves Physical Health of Family Caregivers

Mittelman, MS., Roth, DL, Clay, OJ and Haley, WE. *AJGP, 2007:780-789*
Time to Nursing Home Placement of People with Dementia is Delayed by Counseling and Support of Caregivers

- Nursing home admission significantly reduced burden and depressive symptoms.
- The NYUCI significantly reduced caregiver depressive symptoms and burden during the transition to a nursing home, even though caregivers in the treatment group placed their spouses significantly (557 days) later than those in the control group.

The NYU Caregiver Intervention’s Effects Persist through Nursing Home Placement

- The death of the care recipient led to reductions in depressive symptoms.
- NYUCI led to lower depressive symptoms compared with controls both before and after bereavement.
- Post-bereavement group differences were stronger for caregivers of spouses who did not previously experience a nursing home placement.
- NYUCI led to long term patterns of fewer depressive symptoms suggesting greater resilience.

The Future of the NYUCI

- Web-based training in the NYUCI, including individual certification.
- Web-enabled counseling at a distance via Zoom® (a Skype-like technology).
- Distance Research Study (through 2018).

Web-based Training in NYUCI
Web-based Training in NYUCI

Web-enabled “Distance” Counseling via Zoom® (a Skype-like technology)

Zoom® Research Study

- NIH-funded Research Study (all states)
- Free training and certification in NYUCI family approach ($2500 value) – 15 hours to complete
- Continuing education available (up to 40 hours with optional modules)
- Research - Intervention Group (full-timeline NYUCI process)
- Research - Control Group (ad-hoc calls only)
- Payments per family: $1000 / $500
- Payments can be made to the agency or you personally
- You must enroll at least 1 family (max 24)

Note: Research Study Ends May 31, 2018

Research Study Contact Information

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