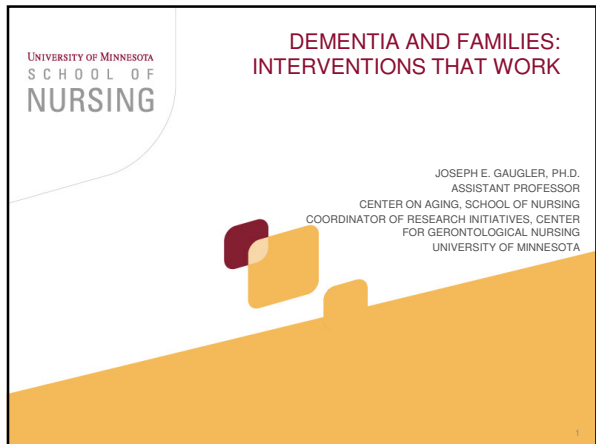


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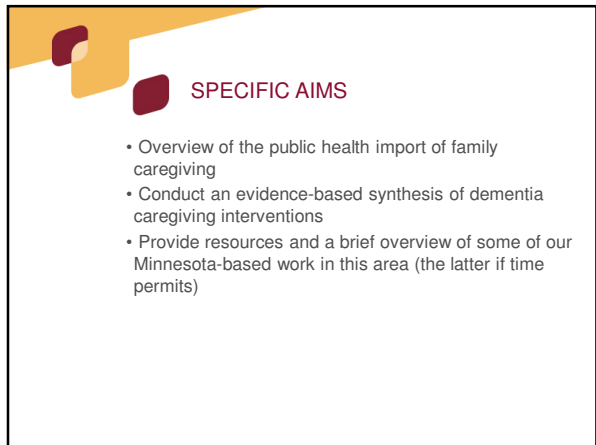
**DEMENTIA AND FAMILIES:
INTERVENTIONS THAT WORK**

JOSEPH E. GAUGLER, PH.D.
ASSISTANT PROFESSOR
CENTER ON AGING, SCHOOL OF NURSING
COORDINATOR OF RESEARCH INITIATIVES, CENTER
FOR GERONTOLOGICAL NURSING
UNIVERSITY OF MINNESOTA



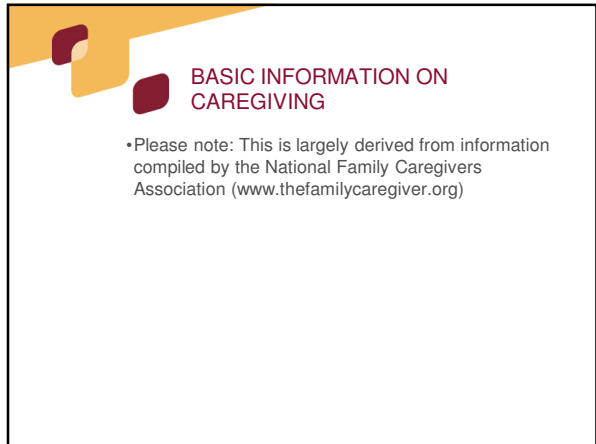
SPECIFIC AIMS


- Overview of the public health import of family caregiving
- Conduct an evidence-based synthesis of dementia caregiving interventions
- Provide resources and a brief overview of some of our Minnesota-based work in this area (the latter if time permits)



**BASIC INFORMATION ON
CAREGIVING**


- Please note: This is largely derived from information compiled by the National Family Caregivers Association (www.thefamilycaregiver.org)






CAREGIVING POPULATION

- Approximately 50 million people provide informal (i.e., unpaid) care to a disabled family member (DHHS, 1998; NCFA, 2000)
- The typical family caregiver is a 46-year old woman caring for a mother (widowed) who does not live in the same household (NAC/AARP, 2004)
- 30% of family caregivers are over the age of 65 (AHRQ, 2001)




ECONOMICS OF CAREGIVING (Stucki & Mulvey, 2000)

- Women who are family caregivers are 2.5 times more likely than non-caregivers to live in poverty
- A typical family caregiver loses \$109 per day in wages due to family care responsibilities
- 13% of the workforce is currently providing care to a disabled family member (Wagner & Neal, 2002)
- The value of informal long-term care has been estimated at 306 billion dollars a year (Arno, 2006)
 - That is approximately twice as much as spent on nursing home and home health care combined




IMPACT OF CAREGIVING

- Spouse caregivers 65+ who have chronic illness histories have a mortality rate that is 63% higher than non-caregivers (Schulz & Beach, 1999)
- The stress of family care responsibilities has been shown to adversely impact a caregiver's immune system up to 3 years after such care ends (Kiecolt-Glaser & Glaser, 2003).
- Other adverse effects include depression, anxiety, and other chronic health conditions




CAREGIVING AND HEALTHCARE

- Families provide the bulk of long-term care in the U.S.
 - 78% of older adults who require help receive it from family members only (Thompson, 2004)
- 22% of family caregivers report needing help in communicating with physicians (NAC/AARP, 2004)
- 40% of family caregivers provide “nursing” help to disabled relatives, including medication administration, changing bandages, and monitoring vital signs (Levine, 1998)



STATE OF THE ART (IN MY OPINION)

- Early cross-sectional work (Zarit et al., 1980)
- Conceptual models designed to guide research on the impact of family caregiving
 - The stress process model, Pearlin et al., 1990
- Longitudinal analyses of the caregiving “career” and long-term outcomes
- Interventions designed to alleviate some of the negative outcomes related to informal care
 - Outcomes include caregiver stress, caregiver depression, and care recipient nursing home admission



EVIDENCE-BASED REVIEW

- Goal: Use evidence-based methods to efficiently identify effective caregiving interventions
 - “Evidence-based medicine is the integration of best research evidence with clinical expertise and patient values” (Sackett et al., 2000; <http://www.ebmyramid.org/samples/complicated.html>)
- Methods:
 - PICO: Problem, intervention, comparison, outcome
 - Identifying “pre-processed” evidence: the 5S approach
 - Appraising evidence
 - Synthesizing evidence

PICO

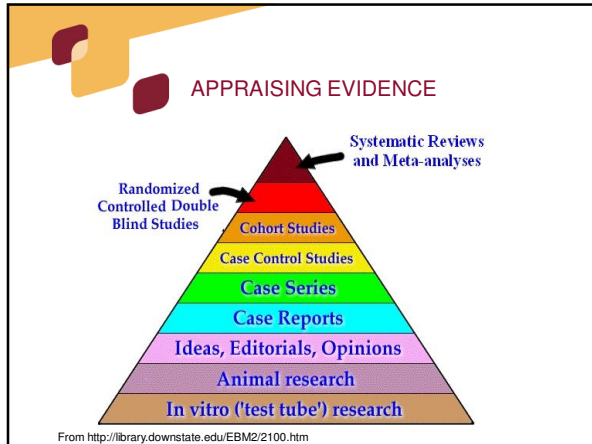
- Population: Family caregivers of persons suffering from Alzheimer's disease or a related dementia
- Intervention: Psychosocial (e.g., education, support groups, training, therapy/counseling, etc.) or community-based (e.g., respite services) programs
- Comparison: Those receiving "usual" care
- Outcomes: Caregiver stress, caregiver depression, care recipient nursing home admission
- PICO question: *Do family caregivers of persons with dementia who receive psychosocial or community-based intervention experience improved well-being and delay nursing home admission when compared to those who receive "usual care?"*

Figure 1. The "5S" levels of organization of evidence from health care research.

From Haynes, 2006, p. A-8; Haynes, R. B. (2006). Of studies, syntheses, synopses, summaries, and systems: the "5S" evolution of information services for evidence-based health care decisions. *ACP Journal Club*, 145(3), A8-A9.


THE "5S" PYRAMID

- **Systems.** Computerized decision-making support (rare)
 - Can link a patient's condition to current best-evidence
- **Summaries.** Evidence-based guidelines or syntheses
 - <http://www.guidelines.gov>;
 - <http://www.clinicalevidence.com/ceweb/index.jsp>
- **Synopses.** Easy-to-read descriptions of systematic reviews or individual studies
 - *Evidence-based journal series*; *Bandolier*; *ACP Journal Club*
- **Systematic reviews.** Meta-analyses or literature reviews
 - <http://www.cochrane.org>;
 - PubMed clinical queries (<http://www.ncbi.nlm.nih.gov/entrez/query/static/clinical.shtml>) (i.e., "Find Systematic Reviews")
- **Single studies.** Reviews of computerized databases
 - PubMed, MEDLINE, CINAHL, PSYCINFO searches




- APPRAISING EVIDENCE**
- Our evidence model (from Ackley et al., 2008):
 - I: Systematic review or meta-analysis of all relevant RCTs (randomized controlled trials) or evidence-based guidelines based on systematic reviews of RCTs
 - We will be mostly at Level 1 for this synthesis
 - II: Evidence from at least one RCT
 - III: Evidence from controlled trials without randomization
 - IV: Evidence from well-designed case-control or cohort studies
 - V: Evidence from systematic reviews of descriptive studies
 - VI: Evidence from a single descriptive/qualitative study
 - VII: Expert opinion

- RESULTS**
- *Systems*
 - Not applicable
 - *Summaries*
 - <http://guidelines.gov>, using the term "caregiving" and "dementia/Alzheimer's disease caregiver"
 - "Caregiving" yielded 18 results
 - Primarily focused on assessment, lack of evidence appraisal/nursing-specific;
 - 1 guideline selected (Singapore Ministry of Health, 2007)
 - "Dementia/AD Caregiver" yielded 29 and 16 results, respectively
 - 1 guideline selected (AAN, 2001/Doody et al., 2001)




RESULTS

- *Synopses*
- Searched *Evidence-Based Medicine* (<http://ebm.bmj.com/>); *Evidence-Based Mental Health* (<http://ebmh.bmj.com/>) & *Evidence-Based Nursing* (<http://ebn.bmj.com/>)
 - Keywords: “dementia/AD & caregiver/caregiving”
 - Focus on syntheses of systematic reviews (not single studies)
- *Evidence-Based Medicine:*
 - “Dementia caregiver” (11 found): 1 duplicate of AAN, 2001
 - “AD caregiver” (6 found): none relevant (pharmacological focus)
 - “Dementia/AD caregiving” (0 found)




RESULTS

- *Synopses*
- *Evidence-Based Mental Health*
 - “Dementia caregiver” (30 found): 1 duplicate of AAN, 2001, 5 single studies, which were saved but not included
 - “AD caregiver” (23 found): 1 found (Linger et al., 2005); others were duplicates
 - “Dementia/AD caregiving” (5 & 5 found, respectively); duplicates only
- *Evidence-Based Nursing*
 - “Dementia caregiver” (31 found): 4 single studies, 1 duplicate of AAN, 2001
 - “AD caregiver” (15 found): All duplicates
 - “Dementia/AD caregiving” (19 & 8 found, respectively); duplicates only




RESULTS

- *Syntheses*
- *The Cochrane Library* (<http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME?CRETRY=1&SRETRY=0>) (focused on Cochrane reviews only)
 - “Dementia caregiver” (11 found): 2 selected (Lee & Cameron, 2004; Thompson & Spilsbury, 1998); others focused on patient-specific interventions
 - “AD caregiver” (4 found): duplicates only
 - “Dementia/AD caregiving” (0 found, respectively)
- *PubMed special query for systematic reviews*
 - “Dementia caregiver intervention” (35 found): 11 selected
 - “AD caregiver intervention” (16 found): 1 selected
 - “Dementia/AD caregiving” (4 & 0 found, respectively)
 - “Respite” (26 found): 7 selected




OVERALL IMPRESSIONS

- Lack of high quality evidence (e.g., randomized controlled trials, blinding, etc.)
- Difficult to classify “type” of intervention
- Variations in study design and sampling
- Variations in outcome measurement
- Statistical power/size of studies included
- Poor quality was particularly apparent in earlier evaluations
- Questionable inclusion/exclusion in some syntheses
- Do we still need more research in this area?
- Overall effectiveness: Moderate at best (e.g., Brodaty et al., 2003)




EVIDENCE-BASED SYNTHESIS

- All of these findings are based on “Level I” level of evidence
- Where possible, I have ranked the findings according to what I consider are the strongest
- Organized into intervention type and findings (effective, possibly effective, not effective)




PSYCHOEDUCATIONAL INTERVENTIONS

- Involves a structured program that offers information about the disease, resources, and services. May also include training caregivers to manage problems (Sørensen et al., 2002, p. 357)
- *Effective*
 - In a meta-analysis, group-based supportive interventions based on a psycho-educational framework were effective in reducing psychological morbidity (Thompson et al., 2007)
 - In a meta-analysis, psychoeducational interventions had consistent short-term benefits across outcomes (Sørensen et al., 2002)
 - In a systematic review, individual strategies were more effective than group or education-based approaches, although teaching coping strategies in group or individual settings seemed to provide short-term psychological benefits (Selwood et al., 2007)
 - In a systematic review, combining social support and problem-solving approaches appeared effective (Cooke et al., 2001)
 - In a systematic review, a brief education intervention appeared to reduce caregiver depression (Peacock & Forbes, 2003)




PSYCHOEDUCATIONAL INTERVENTIONS

- *Possibly Effective*
 - An evidence-based guideline suggests that education may be helpful for dementia caregivers (AAN, 2001)
- *Not Effective*
 - A meta-analysis found that only multi-component interventions were effective (Acton & Kang, 2001)




SUPPORTIVE INTERVENTIONS

- Includes professional or peer-led support groups that focus on exchange of feelings, ideas, and problems/successes (Sørensen et al., 2002, p. 357)
- *Possibly Effective*
 - In a systematic review, combining social support and problem-solving approaches appeared effective (Cooke et al., 2001)
 - In a meta-analysis, supportive interventions had some effect on burden and ability/knowledge but not on other outcomes (Sørensen et al., 2002)




SUPPORTIVE INTERVENTIONS

- *Not Effective*
 - A meta-analysis found that only multi-component interventions were effective (Acton & Kang, 2001)
 - In a systematic review, individual strategies were more effective than group or education-based approaches (Selwood et al., 2007)




RESPITE

- Service designed to give caregiver “time off” from responsibilities; either at-home or site-specific (Sörensen et al., 2002, p. 358)
- *Possibly Effective*
 - In a meta-analysis, respite had some effect on burden, depression, and well-being of caregivers (Sörensen et al., 2002)




RESPITE

- *Not Effective*
 - In a meta-analysis of all controlled trials, respite showed modest benefits for subgroups only and no benefit for nursing home admission; caregiver satisfaction was high (Mason et al., 2007)
 - In a systematic review of respite interventions for caregivers, no consistent or enduring effects were found (McNally et al., 1999)
 - A meta-analysis found that only multi-component interventions were effective (Acton & Kang, 2001)
 - In a systematic review, respite appeared ineffective in reducing caregiver anxiety (Cooper et al., 2007)
 - In a Cochrane meta-analysis, there were no benefits or risks associated with respite (Lee & Cameron, 2004)




PSYCHOTHERAPY

- “Involves a therapeutic relationship between the caregiver and a professional” (Sörensen et al., 2002, p. 358)
- *Effective*
 - In a meta-analysis, psychotherapy had an effect on all outcome variables (Sörensen et al., 2002)
 - In a systematic review, CBT (along with relaxation-based therapy) appeared effective in reducing caregiver anxiety (Cooper et al., 2007)
 - In a systematic review, individual strategies such as multi-session behavior management therapy were found to be effective (Selwood et al., 2007)
- *Possibly Effective*
 - In a systematic review, a psychotherapy study appeared to delay nursing home admission (Peacock & Forbes, 2003)




PSYCHOTHERAPY

- *Not Effective*
 - In a meta-analysis, "individual-based" interventions were not effective when compared to group-based approaches (Thompson et al., 2007)
 - A meta-analysis found that only multi-component interventions were effective (Acton & Kang, 2001)



MULTI-COMPONENT

- Various combinations of education, therapy, support, and respite (Sörensen et al., 2002, p. 358)
- *Effective*
 - An evidence-based guideline found that multi-faceted caregivers interventions are important in dementia treatment (Singapore Ministry of Health, 2007)
 - A meta-analysis found that only multi-component interventions were effective (Acton & Kang, 2001)



MULTI-COMPONENT

- *Effective (cont.)*
 - While a meta-analysis found moderate benefits for all psychosocial interventions considered, multi-component, continuous, flexible support appeared linked to delayed institutionalization (Brodaty et al., 2003)
 - A systematic review of "combined" interventions for dementia caregivers found that these approaches were most effective in improving caregiver mental health and delaying nursing home admission (Smits et al., 2007)
- *Possibly Effective*
 - In a meta-analysis, intervention effects for multi-component strategies were powerful for select outcomes (e.g., caregiver burden, well-being, ability/knowledge), but few studies exist (Sörensen et al., 2002; see also Pinquart & Sörensen, 2006)

OTHER FINDINGS OF NOTE


- A meta-analysis found that Acetylcholinesterase inhibitors (ACEs) had moderate effects in reducing time spent on caregiving and burden (Lingler et al., 2005)
- A meta-analysis (Lee et al., 2007) of 4 studies found that interventions for stroke caregivers had moderate effects, but more research in this area is needed (Lui et al., 2005)
- Lower level evidence suggests that exercise is not effective, whereas there is very preliminary evidence supporting the use of yoga and relaxation techniques (systematic review of Cooper et al., 2007)

CONCLUSIONS

- The quality of evidence is still questionable (see above), but more recent evaluations appear stronger
- Psychosocial interventions that are more intensive, flexible, and individualized appear most effective at meeting the multi-faceted needs of caregivers
- Respite?
- As with all evidence-based approaches, clinical expertise along with patient values must be considered when implementing a caregiving intervention


EXAMPLES

- Multi-component
 - New York University Caregiver Intervention (click [here](#) for replication information and resources)
 - Resources for Enhancing Alzheimer's Caregiver Health II (for more information, click [here](#))
- Psychoeducational/Training
 - The Saavy Caregiver (for replication information and resources click [here](#))
- Psychotherapy
 - Refer to individual studies cited in Sørensen et al., 2002; Cooper et al., 2007; and Selwood et al., 2007



RESEARCH PROGRAM

- *Title:* Comprehensive Support for Alzheimer's Disease Caregivers (R01 AG 022066)
- *Dr. Gaugler's role:* Principal Investigator
- *Funding source:* National Institutes of Health/National Institute on Aging
- *Duration:* 2005-2010
- *Specific Aims:*
 - 1) Testing the benefits of the New York University Caregiver Intervention (NYUCI) for Alzheimer's caregivers at two sites: University of Minnesota and New York University
 - 2) Expanding the scope of the NYUCI by focusing on adult child Alzheimer's caregivers.



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CONTACT INFORMATION

- Joseph E. Gaugler, Ph.D.
- University of Minnesota
- 6-150 Weaver-Densford Hall, 1331
- 308 Harvard Street S.E.
- Minneapolis, MN 55455
- Telephone: 612-626-2485
- Email: gaug0015@umn.edu
- Fax: 612-625-7180
