



Mental Health Needs of Family Caregivers: Identifying, Engaging and Assisting

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Today's Talk

- Who are caregivers and what do they do?
- Impact of caregiving on health and mental health
- Key factors for caregiver strain vs. resilience
- Effective interventions for caregivers

Fundamentals—caregiving is increasingly common

- 52 million informal and family caregivers provide care to someone aged 20+ who is ill or disabled
- 34 million adults involved in caregiving to persons aged 50 or over
- 8.9 million informal caregivers provide care for someone aged 50+ with dementia

Family Caregiver Alliance, <http://www.caregiver.org>



Fundamentals of caregiving

- Most family caregivers are women; spouses and daughters; “informal” (unpaid)
- AD caregiving, 60 hours per week at home; 9 hours even after NHP; 5-10 year “career”
- Hospice lung cancer caregivers, over 100 hours per week
- Differences with other conditions and disabilities (DD, stroke, SCI, MCI)

Percent of U.S. Households With Caregivers by Ethnicity/Race

Figure 1: Estimates of Household Caregiving Prevalence by Age of Recipient

| Type of Recipient | Prevalence | Estimated Number of Household with Caregivers |
|---------------------------------|------------|---|
| Overall | 31.2% | 36.5 million |
| Only child recipients | 1.8% | 2.2 million |
| Only adult recipients | 24.0% | 28.0 million |
| Both adult and child recipients | 5.4% | 6.3 million |

Figure 2: Estimates of Household Caregiving Prevalence by Household Race/Ethnicity

| Race/Ethnicity | Prevalence | Estimated Number of Household with Caregivers |
|------------------|------------|---|
| White | 30.5% | 25.2 million |
| African-American | 33.6% | 4.7 million |
| Asian-American | 20.0% | .9 million |
| Hispanic | 36.1% | 4.8 million |

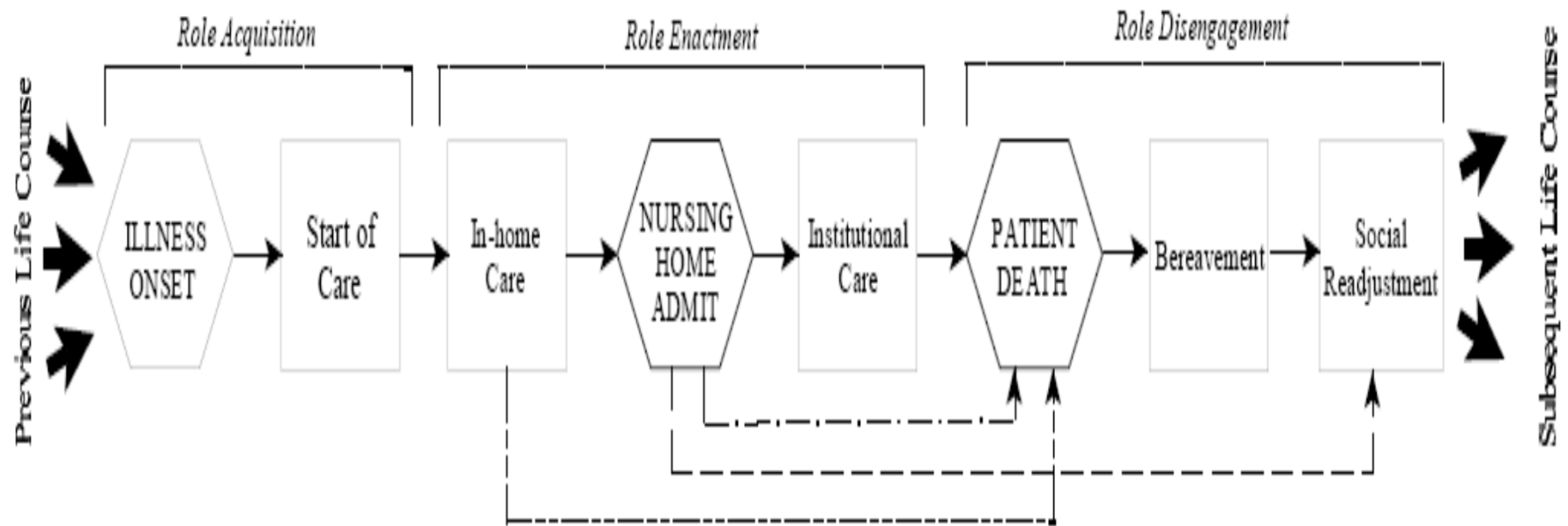
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[HTTP://WWW.CAREGIVING.ORG/DATA/CAREGIVING IN THE US 2009 FULL REPORT.PDF](http://www.caregiving.org/data/caregiving_in_the_us_2009_full_report.pdf)

What do caregivers do?

- “Whatever it takes”
- May range from occasional assistance to full-time care
- Includes physical care, symptom management, emotional support, help with activities of daily living
- Includes support while care recipient is in a facility
- Concept of “caregiving career”

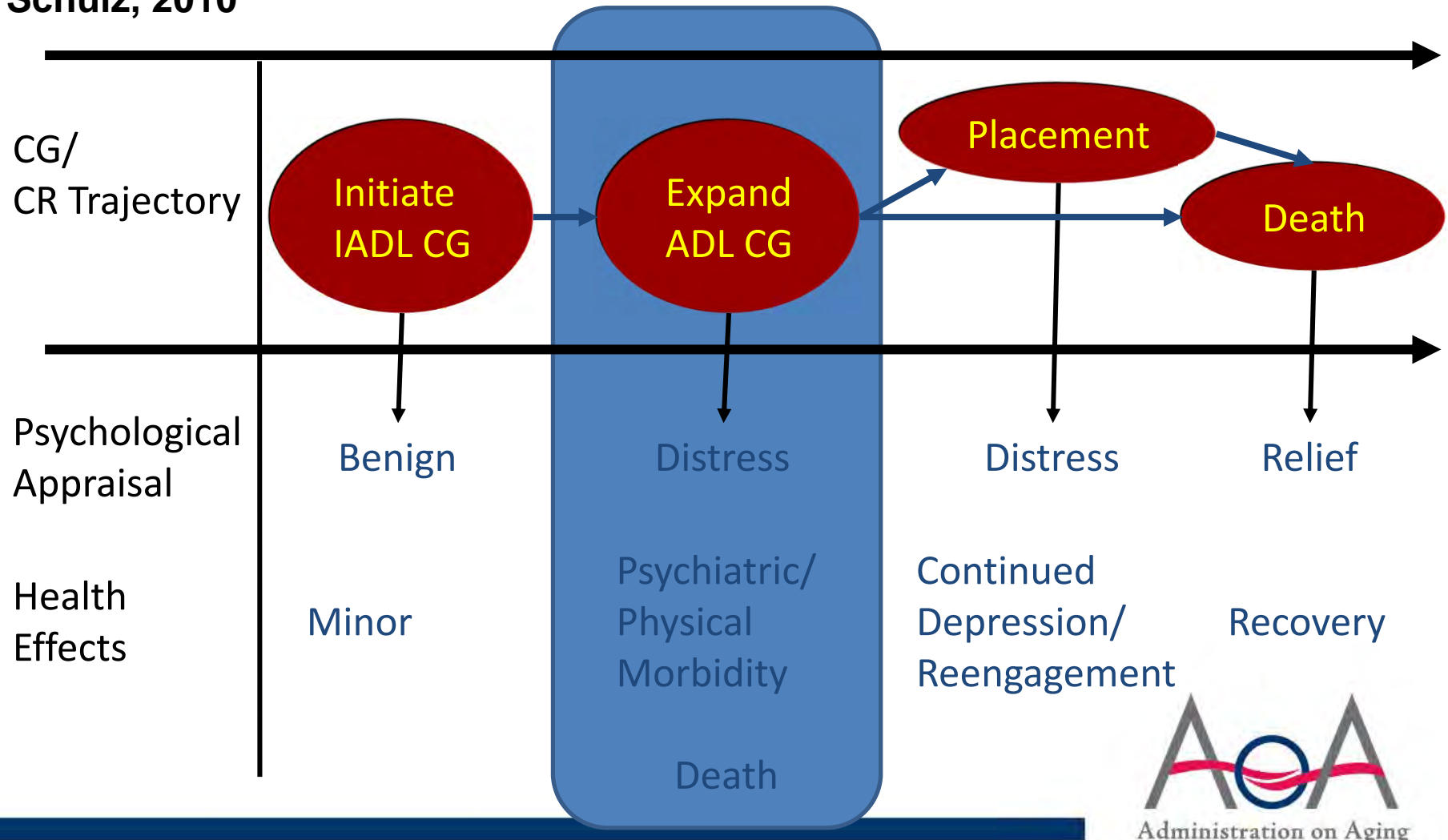
The Caregiving Career



Aneshensel et al., 1995

Chronic Stress Trajectory in Caregiving

Schulz, 2010



Caregiver reports of the most stressful patient problems in dementia

- Dangerous behavior
- Getting lost
- Embarrassing behavior
- Waking the caregiver
- Agitation, restlessness
- Anger, suspiciousness
- Depression
- Not memory problems or ADL problems, incontinence

Haley et al., 1987

Caregiving, Health, & Mental Health

- High CG strain associated with **63% increased mortality** (vs. nonCG & low strain)
- High perception of CG strain (vs. no or low strain) associated with **12% increase in stroke risk**
- AD caregivers show slower wound healing
- Caregivers with high strain show increased depression

Schulz & Beach, 1999; Haley et al., 2010; Kiecolt-Glaser et al., 1995; Pinquart & Sorensen, 2003; Roth et al., 2009

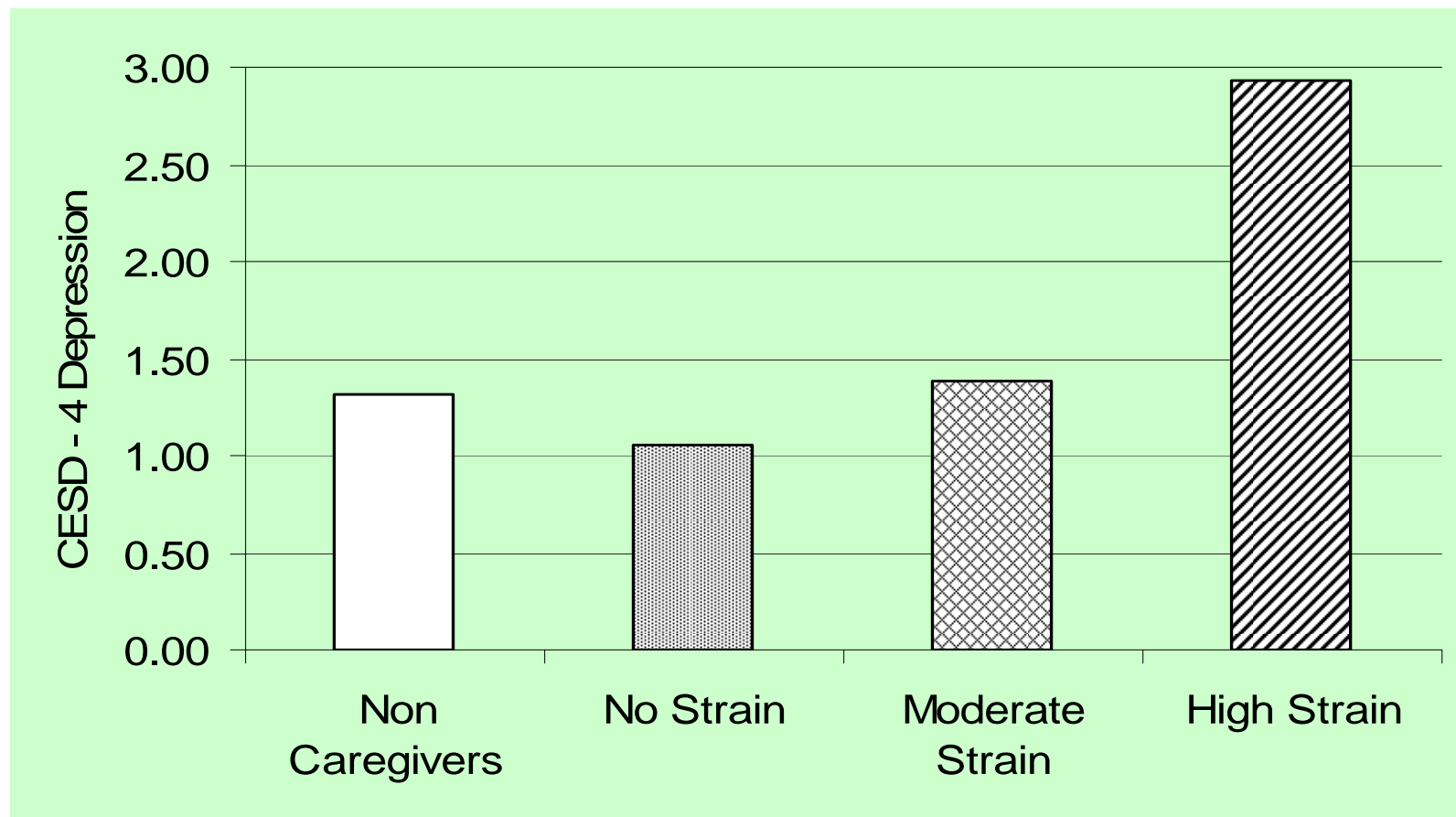
Recent results

From our survey of 43,099 adults over 45:

- Are you currently providing care on an ongoing basis to a family member with a chronic illness or disability?
 - 12% say yes
- How much of a mental or emotional strain is it on you to provide this care? (none, some, a lot)
 - 33% report no strain, 49% “some” strain, 18% “a lot” of strain

Roth et al., 2009

Relationship of Caregiving Strain to Depressive Symptoms

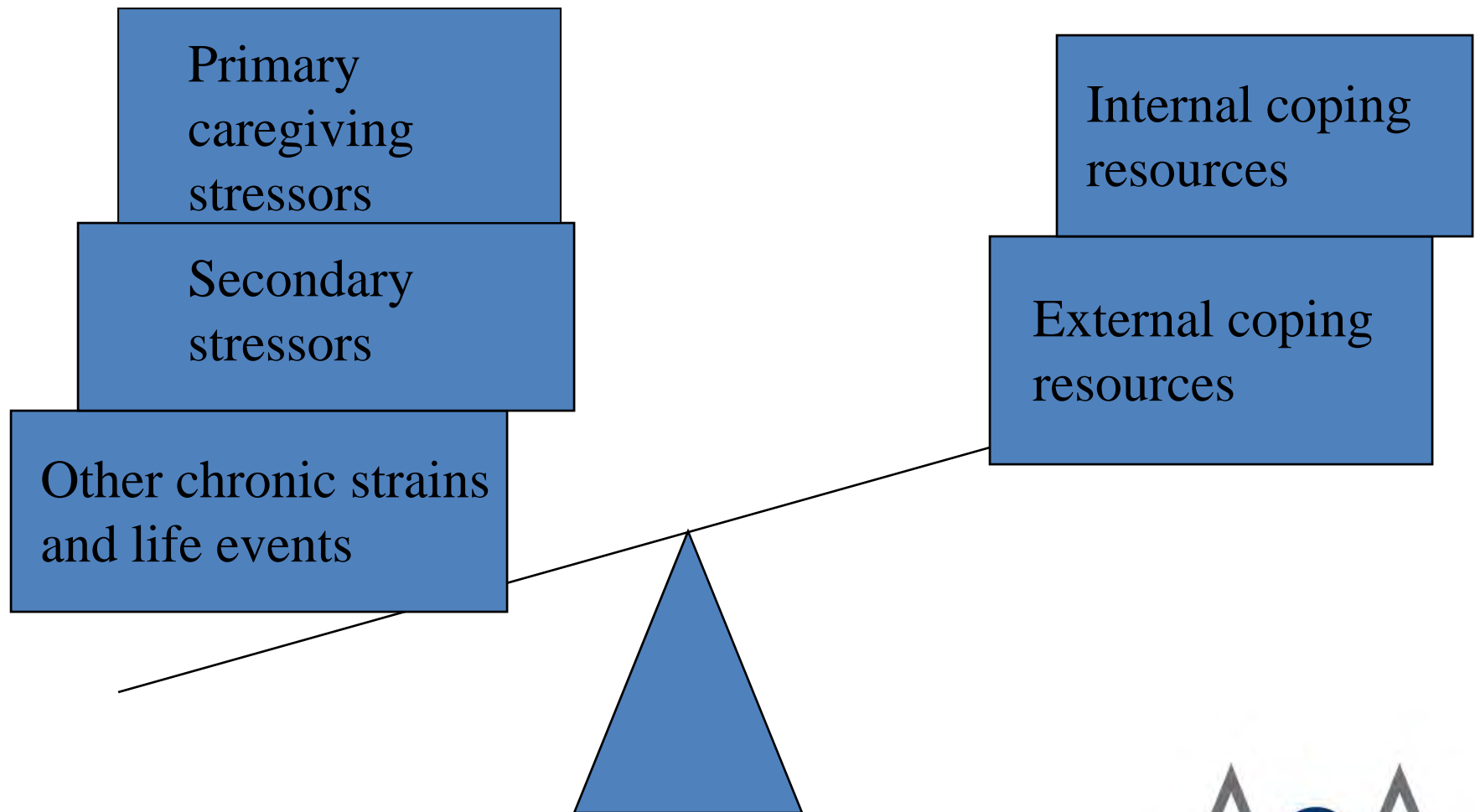


Roth et al., 2009

Caregiving and the Stress Process

- Primary stressors—patient care
- Secondary stressors—spillover effects
- Contextual stressors—life goes on
- Stress appraisal—affected by perceived resources
- Psychosocial resources can include internal (knowledge, coping, personality, spirituality) and external (social support, finances, services)

Caregiving: A Balancing Act



Perkins et al., 2007

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Coping with Caregiver Stress and Burden

Caregivers' feelings of stress and burden can be assessed with standardized questionnaires and interviews. Although stress and burden are not diagnostic labels in and of themselves, they are key components of the profile of psychological distress experienced by many caregivers.



Tools for Adult Caregivers:

- [Zarit Burden Interview](#)
- [Brief Measures of Secondary Role and Intrapsychic Strains](#)
- [Caregiver Self-Assessment Questionnaire](#)
- [Perceived Benefits of Caregiving](#)

Coping with Caregiving


Caregivers develop coping strategies for the objective, as well as subjective, burdens of providing care. Some of these strategies are predictive of either positive resilience or poorer mental and physical health outcomes.

Measures for assessing Caregiving Coping include:

- [Revised Scale for Caregiving Self-Efficacy](#)
- [Perceived Support Scale](#)
- [Picot Caregiver Rewards Scale](#)
- [Coping Health Inventory for Parents](#)


Assessment Issues

- [Assessment Strategy](#)
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In the Caregiver Briefcase

Caregiver intervention can:

- Decrease stressors (lighten the load)
- Alter appraisals (How bad the stressors are, and what perceived resources people have to cope)
- Teach skills or in other ways build internal resources
- Provide or rally external resources

Specific Approaches

Caregiver interventions typically target a particular population, such as caregivers of individuals with dementia or parents of seriously mentally ill adults. Although many common factors exist in interventions, specific populations often benefit from distinct interventions which address their particular needs.

Caregivers for military Veterans suffering from traumatic brain injury and caregivers of older adults with dementia face quite different challenges even though the core issues and the changes necessary to undertake care responsibility may be similar.

The following populations are the focus of particular interventions:

- [Parents of ill children](#)
- [Young Caregivers](#)
- [Long Distance Caregivers](#)
- [Family members of adults with substance abuse problems](#)
- [Family members of adults with serious mental illness \(including dual diagnosis with substance abuse\)](#)
- [Caregivers of individuals with dementia](#)
- [Caregivers of Veterans with traumatic brain injury \(and/or PTSD\)](#)
- [Family members of persons with cancer](#)

Intervention Issues

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Effectiveness of dementia caregiver interventions

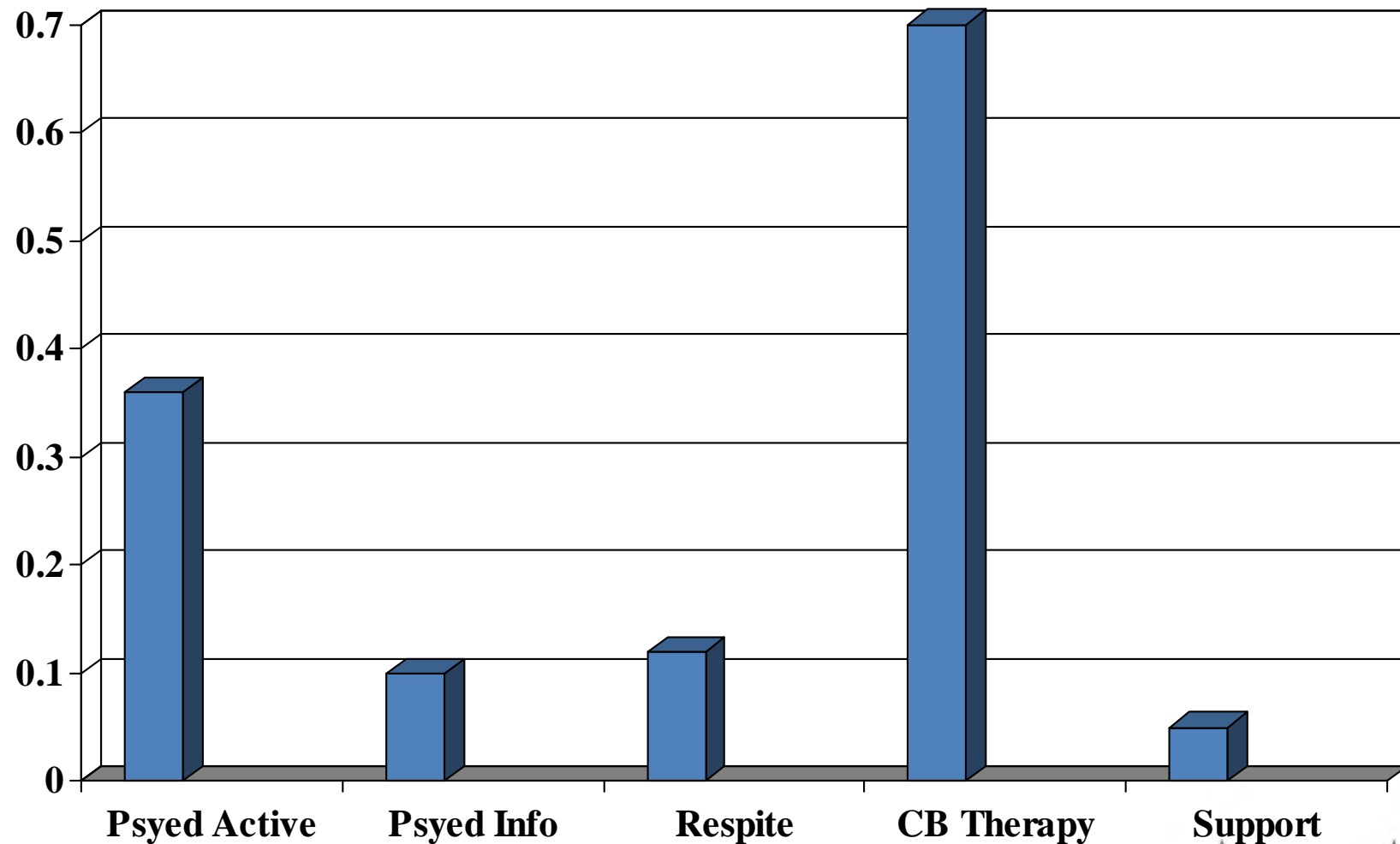
- Psychosocial interventions for CGs improve multiple outcomes: burden, depression, well-being, ability/knowledge, and CR symptoms
- CB therapy & psychoeducational interventions (PIs) with active CG participation best at improving CG depression
- PIs with active CG participation best at improving multiple outcomes
- More limited effects for support, respite

Pinquart & Sörensen, 2006

Common types of interventions

- Psychoeducational—teach caregivers information and skills in managing dementia
 - Distinction, active participation vs. information only
- Support—Unstructured, emphasize support from members
- Cognitive behavior therapy—focus on caregiver emotional reactions, teach ways to manage caregiver reactions
- Respite/adult day care

Effect sizes for depression

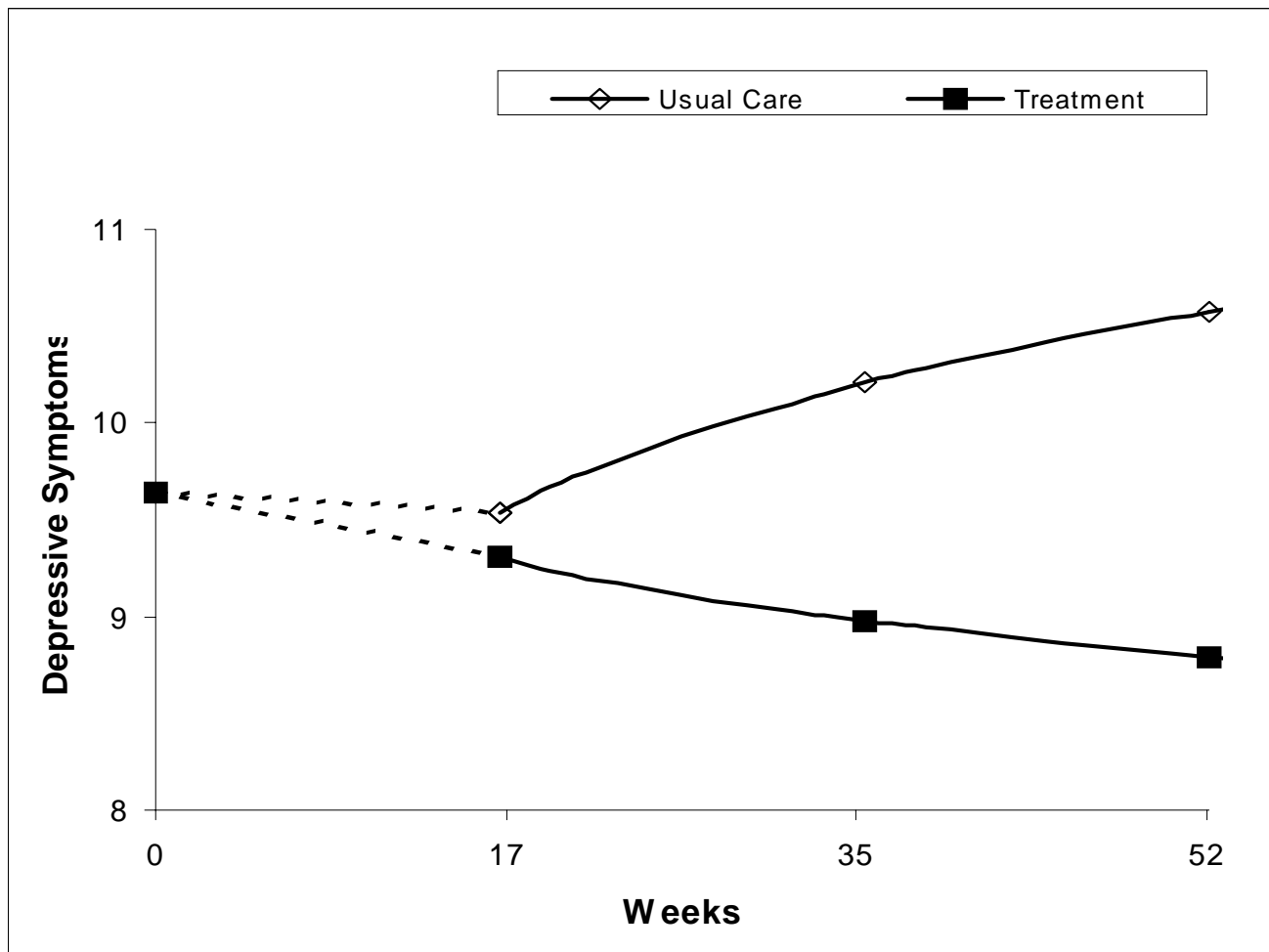


Pinquart & Sörensen, 2006

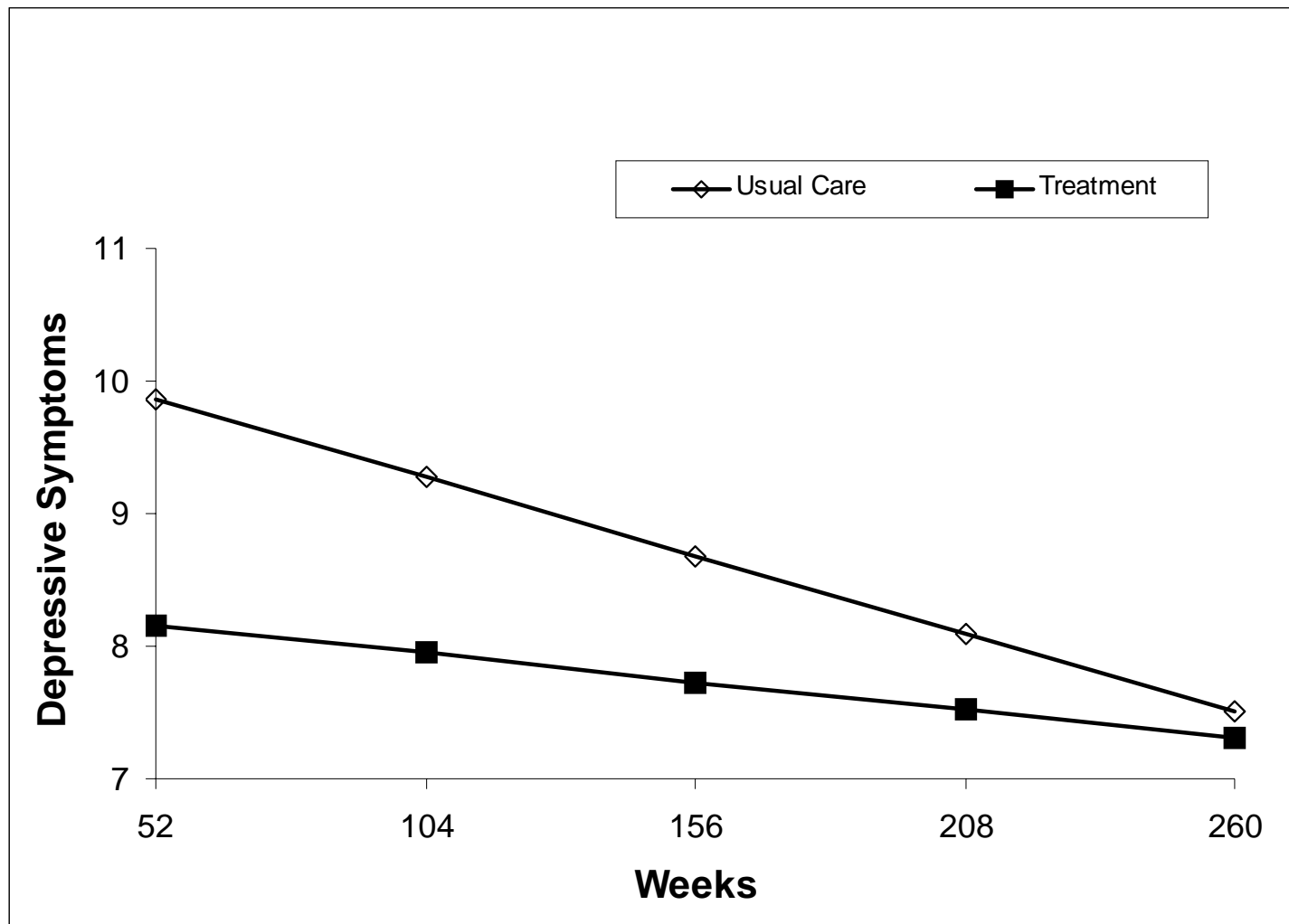
The NYU intervention

- **406 caregivers randomly assigned to usual care or an intensive caregiver intervention program at NYU**
 - o 2 sessions individual counseling
 - o 4 family sessions
 - o support group membership
 - o ad hoc counseling without limit
- **Described in detail in a book**

Mittelman et al, (2002)



Mittelman et al., 2004

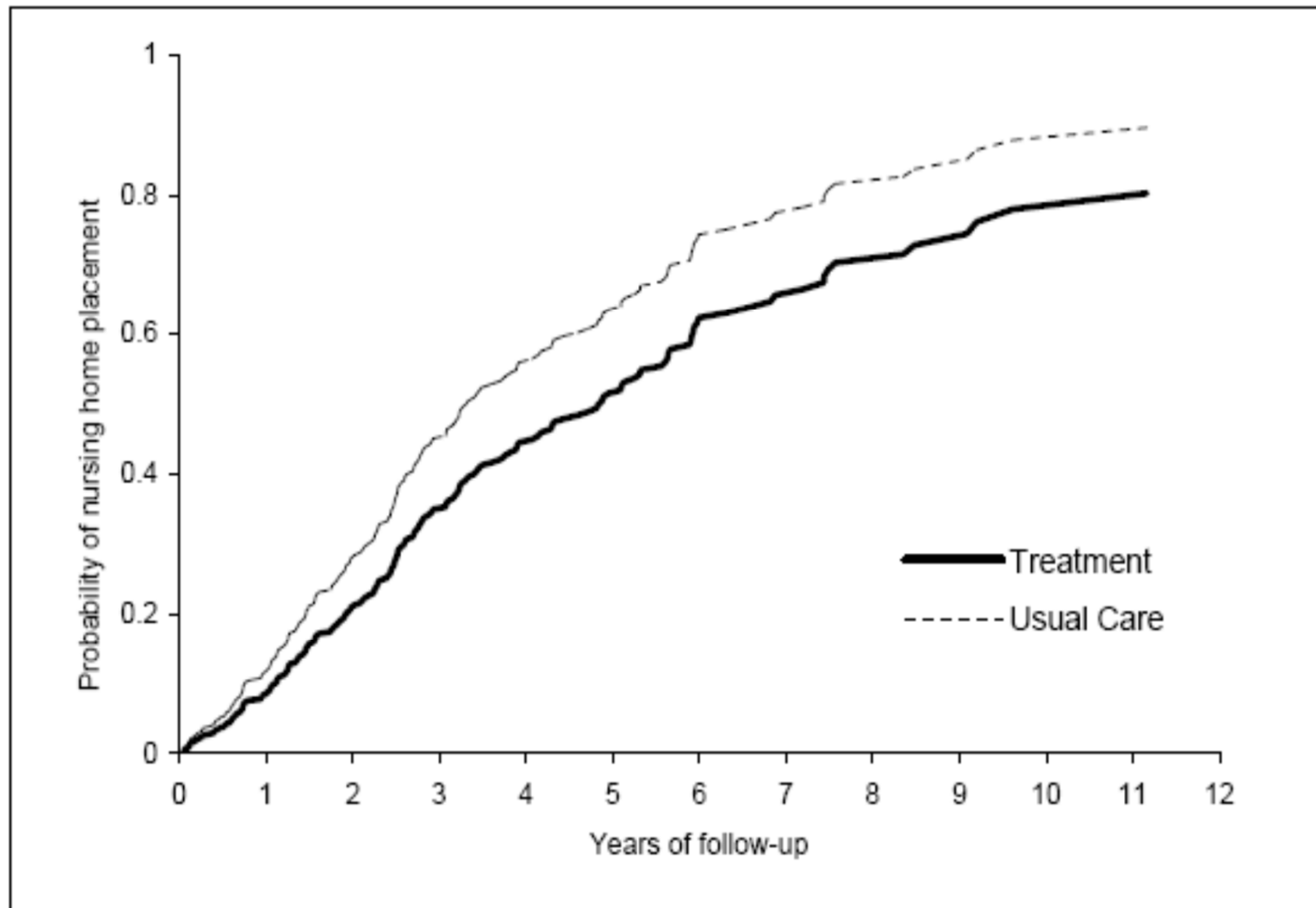


Mittelman et al., 2004

Results--effects on NHP

- Our analyses show that, with longer duration of follow up, the delay in nursing home placement in the treatment group is 557 days, compared with previously reported delay of 329 delays
- Median cost of NH care in Florida is currently over \$75,000 per year

Mittelman et al., 2006



Mittelman et al., 2006

Beyond “efficacy”, to “effectiveness” studies

- Current trials translating evidence based interventions into community using REACH, NYU, & STAR-C protocols
- STAR-C protocol (trains caregivers in behavioral management)
- Used community practitioners to train caregivers
- Random assignment to STAR-C versus usual care

Burgio et al., 2009; Teri et al., 2005

Results

- Community consultants were able to learn and adhere to the behavioral treatment protocol. Caregivers receiving STAR-C training showed significant improvements at 6 month follow up in:
 - Depression
 - Burden
 - Reactivity to behavior problems in the care recipient.
 - Care recipients also showed benefits, including:
 - Decreased frequency and severity of behavior problems
 - improved care recipient quality of life.

Teri et al., 2005

Conclusion

- High strain caregivers at increased risk for depression and health problems
- Intervention for caregivers has the potential to produce long lasting, life changing, benefits for caregivers
- Potential to save costs and to minimize the long term damage to caregivers' lives
- Important to build CG resources and do more to increase caregivers' access to effective intervention

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Questions?



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Today's Talk

- How to get them in the door – overcoming barriers to providing support services to family caregivers
- How to get them to help themselves – overcoming reluctance to reach out for and accept support
- When to refer to a mental health specialist

“I’m an anxious wreck at work”

- Don, 46-year-old, African-American man seeking psychotherapy for anxiety and “career burnout”
- Has worked for 15 years in high-volume, high-pressure job as bank administrator
- But thinks constantly about his mother with COPD, disabled and alone in her home
- Calls her 5 times during the course of each day and then visits her after work

Barriers to Receiving Caregiver Support

- Has never heard of an Area Agency on Aging or family caregiver support program
- Not sure what family caregiving is
- Doesn't think of himself as a family caregiver
- Mother wants no services because she doesn't like strangers in her home
- Family doesn't take "handouts"

Challenge of Outreach

- Don won't be looking for family caregiver support group
- If I refer him to a family caregiver support group (especially early on in his treatment with me), he won't go
- How do we engage him in the process of seeking support for himself and his mother



Introduction

Caregivers may seek services from psychologists directly for assistance with caregiving related challenges or burdens. Many caregivers, however, do not recognize that their caregiving role is one for which they can seek services.

Psychologists may need to open themselves to noticing caregivers' needs in settings where psychological services are provided, and may need to reach out to offer services relevant to caregiving concerns. In other words, traditional referral patterns for services often do not apply for several reasons.

- Caregivers frequently do not identify themselves as caregivers. They instead believe that they are simply functioning as a loved one should.
- They are often so focused on taking care of others that they do not consider seeking help for themselves, even when they are distressed.
- They typically believe that they do not have the time to meet with psychologists or seek other forms of help for themselves because they cannot leave the care recipient unattended
- They may feel embarrassed if they experience a sense of burden or distress because they believe that having such negative emotions means they are not good caregivers.
- They worry that, if they should need to seek help for themselves, others will criticize them for being unable to adequately care for their loved one.

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Outreach (cont.)

- To reach sons like Don, we have to go beyond advertising caregiver services. Two ideas:

1. Community events that define and normalize being a stressed-out caregiver without being explicitly “caregiver” or “support” events.

Educational sessions on taking care of an aging parent (Caregiver Month); on disease specifics (e.g., dementia) that covers family impact

Outreach (cont.)

2. Make greater use of primary care portal
“Making the Link” – a National Association of Area Agencies on Aging (n4a) program – some success but not lasting

Other models – Northern California Care Network for Dementia 0 faxed referrals from physician offices – worked well

NYUCI in Primary Care – caregiver counselor in Vermont primary care offices – good data

Encouraging Self-Care

- Caregivers are notorious for neglecting their own needs
- Don would never have sought services if his physician hadn't twisted his arm and if he wasn't at risk of losing his job
- Telling caregivers that taking care of themselves will better enable them to care for their loved ones is of limited effectiveness

Self-Care (cont.)

- Three Ideas: Marathon Metaphor; Honoring the Mission; Receiving with Grace
- Caregiving as a marathon:
- Have to train to learn to pace oneself
- Have to learn the up-hills and down-hills of the lay of the land (disease)
- Have to learn to replenish along the way
- All are essential – or don't finish the race

Honoring the Mission

- Solicit the story of giving care
- Avoid premature advice-giving
- Inquire about meaning of caregiving in caregiver's life
- Identify and honor the caregiver's sense of mission
- Raise issue of sustainability
- Inquire about sources of sustenance
- http://www.rosalynncarter.org/EBP_links/

Receiving with Grace

- Assumption: Most of us would rather give than receive
- But running best race means taking in sustenance, utilizing support
- Spiritual traditions of seeing giving in receiving – offering others the blessing of doing good
- http://www.rosalynncarter.org/EBP_links/

Mental Health Referral

- Majority of caregivers will never need formal mental health services
- Who does? Those who are so depressed, anxious, angry (abusive), guilty that it is affecting their capacity to function effectively and to provide adequate care
- Issue of severity

Referral (cont.)

- “Caregiver burnout”: dread, tension, irritability, anger, fatigue, sadness, disturbed sleep, difficulty thinking clearly and making decisions
- Often a precursor to Major Depressive Disorder (MDD)
- Don is anxious, distracted and jumpy all day long; fragmented sleep at night

Referral (cont.)

- MDD – sadness, lack of enjoyment, sleep and appetite disturbances, excessive guilt, low self-esteem, fatigue, difficulty making decisions, thoughts about dying; also anxiety, social withdrawal
- Often disabling
- Psychotherapy and drug treatments

Psychologists as Direct Service Clinicians and Consultants



Introduction

Practicing psychologists possess a breadth of training and a blend of skills that allow them to provide a wide range of diagnostic, therapeutic and consultative services.

Psychologists' Roles as Direct Service Clinicians

Practicing psychologists:

- Encourage family caregivers to appreciate and utilize their considerable strengths in assisting ill or disabled family members
- Urge family caregivers to mobilize their family and community networks of support in order to facilitate their caregiving efforts and share their caregiving burden
- Assess family caregivers for depression, anxiety, grief and exhaustion
- Provide psychoeducation to family caregivers about their loved one's disability or illness and about the best means of sustaining themselves through the period of caregiving
- Offer individual, couples and family therapy to bolster caregiver strengths, foster improved family relationships, and decrease psychological symptoms

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What do Psychologists Need to Know to Help Family Caregivers?

Domains of Knowledge

- The courses and treatments, as well as psychological sequelae, of common medical conditions (e.g., heart disease, dementia, traumatic brain injury, stroke, developmental disabilities, diabetes, cancer, lung disease, chronic pain)
- Family development and systems
- Typical caregiver experiences ("strains and gains")
- Health and psychosocial consequences of caregiving
- Social, cultural and spiritual contexts of caregiving
- [Caregiver support systems and resources](#) (e.g., healthcare, social service, housing, community)

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Referral (cont.)

- If possible, refer to a caregiver-savvy, medically knowledgeable therapist (e.g., APA's Psychologist Locator <http://locator.apa.org/>)
- If caregiver is reluctant to go to a mental health provider, urge visit to primary care doctor
- Broach mental health treatment as another strategy to strengthen caregiving capacity – run the best race

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Questions?



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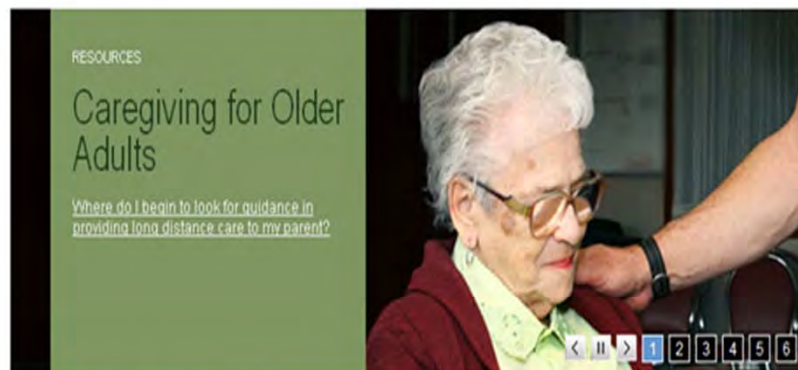


APA Family Caregivers Briefcase

- 2010 APA President Carol Goodheart, EdD selected Family Caregivers as one of her Presidential Initiatives based on the belief that APA can help others to anticipate, recognize, and reduce the stresses on family caregivers across the life span.
- APA Presidential Task Force on Family Caregivers members are: Andrea Farkas Patenaude, PhD, Martha Crowther, PhD, MPH, Timothy Elliott, PhD, ABPP, William E. Haley, PhD, Barry J. Jacobs, Psy.D, and Sara Honn Qualls, PhD. I was APA Staff Liaison.
- It is anticipated that the Briefcase will be useful for years to come, with small changes as the field produces new approaches, new research findings, and new tools and resources.
- The Briefcase is dedicated to the millions of family members who carry a magnificent load of responsibility and care on a daily basis.

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Welcome to the Caregiver Briefcase

Psychologists are becoming increasingly involved with the many challenges of improving the lives of contemporary family caregivers. 2010 APA President Dr. Carol Goodheart convened a Task Force and charged them with the development of a user-friendly, online Family Caregiver Briefcase to help psychologists and other health professionals assist family caregivers through individual and organizational practice, research, teaching and community service.



This Briefcase provides psychologists at all levels of training and experience with information about:

- How caregiving affects all of us.
- Facts about family caregiving.

In the Caregiver Briefcase

- Caregiving Facts
- Practice
- Research
- Education
- Advocacy
- Resources

APA Presidential Initiative on Caregivers

- APA Presidential Initiative Summary
- APA Presidential Task Force on Caregivers Task Force Members: Andrea Farkas Patenaude, PhD, Chair, Martha

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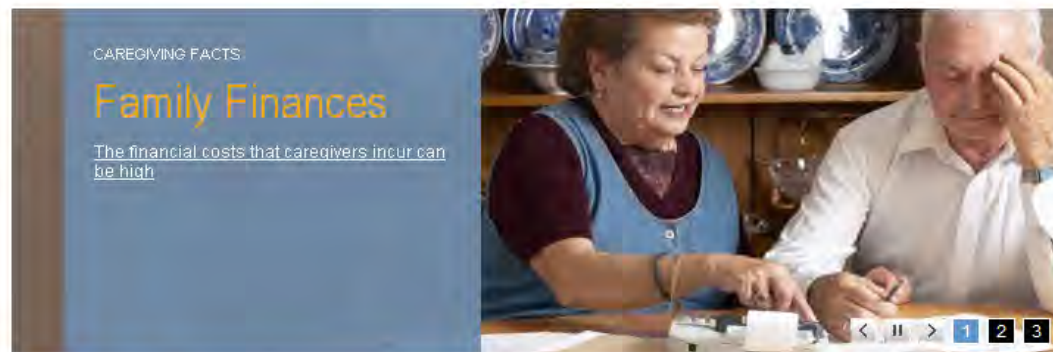
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Caregiving Facts

Family caregiving occurs at every stage along the life span. Although it has been traditionally regarded as an "informal" aspect of health care, many policy makers and stakeholders now acknowledge that family caregivers provide essential services, and in many cases, they operate as front-line health service providers.

This section presents basic information about the increasing number of family caregivers, the many circumstances in which family caregiving occurs, and the many duties and tasks that typify family caregiving. The section also contains information about the health and emotional risks that caregivers incur and emerging insights about the effects family caregivers have on their care recipients.

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What Do Family Caregivers Do?

Introduction

Of the 65.7 million U.S. caregivers, 3.9 million care for only child recipients, 48.9 million care for only adult recipients, and 12.9 million care for both child and adult recipients, according to the National Alliance for Caregiving. A 2009 report from the Alliance also shows that 16.8 million unpaid caregivers provide care to a child under the age of 18 with a special need. In 2008, 9.9 million family members, friends and neighbors provided unpaid care for a person with Alzheimer's disease or other dementia (Alzheimer's Association, 2009).

Family caregivers often provide care over several years. Two-thirds of family caregivers reported providing care for a year or more while 37 percent said they provided care for one to four years. Another 26 percent have been caregivers for more than four years (Opinion Research Corporation, 2005). Caregivers of children are also less likely than caregivers of adults to be caring for just one person (National Alliance for Caregiving, 2009).

Family caregivers operate as extensions of health care systems performing complex medical and therapeutic tasks and ensuring care recipient adherence to therapeutic regimens. They operate as home-based "care coordinators" and personal advocates for care recipients. As health care costs and utilization continue to rise, individuals facing physical, mental or behavioral challenges are increasingly dependent on the ability of family or other informal caregivers to operate competently as formal health care providers. Yet, despite their important function in our society, caregivers do not receive adequate training, preparation, or ongoing support from health care systems.

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What Do Family Caregivers Do?

When the Care Recipient is an Adult

Adult care recipients vary greatly in their caregiving needs, according to the National Alliance for Caregiving. Most of the care recipients age 18 to 49 are limited by a long-term physical condition (54 percent), an emotional or mental health problem (46 percent), a short-term physical condition (35 percent) or a behavioral issue (31 percent) (National Alliance for Caregiving, 2009). Caregivers of adults 50 and older report that the person they help needs care because of long-term physical conditions (76 percent), a short-term physical condition (36 percent) or emotional/mental health issues (25 percent) (National Alliance for Caregiving, 2009).

The amount of time spent caring increases substantially as cognitive impairment worsens. Among people 70 years of age and older, those with no dementia receive an average of 4.6 hours per week of care, while those with mild dementia receive 13.1 hours of care weekly. For those with severe dementia, hours of informal care received rises to 46.1 hours per week.

Care recipients with HIV/AIDS move in and out of their need for extensive care over a long period of time. Unfortunately, the disease itself, and those experiencing it, are often feared and mistreated by those whose care they depend upon as well as by certain aspects of society at large. In addition, treatment, especially medication, can be extremely costly. In one study of informal HIV/AIDS caregivers, the number of hours committed to caregiving was a mean of 20.68 hours/week with a median of 15 hours. A high number of instrumental activities of daily living (IADLs) were performed for each care receiver, and over half of the care recipients – 56.8% – received assistance with at least one activity of daily living (ADL) (Ukockis, 2007).

When the care recipient is an adult, caregiving often requires re-negotiation of roles in adult relationships, such as between two spouses or adult children and their parents, and impacts multiple relationships within a family system – for example, how siblings negotiate meeting parental needs. Caregivers routinely assist their adult care recipients with ADLs, instrumental activities of daily living, and social activities within the home. Common physical health conditions



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What Do Family Caregivers Do?

Caregiving at End-of-Life

End-of-life caregiving presents a number of particular challenges, including the necessity of making life and death decisions about matters such as whether to utilize life-sustaining treatments and hospice care, intense care demands, and witnessing pain and suffering in loved ones.

Decision making at the end-of-life can be particularly stressful for families. Family members may be asked whether to begin tube feeding, institute antibiotic therapy for infections, or to decline medical procedures that might extend duration of life when the quality of life is poor.

Presence of written advance directives or even a history of verbal discussions of end-of-life issues helps families cope with these issues. Family stress associated with the decision to withdraw treatment was high immediately following the death of the decedent and, while it decreased over time, remained high half a year later. Research shows, however, that family stress is highest in the absence of advance directives. Stress is lower when verbal advance directives guide the family, and lowest when written advance directives are in place (Tilden, Tolle, Nelson, & Fields, 2001).

Cultural diversity issues can become particularly prominent at the end-of-life as well, and may affect decision-making. For example, African American older adults are less likely than others to agree to withhold life-sustaining treatment even when quality of life is poor, and cultural values among many Asian groups discourage direct disclosure to dying patients and instead encourage decision-making by family members (Kwak & Haley, 2005).



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Assessment

Psychologists who work with caregiving families, need to consider carefully whom to include in the initial assessment, and at what point in the treatment process to conduct other assessments.

In contrast to psychological work that is focused on evaluating individuals, assessing caregiving families requires the use of a wider lens that includes taking into account care recipients, multiple family members, professionals and direct care workers, as well as considering various environmental contexts of care



What's key to keep in mind is that caregiving not only involves interactions between two people (caregiver and care recipient) but often includes the contributions and influences of many others, including other family members and professionals working with the care recipient.

Primary caregivers may be the people who seek psychological help. But other family members, playing secondary or tertiary roles (often in partnership with professionals and friends) may be just as much in need of psychological care.

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Assessment Tools

Beyond the use of open ended clinical interviews, the Task Force recommends psychologists be familiar with structured interviews and questionnaires related to caregiving for use in some clinical situations. Clinicians will need to tailor their use of assessment instruments depending on the characteristics of the caregiver (e.g. age, cultural background), and the care recipient (e.g. age and specific medical problem or disability). We have provided examples of a number of caregiver intake forms; measures of caregiver mental health; and measures of caregiver stress, burden, coping, and family context. We have also provided care receiver measures of behavior and functioning; cognitive problems; quality of care; health problems; and mental health. Finally we have provided instruments that may be particularly useful with caregivers from diverse cultural backgrounds.



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The Caregiver Intake Interview may be different from assessments psychologists typically undertake to identify individual psychopathology or distress. In order to create strong interventions for a caregiving family, psychologists must gather key information about a range of topics to help determine:

- The nature of the care-recipient's illness or disability
- The family's stage of caregiving (early, middle or late)
- The constellation of individuals involved in care, including community support persons, and treating professionals
- Unique or challenging caregiving circumstances

7 Domains to Assess

Recommended by the Family Caregiver Alliance's (FCA) National Center on Caregiving.

- Background on the caregiver and the caregiving situation

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Mental Health of Caregivers

Caregivers are at elevated risk for developing mental health disorders, so caregivers should, at a minimum, be screened for these conditions. In some situations a full diagnostic evaluation is appropriate (e.g., a caregiver asking for treatment for depression).



Other caregivers seek assistance with the care demands or burdens but do not identify themselves as having mental health problems. This latter group still should be screened to ensure that the elevated risks for mental disorder are appropriately considered.

The following questionnaires are commonly used with adults of any background and have been utilized in caregiving research studies and clinical work as well.

Depression

- [Center for Epidemiological Studies-Depression \(CESD\)](#)
- [Geriatric Depression Scale \(GDS\)](#)
- [Beck Depression Inventory \(BDI\)](#)
- [Primary Health Questionnaire \(PHQ-9\) and \(PHQ-2\)](#)


Anxiety

- [Geriatric Anxiety Inventory \(GAI\)](#)
- [The State-Trait Anxiety Inventory \(STAI\)](#)

Grief and complicated grief


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Culture is known to influence caregiving. Specifically, issues of acculturation, assimilation, cultural values, beliefs and norms can be important for caregivers. We have included assessment tools that were designed to assess the unique aspects of caregiving among diverse groups.

- [Acculturation Rating Scale for Mexican Americans](#)
- [Cultural Justification for Caregiving Scale](#)
- [Suiinn-Lew Asian Self Identity Acculturation Scale](#)
- [The Center for Epidemiological Studies Depression Scale](#)
- [The Revised Memory and Behavior Problems Checklist](#)
- [Zarit Burden Interview](#)

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RESOURCES

For Professionals

Where can I direct my student who is looking for a research topic related to caregiving for his dissertation?

For professionals

Caregiving Resources

This section of the Briefcase is a compilation of web-based materials, tools, and organizations that psychologists may find useful in their work with family caregivers. While in some cases the resource may help inform the psychologist's work with family caregivers, sometimes the psychologist may want to pass on the link or the information directly to the caregiver to help them with specific problems or provide them with an organized framework for the myriad of online caregiving resources.

As research and practice with family caregivers has grown over the past decade, so, too, have the number and breadth of available resources. There is now a wealth of materials about caregiving available on the Web and elsewhere. What follows is not an exhaustive listing but an organized, easy-to-use guide of key resources, including those pertinent for working with all family caregivers across the lifespan, as well as those targeted to specific groups of professionals. These specific groups

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Key Websites

These national organizations maintain web pages that offer rich resources that are highly useful for both family caregivers and professionals who work with them:

[Family Caregiver Alliance \(FCA\)](#)

[Family Caregiving 101 \(NAC & FCA\)](#)

[Family Care Resource Clearinghouse \(AXA Foundation & National Alliance for Caregiving\)](#)

[National Alliance for Caregiving \(NAC\)](#)

[National Caregivers Library \(FamilyCare America\)](#)

[National Family Caregiving Association \(NFCA\)](#)

[Strength for Caring \(Johnson & Johnson\)](#)

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Resources for Diverse Populations and Specific Age Groups

- [Multicultural Caregiving](#)
- [Caregivers of Children](#)
- [Caregivers of Adults and Older Adults](#)
- [Caregivers of Individuals with Disabilities](#)
- [Caregivers of Service Members and Veterans](#)
- [Caregivers of Individuals with Mental Disorders](#)
- [Caregivers of Individuals with Addictive Disorders](#)
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Multicultural Caregiving

[Caregivers of Ethnic Elders](#) (Ethnic Elders Care)

[Caregiving for American Indian & Alaska Native](#) (CDC)

[Caregiving Materials in Spanish and English](#) (National Institute on Aging)

[Caregiver Guide: Alzheimer's Disease](#) (in Spanish)

[Diversity Toolbox: Caring for Diverse Populations](#) (Alzheimer's Association)
Information for African-American, Chinese, Hispanic/Latino and Korean Communities

[Fact Sheets for Caregivers in Spanish and Chinese](#) (Family Caregiver Alliance)

[Family Caregiver's Guide to Hospice and Palliative Care](#) (United Hospital Fund)
Available in Spanish, Chinese and Russian

[Family Caregiver's Guide to Hospital Discharge Planning](#) (in Spanish)

[Hispanic Family Caregiving Report in English and Spanish](#) (National Alliance for Caregiving)

[LGBT Caregiving](#) (Family Caregivers Alliance)

[Native Elder Caregiver Curriculum](#) (National Resource Center on Native American Aging)

[Women and Caregiving: Facts and Figures](#) (Family Caregiver Alliance)

[Caregiver Support](#) (National Women's Health Information Center)

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Resources for Educators

The following are recommended resources for educators interested in incorporating family caregiving into their academic courses or training. Many are useful in work with family caregivers in community or residential settings.

Books Articles Movies Online Resources

The following are examples of books that can be used as teaching resources:

- Coon, D. W., Gallagher-Thompson, D., & Thompson, L. W. (Eds.). (2003). *Innovative interventions to reduce dementia caregiver distress: A clinical guide*. New York: Springer Publishing Company, Inc.
- Feldman, D. B., & Lasher, S. A. (2008). *The End-of-Life Handbook: A compassionate guide to connecting with and caring for a dying loved one*. New Harbinger Publications.
- Heymann, J. (2000). *The Widening Gap: Why America's working families are in jeopardy and what can be done about it*. New York: Basic Books.
- Kramer, B. J., and Thompson, E.H. (Eds.). (2002). *Men as caregivers*. Amherst: Prometheus Books.
- Mace, N. L., & Rabins, P. V. (2006). *The 36 hour day: A family guide to caring for persons with Alzheimer's disease, related dementing illnesses, and memory loss in later life*. Baltimore: Johns Hopkins University Press.
- Qualls, S. H., & Zarit, S. H. (2009). *Aging families and caregiving: A clinician's guide to research, practice, and technology*. New York: Wiley Publishing.
- Shifren, K. (Ed.). (2009). *How caregiving affects development: Psychological implications for child, adolescent and adult caregivers*. Washington, DC: American Psychological Association.
- Schulz, R. (Ed.). (2000). *Handbook on dementia caregiving: Evidence-based interventions for family caregivers*. New York, NY, US: Springer.
- Shanks, L. K. (2005). *Your name is Hughes Hannibal Shanks*. Lincoln, NE: Bison Books.
- Spirito, A., & Kazak, A. E. (2006). *Effective and emerging treatments in pediatric psychology*. New York: Oxford University Press.

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The following are recommended resources for educators interested in incorporating family caregiving into their academic courses or training. Many are useful in work with family caregivers in community or residential settings.

Books Articles Movies **Online Resources**

- [Family Caregiving at End-of-Life](#) is one of 10 modules in a continuing education program for psychologists and other mental health professionals. This program is available online for a fee. (American Psychological Association)
- [Family Caregiving Program](#) has 9 interactive modules that teach family members the skills necessary for caring for older adults, as well as chronically ill and disabled individuals. It also prepares caregivers to take on the responsibility and challenges of caring for a loved one at home (The American Red Cross)
- [Native American Caregiver Curriculum](#) (National Resource Center of Native American Aging)
- [Online and Classroom Dementia Care Training Programs for Direct Care Workers, Other Professionals and Residential Communities](#) (The Alzheimer's Association)
- [Talk, Listen, Connect: Deployments, Homecomings, Changes: Grief Facilitators Guide and Materials in English and Spanish](#) (Sesame Workshop)
- [Implementing a Community-Based Program for Dementia Caregivers: An Action Guide Using Reach Out](#) (Centers for Disease Control & University of Michigan Institute of Gerontology)
- [Visual education center for family caregivers with short videos online focusing on caregiver challenges](#) (Terra Nova Films)

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Resources for Psychologists

In addition to resources useful for both family caregivers AND psychologists, the following resources were developed specifically for professionals:

[General Resources](#)

[Reports](#)

[Videos](#)

[Handouts](#)

[Alzheimer's Association Diversity Toolbox: Caring for Diverse Populations](#)
Provides resources for working with African-American, Chinese, Latino and Korean communities

[Mental Health and Related Resources for Assisting Service Members, Veterans, and Their Families](#) (American Psychological Association)

[Assuring Healthy Caregivers, A Public Health Approach to Translating Research into Practice: The RE-AIM Framework](#) (Centers for Disease Control and Prevention)

[Caregivers Count Tool Toolkit](#) (Family Caregiver Alliance)
An online toolkit to help practitioners assess the needs of family caregivers

[Caring for caregivers: The issues interventions are different for racial and ethnic-minority caregivers](#) (American Psychological Association)

[Catalog of Clinical Training Opportunities: Best Practices for Recovery and Improved Outcomes for People with Serious Mental Illness](#) (PDF, 545KB) (American Psychological Association)

[Coping with Caregiving Intervention Manuals](#) (Older Adult and Family Center, Stanford School Medicine) available in multiple languages

[Cultural Competency and Health Literacy Resources for Health Care Providers](#) (U.S. Department of Health and Human Services Health Resources and Services Administration)

[Doing What's Best for Mom and Dad: Helping contentious siblings find](#)

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Resources for Psychologists

In addition to resources useful for both family caregivers AND psychologists, the following resources were developed specifically for professionals:

[General Resources](#)

[Reports](#)

[Videos](#)

[Handouts](#)

[10 Tips for Family Caregivers](#) (National Family Caregivers Association)

[Caregiver Stress Quiz: Stressed or Strained?](#) (AARP)

[Caregiver Tip Sheet](#) (Administration on Aging)

[Care for the Family Caregiver: A Place to Start](#) (National Alliance for Caregiving & Emblem Health)

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Please feel free to link to the APA Briefcase
from your organization's website:

[http://www.apa.org/pi/about/publications/caregivers
/index.aspx](http://www.apa.org/pi/about/publications/caregivers/index.aspx)

Mental Health Needs of Family Caregivers: Identifying, Engaging and Assisting

Questions?



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CONNECTING WITH
caregivers



Administration on Aging