American Psychological Association Presidential Initiative on Caregivers

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Caregiving is……

- A family issue
- A life span issue
- A public health issue
- A socio-cultural issue
- A health disparities issue
- A mental health and physical health risk factor

Goodheart, 2007.

Caregiving:
Why an issue for Psychologists?

Mental Health of Family Caregivers - a Growing Concern:

- Aging General Population
- Increasing Military Injured
- Smaller Families; Greater Burden
- Chronic Nature of Previously Fatal Conditions
- Trend towards Home vs. Hospital Care
- Cut in support for professional caregivers

Patenaude, 2010.

Goal: Raise Psychologists' Awareness

- Caregiver needs are often invisible.
- Help psychologists understand extent of caregiver services provided, risks for caregivers, challenges and rewards of working with caregivers.
- Provide resources to assist family caregivers through individual and organizational practice, research, teaching, community service.

How Psychologists Can Help

- Recognize the stresses on family caregivers
- Assess and treat the emotional components of those burdens
- Direct family caregivers to other needed resources
- Assist in the development of informed and meaningful policies that support family caregivers

Family Caregivers in Society

- As health care costs/utilization rise, individuals needing care are increasingly dependent on the ability of family /informal caregivers to operate competently as *formal* health care providers.
- Family caregivers operate as extensions of health care systems performing complex medical/ therapeutic tasks &ensuring care recipient adherence to therapeutic regimens.
- Family caregivers provide nearly 80% of long-term care in the United States.

Who Are Family Caregivers

- National estimates: 65.7 million Americans over the age of 18 provide unpaid support to older people/adults with disabilities/special health needs children who live in the community and who have limited ability to carry out daily activities, e.g. bathing, managing meds or preparing meals.
- Market value of their activity far exceeds that spent on formal health care/ nursing home care.
- Inadequate training/support from health systems

Caregiving in the US , National Alliance of Caregivers, 2010

Risks

- The on-going strain exacts a toll, even for people who take pride and satisfaction in being able to provide care.
- Difficulties are magnified when the climate for caregiving is worsened by such factors as poverty, discrimination, substandard access to services & treatment, language or cultural barriers.
- Perhaps not surprisingly, 43% of caregivers report significant unmet psychosocial needs, which makes functioning in the role of caregiver more difficult (Soothill et al., 2001).

Risks

- Health problems (depression, chronic pain, stroke) & premature mortality.
- Older caregivers may be at particular risk because demands may tax their already vulnerable health /physical abilities & compromise immune response systems.
- Caregivers are less likely to engage in preventive health behaviors and thus neglect their own health.
- In response to increased stress, some caregivers increase alcohol and other substance use.

Rationale for my APA Presidential Initiative on Caregivers

- Caregiving is an interpersonal activity with important psychological and social antecedents and consequences.
- Family Caregiving is a familiar role, a role with two faces:
  - One face is love, connection, and the fostering of healing comfort and the growth which comes from meeting difficult challenges.
  - The other face is caregiver burden

Rationale (continued)

- Caregiving crosses economic, social, gender, age, ethnocultural lines.
- Psychology has expertise to offer in improving the lives of caregivers and care recipients across the life span.
- Psychology must communicate its understanding of the needs of different populations of caregivers and its contribution to their well-being more broadly.
- To succeed optimally, we must partner with like-minded groups and organizations to inform and serve caregivers.

Mission

- The 2010 Presidential Task Force on Caregivers is charged with the development of a web-based, user-friendly *Family Caregiver Briefcase for Psychologists* (APA CARES)
- Its purpose is to assist all psychologists in identifying and addressing the needs of family caregivers
- It organizes and provide resources and information in a way that is useful to them in identifying and providing services to family caregivers

APA Briefcase offers:

- Information on psychological and practical burdens of caregiving
- Data on economics of caregiving
- Caregiving exercises for psychologists to demonstrate life-altering aspects of caregiving and recognition of caregivers in one's community
- Ways in which psychologists can help; modules
- Resources

APA Briefcase Contents

- Profiles of Psychologists:
  - Researchers
  - Direct Service Clinicians
  - Team Members
  - Educators
  - Consultants
  - Advocates

APA Briefcase Contents

- Resources
  - Wide array of assessment tools to gather information from caregivers and care recipients across the lifespan
  - Evidence-based interventions
  - Links to other web sites that offer population and disease specific resources

Caregiver Module- Practice

- Common Problems
- Pragmatics - Special Problems in Caring for Caregivers and how to Overcome Them
- Vignettes – problem examples
- Information on how to be an Effective Caregiver
- How to use Resources and empower Caregivers
- Assessment of Caregivers
- Interventions for Caregivers
- Successful Community Programs

Caregiver Modules – Teaching & Research

- Research
  - Understudied Topics
  - Challenges in Caregiving Research
- Teaching
  - Caregivers on Inter-professional Teams
  - Curricula – Books, movies with caregiving themes
  - Syllabi about caregiving

Caregiver Module - Culture

- Cultural Variation in Conceptualization of Caregiving
- Social-economic issues in Caregiving
- Rural concerns First Level

Resources

- Resources for Psychologists
- Resources for Family Caregivers
  - Books
  - Pamphlets
  - Useful web sites (selected)
  - Fact sheets on diseases
  - Fact sheets on the caregiving experience
  - Local resource listing
  - Eligibility criteria for Medicaid, disability etc.

We hope Briefcase will be used by:

- Psychologists who become aware of growing importance of this issue – to strengthen their sense of the breadth and interest of this field
- Graduate students looking for dissertation topics in growth areas
- Practicing clinical psychologists whose patients need caregiver resources and support
- Faculty seeking to integrate health psychology into their curriculum

We hope Briefcase will be used by:

- Psychologists who are themselves caregivers seeking information and support
- Organizational & community psychologists whose skills may enhance support for caregivers in workplaces, schools, senior centers, community organizations
- Health psychologists who may be encouraged to extend support and outreach to caregivers of their identified patients

How Psychologists Support Family Caregivers

- *Family Caregiver Assessment* – to determine needs of family caregivers; and to recognize, differentiate and treat caregiver depression, anxiety, anger, grief and exhaustion in order to develop a support plan
- *Caregiver Education and Counseling* – to help identify available resources and make appropriate decisions regarding the care recipient
- *Individual and Group Therapy* – to aid family caregivers in their management of stress & burden of caregiving and the balance between work and family

How Psychologists Support Family Caregivers

- *Basic and Applied Research* - on the etiology and course of caregiver distress and adjustment, to validate assessment instruments to assess family caregivers, and to develop evidence-based interventions.
- *Training and Education* - of the professional and direct care workforce on caregiver assessment, interventions and resources.
- *Consultation* – to organizations and employers to develop policies and programs supportive of family caregivers.

The Involvement of Many

- We are working with APA Divisions & governance groups to increase the usefulness of the Briefcase for psychologists across populations and settings:
  - Academic settings including community colleges, high schools to address needs of young caregivers
  - Organizational and consulting settings
  - Diverse Ethnic, Racial and Linguistic populations
  - Caregivers of children/ adults with intellectual & developmental disabilities
  - Caregivers of older adults
  - LGBT Caregivers
  - Military families caring for wounded veterans

There are only four kinds of people in this world:

- Those who have been caregivers
- Those who currently are caregivers
- Those who will be caregivers
- Those who will need caregivers

—Former First Lady Rosalynn Carter

THANK YOU

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