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RESEARCH SUMMIT:
*Moving the Research Agenda
Forward in Family Caregiving*

*Convened by the
MetLife Mature Market Institute
and
National Alliance for Caregiving*

June 2007

RESEARCH SUMMIT:

Moving the Research Agenda Forward in Family Caregiving

Background

In June 2007, the MetLife Mature Market Institute (MMI) and the National Alliance for Caregiving (NAC) convened a one-day Caregiving Research Summit in Washington, DC, to 1) identify gaps in caregiving research and 2) identify areas for potential exploration across academic disciplines.

Ten experts in caregiving research spanning many domains and disciplines, including sociology, economics, psychology, social work, and gerontology, were invited to present:

Eileen Applebaum, Ph.D., Rutgers University

Peter Arno, Ph.D., Montefiore Hospital

Lynn Feinberg, Ph.D., Family Caregiver Alliance

Nancy Folbre, Ph.D., University of Massachusetts at Amherst

Candace Howes, Ph.D., Connecticut College

Rhonda Montgomery, Ph.D., University of Wisconsin at Milwaukee

Margaret Neal, Ph.D., Portland State University

Richard Schulz, Ph.D., University of Pittsburgh

Brenda Spillman, Ph.D., Urban Institute

Donna Wagner, Ph.D., Towson University

In addition, staff from the MMI and the NAC attended, along with Congressional Research Service, AARP, and National Health Policy Forum representatives.

The experts presented on research domains within the broad field of family caregiving (defined as “ADL and/or IADL care provided by a family member or friend or anyone with an emotional attachment to an individual who is frail, disabled, or chronically ill”). The domains included:

- Women and work
- Economic value of caregiving
- Caregiver assessment
- Economics of caregiving
- Sociology of women as caregivers
- The caregiver life trajectory
- Intersection of care for elders and children
- Caregiving and health
- Formal services and technology to support caregiving
- Employed caregivers

Summary of Deliberations

In consensus, the group thought that the most important caregiving research studies of the past decade were primarily studies that examined the national picture of caregiving, with those below identified as significant contributors:

- Peter Arno’s calculations (2002, 2004, 2006) of the economic value of caregiving
- Richard Schulz’s macro-analysis of the health effects of caregiving
- The Cash & Counseling evaluation
- The NAC/AARP national surveys
- Jody Heymann’s Work/Family Global Equity Index.
- The MMI/NAC studies on the lost productivity to US employers

The group concluded that the major gaps in research and knowledge include:

- The intersection of family caregiving and paid caregiving—especially common and contradicting expectations, and the boundaries and overlap in people who are both paid and family caregivers or move back and forth between these two states
- Which interventions work for which caregivers, eg, adult day care, support groups, respite—which caregivers respond best and how “much” do they need for the intervention to help?
- The macro-economic and labor force effects of caregiving, especially people trying to get back into the workforce after a “career” of caregiving
- The appropriate role of employers in helping caregiving employees. And why have employers not embraced corporate eldercare?
- Where does family caregiving fit into our national discussion of universal health coverage? How dependent are we on family caregiving?
- Inadequate understanding of the role racial and ethnic diversity plays in the caregiving population
- Regarding long-term care, gaining a better knowledge of :
 - > the overall issue of supply and demand of both the paid and unpaid workforces,
 - > how we should realistically be preparing for the Boomers’ long-term care needs and
 - > how can we better recognize the role family caregivers play in the current long-term care system and the future long-term care system?
- The implications of out-of-pocket costs on caregiver burden
- Better understanding of how the cost of long-term care impacts family budgetary decisions and financial allocations for persons of all ages with disabilities
- Better knowledge of how intergenerational transfers (cash and in-kind) contribute to the nation’s overall GDP. Should the national economic index include quality-of-life factors as well as cash and in-kind?

- What are the legal issues involved in family care for the elderly? For disabled children?
- More longitudinal research on care trajectories over time, especially the relationship of work, retirement, and caregiving
- What defines quality in the caregiving relationship?

Recommendations

There were six recommendations for caregiving research that had the most consensus:

MACRO-MICRO LEVEL RESEARCH

1. The Economic Implications of Caregiver Health

This study would examine health effects of family caregiving and translate them into economic implications. The obvious outcome of the work would be to inform public policy makers and the general public about the broader implications of what is considered currently to be a “private” matter within the family. Academic disciplines to be involved could include economists, psychologists, epidemiologists and health-related professionals.

2. The Workforce Implications of Caregiving

This study would examine the labor force participation of caregivers, their retirement and exit decisions, and their intermittent leave and workplace accommodations. Outcome measures could include labor force implications related to the supply of workers over time, as well as the costs of all workforce aspects to individual workers and employers. The national economic effects could also be estimated. Important aspects of this study would be the comprehensive assessment of loss of benefits, disability costs associated with caregivers and/or care recipients, productivity effects and life-long earnings. Disciplines to be involved could include gerontologists, economists, sociologists, industrial and labor management experts, and actuaries.

3. *Intergenerational Transfers and Caregiving*

This study has the opportunity to inform public policy makers about the importance of intergenerational transfers on many levels including inter-family cash and in-kind transfers, intergenerational transfers that support national programs such as Social Security, and taxation effects. Key disciplines for this work could include economists, public policy experts, actuaries, accountants and financial gerontologists.

4. *Informal and Formal Caregiving within the Health Care Sector*

The design of this study would provide an opportunity to examine the boundaries between informal and formal caregiving, attitudes and behavior of health care professionals towards family caregivers, attitudes and behavior of family caregivers and care recipients towards the health care sector, and the role of allied health in determining the extent to which teamwork or coordination is possible. Key disciplines could include health professions (nursing, health policy, health management and physicians) as well as sociologists, family studies and psychologists.

as assessed by the both the caregiver and the care recipient, as well as the perceived importance of the role of professional help. It is assumed that quality indicators for both family and paid caregiving could be generated from this approach. Key disciplines include psychologists, sociologists, gerontologists, and family studies professionals.

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MetLife Mature Market Institute®

Staffed by gerontologists, the MetLife Mature Market Institute, part of the company's Retirement Strategies Group, has been providing research, knowledge management, education, and policy support for over ten years to Metropolitan Life Insurance Company, its corporate customers, and business partners. MetLife, a subsidiary of MetLife, Inc. (NYSE:MET), is a leading provider of insurance and other financial services to individual and institutional customers.

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National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a nonprofit coalition of national organizations that focuses on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues.

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MICRO-LEVEL RESEARCH

1. *Caregiving Across the Life Course*

This study, a longitudinal design, would track caregiving trajectories through three or four generations. Findings of the study could provide important information for family advocates and caregiving advocates as well as public policy makers and practice professionals. This study could also provide insight into the cultural and ethnic diversity among families and their caregiving activities. Key disciplines could include psychologists, sociologists, gerontologists and economists.

2. *The Caregiving Experience and Correlates*

This study would examine, in depth, the caregiving experience and the factors that sustain, support and enhance caregiving in a family setting. The study could provide important information about the quality of the caregiving experience

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