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Charge to the Committee

Three primary objectives

- ❑ To assess the prevalence and nature of family caregiving of older adults
- ❑ To assess the impact of caregiving on individuals' health, employment, and overall well-being
- ❑ To recommend policies to address caregivers' needs and to help minimize the barriers they encounter in acting on behalf of an older adult

Rapidly Rising Numbers of Older Adults and Fewer Family Caregivers to Help Them

- ❑ Historic demographic changes
 - By 2030, 72.7 million adults age 65+ (>20% of U.S. population)
 - Increasing diversity but national surveys are not powered for subgroup analyses
- ❑ Fastest growing cohort of older adults are those age 80+
 - Most likely to have a physical or cognitive impairment
 - Demand for caregivers is growing rapidly
- ❑ Gap between the demand for and supply of family caregivers is increasing
 - The size of American families is shrinking and the makeup of families is changing

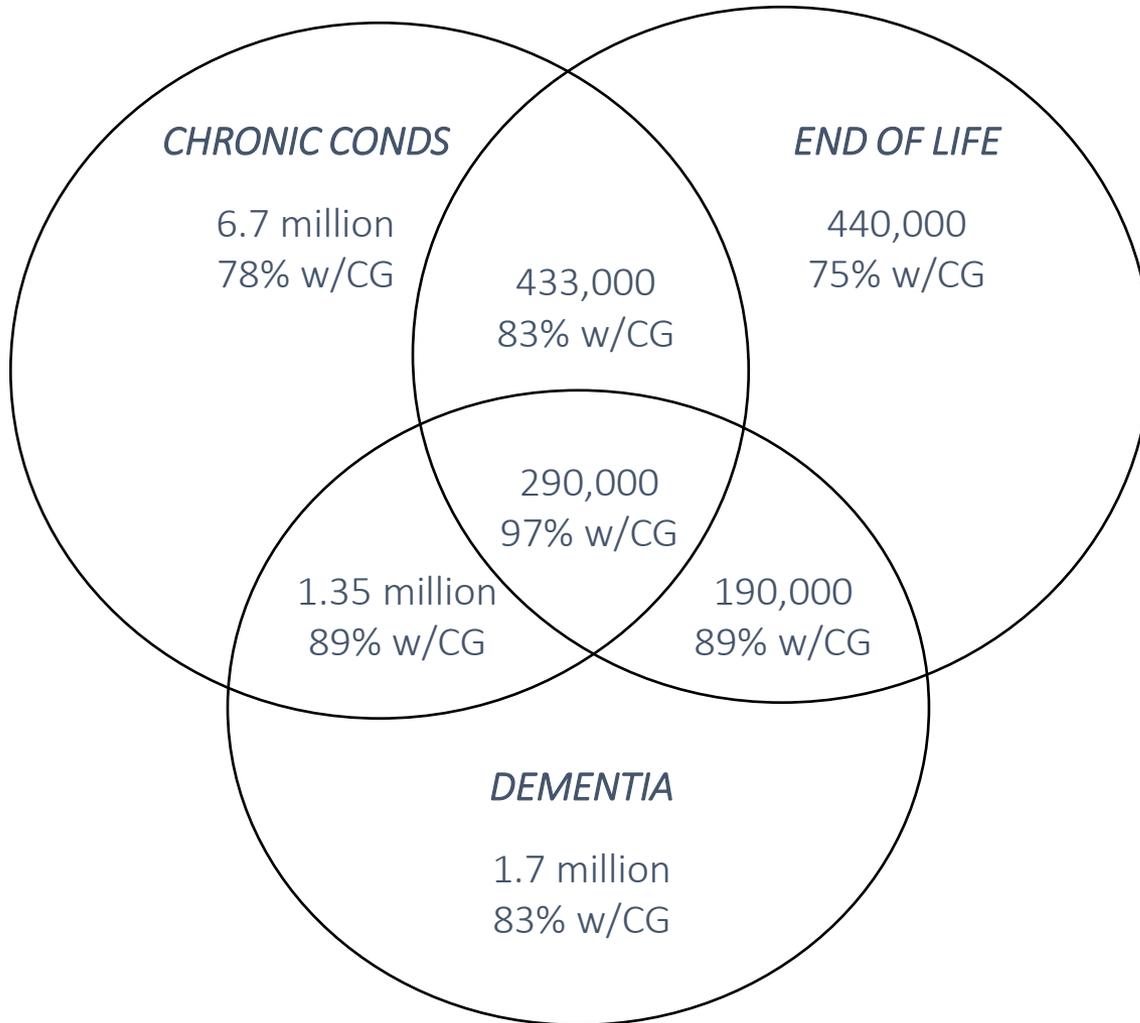
The Family Caregiver Role is Far More Complex and Demanding than in the Past

- ❑ Family caregivers have always been the primary providers of older adults' long-term services and supports such as:
 - Household tasks and self-care (getting in and out of bed, bathing, dressing, eating, or toileting)
- ❑ Today, they are also tasked with managing difficult medical procedures and equipment in older adults' homes, overseeing medications, and monitoring symptoms and side effects, and navigating complex health and LTSS systems
 - Including health care services that, in the past, were delivered only by licensed health care personnel (injections, IVs)
 - And, often, without training, needed information, or supportive services

Not All Caregivers Need Help

- 17-20 million caregivers provide support to older adults; primarily middle aged adult female children and older wives
- Many caregivers do fine, particularly in early stages of caregiving career
- Allocation of limited resources to highest need at risk caregivers
- Well established risk profiles available

High Need/High Cost Patients and Their Caregivers



CHRONIC CONDS = at least 3 chronic conditions and 1ADL/IADL limitation; dementia excluded as chronic condition

END OF LIFE = died within 1 year of baseline assessment

DEMENTIA = diagnosis of probable dementia

NONE OF THE ABOVE
24.1 million, 67% w/CG

High Need/High Cost Patient Caregiver Impacts

- ❑ More hours of care (1/3 report >100 hours per month)/longer duration of care
- ❑ Provide help with more types of tasks
- ❑ Increased caregiver psychological and physical morbidity
- ❑ Increased financial strain (e.g., out-of-pocket expenditures, labor force participation)

*Compared to caregivers of low need patients; Schulz et al., *J. of Palliative Medicine*, 2018

Family Caregiving of Older Adults Can Pose Substantial Financial Risks

- ❑ Many family caregivers of older adults report moderate to high levels of financial strain
- ❑ Family caregivers at the greatest risk of financial harm include those who:
 - are caring for significantly impaired older adults
 - are low-income or have limited financial resources
 - reside with or live far from the care recipient
 - have limited or no access to paid leave (if they are employed)
- ❑ Caregivers may also incur substantial out-of-pocket expenses:
 - medical/medication associated costs
 - assistive devices/home modifications
 - home health aides

Family Caregiving and Employment Related Costs

- ❑ More than half of family caregivers are employed part- or full-time
- ❑ Caregivers may lose income, Social Security/ retirement benefits, and career opportunities if they have to modify work hours or leave the workforce
- ❑ **Many employed family caregivers do not have unpaid or paid leave benefits at work or are not eligible for the unpaid protections of the Family and Medical Leave Act (FMLA):**
 - Daughters, sons-in-laws, stepchildren, grandchildren, siblings
 - Employees of small firms
- ❑ Federal, state, and municipal laws provide some protections for employed family caregivers, but little is known about their impact on caregivers of older adults or employers

Programs and Supports for Family Caregivers of Older Adults

- ❑ Small to moderate effects for wide variety of intervention approaches (education and skills training, counseling, self-care and relaxation training, environmental modifications, respite programs, care coordination) can improve caregiver outcomes:
 - caregiver confidence and ability to manage daily care challenges
 - both the caregiver's and care recipient's quality of life
 - may delay older adults' institutionalization and reduce re-hospitalization, shorten hospital stays

Successful Interventions

- ❑ Incorporate an assessment of caregivers' needs and preferences which are tailored accordingly
- ❑ Actively involve the caregiver in learning skills
- ❑ Address pragmatics of providing care
 - Knowledge about illness, symptoms and progression, available support service
 - Skills to address needs of care recipient, assisting with functional disabilities, managing behaviors, accessing professional services
- ❑ Address emotional toll of caregiving—
 - living with, watching loved one suffer and decline, with little or no ability to mitigate conditions

Programs and Supports for Family Caregivers of Older Adults

- ❑ Additional work is needed to identify optimal strategies to disseminate and maintain effective interventions and programs
- ❑ Additional research is needed to determine the effectiveness of interventions in diverse groups of caregivers
- ❑ Technologies (e.g., Internet, mobile apps) are increasingly being used to support family caregivers:
 - Technology-based interventions are feasible, acceptable, and can improve caregiver outcomes
- ❑ Few studies have considered cost issues, issues of diversity
- ❑ Most studies have focused on caregivers of older adults with ADRD

Family Caregivers in Care Delivery

- ❑ Family caregivers interact with varied professionals within and across diverse service delivery settings
 - Provide information about older adults' health and treatments
 - Participate in medical decision-making
 - Support, enact, oversee older adults' care plan
- ❑ The current care delivery orientation is person-focused
 - Provider payment is directed to the insured individual
 - Health professional education is focused on supporting patients
 - Clinical assessments and data infrastructure capture patient-level information
 - Bioethical orientation is toward support of patient autonomy
 - Legal and regulatory emphasis is on data privacy and security, risk management

Implications of Care Delivery Paradigm

- ❑ Care providers generally do not:
 - Identify older adults who rely on a family caregiver
 - Identify family caregivers who are present in care processes
 - Assess family caregiver knowledge, skill, or capacity to provide assistance in light of their personal circumstances and resources
 - Provide support to family caregivers or initiate appropriate referrals
- ❑ Family caregivers are often implicitly assumed to be available and able to provide care - even as they are marginalized or excluded from care planning
- ❑ Missed opportunities for better preparation and support of caregivers, with consequences for care quality and outcomes of both caregivers and older adults

Missed Opportunities and Drawbacks

Caregivers who are not adequately prepared or supported experience:

- ❑ Stress and anxiety, fear unintentionally making an error or causing injury
- ❑ Suffer burnout or depression when they are asked to do too much

Older adults also suffer when caregivers are not adequately prepared or supported. Older adults may:

- Be marginalized in their own care, or receive care inconsistent with their preferences
- Experience delayed or unmet service needs
- Be at risk for inappropriate medication use
- Experience neglect or potential abuse
- Receive poor quality or fragmented care
- Incur avoidable service use, such as ED visits or hospitalization

Priority Areas for Action

1. Identification, assessment, and support of family caregivers in delivery of care
2. Inclusion of both family and caregiver experiences in quality measurement
3. Support of family caregivers through health information technology
4. Preparation of care professionals to provide person- and family-centered care

Recommendations

A Vision for the Future:

- ❖ No less than a transformation in the policies and practices affecting the role of families in the support and care of older adults
 - ❑ The focus of the nation's health care reforms should evolve from person-centered to *person- and family-centered care*
 - ❑ Support of family caregivers should be recognized as an integral part of the nation's *collective responsibility* for caring for older adults with health and functional needs

Recommendations

1. The Secretary of HHS, working with the Secretaries of Labor and Veterans Affairs, and others, should create and implement a National Family Caregiver Strategy that includes:
 - A. Effective mechanisms to ensure that family caregivers are routinely identified and their needs are assessed and supported
 - B. Medicare and Medicaid payment reform to motivate providers to engage family caregivers effectively
 - C. Training of health care and social service providers to recognize, engage, and support family caregivers

Recommendations

National Family Caregiver Strategy that includes:

- D. Dissemination and funding for evidence-based caregiver services
- E. Evaluation and adoption of federal policies that provide economic support to working caregivers
- F. Expanded data collection to improve reporting and analysis on the experience of family caregivers
- G. A multi-agency research program to evaluate caregiver interventions in “real-world settings and across diverse conditions and populations”.

Recommendations

2. States that have not addressed the needs of family caregivers of older adults should learn from the states that provide services and supports to caregivers and implement similar programs
3. The Secretaries of HHS, Labor, and Veterans Affairs should work with leaders in health care and LTSS, technology, and philanthropy to establish a public-private innovation fund to accelerate the pace of change
4. All the above actions should explicitly address the diversity of older adults and their family caregivers