Family Caregiving in the 21st Century: Policies for a Crumbling Infrastructure

Carol Levine
National Health Policy Forum
Washington DC
September 21, 2007
Why family caregivers matter

- Family caregivers provide most of the care to elderly, disabled, and chronically ill individuals.
- They provide care over years...and years...and years.
- They are (largely) unpaid.
- If paid at a modest rate, their labor would add an additional $350 billion to the health care system’s costs (AARP estimate).
What’s new about family caregiving

- Greater policy emphasis on home and community-based care, which largely means family care
- More and older patients being treated at home with ongoing complex care needs
- More medical and managerial tasks assumed by family caregiver
- Fewer available family members
What do family caregivers do?

Family caregivers as “disenfranchised care contractors”

Responsible for all or most of the following:

- Medication management, including pain medications
- Symptom control
- Operation of medical equipment
- Record keeping
- Personal care
What do family caregivers do?

- Financial and legal management
- Coordination of services
- Nutrition
- Mobility
- Communication with health care professionals
- Household management
- Not to mention jobs, children, other responsibilities....
What makes family caregivers vulnerable?

- Long-term caregivers at risk for physical and mental health problems, including:
  - Immune system deficiencies
  - Joint and muscle problems
  - GI problems
  - Sleep deprivation
  - Depression
  - Anxiety
  - Isolation
  - Death
Caregiving Stress and Nursing Home Placement

- Caregiver physical strain and financial hardship, as well as care recipient behavior, are important predictors of caregiver stress.

- Reducing stress would avoid or defer nursing home entry and is needed to underpin current efforts to return nursing home residents to community-based care.

- Source: HHS, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, January 2007
Family Caregiving and Public Policy: Odd Bed(side) Fellows

- Recent initiatives and advocacy (Family Caregiver Support Program, Lifespan Respite, and several others)

- Though important, they cannot change the basic fragmented system in which:

  Policies are based on individual beneficiary, not family unit (with the exception of hospice)

  Benefit of investment by one sector (e.g., hospitals) goes to another (e.g., home care); where’s the incentive?
Family Caregiving and Public Policy: Odd Bed(side) Fellows

- Policy world almost totally ignores middle-class family caregivers—i.e., most Americans
- Artificial separation of aging services and health care
- Different cultures: Policy world deals with systems and regulations; family caregiving is based on intimacy and intangibles
- Policy world is often incomprehensible to outsiders
Examples of Insider Terminology

- Informal caregiving
- Medical home
- Medication reconciliation
- Hospitalist, proceduralist, surgicalist
- Handoffs
- Skilled and unskilled care
- Medically necessary
- Custodial care
- Respite services
A journey through the health care system – as I saw it in 1990
A journey through the health care system – as I see it today

Jackson Pollock, “Shimmering Substance,” MOMA
A Place to Begin: Transitions in Care Settings

- Move from one care setting to another has serious potential for error and miscommunication with cost implications
- Family caregiver essential source of information about patient and responsible for follow-up care
- Yet family caregivers seen as “nuisances”
- UHF review of 200 articles on transition care found only 2 or 3 references to involving family caregivers
Caregiving Transitions and Culture Shock

- Each transition confronts the patient and caregiver with a new culture, defined broadly as a set of assumptions, rules, expectations, and worldviews.

- Each profession and setting has its own culture, which often confuses family caregivers.

- In each setting, family roles are different and are seldom explained as caregivers move from one setting to another.

United Hospital Fund “Campaign for Family Caregivers”

- Campaign focuses on transitions
- Addresses admissions and discharges in hospitals, nursing homes, and Certified Home Care Agencies
- Three elements:
  1. Awareness
  2. Commitment
  3. Taking action
Health Care Provider Tools

- Responding to issues identified in self-assessment surveys (providers and caregivers)
- Examples:
  - HIPAA statement (in plain language)
  - Caregiver needs assessment
  - Performance improvement plan
  - Medication reconciliation
Family Caregiver Navigation Tools

Help family caregivers be better prepared to support patients through transitions and beyond

- Examples
  - Navigating the ER
  - HIPAA privacy rules
  - Understanding home care
  - Medication management/reconciliation
Timetable for “Campaign for Family Caregivers”

- Health care leaders/caregiver engaged in refining tools and signing on to Campaign –Fall 2007
- Launch planned for early 2008
- Surveys and tools will be widely disseminated through a cutting-edge website and other means

Website: www.uhfny.org