Fractures in the System: The Consumer Experience with Chronic Illness

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Chronic Conditions Among Older Americans

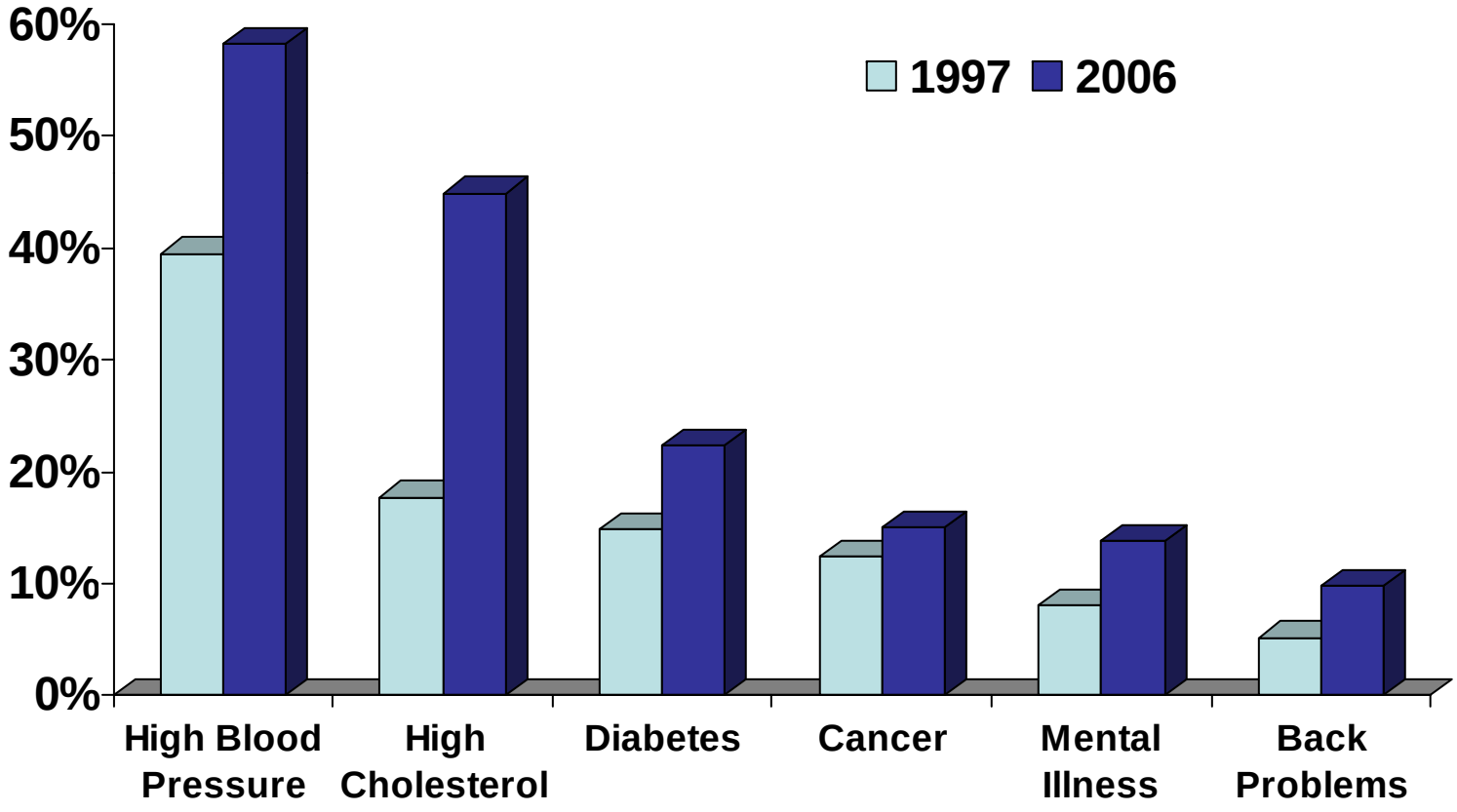
Fractures in the System: Transitions

Focus Groups: Patients' and Caregivers' Experiences

Surveys: Patients and Caregivers Report Problems With Care

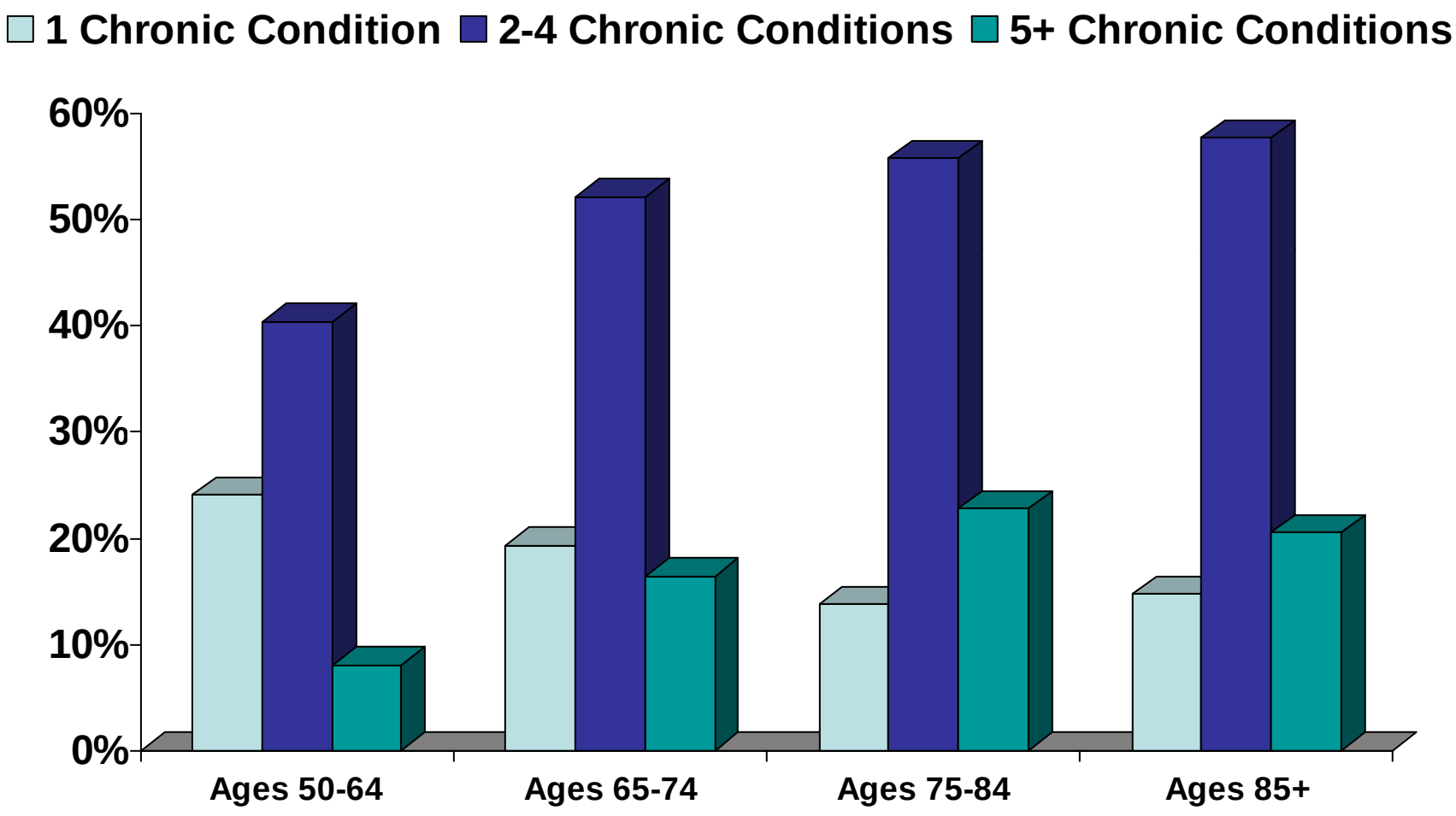
Recommendations

Many Chronic Conditions on the Rise among Medicare Beneficiaries 65+



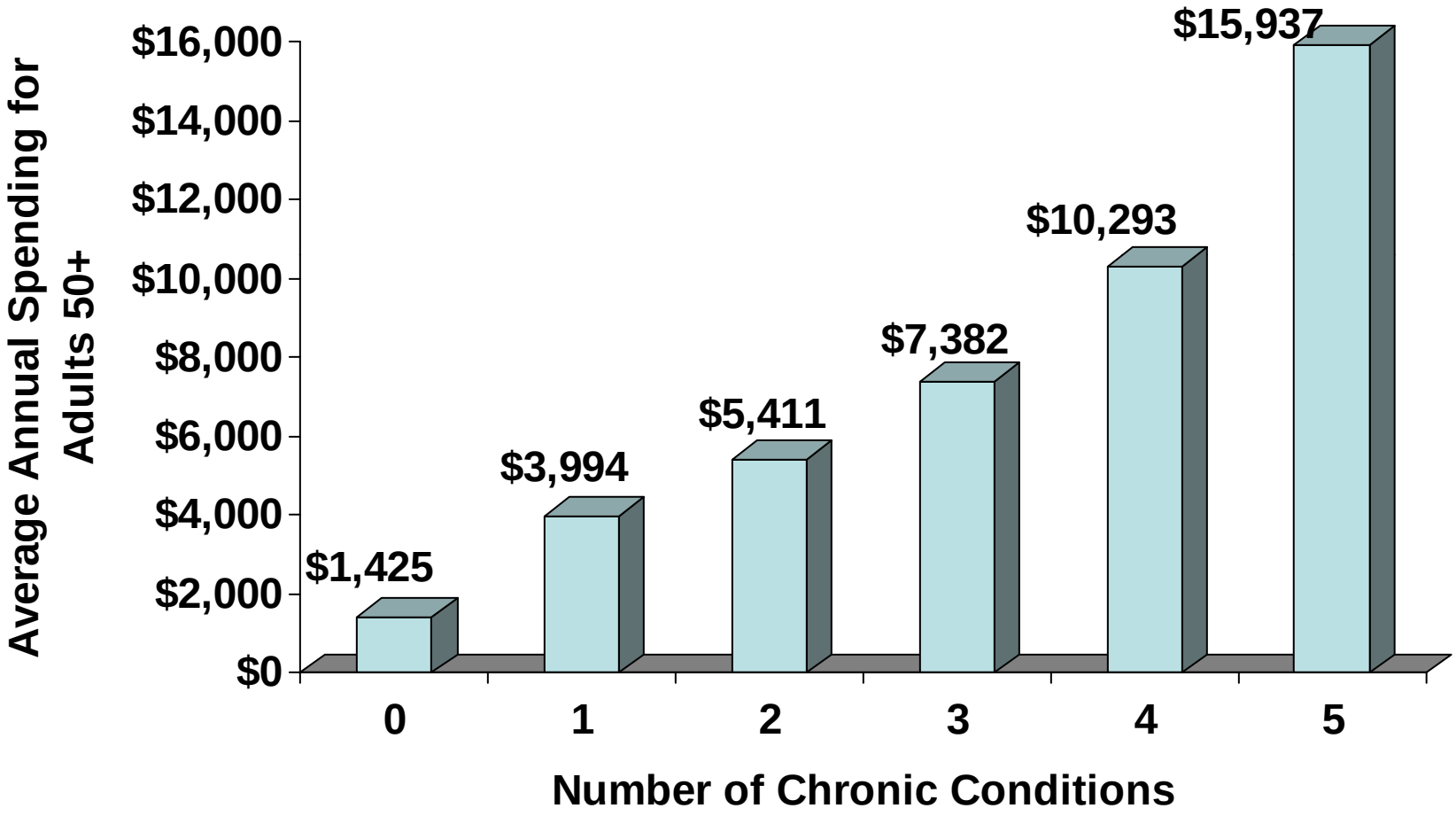
Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Many Older Americans Have Multiple Chronic Conditions



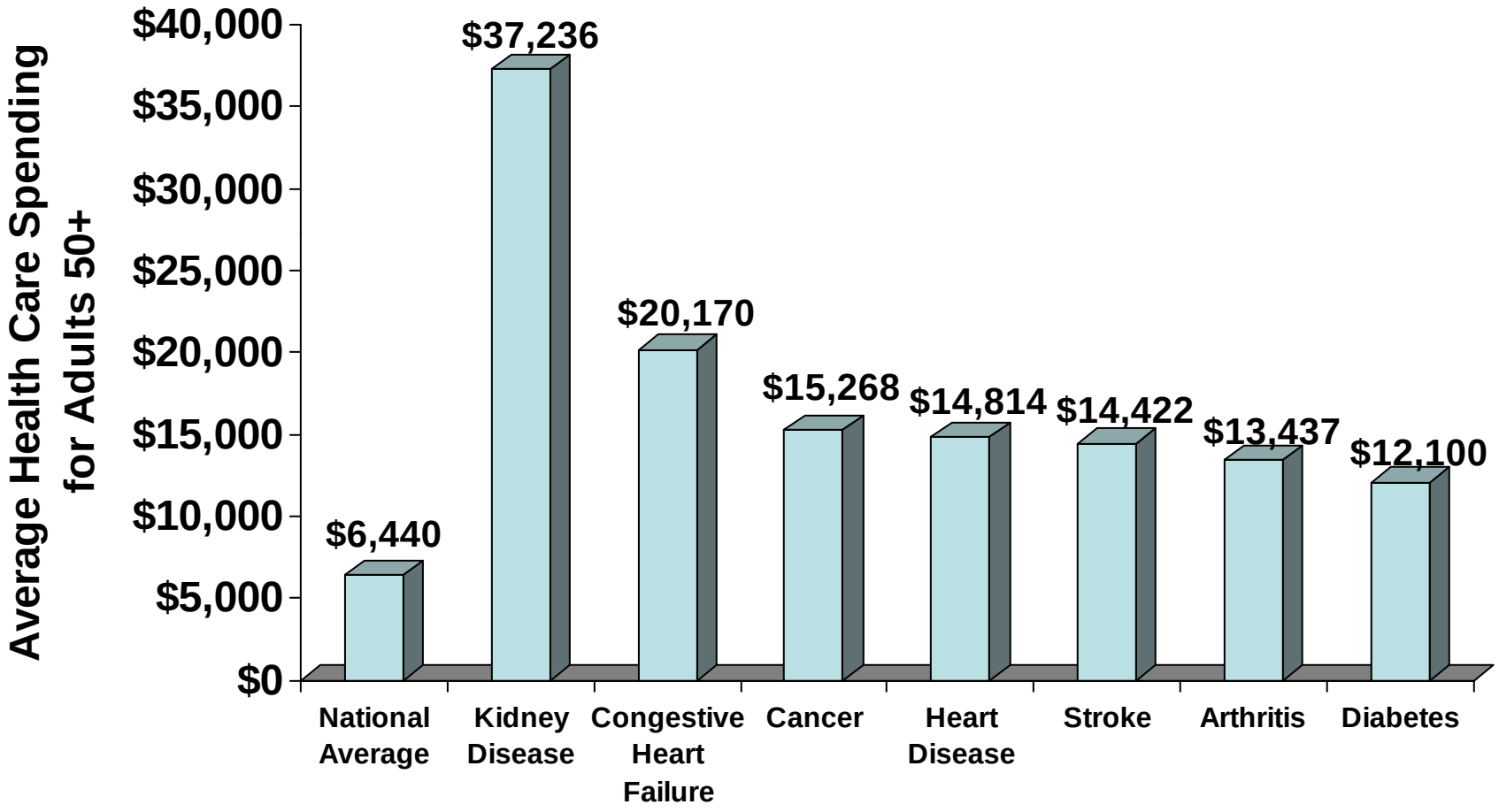
Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Health Spending Increases with the Number of Chronic Illnesses



Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Health Care Spending for Older Americans with Selected Chronic Conditions is Higher Than Average



Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Top Chronic Conditions for Medicare 65+ Based on Aggregate Cost, 2006

Chronic Condition	Parts A & B Total Cost	Change (1997-2006)	Parts A & B Cost/Case	Change (1997-2006)
Hypertension	$163.2 B	81%	$10,653	21%
Heart Disease (other)	$130.4 B	65%	$15,358	24%
Cholesterol	$104.3 B	52%	$8,820	36%
Arrhythmias	$74.9 B	37%	$19,509	24%
Diabetes	$74.6 B	37%	$12,643	20%
CHF	$72.2 B	36%	$25,841	31%
Mental Conditions	$71.3 B	36%	$19,624	26%
COPD	$63.9 B	32%	$18,511	27%

Fractures….Transitions

Transitional care for people with multiple chronic illnesses is a major issue

- Home to hospital —providers operate in a vacuum; resort to ordering tests and procedures
- Hospital to home —research signals problems
  - PA found 30% of patients had no verbal or written discharge instructions
  - 40% readmits related to medication problems—6 out of 10 preventable

Source: AARP. "Beyond 50.09: Chronic Care: A Call to Action for Health Reform." "Washington, DC. 2009 publication forthcoming.

Fractures….Transitions

Hospital to Nursing Home

Critical info is missing; fewer than half of NY NH administrators received readable post-hospital care plans; 2 out of 5 report lack of information on medications

NH to Hospital

Up to half of all NH patients admitted to hospital; often without medical history, care plans, and treatment wishes; duplicate tests

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Consumer Experience: Focus Groups

- AARP Public Policy Institute conducted 6 focus groups
- 3 groups with *chronically ill people* over age 50 who had experienced a transition from a hospital or other health care facility in the last two years
- 3 groups of *caregivers of chronically ill people* who had experienced a transition from a hospital or other health care facility in the last two years

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Patients Report Problems with Transitions

- The most frequently reported issues around transitions between hospitals (and other health care facilities) and home were:
  - Uncertain expectations for recovery and/or prognosis
  - Pain
  - Anxiety
  - Not remembering their clinician's instructions
  - Feeling abandoned

Source: AARP. "Beyond 50.09: Chronic Care: A Call to Action for Health Reform." "Washington, DC. 2009 publication forthcoming.

Caregivers Report Problems with Transitions

- The most frequently reported issues around transitions between hospitals (and other health care facilities) and home were:
  - Finding resources, such as medical equipment and services
  - Arranging for assistance in and around the home, both paid and unpaid
  - Communication with health professionals
  - Finances/affordability

Caregivers Report Problems with Transitions (continued)

- The most frequently reported issues around transitions between hospitals (and other health care facilities)
  - Uncertain expectations for their relative's or friend's recovery and/or prognosis
  - Managing their relative's or friend's expectation
  - Not enough time for competing demands (e.g., care coordination, job, children, self)
  - Stress/emotional strain/guilt

Focus Group Findings…

Many caregivers and patients, <u>especially those newly diagnosed or discharged from a health care facility for the first time</u>, did not know what to expect, where to find resources, or what services they would need, either in terms of health care or support services

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Focus Group Findings…

Many individuals and caregivers felt that the “ball was dropped” after discharge.

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

“David”

an 82-year-old Richmond caregiver caring for his wife, 64, who has terminal cancer and dementia…

“They don’t assist on the transition home. You have to be tough, be an advocate… I’d like somebody to tell me what’s available. I don’t know.”

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

“Eugene”

is a 70-year-old Philadelphia patient with multiple chronic conditions…

“Following you home, that never occurred and, you know, a whole lot can happen between leaving the hospital and getting home.”

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

“Joanne”

is a 79-year-old Philadelphia caregiver…

“We don’t know what we don’t know.”

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Focus Group Findings… Care Coordination Takes Time

Many patients or their family caregivers spend a lot of time arranging for their care

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

“Ruth”

is an 81-year-old Philadelphia patient…

“Sometimes, I have to spend all day on the phone with my doctor, even to get an appointment”

“If you do not get it while you are in there, when you go home, you are out of luck”

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Focus Group Findings…Caregiver Stress

Caregivers report significant stress, altered living arrangements, reduced working hours, and need for emotional support.

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Focus Group Findings…Caregiver Stress

"It would benefit an insurance company a zillionfold if somebody were helping you transition because…when you and the patient come out of the hospital, here you are…two dummies, one sick and one dummy. What do you do? Where do you go? You make a zillion phone calls. You do a lot of things that are stupid and nothing gets done."

Jackie, 79 year old caregiver

Source: AARP. "Beyond 50.09: Chronic Care: A Call to Action for Health Reform." "Washington, DC. 2009 publication forthcoming.

Focus Group Findings… Patients and Caregivers want a Trusted Source of Care

Patients and caregivers want advice and support from a trusted source.

Many patients and caregivers do not trust insurers or providers to act in their best interest.

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Overview: Beyond 50.09 Survey

- AARP Public Policy Institute conducted <u>two national opinion surveys</u> to learn more about chronic illness from the consumer perspective.
- Surveys targeted:

  (1) people (ages 50+) with selected (more serious) chronic conditions who had at least one serious health episode, and received care from a health care facility in the past three years, and

  (2) caregivers (ages 45+) of people who needed assistance, had a serious health episode, and received care from a health care facility within the past three years.

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Patient Engagement

Studies suggest that people who are more knowledgeable, skilled, and confident about handling their chronic conditions, whom we refer to as "engaged", are better able to manage their own care, promote their own health, and make better decisions affecting their condition.

Source: AARP. "Beyond 50.09: Chronic Care: A Call to Action for Health Reform." "Washington, DC. 2009 publication forthcoming.

Patient Activation Measure (PAM)

- Patient Activation Measure (PAM) captures the extent to which patients feel engaged and confident in taking care of their condition.
- The PAM for people with chronic conditions has been tested and validated repeatedly (Hibbard et al. 2004)
- The PAM for caregivers was adapted for first-time use in our caregiver survey.
- The caregiver PAM asks about the caregiver's knowledge, skill, and confidence for managing the health of the care recipient – the level of ability or competence as a caregiver

Source: AARP. "Beyond 50.09: Chronic Care: A Call to Action for Health Reform." "Washington, DC. 2009 publication forthcoming.

Beyond 50.09 Survey Results…

The surveys revealed that a significant percentage of patients and caregivers have experienced serious quality-of-care problems, including medical errors and poor communication among providers.

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Beyond 50.09 Survey Results…

- 26% lack confidence in the health care system
- 30% said provider did not have all the needed info when patient arrived for the visit
- 21% report health care providers do not do a good job communication with each other
- 24% got conflicting info from 2 or more clinicians
- 20% felt health suffered because providers were not communicating

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Beyond 50.09 Survey Results…

- 23% reported medical errors; 61% were “major”
- 16% said unnecessary tests
- 15% said unnecessary hospitalization
- 10% said hospital infection

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Beyond 50.09 Survey Results…

- More than1 in 4 (27%) said they had not done something recommended by a health care professional, such as fill a prescription, get a medical test…

- Most common reason? **Patient disagreed with the clinician's recommendation (32%)..**

Source: AARP. "Beyond 50.09: Chronic Care: A Call to Action for Health Reform." "Washington, DC. 2009 publication forthcoming.

Beyond 50.09 Survey Results…

Indicators that respondents received poor quality care and/or poor transitional care included:

- **Among respondents with chronic conditions**
  - 18% said that their transition care had not been well coordinated
  - 15% had been readmitted to a hospital within 30 days of discharge

Source: AARP. "Beyond 50.09: Chronic Care: A Call to Action for Health Reform." "Washington, DC. 2009 publication forthcoming.

Beyond 50.09 Survey Results…

Indicators that respondents received poor quality care and/or poor transitional care included:

- **Among caregiver respondents**
  - 25% reported that transitional care of their care recipient had not been well coordinated
  - 32% of care recipients had been readmitted to a hospital within 30 days of discharge

Source: AARP. "Beyond 50.09: Chronic Care: A Call to Action for Health Reform." "Washington, DC. 2009 publication forthcoming.

Beyond 50.09 Survey Results…

- People who were <u>not engaged</u> were more likely to report that their health got worse because they did not get the health care they needed

- Quality problems were more likely among caregivers who feel less capable

Beyond 50.09 Survey Results…

- Younger caregivers felt less prepared
- Lower capability: White, male, higher income and higher education
- Higher socioeconomic status is no assurance that they feel capable of caring for someone else

Engagement

- Clinicians need to assess the level of preparation and engagement of patients to manage their care, and the extent to which caregivers feel capable of helping
- Target those who report a lack of engagement for additional support, such as care coordination and community support services
- “Coaching” technique

Chronic Care Delivery Needs to Change

“Barriers to improvements in care for people with chronic disease include the fragmentation of care delivery, poor transitions between and among settings, and misaligned payment incentives that fail to recognize the value of better integration of services”

IOM Report…

The Institute of Medicine's 2001 report *Crossing the Quality Chasm: A New Health System for the 21st Century* presented <u>four areas</u> where health care should be redesigned to organize care around patients' needs

Source: Institute of Medicine (IOM). Crossing the Quality Chasm: A New Health System for the 21st Century. Washington DC: National Academy Press, 2001.

IOM Report…

- Four areas where health care should be redesigned:
  - Care should be based on continuous health relationships;
  - Care should be customized based on patients' needs and preferences;
  - Patients should be the source of control; and
  - Knowledge should be shared and information should flow freely.

Source: Institute of Medicine (IOM). Crossing the Quality Chasm: A New Health System for the 21st Century. Washington DC: National Academy Press, 2001.

Ideal Elements of Quality Chronic Care

- Important components of good chronic care management are found in Wagner's the Chronic Care Model (CCM)
- Six components of CCM:
  - Self-management support
  - Community resources
  - Organization of health care
  - Interdisciplinary teams
  - Decision support
  - Clinical information systems

Source: AARP. "Beyond 50.09: Chronic Care: A Call to Action for Health Reform." "Washington, DC. 2009 publication forthcoming.

Examples of Successful Chronic Care Models

- The Care Transitions Intervention – Coleman, funded by the Hartford Foundation and based at the University of Colorado
  - This program provides individuals and their caregivers with tools and support to encourage them to participate more actively in their care transitions

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Examples of Successful Chronic Care Models

- Transitional Care Model (TCM)
  - Targets older adults with no cognitive impairment who have two or more risk factors, such as poor self-health ratings, multiple chronic conditions, or a history of recent hospitalizations.
  - Central to the model is the master's-prepared advanced practice transitional care nurse who is well versed in national standards of care delivery and experienced in providing comprehensive care and acute and community-based services. (Naylor, 2006)

Source: AARP. "Beyond 50.09: Chronic Care: A Call to Action for Health Reform." "Washington, DC. 2009 publication forthcoming.

Recommendations

- Better Knowledge
  - Expand testing of care delivery models to find out what works…and rapid adoption of those that do
  - Include best practices from chronic disease care in clinical preparation and training
  - Engage patients by giving them information they will understand and act on
  - Support family caregivers and engage them as partners with professionals

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Recommendations

- Better Knowledge
  - Encourage wise use of pharmaceuticals in managing chronic conditions; deal with polypharmacy
  - Improve research on disparities and dissemination of information in this area

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.

Recommendations

- Better Tools
  - Increase use of health information technology
  - Develop better tools for patients to manage their conditions

- Better Incentives
  - Make innovative changes to payment policy
  - Maximize use of the health care workforce
  - Make medications and preventive care affordable

Source: AARP. “Beyond 50.09: Chronic Care: A Call to Action for Health Reform.” “Washington, DC. 2009 publication forthcoming.