

Health Literacy and Older Adults: Reshaping the Landscape

Giving Voice to Older Adults & Caregivers Difficult Conversations and Decisions

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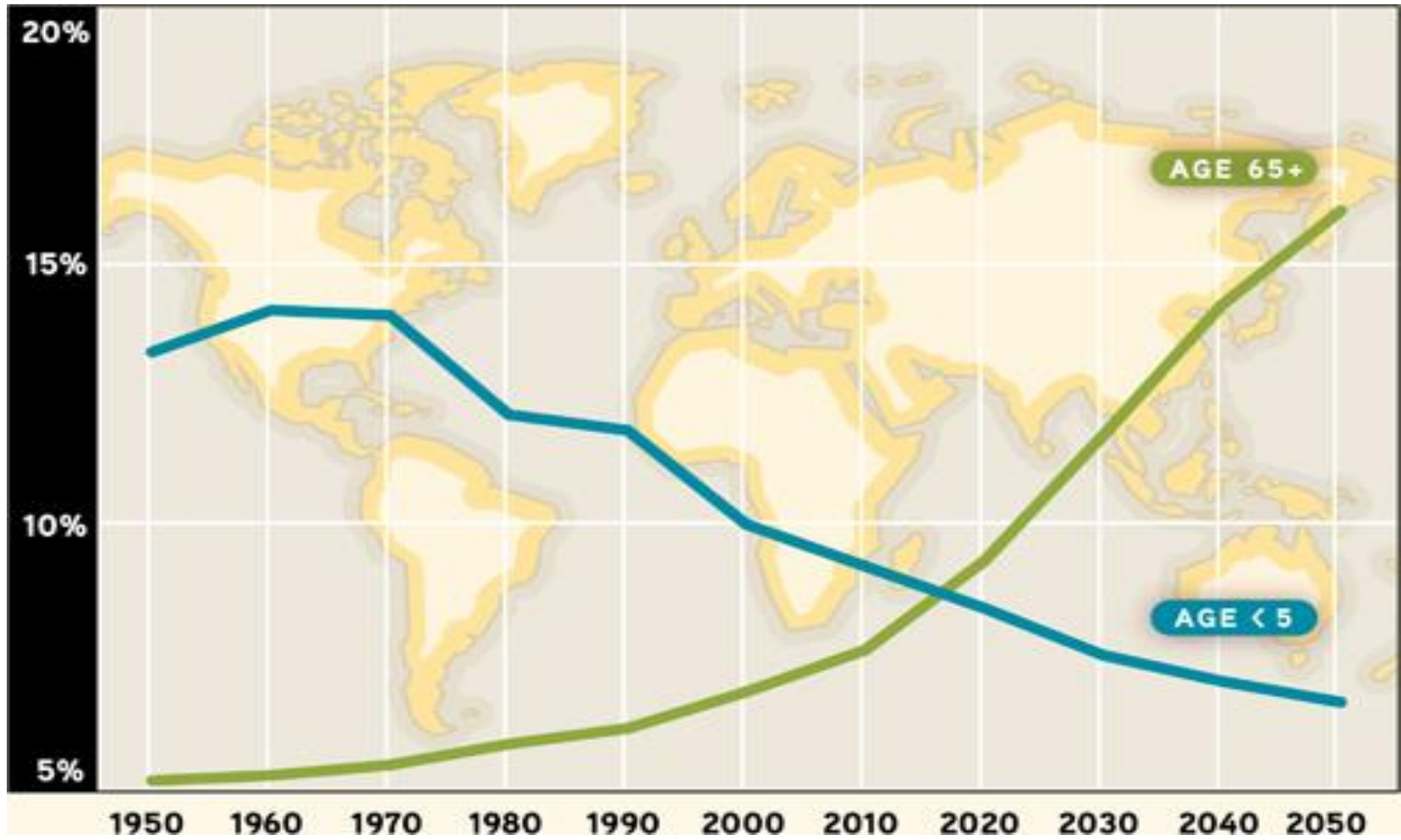


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Overview

1. Population aging
2. Attributes of older adults, common decisions, the complex care environment
3. Engaging families to bridge health literacy demands
 - Older adults' preferences
 - Challenges & opportunities
4. Discussion & Questions

Population Aging: a Global Phenomenon



Source: United Nations Department of Economic and Social Affairs, Population Division.

World Population Prospects. The 2004 Revision. New York : United Nations, 2005.

Heterogeneity: The Defining Feature of Aging

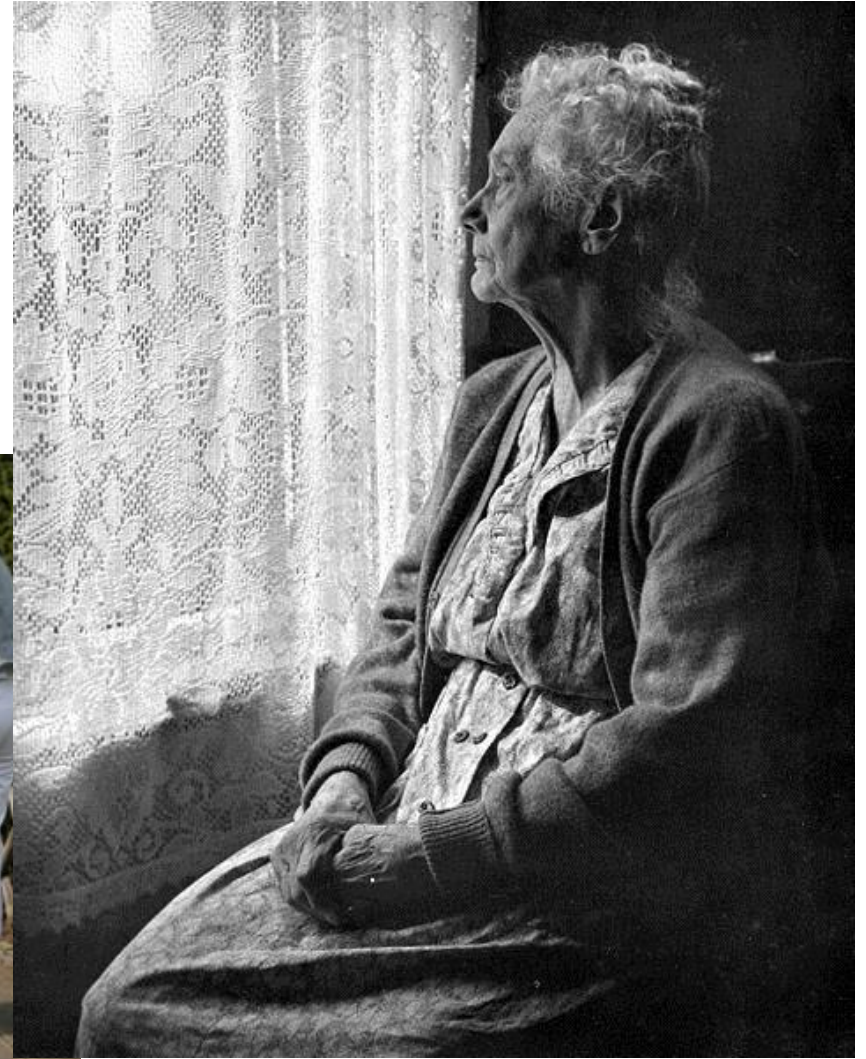


Fauja Singh, age 100
2012 Toronto Marathon
Finisher



The "Iron Nun"
Madonna Buder, age 82
Completed 2012 Ironman
Canada

Heterogeneity: The Defining Feature of Aging



Health Literacy in Older Adults: Relevant Factors

Factors affecting decision-making capacity

- Educational attainment (↓)
- Technological experience, access, skill (↓)
- Cognitive function (↓)
- Hearing function (↓)
- Vision function (↓)

Health Literacy in Older Adults: Relevant Factors

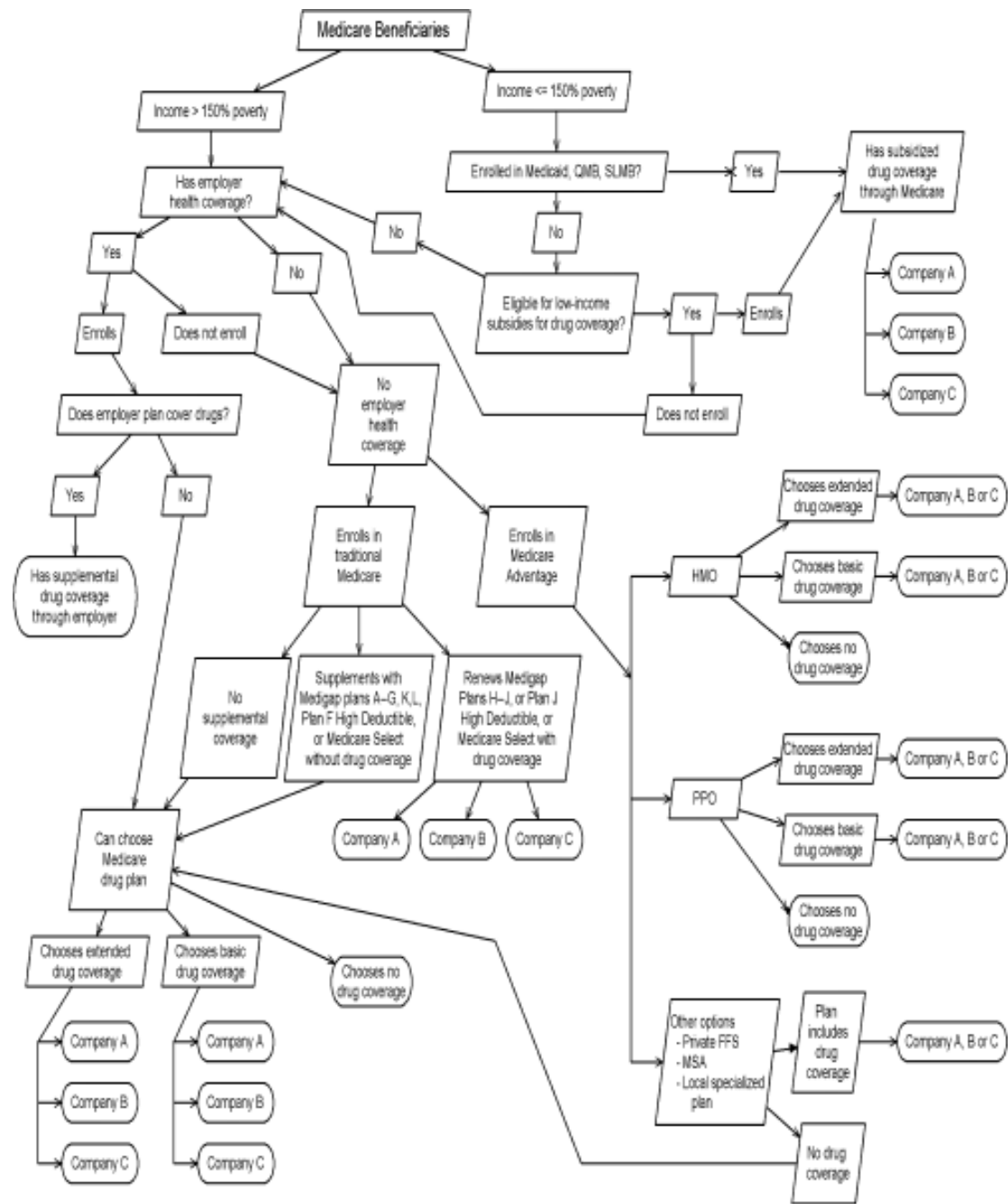
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- Educational attainment (↓)
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Factors affecting decision-making demand

- Chronic medical conditions (↑)
- Complex and costly treatment regimens (↑)
- “Preference-sensitive” vs. evidence-driven decisions(↑)
- Infusion of consumerism in health insurance (↑)

Can Limiting Choice Increase Social Welfare? The Elderly and Health Insurance



Important Decisions

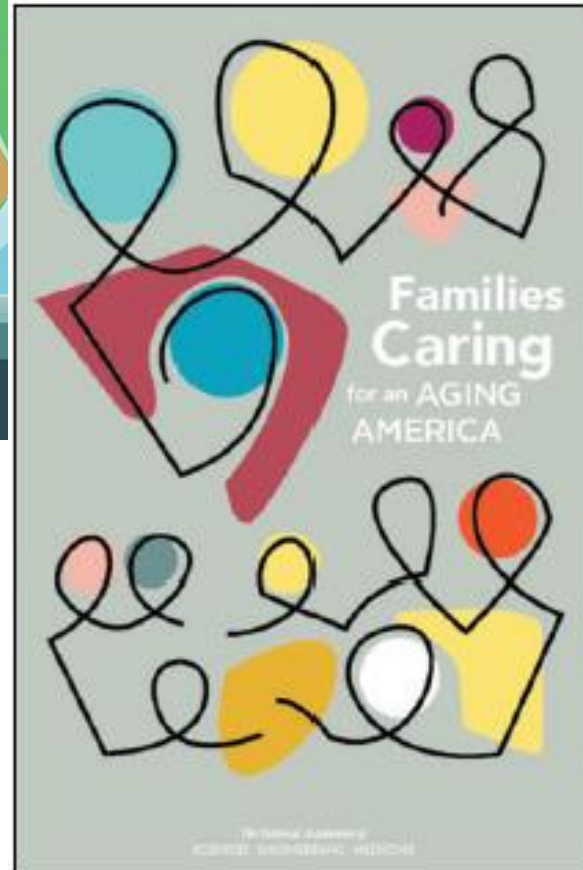
- Health insurance decisions (supplemental coverage; Medicare Advantage; prescription drug coverage)
- Appropriate and timely access to medical care
- Adhering to treatments (prescribed medications, dietary and lifestyle recommendations)
- Financial management; bills and banking (including avoidance of financial predators)
- Accessing public benefits, community services
- Discontinuation of driving; residential moves
- Hiring & firing direct care workers
- Purchase of long-term care insurance
- Advance care planning

RETOOLING FOR AN AGING AMERICA

BUILDING THE HEALTH CARE WORKFORCE



INSTITUTE OF MEDICINE
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Families
Caring
for an AGING
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The National Academy of
Healthcare Engineering Medicine

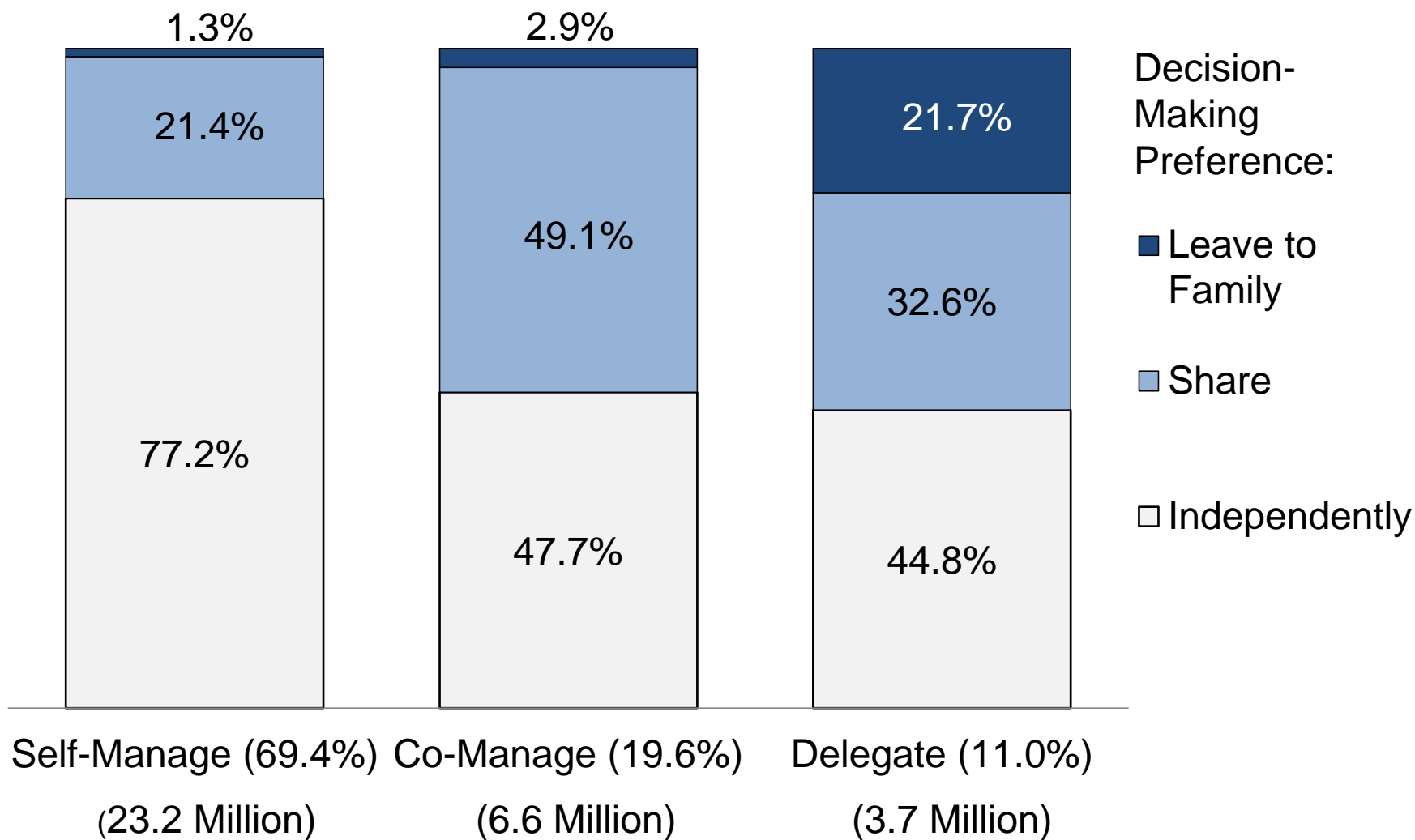
Health-Related Responsibilities Assumed by Family Caregivers

Role	Function
Attendant	Provide personal care
Administrator	Manage household
Health Provider	Deliver medical care
Companion	Provide emotional support
Driver	Facilitate transportation
Advocate	Request services
Navigator	Coordinate care across providers and care settings
Coach	Encourage patient self care activities
Technical Interpreter	Facilitate patient understanding
Patient Extender	Facilitate provider understanding

Family-Centered Care is a Reality

- The majority of older adults' care needs are met by family and other unpaid caregivers (*NASEM 2016; IOM Retooling 2008; Freedman & Spillman 2014*)
- Approximately 40% of older adults regularly attend medical visits with family “visit companions” and they are persistently involved over time (*Wolff & Roter Arch Internal Med 2008, Social Science & Medicine 2011; Wolff, Boyd, Gitlin, Bruce, Roter JAGS 2012; Wolff & Spillman JGSS 2014*)
- Family “visit companions” participate actively in communication in ways that both facilitate and impede information exchange (*Wolff & Roter JGIM 2012; Wolff, Clayman, Rabins, Cook, Roter, Health Expectations 2014; Wolff, Guan, Boyd, Vick, Amjad, Roth, Gitlin, Roter, PEC 2017; Wolff, Roter, Barron, Boyd, Leff, Finucane, Gallo, Rabins, Roth, Gitlin, JAGS, 2014*)

Older Adults Approach to Managing their Health and Decision-Making Preferences With Family



Source: Wolff & Boyd, *Journal of General Internal Medicine*; 2015
Analyses of 2012 National Health and Aging Trends Study

Challenges to Structural Support of Family Caregivers in Care Delivery

1. Misaligned reimbursement – lack of compensation for clinician time and effort to educate, counsel, or support involved family
2. Prevailing orientation toward patient autonomy and privacy
3. Patient-oriented information systems – lack of structured fields to document information about involved family members/friends

A descriptive qualitative study of the roles and behaviors of family companions in primary care visits among older adults with cognitive impairment

Vick JB, Amjad H, Smith KC, Boyd CM, Gitlin LN, Roth DL, Roter DL, Wolff JL

*“If somebody wants to be alone with him, if a doctor wants some alone time with P, that’s fine. But the fact of the matter is he’s not going to remember what was talked about... **Clinicians get angry with me, and they’re like “Let him speak,” as if this is picnic for me, which it is not...** And as a matter of fact, it’s very disturbing to know that he can’t remember that he had a stent put in his heart [last month]...”*

- 60 yo spouse of person with MCI (MMSE 26)

Patient-Family Agenda-Setting

The SAME Page Study

(NCT#02986958; R21AG049967)

Premise: Companions are motivated to support patients during medical visits but lack knowledge of patient health concerns and preferences for communication assistance.

Two Activities:

1. Elicit and align patient-companion perspectives regarding patients' health issues to discuss with the clinician
2. Clarify patient preferences for communication support from the companion in the visit

Study Team: Jennifer Wolff (PI), Jennifer Afill, Cynthia Boyd, Diane Echavarria, Laura Gitlin, Debra Roter, David Roth, Judith Vick

SAME Page Study Participants

- “She is my memory” – patient
- “He doesn’t know that he doesn’t know, so we can’t talk about it.” – companion
- “She has memory problems, but I don't think she's been diagnosed.” – companion
- “We live together. I'm involved in all her activities. I retired for this purpose [to manage their care]. Every doctor we go to, I'm the backbone. When we go into the doctor's office I wait and see; if she answers incorrectly, I step in. I've grown into where I am with her now.” – companion

STEP 1 How can your family member be most helpful today?

	Checked
1. Help you understand what the provider says or means	91.3%
2. Remind you to ask questions or tell the provider your concerns	84.8%
3. Ask questions or give the provider information	82.6%
4. Listen to what your provider says and take notes	82.6%
5. Allow you time alone with the provider for some or all of the visit	52.2%

STEP 2 What do you want to discuss with your provider today?

Patient Priorities

1. Memory problems, n=29/42
2. Fear of falls, dizziness, or balance, n=25/42
3. Trouble concentrating or making decisions, n=24/42

Companion Priorities

1. Fear of falls, dizziness, or balance, n=25/49
2. Bladder or bowel problems, n=22/49
3. Planning for serious illness or progression of current illness, n=21/49

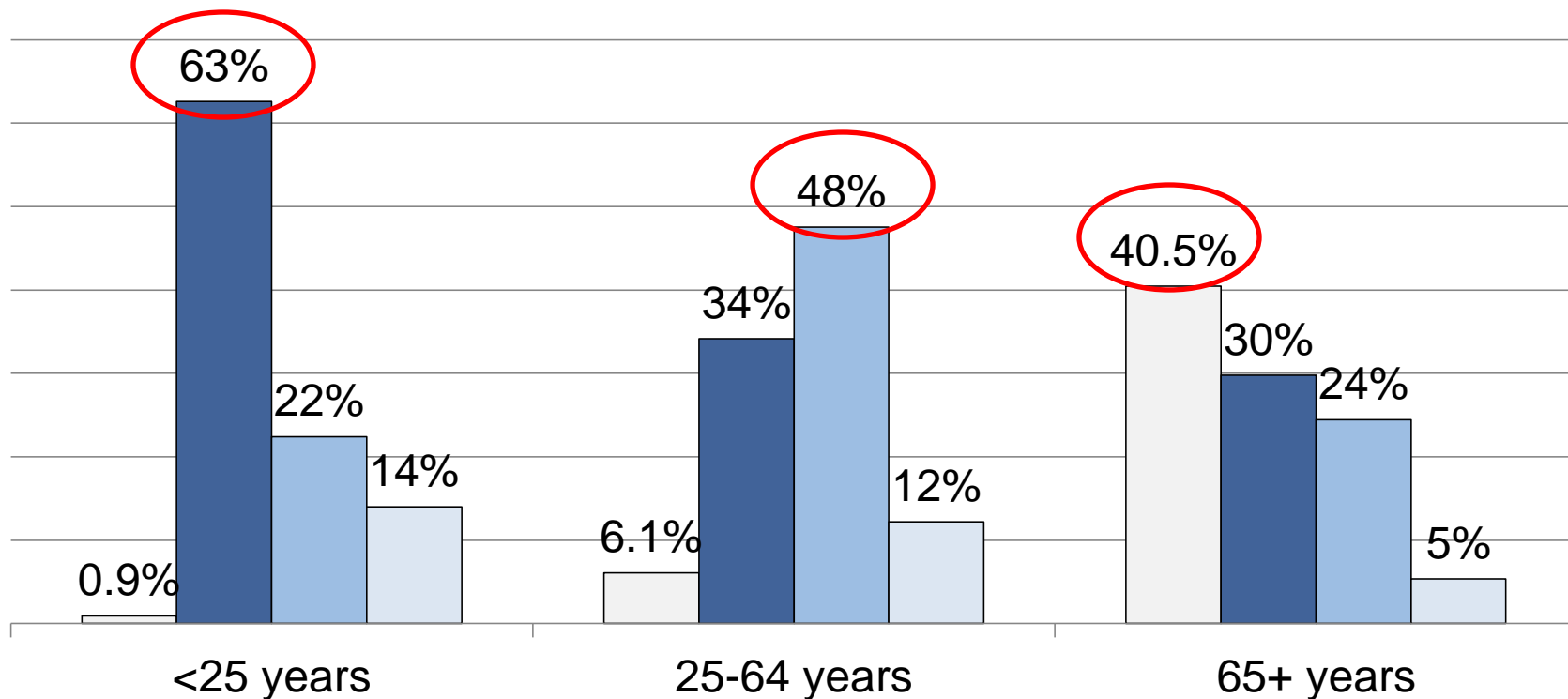
n=49 participants in intervention group of 93 enrolled; 42 of 49 patients responded to checklist.

Bridging the Digital Divide

The Case for Engaging Families Through Shared Access to the Patient Portal

- Capturing and executing patient preferences
- Engaging family “care partner”
 - Legitimacy and respect
 - Convenience and efficiency
 - Timely, comprehensive information access
 - Preparedness to undertake or oversee health management activities
- Capture and stewardship of high quality data
 - Corrections of erroneous information in electronic health record
 - Providers knowledge of **who** is messaging if person other than patient

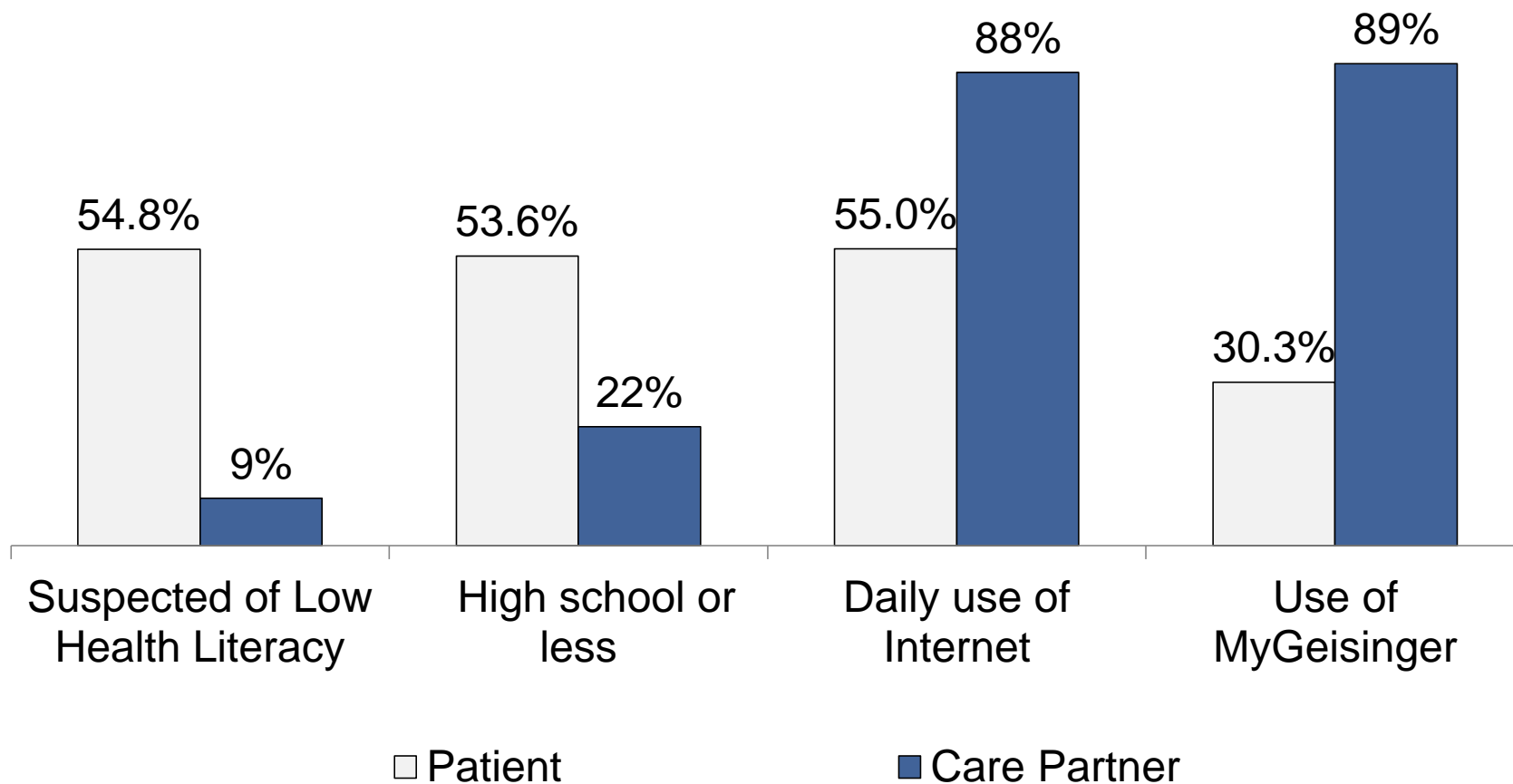
Shared Access at an Integrated Health System: What Are Patients' Motivations for Sharing Access?



- Do not use a computer
- Care partner helps me manage my health
- In case of emergency
- Because my care partner asked me

N=323 patient respondents

Shared Access at an Integrated Health System: A Look at Patients and Their Care Partners



N=323 patients and 462 care partner respondents

Wolff JL, Berger A, Clarke D, Green JA, Stametz RA, Darer J., JAMIA 2017.

Summary

- Older adults are best characterized by heterogeneity, and vary widely in health literacy.
- Many older adults desire or require family when sharing information with providers of care, making health care decisions, and managing their health.
- Health system processes to recognize, engage, and support families are notably absent.
- Engaging family may hold promise as a strategy to bridge health literacy challenges in older adults' face-to-face encounters and electronic interactions.