



A Caregiver's Perspective: Please Prioritize Caregiver Health Literacy

22nd Annual Health Literacy Conference

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Learning Objectives

- List 3 common challenges family caregivers of older adults experience that could be alleviated with improved health literacy
- State 3 reasons why family caregivers should be targeted populations for health literacy interventions
- Describe 3 practical strategies health care organizations and professionals can employ to address health literacy needs of family caregivers

In the Past 3 Years:

Accessibility Challenges:

- Lacked reliable transportation for wheelchair transports
- Difficulty receiving proper clinical care due to lack of appropriate equipment and accommodations

High-risk Health Incidents:

- Developed infection at a surgical site, requiring extensive wound care
- Developed bedsores while in a rehabilitation short-term facility
- Experienced several urinary tract infections, overcame sepsis twice
- Discharged from ER visit with early signs of sepsis

As a caregiver, I
have felt
hopeless, ill-
prepared,
worried, strained,
conflicted,
frustrated, angry,
guilty, responsible
and ill-informed.

Aging Population and Needs (CDC)

- In 2019, 16% of the US population was aged 65+
- Aging increases the risk of many chronic diseases including heart disease, diabetes, cancer, and dementia
- Older adults with chronic diseases have higher risk of becoming disabled and needing assistance
- Research exists on older adults' health literacy and various health outcomes, less is known about caregivers' health literacy

“

“There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver.”

ROSALYN CARTER

Demographics of Caregivers

48
million

- Nearly 1 in 5 Americans serve an unpaid caregiver for someone 50+
- Average: 24 hours per week in caregiving
- 6 in 10 caregivers work while providing care

Duties

- Provide and monitor complex care in home
- Navigate care system
- Advocate for care recipient
- Pay for services to meet care recipient's needs

Types of Care (Beach et al., 2021)

- Household tasks
- Personal care tasks
- **Medical/nursing tasks**
- Any combination of the above three tasks



Caregiver Roles in Medical/Nursing Tasks

Companion
Navigator
Driver
Advocate
Coach
Case Manager
Health Care Provider
Technical Interpreter
(Jacobs, 2021)

Family presence improves quality of medical visits (Jacobs, 2021)

Building trusting relationships among caregiver, care recipient and health care professional requires common goals, clear roles, and a means for timely communication

Health Literacy

(Defined, 2020) (CDC)

- **Personal health literacy** is the **degree to which individuals have the ability** to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.
- **Organizational health literacy** is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Why Health Literacy Matters

(Parvanta & Bass, 2020)

Those with adequate health literacy are more likely to:

- Participate in preventive healthcare (screenings and annual check ups)
- Understand the importance of early detection and management of disease
- Use healthcare services in an efficient way
- Follow and adhere to treatment recommendations

The Costs of Low Health Literacy (Parvanta & Bass, 2020)

- **Inability to manage chronic conditions**
 - Difficulty taking medications properly
 - Difficulty understanding disease management recommendations
- **Higher hospitalization rates**
 - 6% more frequent hospital visits
 - Stay longer when in the hospital (by 2 days)
- **Unnecessary healthcare costs**
 - More trouble accessing health insurance
 - Make more frequent use of the ER
 - Incur 4 times higher annual health care costs
- **Increased mortality**
 - Difficulty managing chronic conditions
 - Less likely to engage in preventive screenings
 - Less likely to be immunized

Feelings and Insights

- ~Self-esteem, confidence, efficacy
- ~Self-monitoring
- ~Self-knowledge & insight
- ~Sense of control
- ~Readiness to change
- ~Sense of power
- ~Optimism & hope

Experiences & Capacities

- ~Learn from past
- ~Active engagement with life
- ~Health service navigation
- ~Coping & obtaining support
- ~Manage psychosocial aspects of disease
- ~Set/achieve disease-related goals
- ~Stress management
- ~Health directed behavior/improve health

Actions & Behaviors

- ~Power sharing/collaborative participation
- ~Mutual decision making
- ~Patient choice/self determinism
- ~Communication

Skill Development

- ~Develop & acquire skills
- ~Health literacy
- ~Digital literacy

Patient Empowerment (Barr et al., 2014)

Caregiver Health Literacy

- Few studies have conceptualized health literacy as competencies that can be developed, and even fewer have focused on health literacy development of caregivers.

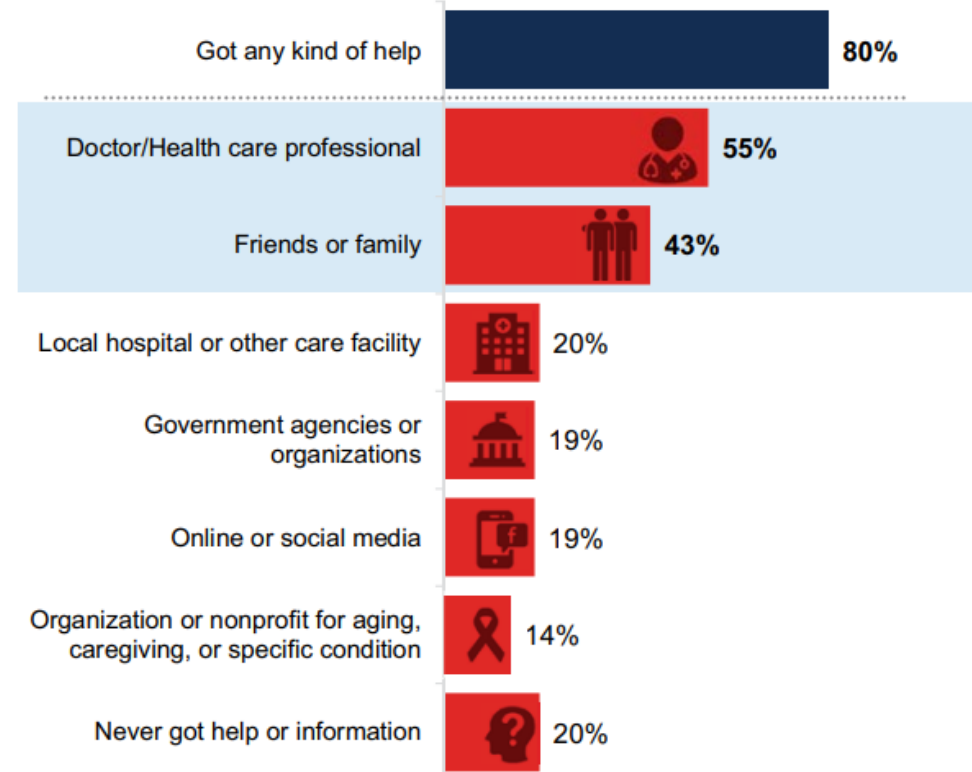
Insights from the Limited Research:

- 20% of caregivers demonstrated low health literacy; those with low health literacy were more likely to have high levels of difficulty with health care provider communication and navigation of services and supports (Fields, Rodakowski, & James, 2018)
- O'Connor and colleagues examined caregiver HL and patient outcomes. Limited caregiver HL was associated with poorer physical function, greater comorbidities and more ED visits in the past year (36.7% vs. 19.3%). Findings suggest that caregivers with limited HL are caring for medically complex patients. (O'Connor, et al., 2022)
- Li et al (2020) found that improving health literacy levels of caregivers contributed to improved dementia care abilities
- Caregiver health literacy should be considered for assessments and interventions designed to identify and reduce the difficulty caregivers experience in healthcare communication and navigation (Fields, Rodakowski, & James, 2018, p. 490)
- Development of HL training for caregivers is needed (O'Connor, et al., 2022)

Caregivers' Sources of Help or Information

Fewer than 3 in 10 say a health care provider had asked about what was needed to care for their recipient

Figure 75. Sources of Help or Information used by Caregivers



M1. Where do/did you go for help or information about caring for your [relation]? Please select all that apply.

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.





how can i increase my health literacy skills



Images



News



Videos



Books



Maps



Shopping



Flights



F

About 271,000,000 results (0.46 seconds)

Speak more slowly when providing instructions. Be respectful and clear without being patronizing. Use graphics and pictures instead of long written instructions. Provide information at an appropriate grade level.

Oct 15, 2014



Institute for Healthcare Improvement

<https://www.ihi.org> › communities › blogs › 8-ways-to-i... ⋮

8 Ways to Improve Health Literacy



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Feedback

Addressing Health Literacy Needs of Family Caregivers

Organizational health literacy is important but ...

- **Health literacy interventions and initiatives have largely focused on health care providers and organizations and not the patient**
- **Interventions to improve personal health literacy are direly needed, for both patients and caregivers**
 - Empower patients and caregivers to increase their health literacy
 - Dedicated efforts to build patient and caregiver skills through varied skill-building experiences (demonstrations, guided practice) and resources

Write your health care provider's answers to the 3 questions here:

1. What is my main problem?

2. What do I need to do?

3. Why is it important for me to do this?

Asking these questions can help you:

- ☒ Take care of your health
- ☒ Prepare for medical tests
- ☒ Take your medications the right way

You don't need to feel rushed or embarrassed if you don't understand something. You can ask your health care provider again.

When you Ask 3, you are prepared. You know what to do for your health.

Your providers want to answer 3

Are you nervous to ask your provider questions? Don't be. You may be surprised to learn that your medical team wants you to let them know that you need help or more information.

Like all of us, health care providers have busy schedules. Yet they want you to know:

- All you can about your health or condition.
- Why their instructions are important for your health.
- Steps to take to keep you healthy and any conditions under control.

Bring your medications with you the next time you visit a health care provider. Or, write the names of the medications you take on the lines below.

Like many people, you may see more than one health care provider. It is important that they all know about all of the medications you are taking so that you can stay healthy.

Ask Me 3® is an educational program provided by the Institute for Healthcare Improvement / National Patient Safety Foundation to encourage open communication between patients and health care providers.

 Institute for Healthcare Improvement

 **Ask Me 3**
Good Questions
for Your Good Health

It Sure Would Have Been Helpful To Have:

- Information on expected challenges and/or high-risk situations
- Information about local resources (care cab service, reputable home health agencies, etc.)
- Trustworthy and helpful sites to go online for educational materials
- Guidance on what questions to ask (don't know what you don't know)
- Care management classes

Keep in mind:

~Health literacy assumptions health care providers may have

~Not everyone is “online”

~Caregivers need more instruction and more support; they should be included in patient-centered care models

“Caregivers are
valuable members
of the healthcare
team”

Attributes and Examples of Health Literate Organizations (Parvanta & Bass)

A Health Literate Organization	Examples
Provides easy access to health information and services and navigation assistance	Makes electronic patient portal user-friendly and provides training on how to use them
Designs and distributes print, audiovisual and social media content that is easy to understand and act on	Involves diverse audiences, including those with limited health literacy in development and rigorous user testing Uses a quality translation process to produce materials in languages other than English
Addresses health literacy in high-risk situations, including care transitions and communications about medicines	Prioritize high-risk situations (e.g. informed consent for surgery and other invasive procedures) Emphasize high-risk topics (conditions that require extensive self-management)

Help Patients and Caregivers Make the Most of Medical Appointment

Before appointment:

- Track and record any symptoms, new or existing
- Prepare list of questions, prioritize them (in case time runs out)
- Prepare list of medications
- Write a brief, concise 1-page health history to share covering important health history they should know

During Appointment:

- Ask questions and express concerns
- Take notes during office visit
- Ask your providers for clarification
- Repeat back/paraphrase what you have been told
- Bring someone you trust with you to the appointment
- Ask for visit summary and supportive written directions/materials
- Be sure of/or arrange next steps before leaving

Questions to Ask Upon Hospital Discharge

- What doctor appointments are needed after discharge? Can you help me schedule them?
- What problems, symptoms, side effects should I watch for?
- What medical equipment is needed? Can you tell me how I should get the equipment?
- Any activity restrictions? Dietary restrictions?
- Any new prescriptions? Directions? Side effects?
- Can you tell me/show me tasks needed for physical care, medical care, etc.?

Image: Brookings

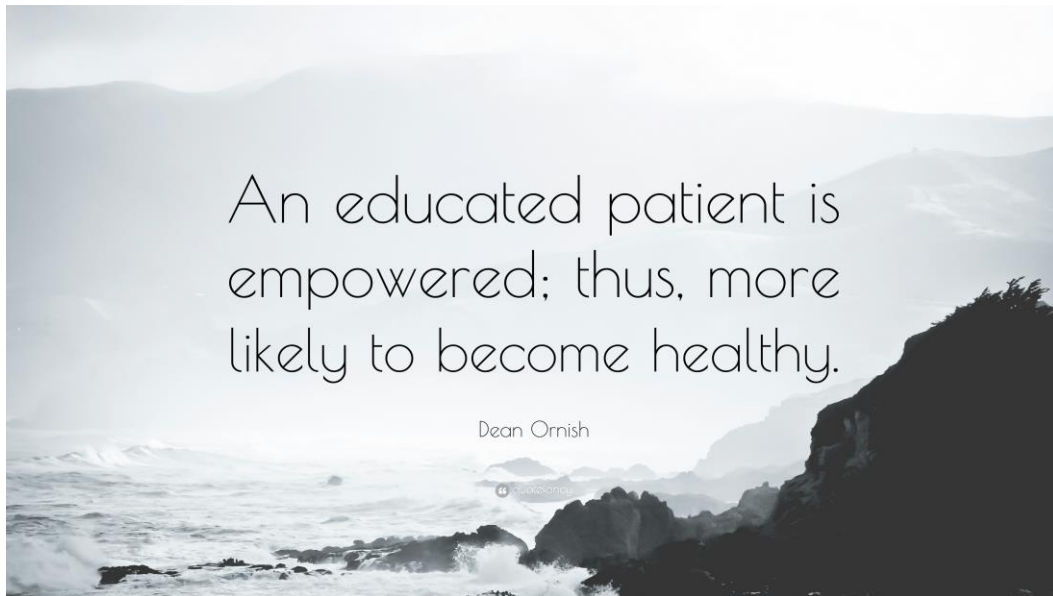
Recognize Limits of Emergency Medicine

~incomplete evaluations

~an ER assessment is typically only a snapshot attempt to identify main problem

~oftentimes, follow up care and further assessment are necessary (duPre, 2010)





“Given the important role that caregivers play in self-management support, insights into caregiver health literacy are critical, particularly if the caregiving role has high clinical demands, or the care recipient has low health literacy” (Yuen, Knight, Ricciardelli, & Burney 2018, p. e203)

More research is needed to understand what opportunities and needs exist for improving patient and caregiver health literacy skills and abilities.

In the meantime, let’s provide patients and caregivers with helpful, empowering information and resources.



Thank you!

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