HEALTH LITERACY AND OLDER ADULTS

RESHAPING THE LANDSCAPE

PROCEEDINGS OF A WORKSHOP

Joe Alper, *Rapporteur*

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

Health and Medicine Division

The National Academies of
SCIENCES · ENGINEERING · MEDICINE

THE NATIONAL ACADEMIES PRESS
Washington, DC
www.nap.edu

THE NATIONAL ACADEMIES PRESS 500 Fifth Street, NW Washington, DC 20001

This activity was supported by contracts between the National Academy of Sciences and Abbvie Inc.; Aetna Foundation; American Dental Association; Bristol-Myers Squibb; East Bay Community Foundation (Kaiser Permanente); Eli Lilly and Company; Health Literacy Media; Health Literacy Partners; Health Resources and Services Administration (HHSH25034011T); Humana; Institute for Healthcare Advancement; Merck Sharp & Dohme Corp.; National Library of Medicine; New York University Langone Medical Center; Northwell Health; Office of Disease Prevention and Health Promotion (HHSP23337043); Pfizer Inc.; and UnitedHealth Group. Any opinions, findings, conclusions, or recommendations expressed in this publication do not necessarily reflect the views of any organization or agency that provided support for the project.

International Standard Book Number-13: 978-0-309-47946-2
International Standard Book Number-10: 0-309-47946-0
Digital Object Identifier: https://doi.org/10.17226/25188

Additional copies of this publication are available for sale from the National Academies Press, 500 Fifth Street, NW, Keck 360, Washington, DC 20001; (800) 624-6242 or (202) 334-3313; http://www.nap.edu.

Printed in the United States of America

Suggested citation: National Academies of Sciences, Engineering, and Medicine. 2018. *Health literacy and older adults: Reshaping the landscape: Proceedings of a workshop*. Washington, DC: The National Academies Press. doi: https://doi.org/10.17226/25188.

The National Academies of

SCIENCES • ENGINEERING • MEDICINE

The **National Academy of Sciences** was established in 1863 by an Act of Congress, signed by President Lincoln, as a private, nongovernmental institution to advise the nation on issues related to science and technology. Members are elected by their peers for outstanding contributions to research. Dr. Marcia McNutt is president.

The **National Academy of Engineering** was established in 1964 under the charter of the National Academy of Sciences to bring the practices of engineering to advising the nation. Members are elected by their peers for extraordinary contributions to engineering. Dr. C. D. Mote, Jr., is president.

The **National Academy of Medicine** (formerly the Institute of Medicine) was established in 1970 under the charter of the National Academy of Sciences to advise the nation on medical and health issues. Members are elected by their peers for distinguished contributions to medicine and health. Dr. Victor J. Dzau is president.

The three Academies work together as the **National Academies of Sciences, Engineering, and Medicine** to provide independent, objective analysis and advice to the nation and conduct other activities to solve complex problems and inform public policy decisions. The National Academies also encourage education and research, recognize outstanding contributions to knowledge, and increase public understanding in matters of science, engineering, and medicine.

Learn more about the National Academies of Sciences, Engineering, and Medicine at **www.nationalacademies.org**.

The National Academies of
SCIENCES • ENGINEERING • MEDICINE

Consensus Study Reports published by the National Academies of Sciences, Engineering, and Medicine document the evidence-based consensus on the study's statement of task by an authoring committee of experts. Reports typically include findings, conclusions, and recommendations based on information gathered by the committee and the committee's deliberations. Each report has been subjected to a rigorous and independent peer-review process and it represents the position of the National Academies on the statement of task.

Proceedings published by the National Academies of Sciences, Engineering, and Medicine chronicle the presentations and discussions at a workshop, symposium, or other event convened by the National Academies. The statements and opinions contained in proceedings are those of the participants and are not endorsed by other participants, the planning committee, or the National Academies.

For information about other products and activities of the National Academies, please visit www.nationalacademies.org/about/whatwedo.

PLANNING COMMITTEE ON HEALTH LITERACY AND OLDER ADULTS: RESHAPING THE LANDSCAPE[1]

AMY K. CHESSER, Assistant Professor, Wichita State University
ANNA CHODOS, Assistant Professor, University of California, San Francisco, School of Medicine
DEIDRA C. CREWS, Associate Vice Chair for Diversity and Inclusion and Associate Professor of Medicine, Johns Hopkins University School of Medicine
LINDA HARRIS, Director, Division of Health Communication and eHealth, Office of Disease Prevention and Health Promotion, Department of Health and Human Services
SHANNAH KOSS, President, Koss on Care, LLC
TERRI ANN PARNELL, Principal and Founder, Health Literacy Partners
RIMA RUDD, Senior Lecturer on Health Literacy, Education, and Policy, Harvard T.H. Chan School of Public Health
YOLANDA TAYLOR BRIGNONI, Integrated Strategic Communications Director, AARP
JENNIFER WOLFF, Professor of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health

---

[1] The National Academies of Sciences, Engineering, and Medicine's planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published Proceedings of a Workshop rests with the workshop rapporteur and the institution.

ROUNDTABLE ON HEALTH LITERACY[1]

BERNARD M. ROSOF (*Chair*), Chief Executive Officer, Quality in Health Care Advisory Group, LLC; and Professor of Medicine, Donald and Barbara Zucker School of Medicine at Hofstra/ Northwell

ANNLOUISE R. ASSAF, Enterprise Benefit Risk Medical Director, Pfizer Inc.

SUZANNE BAKKEN, Alumni Professor of Nursing and Professor of Biomedical Informatics, Columbia University

AMY A. CLARK, Director, Cultivating Health Communities, Aetna Foundation

GEMIRALD P. DAUS, Public Health Analyst, Office of Health Equity, Health Resources and Services Administration

TERRY C. DAVIS, Professor of Medicine and Pediatrics, Louisiana State University Health Sciences Center

CHRISTOPHER DEZII, Director, Healthcare Quality and Performance Measures, Bristol-Myers Squibb

JENNIFER A. DILLAHA, Medical Director for Immunizations, Medical Advisor, Health Literacy and Communication, Arkansas Department of Health

JAMES DUHIG, Head, Risk Communication and Behavioral Systems, Office of Patient Safety, AbbVie Inc.

ALICIA FERNANDEZ, Professor of Clinical Medicine, Department of Medicine, Division of General Internal Medicine, University of California, San Francisco

LISA FITZPATRICK, Senior Medical Director, DC Department of Health Care Finance; and Professorial Lecturer, George Washington University Milken Institute School of Public Health

LORI K. HALL, Director, Health Literacy, Global Medical Strategy and Operations, Eli Lilly and Company

LINDA HARRIS, Director, Division of Health Communication and eHealth, Office of Disease Prevention and Health Promotion, Department of Health and Human Services

NICOLE HOLLAND, Assistant Professor and Director of Health Communication, Education, and Promotion, Tufts University School of Dental Medicine

JOAN KELLY, Chief Patient Experience Officer, New York University Langone Medical Center

---

[1] The National Academies of Sciences, Engineering, and Medicine's forums and roundtables do not issue, review, or approve individual documents. The responsibility for the published Proceedings of a Workshop rests with the workshop rapporteur and the institution.

ELLEN M. MARKMAN, Lewis M. Terman Professor of Psychology, Stanford University
MICHAEL M. McKEE, Assistant Professor of Family Medicine, University of Michigan Medical School
LAURIE MYERS, Global Health Literacy Director, Merck Sharp & Dohme Corp.
CATINA O'LEARY, President and Chief Executive Officer, Health Literacy Media
MICHAEL K. PAASCHE-ORLOW, Professor of Medicine, Boston University School of Medicine
TERRI ANN PARNELL, Principal and Founder, Health Literacy Partners
KIM PARSON, Strategic Consultant, Proactive Care Strategies, Humana
LINDSEY A. ROBINSON, Thirteenth District Trustee, American Dental Association
STEVEN RUSH, Director, Health Literacy Innovations, UnitedHealth Group
OLAYINKA SHIYANBOLA, Assistant Professor, Division of Social and Administrative Sciences, Univeristy of Wisconsin–Madison School of Pharmacy
VANESSA SIMONDS, Assistant Professor, Community Health, Montana State University
MICHAEL VILLAIRE, Chief Executive Officer, Institute for Healthcare Advancement
EARNESTINE WILLIS, Kellner Professor in Pediatrics, Medical College of Wisconsin
AMANDA J. WILSON, Head, National Network Coordinating Office, National Library of Medicine
MICHAEL S. WOLF, Professor, Medicine and Learning Sciences, Associate Division Chief, Research Division of General Internal Medicine, Feinberg School of Medicine, Northwestern University
WINSTON F. WONG, Medical Director, Disparities Improvement and Quality Initiatives, Kaiser Permanente

Health and Medicine Division Staff

LYLA M. HERNANDEZ, Senior Program Officer
MELISSA G. FRENCH, Program Officer
ALEXIS WOJTOWICZ, Senior Program Assistant
ROSE MARIE MARTINEZ, Senior Board Director, Board on Population Health and Public Health Practice

Reviewers

This Proceedings of a Workshop was reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the National Academies of Sciences, Engineering, and Medicine in making each published proceedings as sound as possible and to ensure that it meets the institutional standards for quality, objectivity, evidence, and responsiveness to the charge. The review comments and draft manuscript remain confidential to protect the integrity of the process.

We thank the following individuals for their review of this proceedings:

LILY CHU, International Association of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis
W. DANIEL HALE, Johns Hopkins Bayview Medical Center
TONY SARMIENTO, Silver Spring Village
LAURA TREJO, Los Angeles Department of Aging

Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the content of the proceedings nor did they see the final draft before its release. The review of this proceedings was overseen by **NANCY FUGATE WOODS,** University of Washington. She was responsible for making certain that an independent examination of this proceedings was carried out in accordance with standards of the National Academies and that all review comments were carefully considered. Responsibility for the final content rests entirely with the rapporteur and the National Academies.

Acknowledgments

The sponsors of the Roundtable on Health Literacy made it possible to plan and conduct the workshop on Health Literacy and Older Adults: Reshaping the Landscape, which this proceedings summarizes. Federal sponsors from the Department of Health and Human Services are the Health Resources and Services Administration; National Library of Medicine; and Office of Disease Prevention and Health Promotion. Nonfederal sponsorship was provided by AbbVie Inc.; Aetna Foundation; American Dental Association; Bristol-Myers Squibb; East Bay Community Foundation (Kaiser Permanente); Eli Lilly and Company; Health Literacy Media; Health Literacy Partners; Humana; Institute for Healthcare Advancement; Merck Sharp & Dohme Corp.; New York University Langone Medical Center; Northwell Health; Pfizer Inc.; and UnitedHealth Group.

The workshop presentations were interesting and stimulated much discussion, and the Roundtable on Health Literacy would like to thank each of the speakers and moderators for their time and effort. Speakers and moderators were Amy K. Chesser, Deidra Crews, Z. Colette Edwards, Susan Goodman, Lisa Gualtieri, Shannah Koss, Terri Ann Parnell, Bernard M. Rosof, Rima Rudd, Nora Super, Yolanda Taylor Brignoni, Stephen B. Thomas, Anne Tumlinson, Jennifer Wolff, and Mary Ann Zimmerman.

Contents

APPENDIXES

Box, Figures, and Table

BOX

FIGURES

TABLE

Acronyms and Abbreviations

AAA	Area Agency on Aging
BRFSS	Behavioral Risk Factor Surveillance System
EHR	electronic health record
HAIR	Health Advocates In-Reach and Research
HIPAA	Health Insurance Portability and Accountability Act
LTSS	long-term services and supports
n4a	National Association of Area Agencies on Aging
REALM	Rapid Estimate of Adult Literacy in Medicine
S-TOFHLA	Short Test of Functional Health Literacy in Adults
TOFHLA	Test of Functional Health Literacy in Adults

1

Introduction[1]

Adults age 65 and older[2] make up the fastest-growing segment of the U.S. population. The U.S. Census Bureau projects that between 2012 and 2050, the number of older adults will reach 83.7 million persons, nearly double the estimated population of 43.1 million in 2012, and account for 20.9 percent of the U.S. population.[3] At the same time, the complexity of health care delivery continues to grow, creating challenges that are magnified for older adults, given that age is one of the highest correlates of low health literacy (Baker et al., 2000; Kobayashi et al., 2016). As Bernard Rosof, chief executive officer of the Quality in Health Care Advisory Group, stated in his opening remarks, this creates a shared obligation between health care and the health care team to use the principles, tools, and practices of health literacy so that patients and families of older adults can more easily navigate discussions related to chronic disease, polypharmacy, long-term care, palliative care, insurance complexities, the social determinants of health, and other factors that create challenges for older adults, particularly among underserved populations nationwide. Given the importance of social determinants of health and the added health risks

---

[1] This section is based on the presentation by Bernard Rosof, chief executive officer of the Quality in Health Care Advisory Group, and his statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

[2] In this publication, the generic term "older adult" refers to someone age 65 and older unless specified otherwise.

[3] For more information, see www.census.gov/prod/2014pubs/p25-1140.pdf (accessed April 2, 2018).

associated with isolation in older populations, Rosof noted, health literacy in this context encompasses navigation and understanding the available community social services and supports in addition to clinical care.

To gain a better understanding of the health communication challenges among older adults and their professional and family caregivers and how those challenges affect the care older adults receive, the National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy convened this 1-day public workshop featuring presentations and discussions that examined the effect of low health literacy on the health of older adults.[4]

Rosof noted that the workshop's presentations and discussions were designed to meet four objectives:

1. Describe the health literacy challenges that older adults face as they try to maintain their health, their independence, and their place in the community.
2. Speak to how the dynamics of family and informal caregivers add a layer of complexity to the health literacy challenges with regard to determining individual needs and preferences.
3. Raise awareness of the changing needs of older adults, as well as the new and challenging language and systems they must deal with, including those in health and community services and technology.
4. Highlight strategies to bridge health literacy gaps that directly impact the health and quality of life for older adults.

ORGANIZATION OF THE PROCEEDINGS

The workshop (see Appendix A for the Workshop Agenda) was organized by an independent planning committee in accordance with the procedures of the National Academies. This publication summarizes the discussions that occurred throughout the workshop and highlights the key lessons presented, practical strategies, and the needs and opportunities for improving health literacy among older adults in the United States, as well as for their caregivers and family members (see Box 1-1 for the Statement of Task). Chapter 2 reviews the current landscape regarding health literacy in older adults. Chapter 3 discusses health literacy in the context of families and the community and how improved health literacy can reduce disparities in care and foster independence among older adults. Chapter 4 looks at how health care systems can use health literacy principles and tools to improve health system navigation, as well as how technology can be either

---

[4] The planning committee focused on English-speaking older adults living in the United States.

BOX 1-1
Statement of Task

An ad hoc committee will plan and conduct a 1-day public workshop that will feature invited presentations and discussion of health literacy and healthy aging. Potential areas of focus include the changing health needs of older adults, chronic disease and medication management, health communication challenges for older adults, health literacy needs and challenges for caregivers, and other topics related to health literacy for older people.

The committee will define the specific topics to be addressed, develop the agenda, and select and invite speakers and other participants. A proceedings of the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

a facilitator or a barrier for older adults. Chapter 5 recounts a moderated discussion about the day's presentations and presents the roundtable's reflections on the key lessons learned at this workshop.

In accordance with the policies of the National Academies, the workshop did not attempt to establish any conclusions or develop recommendations about needs and future directions, focusing instead on issues identified by the speakers and workshop participants. In addition, the organizing committee's role was limited to planning the workshop. This Proceedings of a Workshop was prepared by workshop rapporteur Joe Alper as a factual summary of what occurred at the workshop.

2

The Personal Landscape

The workshop's first panel session featured two presentations that provided an overview of the health literacy landscape from the perspective of older adults. To set the stage for the day's discussions, Mary Ann Zimmerman, founding director of Silver Spring Village,[1] offered a personal perspective on how health literacy affects her interactions with the health care system as an older adult. Amy Chesser, assistant professor in the Division of Aging Studies in the Department of Public Health Sciences at Wichita State University, then reviewed what research has been found regarding health literacy and older adults. An open discussion moderated by Shannah Koss, president of Koss on Care, LLC, followed the two talks.

A PERSONAL PERSPECTIVE[2]

Introducing herself as the workshop's "official old person," Mary Ann Zimmerman began her presentation by noting that she is an only child who has no family caregivers whose parents taught her to be independent and not assume that anybody would take care of her. "That is something I still

---

[1] Silver Spring Village is a nonprofit organization, the mission of which is to build a supportive network of neighbors helping neighbors remain in their homes as they age. Most of the Village service area encompasses the commercial core of Silver Spring, Maryland. For more information, see http://silverspringvillage.org/content.aspx?page_id=0&club_id=902719 (accessed June 18, 2018).

[2] This section is based on the presentation by Mary Ann Zimmerman, founding director of Silver Spring Village, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

have in my head and still try to practice," said Zimmerman. One piece of taking care of herself, she added, was dealing with the importance of health care and health insurance. She also recalled how her parents were each other's caregivers as they aged. Like many seniors, they wanted to age in place, which is what Zimmerman is trying to do today. Her parents were involved with their local Area Agency on Aging (AAA) programs in their hometown of Jackson, Michigan, and they were active in their community. As they were aging, her parents looked at the cost of assisted living facilities, which were rather new in those days, and concluded that they could stay in their home with the help of Michigan's Region 2 AAA programs and other offerings in their community, and care for one another. For Zimmerman, the experience of watching her parents successfully age in their community was a prelude to her involvement with the village movement today.

After having spent the first half of her working life as a civil engineer, Zimmerman left the technical world and worked as an independent consultant on organizational development. Today, she lives near the metro station in downtown Silver Spring, a Washington, DC, suburb, which enables her to avoid using a car. When she transitioned from having a "regular" job as a civil engineer to be an independent consultant, getting health insurance was not easy, particularly because she had a preexisting condition. Today, she is on Medicare and supplemental insurance and considers herself generally healthy, aside from the fact that she is undergoing chemotherapy for inoperable colon cancer and has spinal stenosis, non-diabetic peripheral neuropathy, some osteoporosis, and glaucoma.

Looking back over the past 4 months, she has averaged seven or eight visits per month with her nine doctors and support staff, which she said requires spending a great deal of time in the health care system while trying to carry on with daily life. Her biggest frustration has been with the hospital system, which she said is nebulous in some ways. Not all of her doctors, for example, are part of the hospital system, and those that are not have some privileges, but not all, including access to the hospital's electronic health record (EHR) system. "So, plenty of confusion, difficulty communicating, and duplication of effort," said Zimmerman. Another seemingly trivial frustration has been that the hospital system had her listed under three different names—Mary Ann, which is her real name, along with Maryann, Mary A., and Maryanne—and the records for these different versions of herself were not connected. The solution, she said, was to go by her birthday and be assigned a number that linked the three incomplete EHRs regardless of how someone enters her name into the medical record.

Another frustration has been with support organizations. Two hospitals in the same health system, said Zimmerman, work with a different visiting nurse group, causing challenges. An issue arose when a new medical supply company bought the one that had been providing her with good service for the infusion supplies that enable her to undergo most of her 48-hour chemotherapy regimen at home. The confusion that resulted when the supplier changed caused complications with her chemotherapy, but she and her health system are working on a solution. She noted that the EHR system and portals could help with service coordination, but instead, the multiple EHRs and portals vary in their functionality and ability to communicate. In addition, the information that she enters and that her staff and doctors enter do not always agree. Her solution has been to make hard copies of everything related to her conditions and care, but because those records now fill a couple of file drawers, she cannot bring everything in paper form to an appointment with one of her doctors.

A key solution to her issues has been her involvement with Silver Spring Village and the notetaking services it offers to help her deal with her own medical records and interactions with the medical system. Clinical staff have also been lifesavers by helping Zimmerman navigate through or around roadblocks. In particular, her primary care physician has served as a sounding board/second opinion and has helped lead her to the right places in the health care system and make good decisions. She also credited her specialists and their staffs for being open with her and helpful in dealing with various challenges in accessing the services and care she needs. To help her judge how well her clinicians help her, she asks herself four questions:

1. How well do the doctors and their staff communicate internally with other doctors and with her?
2. How well do they explain things and take follow-up actions? Can they find 5 extra minutes when something is not working right to help fix it or does she have to set another appointment?
3. How easy are they to contact?
4. What is the culture of their institution and the attitude of their supervisors in working with the patients and their goals?

Zimmerman said she has concluded that there is only so much extended family can do to help her—she does have relatives who live in other parts of the country—and that the same can probably be said for close family. She noted that it is easy to become overwhelmed by the extent of the interactions with the health care system. "I like to think my brain is usually functioning, and it is certainly there, but there is way too much information," she said, referring to most of the materials she is given by her clinicians and the health care system. Often, she said, she can find information to clarify a confusing point, but then finding that information a second time can be a challenge. On the other hand, being asked the same question repeatedly at every clinical encounter can be equally frustrating. No matter how many times she is asked what her parents died of some 25 years ago, the answer already recorded in her EHR is going to be that she does not remember.

Concluding her presentation, Zimmerman said that while she enjoys life 80 percent of the time, she does on occasion yell and scream out of frustration. While she considers herself independent, she acknowledges that her definition of "independent" has changed over time—what helps, she said, is that she has friends whom she trusts and who understand how she defines having a good life.

WHAT DO WE KNOW ABOUT HEALTH LITERACY AND OLDER ADULTS?[3]

To explain how she conceptualized research on health literacy and older adults, Amy Chesser said she first looked to the literature to see if there are solid definitions of health literacy and older adults. She then looked for and validated reliable survey or measuring instruments and health literacy interventions for older adults. Although there are at least 17 definitions of "health literacy" in the peer-reviewed literature (Sorensen et al., 2012), the definition she used was "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (IOM, 2004, p. 4) because it seems to include the main constructs of the other definitions.

According to the 2003 National Assessment of Adult Literacy, only 3 percent of older adults were proficient with health literacy skills.[4] Chesser said there are age-related changes that contribute to the decline of health literacy over time, including a decline in cognitive abilities, the development of physical impairments such as hearing and vision loss, psychosocial issues, and a sense of embarrassment and shame. The good news, she said, is that she and some colleagues are hoping to collaborate and create information about health literacy at the population level. The Health Literacy Regional Network to which she belongs started with investigators in Arkansas, Kansas, Missouri, and Nebraska and has since spread to Georgia, Iowa, Kentucky, Minnesota, and Wisconsin. Chesser and her collaborators have worked with the Centers for Disease Control and Prevention to develop a three-question screener for health literacy that is available for all states as part of the Behavioral Risk Factor Surveillance System (BRFSS) survey. Survey results from Kansas in 2014 found that 31.4 percent of the state's

---

[3] This section is based on the presentation by Amy Chesser, assistant professor in the Division of Aging Studies at Wichita State University, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

[4] For more information, see nces.ed.gov/naal (accessed April 2, 2018).

residents had high health literacy, 61.1 percent had moderate health literacy, and 7.5 percent had low health literacy.

Older adults, said Chesser, are typically grouped together into a category of 65 years and older, a number set arbitrarily by researchers that has increased over the years from 60 to 62 and now 65. Several investigators have begun dividing older adults into two groups, each containing three subgroups: the young-old (ages 60 to 69), middle-old (ages 70 to 79), and very old (ages 80 and older) (Forman et al., 1992); or the young-old (ages 65 to 74), middle-old (ages 75 to 84), and oldest-old (ages 85 and older) (Zizza et al., 2009). There are also a variety of measuring tools for health literacy available. Typically, she said, people use the Rapid Estimate of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy in Adults (TOFHLA), and Short Test of Functional Health Literacy in Adults (S-TOFHLA) for measuring health literacy in older adults. One tool that is gaining recognition as a close proxy for health literacy is the Single Item Screener, which asks how confident people are in filling out medical forms by themselves (Morris et al., 2006).

Chesser noted that as of 2014, there were no studies in the literature that reported validating any tool for assessing health literacy in older adults (Chesser et al., 2016). She and her colleagues used the Single Item Screener and S-TOFHLA to see how they compared and had mixed results, though the study included only 69 individuals. “Validation and standardization of tools could be key for integrated health literacy screening in the primary care setting,” she said.

Merriam-Webster’s Dictionary defines ageism as prejudice of discrimination against a particular age group and especially the elderly, and Chesser used this definition to search PubMed for U.S. studies on ageism. Of the 38 articles she and her colleagues found, the largest number dealt with teaching ageism to or assessing ageism for nursing, physical therapy, and medical students. A second, much smaller grouping discussed adults discriminating against older adults. A third group, which Chesser said she was most curious about, examined within-group ageism among older adults, and when she delved into this literature, she found it was mostly about death theory of some sort. The bottom line here, she said, is that the field of health literacy and ageism is wide open for research.

Recently, Chesser and her team completed a pilot study on ageism and knowledge to investigate whether a relationship exists between the level of knowledge of aging and ageist attitudes. The study recruited a convenience sample of 123 students enrolled at Wichita State University and used two reliable and validated tools called the Fraboni Scale of Ageism and the Palmore Facts on Aging Quiz. The mostly female, mostly white student participants, more than half of whom were seniors in undergraduate studies, had an overall low score on knowledge, but an overall neutral attitude toward older adults. "Our results indicated a significant negative relationship between knowledge and ageism," adding that greater knowledge about aging correlated with positive attitudes about the subject *and* that attitudes grew even more positive as the age of the surveyed students increased.

Chesser referred to what she called a landmark study from 2000 that administered the S-TOFHLA and Mini Mental Status Exam, a measure of cognition, on a sample of more than 2,000 participants (Baker et al., 2002). The important finding from this study was that the S-TOFHLA scores declined for every year of increase in age. Even after adjusting the results for scores on the Mini Mental Status Exam, health literacy decreased with every increased year in age. Differences in newspaper reading frequency, visual acuity, chronic medical conditions, and health status did not explain the lower literacy of older participants, Chesser added.

She and her colleagues at Wichita State have conducted two studies in this area. The first study used BRFSS data on cognition collected by the State of Kansas Health Department and a three-question screening tool for health literacy. "What we found was that high health literacy or moderate health literacy after the age of 65 decreases with each subsequent year of life," said Chesser, confirming the results of the study she had just mentioned. Cognitive decline was among the single most important predictors of health literacy in older adults, she added. Her team also updated its systematic literature review (Kopera-Frye, 2016) and found 1 textbook and 125 published articles (see Table 2-1) that contained the terms "health literacy" and either "older adults," "elderly," "oldest-old," or "geriatrics." None of the identified publications included the term "oldest-old," and only 29 came from the United States. After perusing each of the articles, only 20 studies included adults ages 65 and older. Of those, further screening eliminated another 10 articles from consideration.

TABLE 2-1 Results of a Literature Review on Health Literacy and Older Adults

Years	Number of Publications
2000–2005	3 articles
2006–2010	26 articles 1 book[a]
2011–2015	59 articles
2016–2017	37 articles
TOTAL	126 publications

[a] Brougham, 2009.

SOURCE: Adapted from a presentation by Amy Chesser at the workshop on Health Literacy and Older Adults on March 13, 2018.

Of the 10 articles remaining, none tested interventions with participants over age 65, and none broke the analysis into the three groups for older adults. Most of the articles that passed practical and methodological screening were assessment studies, said Chesser. One case study (Cutilli and Schaefer, 2011) did test an intervention in a geriatric population, she added. As a final note, she said her team found more than 190,000 articles on health literacy. "If you look at the health literacy in older adults in comparison to health literacy in general, there is a great deal of work to be done," she said.

DISCUSSION

Koss began the discussion by asking Zimmerman and Chesser to talk about the one thing they would change about the older adult communication experience with health care and the community. Zimmerman said that automated phone systems with long and multiple menus of buttons to push and long wait times before reaching a live human are a particularly vexing problem for her. Chesser, from her experience helping her older parents navigate their way through the health system, wished that health care providers would slow down when talking to older adults and meet the patients where they are, not where the provider is.

Koss then asked if there are models for bringing the range of perspectives in the community and health care system together, and if there is a need to balance a community model and medical model perspective. Zimmerman replied that for her, no one size fits all, particularly regarding the use of big data. When big data are used today, they appear to make broader generalizations about care rather than to hone in on the needs of the individual and fine tune care that addresses individual differences. On the community side, she noted that the primary focus of the village movement is to help neighbors age in place. By doing that, she said, the village model helps reduce resource needs and costs in other areas. A model Chesser said she finds attractive is the patient-centered medical home model that integrates patient-centered medical neighborhoods and community services for older adults. In her mind, combining that model with a health literate health care organization would have the potential to optimize services for older adults.

Commenting on Zimmerman's emphasis on remaining independent, Catina O'Leary from Health Literacy Media said she appreciated the connections Zimmerman made among health literacy, empowerment, and independence. O'Leary then asked Chesser if she had any ideas for promising interventions based on knowing that cognitive decline drives much of the health literacy challenges for older adults. Chesser said the key in her mind is for clinicians to slow down when they are providing information, even when using universal precautions or teach back. Having clear communication at the pace of the person rather than just moving through information quickly would, in her opinion, help compensate for cognitive decline. Zimmerman commented that the social workers she deals with, such as those at the infusion center where she receives part of her chemotherapy, are good at working at the individual's pace and connecting with each person by listening to and learning about what is important to each individual.

Kim Parson from Humana asked Zimmerman how she identifies trusted sources of health information. Zimmerman replied that her primary care physician has been a major source of information, in part because he likes to understand a wide range of subjects. She explained that her primary care physician knows she likes to read, and he refers her to sources of information that he knows she will be able to understand. He is also available almost any time of the day by phone or email, which she values greatly. She noted that she trusts her doctors as sources for information because they talk to each other and talk to her in understandable English. Other trusted sources of information for her have been the chemotherapy center, the National Cancer Institute, and several professional organizations. For dietary information, she uses Google.

Michael Wolf from the Feinberg School of Medicine at Northwestern University said he and his colleagues have been conducting a cohort study for the past 10 years on adults who were 55 at the start of the study. This study has focused on how older adults perform real-world skills rather than how well they perform on one of the standardized tests, such as TOFHLA. The goal of this project, said Wolf, is to study both what happens to health literacy skills with age and what people do to compensate for any diminished skills, particularly as their cognition becomes distracted by dealing with multiple chronic conditions and the various physical challenges associated with aging. Given what he has observed, he does not believe that teach back or communication skills training will help, and that it will be necessary to leverage technology in some way to help communicate more effectively with older adults. "We need to figure out how to integrate or have interoperability among health care systems and health communication tools," said Wolf.

Zimmerman responded that one thing she has found immensely helpful is a notetaking service that Silver Spring Village offers. It is a non-professional service, although the notetakers do receive training. A notetaker accompanies an individual to a health care appointment. Not only does this service provide Zimmerman with a written recap of what was discussed at the appointment, but it also helps her prepare to meet with the doctor, to figure out ahead of time what she wants to discuss with her physician, and to commit that information to paper. This process, she said, has made meetings with her physicians more productive. Chesser said she would like to see the EHR contain relevant links to trusted sources of information that an individual could go to after a clinical visit and learn more about what was said at the visit.

Bernard Rosof from Quality in Health Care Advisory Group remarked that the social determinants of health—education, housing, transportation, food, neighborhood, and community resources—influence health literacy and may be more important than the clinical services that are delivered to the health of older adults. Zimmerman replied that access to assorted services in the community can help individuals interact more effectively with the health care system and get the information they need. Chesser agreed that the items on the list Rosof mentioned, what she calls life, are more important than a clinical encounter, but how to measure their effect on health literacy is a challenge in that it would require community research, longitudinal studies, and even community-based participatory research. "All of those things that take dollars and they take extra planning and you do not have a captured cohort of any kind," said Chesser. That said, she noted that she thinks it is more important to measure the effect of life than to measure the effect of the clinical encounter. Stephen Thomas, professor of health services administration and director of the Maryland Center for Health Equity at the University of Maryland, College Park, School of Public Health, suggested that another factor may be playing a role in communication issues facing older adults: empathy decline on the part of clinicians. In light of this, he emphasized that "all the burden cannot be placed on the patient and the neighborhoods in which they live."

Rima Rudd from the Harvard T.H. Chan School of Public Health challenged the notion that cognitive decline is the strongest predictor of health literacy. She noted that the first study that linked cognitive decline to literacy (Baker et al., 2000) was flawed in that it timed people's responses. When elders took the TOFHLA instrument untimed, they did much better, she said. "There are mitigating issues and I would just be very slow in absolutely linking cognitive decline to lower health literacy," said Rudd. Koss added that she has observed the same when assessing young adults with attention deficit hyperactivity disorder.

Linda Harris from the Division of Health Communication and eHealth at the Office of Disease Prevention and Health Promotion asked Zimmerman if there are questions that her providers should be asking her to help them prepare to work and communicate more efficiently and effectively with her. Zimmerman replied that her doctors have spent time trying to understand what is important to her and what she wants to get out of her treatment. She noted that her physicians have been good about not using overly technical terms with her and referring her to health literate information that she might find useful. They have also been doing their own evaluation, by listening to her, of how much information at what level of technical detail she wants and adapting their communications based on those observations. She again mentioned the notetaker who accompanies her and said the notetaker helps ensure that she and her doctors are communicating effectively.

Cindy Brach from the Agency for Healthcare Research and Quality noted that she and a colleague, Cynthia Baur, director of the Horowitz Center for Health Literacy at the University of Maryland School of Public Health, created an issue brief on health literacy that did break down the population over age 75. In the 65- to 75-year-old category, 23 percent of the individuals surveyed scored in the "below basic" category and 28 percent were in the "basic" category. In the older than 75 group, 39 percent scored in the "below basic" group and 31 percent fell in the "basic" category. "I get very disheartened because we have talked in the roundtable about the mismatch between the demands and the skills, and I think in this population it is just so striking how far we are from making those match," said Brach. She added that organizations such as Silver Spring Village represent a way of filling that gap between demands and skills with an array of volunteers. Zimmerman responded that Silver Spring Village decided to be driven by volunteers, but there is some concern within this organization that the needs of the village members will outpace the ability to meet those needs as the members age. That said, she suspects that technology will play a bigger role in providing services in the future given that the 50-year-old members are much more comfortable with technology than are older members such as herself.

Anthony Sarmiento, president of Silver Spring Village, noted there are 250 to 300 similar villages around the country that are part of the Village to Village Network. He added that there is tremendous variation among them in terms of organization, capacity, and number of members. What they all share is the support they provide for older adults that helps them remain in place in their communities and that they rely, at least in part, on member dues.[5] Given the latter, each village's ability to serve its members indicates the cumulative disadvantage or advantage of various neighborhoods. The villages, he said, are largely white and middle class, with fewer villages in rural communities or disadvantaged neighborhoods. One challenge facing the Village to Village Network is whether it can sustain the villages in communities in which the members are either dispersed or have fewer resources.

Sarmiento then noted that the FrameWorks Institute has been doing research and published three reports emphasizing the importance of challenging the internalized ageism among older adults themselves (Lindland et al., 2015; O'Neil and Haydon, 2015; Sweetland et al., 2017). Considering this body of work and other reports, like the Organisation for Economic Co-operation and Development's Programme for the International Assess-

---

[5] For more information about the Village to Village Network and its operations, see www.vtvnetwork.org (accessed June 18, 2018).

ment for Adult Competencies' Survey of Adult Skills, he wondered if this type of research could inform work on health literacy in older adults (Paccagnella, 2016). He added that despite the advances in knowledge that such research has produced, adult education programs struggle to best serve older adults.

3

The Family and Community Landscape

The workshop's second panel session featured three speakers. Jennifer Wolff, professor of health policy and management at the Johns Hopkins Bloomberg School of Public Health, addressed how adults and caregivers need to have difficult conversations to make important decisions. Stephen Thomas, professor of health services administration and director of the Maryland Center for Health Equity at the University of Maryland, College Park, then spoke about how health literacy can be a tool for easing disparities among vulnerable older adults. In the session's final presentation, Nora Super, director of the Aging and Disability Business Institute of the National Association of Area Agencies on Aging, discussed community living and independence for older adults. An open discussion moderated by Terri Ann Parnell, principal and founder of Health Literacy Partners, followed the three presentations.

GIVING VOICE TO OLDER ADULTS AND CAREGIVERS: DIFFICULT CONVERSATIONS AND DECISIONS[1]

Jennifer Wolff began her presentation by discussing the broader context of population aging, noting that population aging is a global phenomenon, not just a demographic trend affecting the United States. Today, for the first time in history, there are more individuals aged 65 and older than there are

---

[1] This section is based on the presentation by Jennifer Wolff, professor of health policy and management at the Johns Hopkins Bloomberg School of Public Health, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

children under age 5 (see Figure 3-1), and the population of older adults is known for its heterogeneity, she added. "I want to emphasize that many older adults have very high health literacy and continue to function at high levels in all facets of life, from academics to business to public service and politics," said Wolff.

Despite the promise of more years and good health, Wolff said the reality is that most individuals do accumulate age-related deficits, particularly as they enter their 8th, 9th, and 10th decade of life. For example, the numbers of Americans with Alzheimer's disease and related dementias is expected to roughly triple over the coming 30 years from about 5 million Americans today to 14 million by 2050, driven largely by the aging of the baby boomers into very old ages. "How we as a society plan to meet the needs of the growing numbers of older Americans with complex health needs and disabilities in the decades to come is an important issue that will only become more pressing in the coming years," said Wolff.

Although heterogeneity is the defining feature of older adults as a population, they are at greater risk on average for being less equipped to successfully navigate health system demands, explained Wolff. As a cohort, older adults tend to be less educated than working-age adults and are less likely to have technology experience and the skills and access to a computer

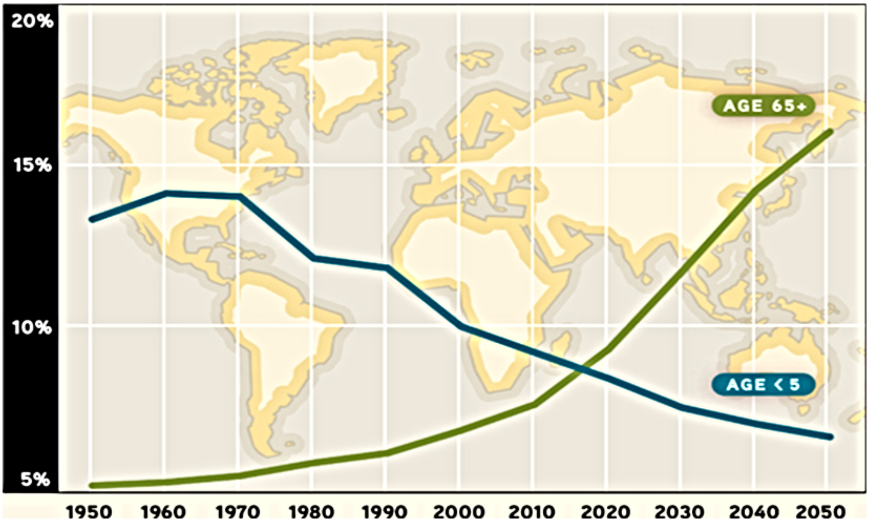

FIGURE 3-1 Population aging is a global phenomenon.
SOURCES: As presented by Jennifer Wolff at the workshop on Health Literacy and Older Adults on March 13, 2018; UN DESA, 2005.

or a mobile device. At the same time, they are at greater risk for age-related physiologic impairments that affect cognitive, hearing, and visual function in ways that leave them less able to participate actively in verbal dialogue, as well as to attain and process information from print content. Wolff said,

> Because older adults are at higher risk of low health literacy, they in many ways face double or even triple jeopardy in that they are less able to attain and process information to make appropriate health decisions while confronting a broader range of complex health decisions that bring them into frequent contact with the care delivery system.

Older adults also face a health insurance environment that is more complex than for typical working-age adults, she added. Citing a 2006 paper (Hanoch and Rice, 2006) that argues that Medicare beneficiaries, in the aftermath of the introduction of the Medicare Part D benefit, are faced with too many choices, she noted that income and eligibility intersect in a range of highly complex decisions that can hamper rational decision making, particularly among individuals who have lower educational attainment or cognitive impairment (Kuye et al., 2013).

Although low health literacy can affect an important but relatively narrow set of decisions related to enrollment in a health insurance plan, the adequacy of health literacy does affect a much broader range of decisions, said Wolff. These many decisions include routine daily activities, such as when and how to access appropriate and timely medical care, knowing and understanding treatments and adhering to them, and accessing publicly available benefits and community service. Low health literacy can make it difficult for older adults to hire and fire direct care workers who can help them manage functional impairments and to prepare for future long-term care and medical needs in the event of incapacity by purchasing private long-term care insurance plans or engaging in advanced care planning.

Shifting gears, Wolff addressed the role that families often play in bridging health literacy deficits. Citing the Institute of Medicine report *Retooling for an Aging America* (IOM, 2008), Wolff pointed out that family caregivers typically fall into that role accidentally and without any formal training. The report, she said, contrasts the family caregiver workforce with the health professional workforce, which is well educated and credentialed to function in a narrower scope of practice and typically in settings specifically intended for care delivery. The more recent National Academies report *Families Caring for an Aging America* (NASEM, 2016) makes a number of important recommendations that call for specific research, policy, and practice change to support a shift toward family-centered care. Some of these recommendations, she said, may be relevant to the roundtable's deliberations.

One major finding from the latter report is that family-centered care is the reality in which many older adults manage their health. “We know, for example, that two-thirds of older adults with disabilities manage their health in the community with the help of family caregivers,” said Wolff, who was a member of the committee that authored the report. She and her colleagues have found that about 40 percent of older adults regularly attend medical appointments with a family or other unpaid companion (Wolff and Roter, 2008, 2011; Wolff and Spillman, 2014; Wolff et al., 2012). These adults, she said, tend to be sicker, have a lower education level, and are more likely to have cognitive impairment. Family members are not present just at a single visit, but tend to be involved consistently over time, which she said speaks to the role that family members play in coordinating care. Her research, she said, showed that the roles family members play are highly varied and can both benefit as well as detract from the quality of communication (Wolff and Roter, 2012; Wolff et al., 2014, 2015, 2017b). “For example, we know that when older adults with lower mental health function attend medical visits with a family member, those visits tend to be shorter and there is less discussion of psychosocial issues,” said Wolff.

In one study, she and a colleague asked about older adults’ engagement in health care activities and how they prefer to involve both doctors as well as family members and friends in medical decisions (Wolff and Boyd, 2015). They found that more than two-thirds of older adults reported managing their health independently, nearly 20 percent co-managed their health with family or friends, and 11 percent reported delegating management of their health to family or others (see Figure 3-2). For each of these three groups, Wolff and her colleague examined preferences for making medical decisions independently. More than three-quarters of older adults who self-manage their health report making medical decisions independently, whereas less than half of older adults who report co-managing their health or delegating their health management activities to others make decisions independently. Wolff said,

> Collectively, these data speak to the heterogeneity of older adults and support the notion that respecting older adults’ preferences mean predominantly different things to different people. For some, it means respecting patients’ autonomy. For others, it means either engaging families collaboratively or allowing families to make decisions on behalf of the older adult.

One of the major conclusions of *Families Caring for an Aging America* was that there are numerous challenges to providing structural support for family caregivers and care delivery, said Wolff. For example, the traditional entrenched systems that govern financing and delivery of services are not well aligned to support family caregivers. In addition, the bioethical and

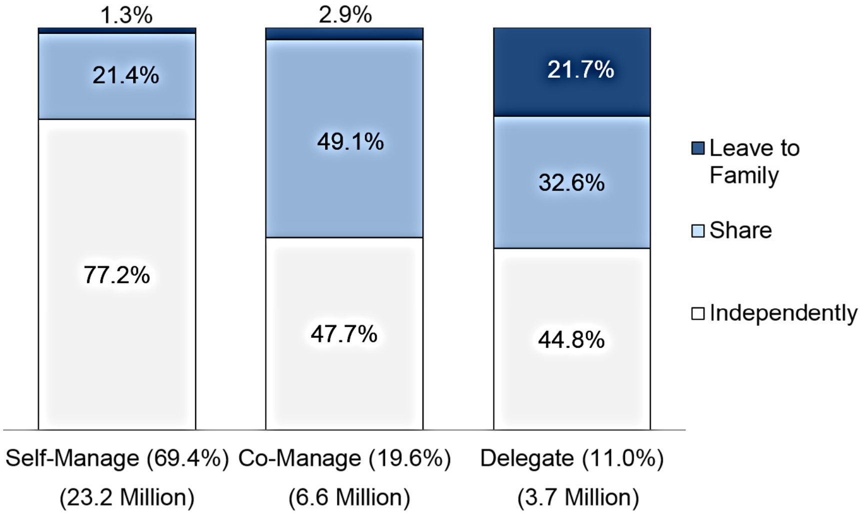

FIGURE 3-2 The approach older adults take to managing their health and decision-making preferences with family.
SOURCES: As presented by Jennifer Wolff at the workshop on Health Literacy and Older Adults on March 13, 2018; Wolff and Boyd, 2015.

legal regulatory frameworks that prioritize patient privacy and the protection of personal health information often impede access for family members despite the fact that it may be appropriate and beneficial when they are involved in coordination of care or managing medications or prescribed treatments for older adults in the community, she added. Moreover, when providers are formulating care plans that will require assistance in bridging deficits in physical or cognitive function, family members typically are not involved in those discussions. “As a result,” said Wolff, “the caregiver’s ability or knowledge to manage care is of questionable veracity or simply not asked for.”

The lack of a defined role for family members in care delivery in both face-to-face and electronic interactions often leaves them in an adversarial position with providers when it comes to advocating on the behalf of a patient, having a voice in care delivery, or being able to access information needed to manage care effectively. To help remedy this situation, Wolff and her colleagues have been iteratively developing and testing a patient/family agenda-setting checklist that is meant to be completed in the waiting room in advance of a medical encounter. The strategy, she explained, is predicated on the idea that these family members, or companions, are motivated to support patients during medical visits, but they may not know about the patient's concerns about the encounter as well as the patient's preferences for communication assistance.

The checklist takes the patient and family through two different activities designed to get them on the same page by aligning their perspectives on the agenda for the visit and clarifying the role of the companion in the visit. A pilot study, which excluded older adults with significant cognitive impairment, found that this approach was feasible, acceptable, and led to improvements in the patient-centeredness of care from coded audio tapes of medical visits (Wolff et al., 2014). A subsequent study, just completed, focused on older adults with cognitive impairment in primary care and also found promising results. Overwhelmingly, said Wolff, patients wanted family members to play an active role in communicating during the visit. The study found that patients' and families' concerns for their visit sometimes aligned, but sometimes did not. Patients, she said, were more concerned about memory problems and trouble concentrating or making decisions, while families were more concerned about bladder or bowel problems and planning for serious illness or progression of current illness.

Wolff concluded her presentation by commenting on strategies for engaging families in electronic communication through a consumer-oriented patient portal. As Zimmerman mentioned in the first panel, electronic interactions are increasingly becoming a mainstream mode of communication, but older adults often do not have enough technology skills and access to technology to be able to engage in electronic interactions. There are several reasons, however, that engaging families through the patient portal could be beneficial in terms of capturing and respecting patients' preferences for involving family in terms of engaging family, she said. Many EHR vendors even offer the capacity to allow patients to enroll family care partners and to provide them with their own identity credentials.

In studies conducted in partnership with the Geisinger Health System, Wolff and her colleagues surveyed Geisinger patients who had registered for the patient portal and had shared access with a family member or friend. They found that more than a decade after this functionality became available, less than 1 percent of adult patients had shared access to their patient portal account with a family member or friend (Wolff et al., 2016b). Patients' motivations for sharing access varied widely by age, said Wolff, with the older the individuals, the more likely the reason for sharing access was that the patients themselves did not use a computer (see Figure 3-3). Older individuals were also more likely to report that the care partner helped them to manage their health (Wolff et al., 2016a). Wolff and her colleagues surveyed care partners and found that they were far less likely to be suspected of having low health literacy (Wolff et al., 2017a). In general, care partners had more education, higher levels of Internet use, and more regular use of the patient portal (see Figure 3-4).

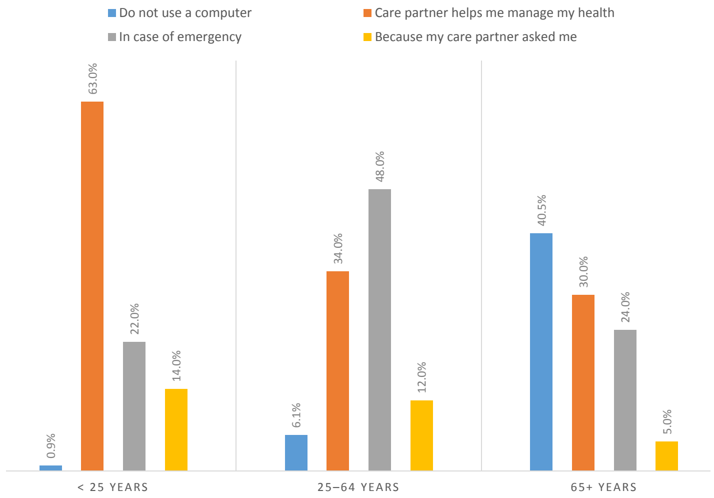

FIGURE 3-3 Patient motivations for sharing access to the patient portal of an integrated health system.
SOURCES: Adapted from a presentation by Jennifer Wolff at the workshop on Health Literacy and Older Adults on March 13, 2018; Wolff et al., 2016a.

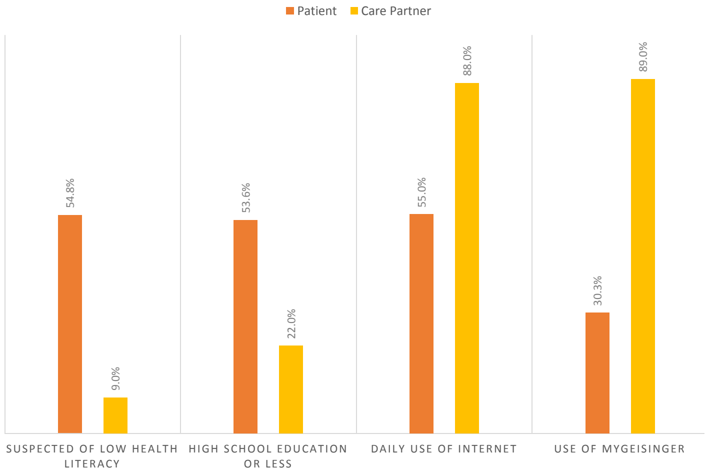

FIGURE 3-4 Comparing patients and their care partners.
SOURCES: Adapted from a presentation by Jennifer Wolff at the workshop on Health Literacy and Older Adults on March 13, 2018; Wolff et al., 2017a.

In summary, Wolff said that older adults are best characterized by heterogeneity. They vary widely in health literacy, and many 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 of older adults are notably absent, she said, but engaging family may hold promise as a strategy to bridge health literacy challenges in older adults' face-to-face encounters and electronic interactions.

HEALTH LITERACY AS A TOOL TO EASE DISPARITIES AMONG VULNERABLE OLDER ADULTS[2]

"Institutional commitment matters. It cannot be lip service," said Stephen Thomas as he began his presentation. "The people we serve are tired of being studied because they are still suffering. That is my message to all of us investigators here. It is time to start taking action." Health literacy, he added, should not be talked about without doing so in the context of the social determinants of health. The same is true of age, he said. "Age must be contextualized." Thomas continued:

> Our aim here is to move beyond a biomedical model to address the underlying drivers of these disparities, address issues such as breaking the cycle of poverty, increase access to quality care, eliminate environmental hazards in homes and neighborhoods, and implement interventions that have been tailored to the very communities we are trying to reach.

In his opinion, everyone attending the workshop should be ashamed and sad that so much of the accumulated research has not been implemented to address health disparities, and they should be angry at the decline of empathy in the health system. "There is something wrong in our system when we have lost the 'caring' part of care giving," said Thomas.

According to Healthy People 2020, a health disparity is a "particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage."[3] This difference, said Thomas, is often caused by something such as systemic discrimination. The flip side of health disparity is health equity, which again, according to Healthy People

---

[2] This section is based on the presentation by Stephen Thomas, professor of health services administration and director of the Maryland Center for Health Equity at the University of Maryland School of Public Health, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

[3] For more information, see www.healthypeople.gov/2020/about/foundation-health-measures/disparities (accessed April 3, 2018).

2020, is "the attainment of the highest level of health for all people."[4] It is unfortunate, he added, that the highest attainable level in the United States is not the best in the world. "We should be ashamed about that, too," said Thomas.

History matters, Thomas said, and these issues of health literacy and access to care have been present throughout the history of America, especially for African Americans. Booker T. Washington was the first to recognize that African Americans had to take charge of their own health, and from 1915 to 1951, he launched the National Negro Health Movement, which in the 1930s became the federal Office of Negro Health Works. In 1951, in the name of integration, the office was decommissioned, but in 1985, the Secretary of Health and Human Services created the Office of Minority Health with what Thomas said was "almost amnesia to the success of the Negro Health Movement." He noted that many African Americans, not long out of slavery and still hampered by Jim Crow laws, could not read, but this movement worked because of the creative methods used to engage the population. "This experience should be harvested for what we should be doing today," said Thomas.

Underlying health disparities, Thomas said, is an issue of trust in the medical profession, which is to be expected given the negative African American experience with the health care profession, including the Tuskegee Syphilis Study, among others. The Tuskegee Syphilis Study used sophisticated plain-language methods, not to empower the men enrolled in the study, but to get them to do what the researchers wanted them to do. "It was never a secret," said Thomas. "They learned the cues of the community and manipulated them to get what they wanted." Those same methods, however, can be used for good, which is part of what the NIH Bioethics Research Infrastructure Initiative is trying to do to build trust in the African American and other minority communities.[5]

The first generation of disparities research to achieve health equity documented the problem, and the second generation explained the reasons the problem exists. This workshop, said Thomas, has put cognitive decline on the table as one reason, and research has shown that poverty is another reason. Third generation research provides answers, such as those developed by the work with Geisinger that Wolff described. The problem, he said, is that "our science lives in our journals and is not being implemented," which is why he and several colleagues have called for a fourth generation of disparities research (Thomas et al., 2011). This fourth generation of disparities research is tied to social determinants and recognizes

---

[4] For more information, see www.healthypeople.gov/2020/about/foundation-health-measures/disparities (accessed April 3, 2018).

[5] For more information, see www.buildingtrustumd.org (accessed April 3, 2018).

the role that race and poverty play and builds off the previous generation of research to act and restore credibility in the very communities that have lost trust in the medical and research professions.

To illustrate what acting looks like, Thomas first reminded the workshop of a 2001 federal campaign called Take a Loved One to the Doctor Day. This expensive program developed great materials and a good website, he said, but in the communities where health disparities are the greatest, people did not have a doctor. The basic idea, though, was good, and he and his collaborators have turned it on its head to produce Take a Health Professional to the People Day. "What we did was take physicians, nurses, pharmacists, the whole array of us, out of the hospital and we put them in Black barbershops and beauty salons," Thomas explained. As an aside, he noted that no self-respecting African American barber would ever tell a customer that he would get them in and out in 15 minutes.

Thomas and his team have taken this one step further and created Health Advocates In-Reach and Research (HAIR), a network of 10 barber shops and beauty salons in African American neighborhoods in the Washington, DC, metropolitan area that hosts health professionals with the goal of reducing health disparities through community building and health education (Linnan et al., 2012). He and his team are now launching the National Association of Black Barbershops and Salons for Health to bring health professionals to a new place for engaging the nation's most vulnerable citizens. As a final note, he pointed out that physicians would love to have the relationship with their patients that these barbers and salon operators have with their customers.

COMMUNITY LIVING, FOSTERING ENGAGEMENT, AND INDEPENDENCE[6]

Returning to the subject of aging, Nora Super first recounted the four key themes of the White House Conference on Aging, which was held in 2015: retirement security, healthy aging, long-term services and supports (LTSS), and elder justice.[7] The White House's focus on healthy aging focused on four main priorities: promoting health and preventing injury, optimizing cognitive health, maximizing independence, and promoting community and civic engagement. Although she has worked on healthy aging issues for years, she noted that when she served as executive director of the White

---

[6] This section is based on the presentation by Nora Super, director of the Aging and Disability Business Institute of the National Association of Area Agencies on Aging, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

[7] For more information, see archive.whitehouseconferenceonaging.gov (accessed April 4, 2018).

House Conference on Aging, she learned about programs on aging at the Departments of Housing and Urban Development, Labor, Transportation, and Treasury, which she did not know existed. One piece of information from the discussions on preventive health services was that health professionals do not do a good job explaining for their older patients, particularly those from minority populations, what preventive services are available free for all Medicare beneficiaries.

Though the vast majority of people want to stay in their homes as they age, many will need support and assistance to do that. As a result, the need for support and services for older Americans will increase as people age (Freedman and Spillman, 2014a). In fact, said Super, a new study showed that 59 percent of the population over age 80 needs LTSS. For those who live in rural communities, there are big challenges to finding and accessing that support, challenges that are exacerbated by the fact that those communities themselves are aging. In some areas of the country, said Super, more than one-quarter of the population is over the age of 65. To help older adults find the supports they need, the National Association of Area Agencies on Aging (n4a) runs a national call center and the Eldercare Locator website.[8] Most of the callers are older adults and not their caregivers, said Super, and the top reasons for calls include a need for transportation, home and community-based day services, housing options, medical services and supplies, and health insurance information.

The complexity of the Medicare and Medicaid systems can overwhelm many older adults regardless of education level, said Super, and yet Congress has threatened to eliminate federal funding for state insurance counseling programs that provide unbiased research and help patients navigate these systems. Transportation is another disconnect, she noted, between what older adults need to remain independent and what the health care system provides. Super noted that of the people who call the Eldercare Locator looking for help with transportation, the majority are seeking help for current needs for transportation to medical appointments, and yet many health care plans complain about no-show rates among older adults. As an example of how one community dealt with this problem, a Medicare Advantage plan partnered with a Boston area agency on aging program to arrange for transportation services to bring older adults to their medical appointments. One elderly wheelchair-bound patient who lived on a third floor and had regularly missed her appointments has never missed one since this program began.

Social isolation among older adults is an issue starting to be noticed by the research community and policy makers. One in five people over

---

[8] For more information, see www.eldercare.acl.gov/Public/Index.aspx (accessed April 4, 2018).

age 50 is affected by isolation (AARP Foundation, 2014), and isolation is associated with functional decline and a 45 percent greater risk of death. Prolonged isolation, said Super, can be as bad for one's health as smoking 15 cigarettes per day. She noted that Meals on Wheels America has observed that one in four people who receive their meals at home have dementia and live alone.

To address some of the issues that older Americans with dementia face, the White House Conference on Aging launched Dementia Friendly America, 1 of 75 initiatives to come from the conference.[9] This program, modeled after Minnesota's ACT on Alzheimer's program[10] and run by n4a, has the goal of catalyzing a movement to more effectively support those living with dementia and their care partners. Dementia Friendly America began with 8 pilot states that hoped to have 15 participating communities within the year, but the program exceeded its goal and now has more than 200 Dementia Friendly America communities in 37 states. Dementia, said Super, is an issue that cuts across racial, economic, and partisan boundaries.

The Aging and Disability Business Institute at n4a works to connect community-based organizations with the health care sector. Super explained that the health care sector has shown a growing interest in working on the social determinants of health, and community-based organizations are the experts in these areas, particularly in working with more complex patients, such as those with disabilities and older adults. By bringing health systems and community-based organizations together, the Business Institute hopes to teach each of those sectors how to talk to and work with one another. It offers a resource center that provides nuts and bolts instruction on how to structure service contracts, for example, and how to work toward making policy changes that can benefit those in need.

One of Super's favorite programs, also launched at the White House Conference on Aging, is the Geriatric Workforce Enhancement Program developed by the Health Resources and Services Administration. This program aims to create a workforce that maximizes patient and family engagement and improves health outcomes for older adults by integrating geriatrics with primary care as a means of addressing the severe shortage of geriatricians. The program emphasizes creating and delivering community-based programs that will provide patients, families, and caregivers with knowledge and skills to improve health outcomes and the quality of care for older adults. One program in the Fort Worth area, for example, has brought together the University of North Texas Health Science Center, Texas Christian University, JPS Health System, and the Area Agency on Aging of Tarrant County to train and deploy a range of health profession-

---

[9] For more information, see www.dfamerica.org (accessed April 4, 2018).

[10] For more information, see www.actonalz.org (accessed April 4, 2018).

als throughout the region, including doctors, nurses, physician assistants, pharmacists, physical therapists, social workers, and dieticians, to improve care for older adults.

Another promising program is the Seniors Assisting in Geriatric Education program, which Super said reminds her of the barbershop and beauty shop program that Thomas described. Interprofessional student teams visit older adults in their homes, where many of the students work with an older adult for the first time. There, they may learn that an older adult's skin is thinner and her veins pop out. In many cases, the medical residents learn that the Meals on Wheels delivery is the only meal some older adults receive all day and yet they share that meal with their pets. "It brings a new understanding of what health means to physicians and health professionals," said Super, "so prescribing a drug in the hospital might not be the best thing if these people are not even getting basic nutrition at their homes."

DISCUSSION

Parnell started the discussion by commenting on Wolff's remark about the lack of a defined role for family caregivers. She asked Wolff and Thomas for suggestions on developing strategies that could be more inclusive of family caregivers while still respecting patient preferences. Wolff replied that the challenge of defining a role for family in delivering care starts with nomenclature. "We often refer to family caregivers as 'family caregivers,' but the people who are providing care often do not identify with that term," said Wolff.

> For many people, that is just what you do if you are a spouse or an adult child, so how we identify what the roles are and what the triggers are that move someone from a more normative to a caregiver role is a challenge.

She noted, too, that family members are often serving in roles that are not always about health and disability, such as serving as translators or as a walking medical record.

One strategy Wolff has taken has been to focus on developing simple strategies that are feasible to implement and that empower patients and families to have the discussions needed to clarify what help the patient would like to have. This type of discussion is important, said Wolff, because the patients should establish the role their family plays in managing care. At the same time, clinicians need to be brought into these discussions so they can understand and respect that when patients rely on a family member for care that the family member must be part of the discussion. In her opinion, there are several cultural and technological shifts that will help include family caregivers in discussions with a patient's clinical team. She noted that one shift is the move toward the diffusion of consumer-oriented health information. Another shift is that patients can often now share access to their patient portals with their caregivers, according to their preferences.

Thomas noted that in the neighborhoods where he has lived, family is not at all related by blood, so the dynamics of involving those individuals in care become complicated because of legal issues. For him, the solution is to reintroduce medical students and residents to the concept of social medicine and getting care back into caregiving. Super pointed out that as health systems are paying increasing attention to the social determinants of health, they tend to want to re-create services, medicalize them, and not work with the community-based organizations that are already providing those services and are trusted partners in the community. Often, a small contract between a health system and a community-based organization to hire one extra person to handle care coordination and follow-up is a much more effective approach than creating a new service that does not have the same standing in the community. "Recognizing what both parties can bring to the table, allowing them to practice at their highest level, and working in the community are some of the successes that we'll have in addressing the aging population," said Super.

Winston Wong from Kaiser Permanente asked the panelists for their perspectives on introducing telehealth technologies into interactions with older adults, and if there are any warnings they would give health care systems with regard to how to leverage that technology in a way that adversely affects communication among the patient, caregiver, and clinician. Super replied that there is a great deal of promise in telehealth, though too often the developers of applications may never have interacted with an older adult. At the same time, Lyft and Uber are trying to serve as a means of getting older adults to medical appointments and are trying to design apps that an older person could use without getting confused. She also noted that there was a program that gave older adults an iPad and assigned them to a nurse who could follow up with them as a means of reducing readmissions. What this program discovered was that the older adults liked this form of communication because they did not want people coming to their homes and seeing how messy they might be. The program was also able to connect culturally competent health professionals with participants who better identified with their ethnicity. The result was that outcomes improved for these adults.

Thomas said it is important to not let technology be a cop-out. "High tech works after high touch, and the real promise is not in portals," said Thomas, who pointed out that people are not using the portals that already exist. An area where he does see promise is in the miniaturization of diagnostic tools that will enable the clinical team to monitor patients remotely or allow the clinical team to take the diagnostic equipment with them into the community. One issue that will need to be addressed, though, is shame—the feeling that people do not want to be judged for the condition of their homes. He also noted that talking about telehealth in the context of saving money, rather than improving care, diminishes the power of the technology and the people who provide care.

Wolff agreed that telehealth does have potential to improve care for older adults, but only if it is used in the context of patient preferences and the ability of older adults to use these technologies. Given that caveat, telehealth does have the potential to leverage limited existing resources, such as the geriatric psychiatrist who would never be able to visit every patient personally, but could hold consults via an iPad. "I think it has a lot of promise, but also requires thoughtful attention to developing it in a way that really extends and improves quality of care and efficiency of care," said Wolff.

Michael McKee from the University of Michigan Medical School reminded the workshop that one in five people have some form of disability, yet disability is often at the tail end when thinking about equity, inclusion, and diversity. Super agreed with McKee and said that the aging and disability communities do not really understand each other. She noted that when the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities were combined in 2012 to form the Administration for Community Living, disability organizations and aging organizations were brought together in an arranged marriage that can be uncomfortable at times, particularly given the history of mistreatment of the disabled community by the health care system. At the same time, Super said she has learned a great deal from her colleagues in the disability community about their many challenges and approaches to solutions that are different from those that the aging community has typically addressed.

Wolff agreed with Super that the communities are very different. Individuals who are living with disabilities tend to be working age adults who have grown up with expectations of integration and work, whereas older adults who are experiencing age-related impairments are typically less actively engaged in driving their care. Older adults, she said, "tend to be a little more passive in interacting with the medical community, and they tend to be less interested in sort of consumer-oriented, consumer-directed care." Wolff noted the challenge of developing specific strategies for dealing with the wide range of disabilities that affect how people interact with and get care from the health care system.

Olayinka Shiyanbola from the University of Wisconsin–Madison commented on the difficulty older adults have in understanding why they are taking specific medications, which points to the importance of pharmacists not only talking to older adults but getting out into the community and meeting these individuals where they live. One thing she has seen, though, is the focus on education versus health literacy in communities of color, and she asked Thomas if he had any insights into why it is given that education is not directly related to health literacy. Thomas responded by relaying something a pharmacist told him, which is that pharmacists are more than just distributors of pills and that they often feel marginalized in the hierarchy of medical professionals. What his program does is hold the equivalent of a brown bag day when community members can bring their loved ones' medication to the barber shop and the pharmacist will answer any questions. How the pharmacists handle billing for their time is something he is unsure about, but the pharmacies that provided their pharmacists seemed more concerned about providing full-fledged health professionals and having them meet and talk to people where they are.

Parson offered a comment that the complexities of decision making in everyday life, beyond those about medical care, are creating challenges for adults as they age. She wondered if the complexity of the health care system is a factor in health decline simply because the overwhelming amount of decisions is helping feed that decline.

Earnestine Willis from the Medical College of Wisconsin asked Thomas if he has studied outcomes from the HAIR program to know if it has precipitated institutional change and if he has considered implementing it in independent living environments. Thomas said no to her second question, largely because he has been operating these programs on a shoestring budget. He is looking for the kind of investment that can disseminate this program into other settings and noted that hospital systems in Maryland are starting to see this type of outreach program as fulfilling their community benefit requirements. One problem, however, is that the health systems are not sharing the data they are collecting, which makes it difficult for him to demonstrate for a broader audience that this program works. He did note that a recent publication highlighted the success of using African American barbershops to address hypertension in African American men (Victor et al., 2018). The one concern Thomas has is that rushing into these humble places could destroy their unique setting. "These are all mom and pop operations where social norms are set," said Thomas, "but it is the place where we can make change."

Regarding Willis's first question, Thomas said he has observed that the doctors talk differently in the barbershop, using plain language automatically. In addition, pulling the clinicians out of their comfort zones helps them feel what the patients feel like when they come to the doctor's office and is generating a certain amount of empathy. He noted that because of the community that exists inside a barbershop or beauty salon, talking to one person helps educate everyone in the shop because they are all listening. Rosof ended the discussion by reminding the workshop participants of Dr. Donald Berwick's advice to the Yale Medical School graduating class of 2010: "Take off your white coat and sit among the people who need you and you will learn more perhaps than you have in your 4 years in medical school."

4

The Health System Landscape

The workshop's third panel session featured presentations by two speakers who discussed how the health system is addressing some of the challenges facing older adults. Anne Tumlinson, founder of Anne Tumlinson Innovations and founder of Daughterhood.org, addressed navigation of long-term services and supports (LTSS). Lisa Gualtieri, assistant professor of public health and community medicine at the Tufts University School of Medicine, addressed whether technology deployed by a health care system can facilitate or serve as a barrier to care for older adults. Following the two presentations, Deidra Crews, associate professor of medicine and vice chair for diversity and inclusion at the Johns Hopkins School of Medicine, moderated an open discussion with the panelists.

NAVIGATING LONG-TERM SERVICES AND SUPPORTS[1]

Anne Tumlinson had spent most of her career thinking that if the nation can create a way to pay for long-term care, it would solve all the problems with caring for older Americans. Then she started having family members and friends who had to interact with the nation's health and long-term care system and realized that she did not know anything. "One of the most surprising things that I learned in the process of having personal experiences with the system is that just because you have money to pay for

---

[1] This section is based on the presentation by Anne Tumlinson, founder of Anne Tumlinson Innovations and founder of Daughterhood.org, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

something does not mean you are going to get good care, and it does not mean you will be able to find it," said Tumlinson.

Frailty in old age, a risk everyone faces, is shorthand for the experience of needing LTSS. That need arises, Tumlinson said, from lacking the ability to perform certain types of basic activities of daily living, such as feeding or dressing oneself, without assistance from someone else. According to the Urban Institute, which has developed a model that estimates the risk of needing LTSS over the lifetime, half of all Americans who cross age 65 can expect to need a high level of LTSS at some point in their lives as a result of needing help with two or more activities of daily living or some kind of severe cognitive impairment (Favreault and Dey, 2016). Of those who do need LTSS, about half will need them for 2 or more years, and about 25 percent will need them for 5 or more years. Women, she added, are more likely than men to need LTSS before they die.

Based on an analysis of the 2011 National Health and Aging Trends Survey, approximately 10 percent of the population aged 65 and older living in the community—approximately 3.5 million people—has a high need for LTSS (Freedman and Spillman, 2014b). This figure is based on using a narrow definition of LTSS of requiring help with two or more activities of daily living or having severe cognitive impairment and needing help with one activity of daily living or three instrumental activities of daily living, which include activities such as doing laundry, shopping for groceries or personal items, handling bills and banking, making hot meals, or handling medications or injections. Using a broader definition of LTSS need that includes difficulty with two or more activities of daily living, requiring help with one or more activity of daily living, or severe cognitive impairment and needing help with one activity of daily living or three instrumental activities of daily living, the estimate soars to more than 20 percent of the population, or more than 7 million older adults, that requires LTSS.

Having a need for LTSS, added Tumlinson, comes with a doubling of one's health care costs (Windh et al., 2017) (see Figure 4-1). Though Medicaid and long-term care may be synonymous in the minds of many policy makers, only one-third of the 3.5 million older adults who need LTSS are eligible for Medicaid (see Figure 4-2). This is the population, she said, that accounts for an outsized proportion of Medicare spending.

Approximately 75 percent of older adults with a high need for LTSS live at home, with the rest living in a nursing home, assisted living facility, or other facility-based care (Freedman and Spillman, 2014a). Nearly all of those living at home are cared for by family caregivers, and half of them are being cared for exclusively by family caregivers, Tumlinson noted. Eventually, individuals who need help lasting longer than 2 years start using paid care of some kind, and the out-of-pocket costs associated with paid care are substantial (see Figure 4-3). In total, the average lifetime spending for

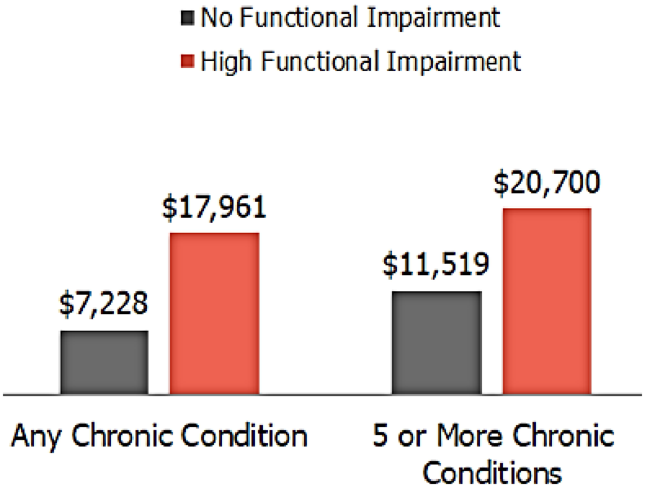

FIGURE 4-1 Functional impairment drives health care costs.
SOURCES: As presented by Anne Tumlinson at the workshop on Health Literacy and Older Adults on March 13, 2018; Windh et al., 2017.

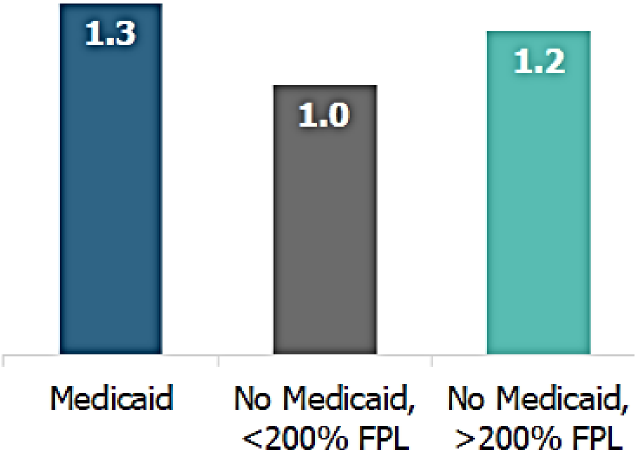

FIGURE 4-2 Medicaid eligibility among seniors who need LTSS (millions of beneficiaries in 2011).
NOTE: FPL = federal poverty level; LTSS = long-term services and supports.
SOURCES: As presented by Anne Tumlinson at the workshop on Health Literacy and Older Adults on March 13, 2018; Windh et al., 2017.

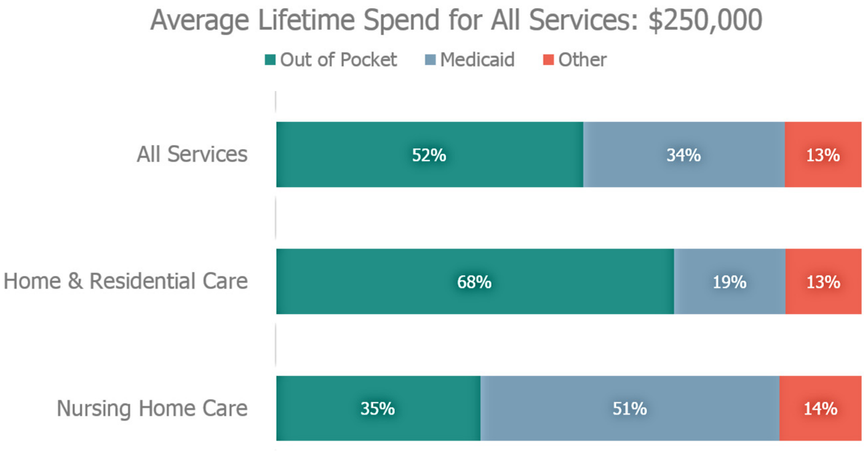

FIGURE 4-3 Distribution of costs associated with paid care to provide LTSS.
NOTES: LTSS = long-term services and supports. Percentages may not add up to 100 percent due to rounding.
SOURCES: As presented by Anne Tumlinson at the workshop on Health Literacy and Older Adults on March 13, 2018; Favreault and Dey, 2016.

all paid care services is $250,000 (Favreault and Dey, 2016). Tumlinson noted that the disparity between the out-of-pocket costs for home- and community-based care and nursing home care results from Medicaid policy, which she explained guarantees financing for nursing home care, but not home- and community-based care. The bottom line, said Tumlinson, is that the nation is financing long-term care primarily through the unpaid care provided by family caregivers.

In addition to providing hands-on caregiving that family members are providing—helping with bathing, eating, and dressing—they are also doing a significant amount of management and coordination, as well as making decisions about and handling challenging financial, legal, and family issues (see Figure 4-4). Family caregivers, said Tumlinson, not only have to navigate the medical system for their loved one but they are also navigating the entirely separate LTSS system. The latter requires finding a home care worker or finding an assisted living facility, senior housing, or adult day care center. "I would say they are making [these decisions] in a vacuum," Tumlinson claimed. "We do not have an infrastructure to support the kinds of decisions that people have to make." She recalled how a friend and mentor of hers, an expert in long-term care, once said to her that if he had to find home care for his elderly aunt, he would not know where to start

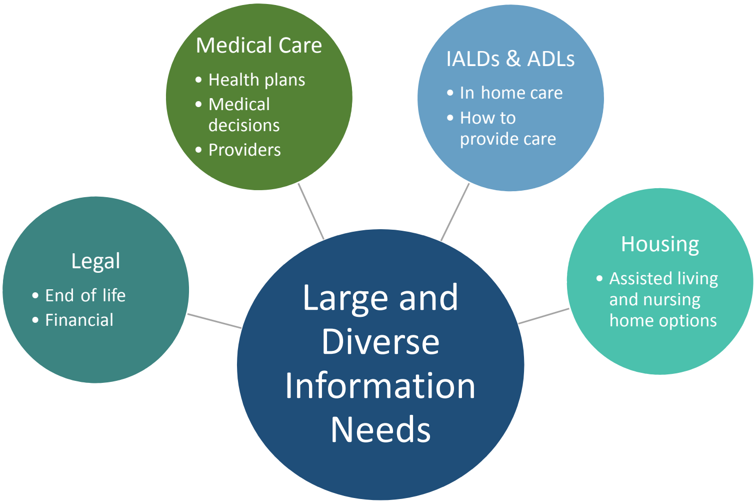

FIGURE 4-4 LTSS need leads to a wide range of decisions to make.
NOTE: ADLs = activities of daily living; IALDs = instrumental activities of daily living; LTSS = long-term services and supports.
SOURCE: Adapted from a presentation by Anne Tumlinson at the workshop on Health Literacy and Older Adults on March 13, 2018.

other than opening the Yellow Book. "I started calling this the Yellow Book problem," said Tumlinson.

One source of help is area agencies on aging, but there is not enough funding for these organizations to meet the needs for information and support for the growing number of older adults. What is missing, said Tumlinson, are the following three things:

1. An ability to match family members with the right types of service supports based on their goals and preferences.
2. Resources to support family caregivers in the coordination of all of those services.
3. The ability to support family caregivers in the communication that they must engage in among all the disparate parts of the system.

As an example of how hard it is to navigate the long-term care system, Tumlinson talked about Daughterhood.org, the organization she founded and runs. This organization is a community of women across the country, many of whom form local daughterhood circles, that aims to support and build confidence in women who are managing their parents' care. Recently, she surveyed the members and asked them what their primary challenge is in finding information. The 100 or so respondents said that information on the Internet is too dispersed or hard to trust; that most "finders," such as those on Alzheimers.org or eldercare.gov, produce long lists that do not reflect quality; and that many "free" referral sources are biased because they get paid for referrals.

There is also an emotional context to the issues facing family caregivers, who primarily feel overwhelmed, guilty, and alone. "It is hard to consume information when you are panicking and you feel overwhelmed," said Tumlinson. The other point she made was that health care information that family members receive when their loved one is discharged from the hospital is usually medically focused and excludes long-term care. "It does not say which home care agency or nurse agency to call or how to find an adult day care center so you can go back to work," she said. "What we need is a care delivery system that revolves around the consumer and family needs and a way for our so-called value-based delivery system to really support this."

Concluding her presentation, Tumlinson spoke about some innovative, technology-based caregiver solutions that are evolving across three domains: matching, coordination and management, and communication. Matching applications use online directories and in-person support to help individuals find and connect with traditional long-term care providers in their market. Coordination and management applications provide personalized support to address a range of navigational and management issues, such as coordination of health care services, communications with older adults, and applications that use technology to support communications across delivery systems of caregivers and providers. The main challenge for all these applications is formulating a business model that will enable the developers of these applications to make money. "Consumers are not ready to pay out of their own pockets for navigational assistance, despite the fact that they so clearly need it," said Tumlinson, and selling these applications to employers, providers, and even financial services firms has proven difficult.

TECHNOLOGY AS A FACILITATOR OR BARRIER FOR OLDER ADULTS[2]

In the last workshop presentation, Lisa Gualtieri discussed RecycleHealth, a nonprofit organization she founded in 2015 to collect fit-

---

[2] This section is based on the presentation by Lisa Gualtieri, assistant professor of public health and community medicine at the Tufts University School of Medicine, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

ness trackers that people are no longer using and give them to people who might benefit most from their use. To date, RecycleHealth has collected more than 3,000 trackers, including some donated by vendors. She and her colleagues have been using them to conduct research primarily with older adults to learn if they would accept them, use them, and, as a result, increase their physical activity level. Her organization has also worked with community-based organizations to distribute trackers to underserved populations including developmentally disabled adults and veterans with post-traumatic stress disorder.

One new initiative Gualtieri has started works with physicians to understand how data from trackers and other digital health devices can be integrated into clinical care. The goal is to provide them with a display of accurate information about their patient's activity level since their last appointment and enable them to open discussions about exercise with their patients while being mindful of the limited time physicians have to review the data that trackers produce. From the research she had done with older adults, Gualtieri has found that pivotal points in people's lives, such as retirement, illness in the family, and death of a spouse, can dramatically change their activity levels (Gualtieri et al., 2016). One key finding from this study was that most people are surprised when they find out how little they exercise in a given day. Other findings were that getting people to make small changes, such as using the stairs instead of the elevator, produces a real increase in activity level that is quantified by the tracker, and that trackers are great for providing a visual reminder of a person's commitment to increase activity.

What Gualtieri really wants to uncover are the barriers and facilitators to tracker use, which leads to the larger question of what keeps older adults from accessing digital health. What much of the research she has seen concludes is that older adults are interested in using digital health technologies, but often they are not doing so (see Figure 4-5). When she was recruiting older adults at senior centers in lower-income areas around Boston, she observed that cost and training were two barriers to adoption. "But what we started to discover is that there was a wealth of issues beyond these," she said. One barrier was that while many older adults own smartphones, they are many generations old or the individuals were on pay-as-you-go plans and could not download apps. Another was that many individuals had never downloaded an app themselves. "We started to see that the barriers to adoption were endless," said Gualtieri.

Even the design of apps presented challenges to many people. For example, many apps use a spinner to enter in date of birth, and older adults would get frustrated with having to keep spinning to reach their birth year. Gualtieri said some older adults would joke that they had to spin a lot to reach their birth year. Another issue was that the default on some of the

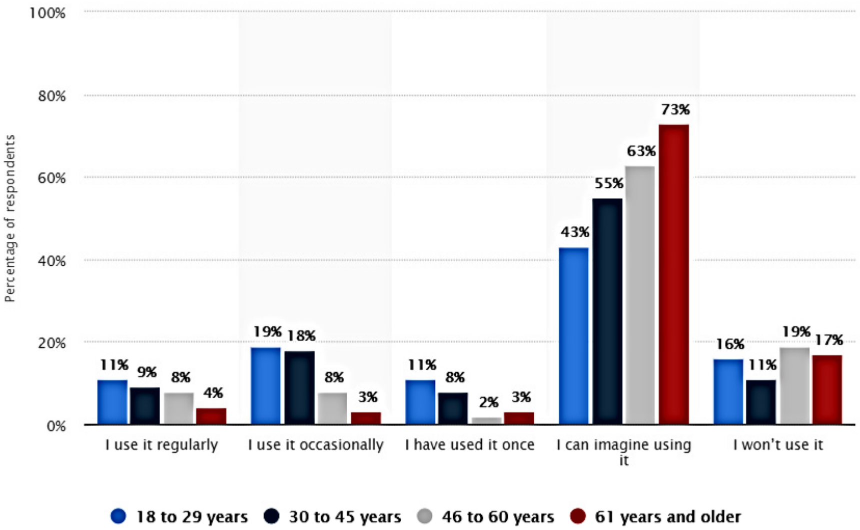

FIGURE 4-5 Percentage of U.S. adults who would be willing to use an app to measure health metrics.
SOURCES: As presented by Lisa Gualtieri at the workshop on Health Literacy and Older Adults on March 13, 2018; www.statista.com/statistics/698633/us-adults-that-would-use-an-app-to-measure-health-metrics-by-age (accessed July 26, 2018).

activity apps was 10,000 steps per day, which she said was far beyond the capabilities of these older adults, as well as many younger adults. "We would provide them guidance based on their current activity level of what might be a good starting point and show them it was easy to change this setting," said Gualtieri. Her conclusion was that while smartphones are being widely adopted, that does not mean people are adept enough at using them to access the wealth of available digital health tools. "Not being able to access and comfortably use technology becomes a barrier to digital health technologies," she said.

In Gualtieri's opinion, a new digital divide is being created, and many older adults are on the wrong side of the divide even if they have a smartphone. Coming to this conclusion has prompted her to try to understand what older adults need to have access to and need to learn to comfortably and adeptly use these new technologies without feeling inept or old simply because the technology is not well designed for this group of older adults or even marketed to older adults.

Gualtieri and her colleagues have been looking at facilitators as well as barriers, and one facilitator is having access to hands-on help that not only enables older adults to use technology successfully but to feel comfortable using it and not have to depend on having their grandchild set up the device. What she and her interns and students do is go into senior centers and connect with these older adults before trying to teach them about their devices. One of her interns, she recounted, was so calm and patient with these older adults: She was happy to let them tell their life story, and they would enjoy the process of learning how to use their tracker. Now, said Gualtieri, she gets hugs when she goes to these senior centers, and people brag about how many steps they had already taken that day. The challenge, she said, will be to scale this type of high-contact program.

As to how more people can access technology, one step will be to develop apps that work on older versions of smartphones and smartphone operating systems, and another will be to design apps and devices that appeal to and are usable by older adults. For example, Nokia donated some trackers that look like watches but have an extra dial that displays step count. "We discovered that the older adults we were working with liked how it looked, and they liked the comfort of the band, instead of the more typical plastic bracelet-like bands," said Gualtieri. For many vendors, older adults are not a target population, something that is obvious when reading the directions on how to set up and use most technologies and applications. "As people working in health literacy know, offering simple explanations will increase access for all," said Gualtieri. One recommendation she offered to vendors is to provide paper, in-person, phone, and online support tailored to the needs and language of older adults. Another was to design their devices and apps to enable information flow and messaging between patient and doctor; that accounts for the complex health needs of older adults and their relationships with clinicians and caregivers.

During her research, one complaint she has heard from older adults is that they have trouble sleeping. Given that, Gualtieri wondered if technology that tracked sleep might benefit many older adults. "That is not something that I have explored as part of my research group, but it is something that I think has enormous potential," she said. In her final comment, she offered what she considered the most important message for an audience that specializes in health literacy, which was to think carefully about how digital literacy coupled with health literacy can be the road for older adults to access, use, and benefit from digital health.

DISCUSSION

Crews began the discussion by asking Tumlinson to list some of the barriers she sees to further innovation in the space of long-term care support. One barrier, Tumlinson replied, is that the need for information to navigate the health care system is often not connected to the need for information to navigate the long-term care system. That information needs to be integrated, she said. A lack of a financing system for long-term care is another barrier, as is information on how to value the various care services that are available. A third issue, she said, is that there is often a great deal of conflict in families and with medical professionals as to what the best course of care is for an individual.

Crews then asked Gualtieri for her ideas as to what would make the older adult market attractive to manufacturers and developers. Gualtieri replied that this issue comes down to one of perspective in terms of whether it is more important to make as much money as possible or to help more people achieve their health goals and still profit. She added that even with the growing population of older adults, too many manufacturers do not see older adults as a high-profit market and that it would be advantageous to their business model to design their products to appeal to older adults.

Christopher Trudeau from the University of Arkansas for Medical Sciences asked Tumlinson to talk about the general legal needs that she has seen most often through her interactions with Daughterhood. "The greatest challenge that I hear about is confusion over roles among siblings," said Tumlinson, which she said leads to issues about money and control. Another area of conflict she has seen is when one sibling is providing all the care for a parent and wants to be paid and another sibling disagrees. What is needed for those situations, she said, is a legal and social framework to help the family function as a caring system for their older parent.

Trudeau also asked if Tumlinson had any ideas on how to design a long-term care delivery system that integrates the legal, social, and medical sides. Tumlinson said she did not have an answer to that question, but whatever the answer is will depend on long-term care providers or medical providers recognizing and identifying the legal and social needs as they arise in the context of their practices.

Thomas posed the question of why there is no equivalent to Angie's List for long-term care. Tumlinson said Thomas is one of many people, including herself, who have asked that same question. In fact, she added, there is something similar, called caring.com, but people do not want to subscribe to it as they do to Angie's List. Tumlinson explained that, as a result, caring.com is supported by the facilities that advertise with the site, which gives them higher placement in the generated lists. She added that another issue is that people do not want to review sites because they worry about the ramifications for their family members. Part of what Tumlinson is trying to do with daughterhood circles is create friend groups from existing communities so that people can get word-of-mouth referrals, just as they do when they need a plumber.

Jay Duhig from AbbVie Inc. applauded Gualtieri's pointing out that adoption is more than just "if you build it, they will come." He asked her if any of her research has looked at the effectiveness of providing a device in concert with a drug or other therapy as part of a treatment regimen. Doing so might address a patient need and create a market for such a device. In fact, said Gualtieri, she has a friend who is a psychiatrist who gives some of the trackers she collects to patients when he gives them new medications as a means of looking for side effects, such as becoming increasingly sedentary or having sleep problems. She also provided a tracker to someone who was in a rehabilitation center and had that person use it to track the progress the individual was making in physical therapy. Establishing a tracker lending library might be one way of encouraging physicians to prescribe a tracker along with a new medication. "That might be my next research project," she said.

Lawrence Smith from Northwell Health asked if it makes a difference in terms of success at home whether the older adult has sons or daughters and how far the child lives from home. Tumlinson said that she does not know of any research that asked those specific questions, but she does have research on what a difference it makes when the family member has support. One study she did with an organization that provides nurse practitioner support to the family caregiver looked at integrating the family caregiver into the medical team and providing the caregiver with some monetary support as a means of reducing emergency department and ambulance use. The results showed a reduction in hospital use. "More support for the family helps it do a better job and creates better outcomes," said Tumlinson.

Koss noted that the Consumer's Checkbook in Washington, DC, and San Francisco both list local resources with provider ratings, as well as an Angie's List–type service for several health care services. She then noted that elder abuse occurs most often at the hands of a family member, and the more isolated an individual is, the easier it is to abuse the person emotionally, financially, and physically. She also said she is a firm believer in the individuals stating their preferences, but the tensions among family members around the preferences and how they get resolved often falls to the legal system. Given that, she asked the panelists how to take those facts into account when thinking about how to involve families in the care of their older adults.

Tumlinson responded that she has no ideas for avoiding the legal system in those types of situations, though she suspects that better educating everyone about all the issues involved in caring for their older family members would help. "It is just so important for individuals to set up their wishes, make them clearly known, and really think through the ramifications in advance of being in a dire situation," she said. When people ask her how to prevent themselves from being a burden to their children, her advice is to tell them what they want now and give them permission now to take steps such as taking away their keys when the time is right in the future or what to do if one sibling becomes difficult. "These are conversations that the sooner you can have them with each other in as honest a setting as possible, the less you are going to be running into situations where you have lost control of a loved one's care," said Tumlinson.

Regarding elder abuse, Super noted there are technology solutions that can address financial exploitation and there are arrangements that can be made with banks to prevent a sibling from making unusual withdrawals or transfers of funds. The broader issue is that most instances of elder abuse arise from an economic need, lack of education, or other societal need that must be addressed. As an example, she cited a case in which adult protective services stepped in to take charge of an elderly woman who had horrible bed sores and found that her illiterate adult son had never been told that he had to turn his mother to prevent bed sores. "I do not think that he meant to abuse his mother," said Super. "He simply did not have the skills he needed to care for her."

Lindsey Robinson from the American Dental Association noted that many medications older Americans take can have a significant effect on oral health. She wondered if families and caregivers are aware of the relationship between oral health and medications and if they have a hard time finding dental care for their loved ones, particularly given that Medicare does not include a dental benefit. Tumlinson replied that this a big issue, and there is little understanding among the public about the ramifications of medications. She has also heard of a great deal of stress among caregivers around dental care for their parents.

Super commented that n4a has a new national resource center for engaging older adults. The grant for this program requires a focus on creativity and arts, technology, generational issues, and lifelong learning. She also noted that there is a program in New York City, Older Adults Technology Services, that provides older adults with hands-on training to use their own devices, as well as on how to use technology-enabled exercise equipment. She then asked Gualtieri if she has looked at hands-on training that benefits older adults with technology. Gualtieri replied that many programs similar to the one in New York are focusing on clients at senior centers to increase the digital literacy of older adults. The problem, she said, is that devices such as iPhones are marketed as being easy to use, which leaves people thinking they should be able to learn how to use them on their own. Too often, when they cannot, they enlist someone to set the device up for them, which does not provide the opportunity to learn more about the device. This is why she believes in the importance of hands-on training. When RecycleHealth gives a tracker to someone, she or one of her colleagues sits with them and walks them through the set-up process and helps them configure the device to meet their needs and change the settings as they progress. Classes are fine, but hands-on instruction is what is really needed when working with older adults, she said.

Zimmerman commented that Silver Spring Village offers an informal program on technology just for people with Android devices. It is offered every 2 weeks at the local recreation center, and it involves village members helping other village members, which Zimmerman said makes the program work. She also noted a problem she has with trackers, which is that she does not have touch sensation in her fingers anymore, which makes it impossible to pull little buttons out from the side of the device to configure it. Gualtieri agreed that form factors are important for older adults and that dexterity can be an issue with many devices. She also noted that some devices send too many messages that do nothing to help motivate and support people in reaching their fitness goals.

Nicole Holland from the Tufts University School of Dental Medicine asked if trust issues related to big data and tracking health information are a barrier for older adults to use technology. Gualtieri replied that she asked people in her initial studies if they were concerned about the privacy of their information. "We got the exact same from almost everybody, which is given credit card breaches, given whatever the latest massive breach in the news was, if somebody has access to my height, weight, and how many steps I walked today, I do not really care," said Gualtieri. People are so numb to some of the privacy issues that she worries that the trust level is greater than it should be.

Alicia Fernandez from the University of California, San Francisco, remarked that she takes care of very low-income individuals, usually immigrants, and for a while she tried misguidedly to get her patients to use their automatically loaded fitness app on their smartphones to keep track of their steps. She also recounted how 6 or so years ago she tried to buy her mother, who was having issues with cognitive impairment, a simple phone and would have been willing to pay twice what she paid for her smartphone. None existed then, which she says is a market failure. She noted that who pays for care is a critical issue. In San Francisco, for example, ride-sharing services are starting to bill Medicaid for ride shares to medical appointments, and that a service called GoGoGrandparent allows an older adult to call someone who will then order a ride share using preloaded information. "Perhaps that is the way to go rather than trying to train every individual to be able to do these things," said Fernandez. She wondered, too, if it might be more useful to provide a walking partner who wears the tracker instead of training an older adult to use one.

Gualtieri agreed that there is a significant market failure when it comes to products for older adults. There have been smartphones designed to be simple, but she wonders if they were tested with the intended population and designed with a real understanding of what functions an older adult wants in a simpler phone. Regarding who pays for these technological solutions, Gualtieri said the challenge is to develop a cost–benefit argument. “If you can give someone a tracker and it is going to increase people’s health, decrease hospitalizations, et cetera, then it is a worthwhile expenditure for an insurance company,” she said.

Gualtieri has studied the failure of corporate wellness programs and believes there is a lesson that can be applied to the use of technology with older adults. The programs that failed, she said, were offering a service that many employees did not care about or want. Similarly, handing a tracker or providing a smartphone app to someone who does not want it or care about it is not going to lead to success. The problem, she said, is that programs pay for these services or technologies without thinking about how to integrate them into people’s lives and what kind of training is needed to help them use services or technologies in a way that fits into their lives.

Addressing the idea of walking partners, Gualtieri said the social support aspect of having a walking buddy is powerful, but the challenge is orchestrating how walking groups form. “You need people who like each other and have something to talk about because that is motivating, and it makes it fun instead of just exercise,” said Gualtieri. “You need people who have similar schedules and who walk at similar paces for something like this to work well.” One thing she suggested to members of one of the senior centers where she worked was to organize car pools for walking sessions at the mall when the weather was bad.

5

Reflecting on the Day's Presentations

The last portion of the workshop provided the participants and roundtable members with the opportunity to reflect on the day's presentations. First, Rima Rudd, senior lecturer on health literacy, education, and policy at the Harvard T.H. Chan School of Public Health, moderated a discussion with four panelists: Z. Colette Edwards, national medical director for Associate Health and Well-Being at Humana; Susan D. Goodman, author of the Acting Our Age: Women's Lives at 85+ blog;[1] Yolanda Taylor Brignoni, strategic communications director at AARP; and Mary Ann Zimmerman, who spoke in the workshop's first session. This was followed by an open discussion with the workshop participants. The workshop concluded with the roundtable members providing their thoughts on the day's proceedings.

MODERATED PANEL DISCUSSION[2]

Rima Rudd began this session by reminding the workshop that the literacy and numeracy skills of older adults in all industrialized nations are lower than those of working adults and that there are health consequences

---

[1] For more information, see actingourageblog.com (accessed April 5, 2018).

[2] This section is based on the discussion moderated by Rima Rudd, senior lecturer on health literacy, education, and policy at the Harvard T.H. Chan School of Public Health, and among the speakers Z. Colette Edwards, national medical director for Associate Health and Well-Being at Humana; Susan D. Goodman, author of the Acting Our Age: Women's Lives at 85+ blog; Yolanda Taylor Brignoni, strategic communications director at AARP; and Mary Ann Zimmerman, founding director of Silver Spring Village, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

to limited literacy. These consequences, she said, are well documented regarding health promotion, disease prevention, health care management, disease management, decision making, and other aspects of health. Research has also identified the multiple physical, social, emotional, and cognitive changes that take place with aging. Rudd said,

> However, what we do not know quite as well and what we have not researched quite as well, are the shifting landscapes, the physical and social and normative environments that we, as older adults, are expected to navigate regarding new territories, new languages, new decisions, new devices, and new technologies.

As a member of the planning committee for this workshop, Rudd explained that the planning group used the metaphor of multiple landscapes to shape the day's discussions. "We highlighted the personal landscape, the landscape of the family, of the community, and of health institutions," she said.

> In so doing, we wanted to draw attention to how health literacy could enhance the experience of older adults as they navigate not only the pathways within health institutions and health services, but also the social normative structures that influence our everyday lives, that influence how and where we live, how and where we die, our interactions with others and with other institutions, what the silences are, what we are expected to keep silent about, and what we are expected to talk about.

Rudd noted the importance of determining how health literacy can enhance, modify, and change these structures so the system becomes easier to navigate. To her, the main issue is not to change the older adult and figure out how to enhance the skills of the older adult, though those are important and not to be dismissed. Rudd said,

> The emphasis is on how to keep our eye on the journey, how we keep our eye on the terrain, how we keep our eye on the environment, and what we can do to make modifications to make this journey a little bit more pleasant, a little easier, and something that is more joyous to navigate in some ways.

With that as her introduction to the session, Rudd asked the four panelists to comment on how they have gained insights into the experience of older adults. Edwards replied that she has gained insights from varied settings, including her 7 years as a practicing physician, as the caregiver for an elderly aunt who lived to be 100 years old and for her parents, and in her current position, where she focuses on the associates and their dependents covered by Humana. She has also participated in the health disparities scholar program at the National Institutes of Health, led health disparities work for a previous employer, and conducted health and wellness coaching. "I have seen people in various settings and looked at the issues from a lot of different angles," said Edwards.

Goodman said she has been a "boots-on-the-ground" person in several elder care situations during her lifetime. Over the past 3.5 years, writing for her blog, she has interviewed some 40 women ages 85 to 105. In speaking with these representatives of two generations of women who are aging positively and healthily, even in the face of serious chronic illness, she has gained a good perspective on how they manage their care in today's complex health and long-term care environments. She noted that these women are part of a marginal group that does not often get the opportunity to sit and talk with someone for a few hours. "That has been my opportunity and it has been very rich and very enlightening, and I hope my readers feel that way as well," said Goodman.

Taylor Brignoni said her job as strategic communications director for AARP is to make sure the organization is communicating in one voice about health across the 35 to 50 communication vehicles that AARP uses to deliver information that its 38 million members can use to make solid health decisions. Prior to her current job, she was a health reporter for many years.

Zimmerman said she has gained insights and knowledge through the many connections to the larger community that she has made in her role with Silver Spring Village. The value of those connections has been reducing isolation, she said, and creating a group of people who all live within a 2-square-mile area and yet had never met each other. "In developing this community, I had things I thought I would learn and get out of it, but I have also gained friendships and trust," said Zimmerman. "We have learned from each other in ways I had not expected and find I really needed." Another community she has joined includes the regular patrons at the two coffee shops and one restaurant within a two-block radius of her home. The members of these ad hoc groups talk with one another about the concerns they have about aging and pass around ideas for things to investigate, she said. A third community includes the people who live in her 500-unit apartment building. "It is a mixture of anything one could want," she said, adding that there is a valuable form of health literacy that has come for all those community groups.

Next, Rudd asked the panelists to note any major insights they gleaned from the day's discussions. Zimmerman applauded Thomas's call to move into a fourth generation of disparities research that moves beyond theory and into action. "Theory is absolutely needed, but I believe we are at the point of needing to move to that next step of actually doing something," she said.

What struck Taylor Brignoni was the need to think through what people need to get from the information they are being given and to not assume that people understand concepts such as co-payment and co-insurance or understand jargon. For her, introducing people to the language of health care and long-term care and helping them to understand that language is important for breaking down silos and building trust in these communities.

What struck Goodman was the discussion about ageism as it related to the different age groups among elders. U.S. society, she said, is fearful of aging, and making fun of wrinkles and sagging skin is thought to be funny. The stereotypes of older adults that she has seen are rigidity, crankiness, depressing and depressed, and unwilling to learn or move forward, and yet older adults can be extremely resilient and adaptable. She recounted that one older woman told her she said she would never use a walker, until she realized that she was sitting in her room all the time and would continue to do so unless she adapted to the reality of her physical condition. Goodman said she has been impressed by the openness older adults have to learning new things and adopting technology. "They are on Facebook, FaceTiming with their grandkids, and using Uber and Lyft," she said. "They understand that the world has a new language, and some are able and willing to venture in."

Goodman said she has also been impressed with how many older adults are at peace with their lives, not filled with regret or anger, and happy and blessed to be where they are today despite having experienced hardships and setbacks along the way. The one thing that the workshop did not address was that many family caregivers are themselves older and have their own health issues.

Edwards said the day's discussions drove home something she has believed firmly for many years: the importance of really listening to people. "Despite all the technology and all the advances, it still comes down to people," said Edwards. "Every time we try to take people out of the picture, it does not work out well and everybody seems surprised." She also noted that focusing on health literacy and health disparities for a sub-segment of the population typically results in improvements for everyone, because so often the underlying root causes reflect systemic issues. One striking observation she has made regarding an example of ageism was the tendency of clinicians to speak to her when she accompanied her aunt to an appointment even though her aunt had no cognitive issues at all and was fully aware of what the clinician was saying. "I think there are factors within the system and our culture that often lead to a certain point or age at which the system often stops seeing people and what their capabilities are," said Edwards. "Today has further reaffirmed the importance of addressing that issue."

Rudd's third request of the panelists was for them to draw from their insights and offer some ideas of what needs attention regarding health literacy and how the lessons learned at the workshop can translate into actions within health care institutions and within public health systems. Edwards said one action she and her colleagues at Humana are going to take is create a care advocacy boot camp to help patients and caregivers recognize the importance of being assertive as they navigate the health care landscape and the power they have to drive changes both one person at a time and in the system over time. Noting that she writes a blog called Be a Health Care Rebel, she said every person is the expert about themselves, and that no one else is ever going to be inside each person's body or mind. "Trust your gut, and if something does not make sense, it probably does not make sense no matter how many degrees someone has behind their name," said Edwards. She urged the audience to avoid being distracted from their truth by the big words they may hear from a health care professional. It is important to gain the skills to have confidence to ask questions because that might literally save one's life or the life of a loved one. "That is the one thing we are going to be working on, general advocacy in the health care system," she said. One example of the type of confident and informed advocacy she has in mind is how parents become transformed when they are advocating for their children when dealing with the health care system.

Goodman thinks about how storytelling could be put to effective use, something that several organizations such as the Alzheimer's Association use to help nursing home and assisted living facility staff find out about those in their care so that each person becomes someone real. Needing to be heard and seen by a medical provider is important for an older adult, she said. To make that point, she told the story of an 86-year-old African American woman who was having trouble with swelling in her hands and feet. The first three times she went to the doctor she was told to go home and take a Tylenol. The fourth time, she announced she was not going to leave the office until the doctor ordered some tests to find out what was wrong. It turned out that she had rheumatoid arthritis, for which she is now receiving treatment. The woman told Goodman later that she had grown up in the segregated South and that her health was not considered important there, either. What made this story more interesting was that this woman's daughter, who accompanied her on these visits, was a doctor and still nobody was focusing on the patient or taking the time to discover that this "old woman" was responsible for diversifying the book collection at Amherst College library. "She was a lot more than swollen hands and feet," said Goodman.

Goodman also noted that when she worked in subsidized senior housing in Boston, there was an exciting program at Tufts University School of Medicine that would send medical students into these housing developments one afternoon per week for an entire semester. Their mission, Goodman explained, was to learn to listen. Goodman said,

> There was such an opportunity for the future doctor and the residents to get to know each other, and at the final good-bye celebration, there were several students who stood up and said, "I was afraid to come here. You guys rock and I want to be a geriatrician." That is what I think we need to look at.

Noting this program's similarity to Thomas's barbershop and beauty salon initiative, she said these are the type of programs needed to give young clinicians the experience of relating one on one to their patients.

Taylor Brignoni focused on the messages about the importance of building trust and breaking down silos that she heard about throughout the day. She echoed Edwards's call for reinforcing the importance and positive impact of getting to really know the whole person rather than the more narrow context of a collection of diagnoses. "Unless you really get to know those patients, you will find that the system can relegate them into a category of symptoms or ailments," she said. Recalling the story that Super told earlier in the day about the woman who was not going to her medical appointments because she needed to be carried down three flights of stairs to get to those appointments, Taylor Brignoni said this woman's health care providers would never know that about her unless they break down silos and get to know her. Establishing trust, she said, allows a person to feel safe enough to tell the provider about the challenges they face without feeling that they will be judged. In her opinion, many health literacy barriers people face would be lowered if they felt they could trust their providers to ask questions and if the providers went into these communities to form the type of connections that doctors used to have with their patients and communities. Taylor Brignoni noted that while technology is great, there will always be human error, and so trust once again becomes an important issue.

Zimmerman said she agreed with everything the other panelists said, particularly about the importance of building trust and listening. She recounted how in 2016 she had a nurse and a physical therapist who would come to her apartment and talk to her and learn about her particular needs. The nurse focused on what she could provide knowing that Zimmerman had long-term care insurance, while the physical therapist concluded that Zimmerman might be injured on one of her walks to get coffee if she continued using the flimsy walker she had. "I had not realized before I started the conversation with these two that we patients know what we want," said Zimmerman, who added that she could not have articulated her needs well enough except for the fact that these two professionals listened to her and provided feedback. "That interaction got me to be able to define and prioritize what I needed," she said.

Rudd commented on the interesting balances among an emphasis on advocacy, on telling and collecting stories, and on making the invisible visible by listening that seemed to be resonating with the panelists. She then asked them for any additional insights they wanted to pass along before opening the discussion to the rest of the workshop. Edwards replied it is important to consider the effects of caring for an older adult on the health of the caregiver so the clinician does not end up treating two people. Rudd responded that intergenerational caring can be a blessing as well as a burden by providing an opportunity for the youngest generation—the grandchildren of the older adult—to observe, learn, and have compassion.

Goodman said the day's discussions left her feeling hopeful because the workshop participants know what needs to happen. Her hope is that it will not take long for those in the medical community to realize they need the time to just sit together with their patients, get to know each other a little bit, see beyond the symptoms, and have the opportunity to see individuals as whole persons and truly assist them. She noted that she has had the opportunity because of her blog. Taylor Brignoni said she would like to see more attention paid to how the health system and communities can support the family caregiver because of the great deal of stress they are under and the critical role they play in providing care for older adults. She noted that AARP has a caregivers' program, and caregivers are often asking what they can do to help themselves deal with the stress of caring for a parent or other older adult and the guilt of feeling overwhelmed. Zimmerman offered the idea of bringing in the community to help with various tasks and to relieve the caregiver on occasion.

OPEN DISCUSSION

Kim Parson from Humana asked the panelists to comment on the effect that depression has on the lives of older adults and caregivers. Goodman said the older adults she sees who have insights about depression tend to seek treatment and not let it have too big of an effect on their lives, but she suspects many more people have depression and are not saying anything. As a result, their caregivers and providers are not recognizing the symptoms either. Edwards added that a high percentage of older adults will develop chronic conditions as they age, which then lends itself to being depressed and, in turn, affects how well those individuals can take care of themselves and focus on doing the things they need to do to be healthy.

Another repercussion of depression, Edwards pointed out, is that someone who has had a heart attack and is depressed is much more likely to have a second heart attack. She also noted that someone who is lonely is more likely to be depressed, which causes them to withdraw from life and be even more lonely. The challenge, said Edwards, is to have conversations with older adults that can tease out the symptoms of depression. Simply asking someone if they are depressed is usually not a fruitful approach, she said. Rudd said that literacy feeds into this problem because limited literacy usually translates into limited vocabulary, and vocabulary is needed to express feelings that are not concrete. "The mixture of normative behavior and limited literacy skills through limited vocabulary perhaps can really exacerbate the problem of expressing your needs and expressing your feelings," said Rudd. Edwards added that limited health literacy plays an outsized role just at a time when life is getting increasingly complicated, and Rudd wondered what a health literacy focus can do to help mitigate these issues and increase access to care. Koss referred to the Plan, Do, Study, Act model of how to evolve change that could be particularly applicable to community, family, and caregivers.

Michael Villaire from the Institute for Healthcare Advancement told the workshop about a program his organization is running together with a broad-based collaborative of faith-based, city, nonprofit, and for-profit organizations. This program has promotoras—community workers—going into their communities, finding isolated seniors, and bringing them back into the system. The promotoras conduct a series of interviews and work with older adults to try to reconnect them to their communities so they can use various services. In addition, they hold a senior week, with a senior health fair and senior prom to promote inclusion of seniors in their communities.

Villaire also noted that his nonprofit has written a series of self-help health books at the third- to fifth-grade levels, one of which is *What to Do for Senior Health*. It comes with a resource kit that contains an easy-to-read advance directive form; an exercise video that helps older adults improve their strength, balance, and flexibility as a means of reducing falls; and a home safety assessment for fall risks. His team has also partnered with service organizations and Home Depot to go into homes to address fall hazards and install grab bars and the like. He has partnered with a dual-eligible managed care organization to conduct a randomized controlled trial to see if this intervention does reduce the incidence of falls.

Laurie Myers from Merck Sharp & Dohme Corp. noted that caregivers themselves may have limited knowledge, and she wondered what the field of health literacy could do to help support caregivers as a means of improving prevention and wellness efforts. Goodman said the important thing is to recognize, respect, and understand what the caregiver is going through when caring for an older adult and provide some form of community for them to get together and voice their frustrations with others in the same situation. Taylor Brignoni said AARP, as part of its caregiving experience program, has created a series of videos to provide step-by-step instructions that can help caregivers deal with specific situations, such as administering medication or moving a bed-ridden person to prevent him or her from developing bedsores.

> I think while the community is a huge part, and that you definitely need to make sure that the caregiver can ask those questions and feel like there is a safe space to have that kind of conversation, it is important to give them the skills and the tools they need so they are not as stressed out.

Lisa Fitzpatrick from the DC Department of Health Care Finance recounted how an elderly woman she met told her she had prediabetes and asked her what that meant; the woman did not know that Fitzpatrick is a doctor. When Fitzpatrick asked this woman why she had not asked her doctor that question, the woman replied that he is a good doctor, but very busy, and she did not want to bother him. This encounter prompted Fitzpatrick to wonder how community members can become more engaged with their older adult neighbors and be a source of information or a conduit to trustworthy sources of information.

Fitzpatrick noted that she is cynical about the prospect of practicing clinicians changing their behaviors and suggested the emphasis should be placed on clinicians in the pipeline. Zimmerman replied that as she has gotten to know her established physicians and become more comfortable asking them questions that they start treating her more as an equal, and the conversations improve. Fitzpatrick suggested that Zimmerman got lucky and that her doctors are outliers. Edwards remarked that there is a huge opportunity to work with the American Association of Medical Colleges to embed better practices and community involvement into medical education from the very beginning so that they become part and parcel of what a medical student or other health care professional learns and is expected to do.

Edwards also offered the possibility that changes in the reimbursement and health care financing system that emphasize outcomes will promote change. "When the focus is on having great outcomes, it becomes more difficult to have great outcomes if you have health literacy issues," she said. In addition, she said,

> the more you work on the health literacy of your patients, the more it feels like you are getting back to what you really wanted to do in terms of taking care of patients and bringing more joy into your life. Physicians are burning out because they are not getting those warm and fuzzy feelings because of everything else going on in the system.

Jay Duhig from AbbVie Inc. asked the panelists for ideas on how health literacy can encourage or incentivize other parts of the health care system, specifically manufacturers, to have a similar level of engagement and focus on older adults. Taylor Brignoni said that one of AARP's focuses has been on trying to disrupt the medical products industry, to make sure these businesses see how much older adults spend and how, and if they design their products with that population in mind, it can benefit their bottom line. At the same time, AARP is connecting manufacturers with this target population to bring them into the development pipeline to serve as testers and members of focus groups.

Steven Rush from the UnitedHealth Group noted that the complex health care system gets more complex as people get sicker and older. "The cognitive burden that occurs throughout the entire process is magnified as we get sicker and we have less capability to process information," said Rush. He noted the resource kits and books Villaire spoke about and the videos that Taylor Brignoni mentioned as the type of interventions the health literacy field has talked about for some time. He also applauded the workshop's speakers for talking about shared decision making and making language more understandable, two other areas in which health literacy has been active for years.

Villaire said he wanted to flip the discussion to hear about engagement and volunteer opportunities for older adults that would enable them to connect with their communities. His organization, for example, gets older adults to read to children, and the American Association of Critical-Care Nurses has a program for bringing seniors into the neonatal intensive care unit to cuddle babies that need to be held to thrive. Zimmerman said that, in some ways, is the whole purpose of Silver Spring Village. "A lot of the members are volunteers for administrative things or direct services to other seniors," she said. She also noted that as the village has evolved, it has increased the number of volunteer options in the broader community, including reading for children. Goodman noted that such opportunities can give older adults a sense of purpose and importance.

Larry Smith from Northwell Health said that cognitive decline is the number one reason why an older adult will no longer be health literate. Combining cognitive decline with serious chronic illness makes it even more likely that health literacy will decline. Given that, he asked,

> Where is the role of clear-cut advance directive discussions, documentation, making sure that the caregiver who ultimately may be the health care proxy understands that their job is to decide based on that person's values, not their own values? If we do not get advance directives while the person is still capable of being health literate, it is too late.

Zimmerman said that helping with advance directives and estate planning were among the first services that Silver Spring Village offered, and it still provides them every couple of months. She added that these programs are open to the broader community, not just village members. Edwards said she has started seeing groups pop up to address that issue. The challenge, she said, is getting people to think about advance directives and estate planning at a time when it is not a concern for most people. She is encouraged, though, by the increasing number of health care organizations that are starting to ask their members if they have advance directives on file and providing help for those who do not.

Bernard Rosof from Quality HealthCare Advisory Group asked Smith how Northwell, with its innovative educational programs with no real classes, addresses the issue he raised. "We teach communication skills using a very high proportion of standardized patients with videotape review," said Smith, "and asking people for advance directives is one of the standard exercises that every student does." His program also gets physicians, when they have those conversations with their patients, to ask permission for the students to be in the room and hear how a physician with a good relationship with a patient has that conversation.

REFLECTIONS FROM THE ROUNDTABLE

A roundtable tradition is to finish each workshop with each member identifying one or two key messages they heard during the day. Terri Ann Parnell from Health Literacy Partners said the key points she would take from the workshop were the important roles that advocacy, empathy, building relationships, incorporating the social determinants of health, and broadening the view of health literacy play when dealing with older adults. In her opinion, the social determinants of health are more important than some of the medical indicators that are studied. She also noted that the multigenerational nature of caring for older adults in the United States offers wonderful opportunities for learning to span these generations.

Christopher Trudeau from the University of Arkansas for Medical Sciences commented that as an only child, the workshop today made him think about the caregiving he is going to be giving to his parents and that he will need support and training to be that caregiver given that he knows how to provide some but not all aspects of the care they will likely need. He said he was interested to hear about caregiving boot camps as a way to not only train people regarding potential health care roles, but also train them on their responsibilities and obligations as a caregiver. He noted that in the legal world in which he works, there are some protections at the state level to make sure that caregivers are doing their jobs well, but not at the caregiver level when the person being cared for is still mentally competent. He was also struck by the importance of trust and the need to combine trust in the health system with caregiving. "Would that mean training caregivers in the barbershop?" he asked. His final takeaway concerned the intersection of the medical and legal worlds regarding older adults and the issues involved with advance directives and estate planning.

Rush said he was not aware of the sensible reclassification of older adults into young-old, middle-old, and old-old. In his opinion, that reclassification should help inform future research on older Americans. His other key message was that the workshop once again reiterated how important it was to convey information to patients and caregivers in a manner that increases understanding of how to best provide care for older adults.

Catina O'Leary from Health Literacy Media was struck by the fact that she will not only be a caregiver for a parent as an only child, but would simultaneously be a caregiver for her children. At the same time, she realized that everyone at the workshop was in a similar boat. "We are all struggling with what this means for me as a person and then what this means for our work and how we situate this among the big life problems," said O'Leary. "We have to get serious about this and do more than we are doing. That is important. It crosses both the personal and professional." The comments that speakers made about resilience and adaptability were important because it is too easy to think about burdens and deficits and forget that people are remarkably resilient and adaptable. Given that, it will be important to figure out how to best help older adults and their caregivers to be their strongest, she said.

The issue of trust and culture are topics that have come up in multiple roundtable workshops over the past 2 years, O'Leary noted, as has the subject of cognitive decline. Regarding the latter, she said, people can have problems with language and understanding what words mean and be experiencing physical and mental changes that affect understanding. She was intrigued by the fact that interventions are moving beyond the standard tools of health literacy and into the community, which to her raises the issue of treating people as a whole, of considering who they are, what they find important, and how they want to be treated, heard, and seen. "We can do all of that all the time if we bring our best selves to practice and we practice with them," said O'Leary. "I think Mary Ann [Zimmerman] did a nice job reminding us that people know what they want and what they need and that they want to be partners in care, and they have the capacity to do so when we all show up together and recognize humanity in all kinds of spaces."

The key idea that Earnestine Willis from the Medical College of Wisconsin gleaned from the workshop was that the aging process is heterogeneous. When she looks at this idea from the perspective of the individual, she can see that it is important to ensure that people continue to have a sense of purpose in their lives. The issue of distrust of the health system resonated with her because she sees that every day in the health system where she works. For her, this raises the question of whether health literacy alone can get people and communities past that distrust. She noted that in her role as an educator of health professionals, she sees that young people today understand their role as an advocate for the people for whom they care. "It gives me hope that there is a generation of young people who see that their job goes beyond just doing tests and giving a diagnosis," said Willis. "They can connect to the whole person." Her final comment was that the disparities that she sees in communities remind her of the need to focus on building the type of village about which Zimmerman spoke. Too many people she sees in her practice have lost their village. "Neighborhood cohesion becomes a critical piece of us getting people back to health," she said.

Picking up on Willis's optimism about the current generation of students, Parson is hoping that this is a generation that does not see race and age when they start taking care of people and that this will change the way conversations occur. The day's discussions also reinforced the importance of putting the individual at the center of care and of co-creating effective solutions to the challenges they face in getting care.

Myers was excited to hear the discussions about the role of the community in caring for and supporting individuals outside of the doctor's office. She noted the significant role that insurers, pharmaceutical companies, pharmacists, and civil organizations should have in conversations about caring for the nation's older adults and the obligation they have to participate in those conversations. She supported the idea of research that translates findings into action, which reminded her of the need to address diversity in clinical trials, not just in terms of race, ethnicity, and gender, but age, too, given the importance of understanding how medicines work differently across the age span. Myers also suggested that health literacy can serve as a potential approach to addressing community trust. Her final point was that the day served as a reminder to include the perspective of the caregivers of older adults when thinking about today's emphasis on getting the input of patients into the drug development process.

Vanessa Simonds from Montana State University noted that the issues discussed at the workshop will affect her directly as her young-old parents start having health issues and start interacting with the health care system whose complexity will increase the demands on them. She added that she appreciated the attention to racism and rural issues, both of which affect her family and make the context of care more complex, and the attention to building trusted relationships by finding places where people feel safe and comfortable, which can help mitigate complexity.

Olayinka Shiyanbola from the University of Wisconsin–Madison School of Pharmacy said her important learnings were that patient-centered care cannot occur without health literacy, and there is a need to teach patients and help them build confidence to ask the right questions. The other key insight she gained was about the importance of connecting with the community and how going into the community seems to get health care professionals to talk in health literate terms naturally. For her, that is a lesson that she will go back and incorporate in the way she teaches pharmacy students so that they realize that sometimes they need to get out into the community as a means of reinforcing the ability to communicate in a health literate manner.

Terry Davis from the Louisiana State University Health Sciences Center in Shreveport said she enjoyed hearing from a new group of people and forming new connections outside of the health literacy field. During the day, it struck her that consumer health-related technology is here to stay, so it is imperative to make it more user friendly for people like her who dislike patient portals and passwords.

Michael Wolf from the Northwestern University Feinberg School of Medicine agreed with Davis and said that opportunities are lost to work with certain technology tools because they are too complicated. The challenge, he said, is to determine how to harness some of these tools and modify some of these platforms so they will be useful and used by older adults. Wolf also appreciated the discussion on community and how community-based efforts may be able to help ameliorate the shortage of all levels of caregivers who can manage the multiple chronic conditions that older adults will experience. His one wish was that the workshop would have addressed how to fix a health system that is overly complex for the nation's growing population of older adults.

Jennifer Dillaha from the Arkansas Department of Health said that one concern of hers is that many geriatric patients in the United States do not receive the standard of care because they are older and supposedly do not need that level of care. Even in the cases when attempts are made to give them appropriate care, the training most health care professionals receive in geriatric medicine is poor, and clinicians struggle with providing appropriate care for many of the illnesses and conditions that affect older adults. "We have a context in which the quality of care is poor and then you layer on top of that low health literacy, and it is really a distressing and concerning situation," said Dillaha. Like other members of the roundtable, she also appreciated the emphasis on community-based services because that is where networks to support older adults and help them deal with low health literacy must develop to meet the growing demands that older adults are already placing on the nation's health care system.

Duhig applauded the workshop's emphasis on people's experiences and how they tied into the evidence base and ongoing research. He also noted the challenge of making technology more accessible for older adults and his concern that failing to do so will have large-scale negative consequences as consumer-facing technology becomes more widely adopted by the health care system. In his view, little attention has been paid to the fact that the experience of interacting with technology is different from that of someone who has grown up with technology, and that difference will require considering language, culture, and access when designing technology for older adults.

Nicole Holland from the Tufts University School of Dental Medicine was struck by the heterogeneity of older adults' experiences of independence as they age and how their relationships with family and community change. Her other comment concerned the relationship between plain language and trust as it relates to the biases that come with race, culture, and age and what it means in terms of teaching students the best practices in health literacy.

For Villaire, health literacy is about removing barriers, leveling the playing field, and being as inclusive as possible. In that vein, what struck him was the issue of social isolation that was mentioned several times during the day and the fact that caring for older adults is not solely the responsibility of the health care system. Community is key, he said, because community can create an atmosphere of inclusion, conversation, and mentorship. Age, he said, is just a label and only one aspect of who a person is, and age should not be used to pigeonhole and exclude people.

Fitzpatrick said the most striking thing she heard was the need for disruption in the long-term care industry. She noted that when she worked in the Medicaid area, she thought constantly about disparities, but she never considered disparities outside of the Medicaid population. "We are at a time when there is disruption everywhere, but I do not see many people trying to disrupt this space in long-term care," said Fitzpatrick. One concern that the day brought up for her was that technology has the potential to exacerbate health disparities, though it can also help reduce social isolation. She recounted how her father recently asked for a smartphone to replace his old flip phone because he felt disconnected from the rest of the family since he could not be part of group chats or receive pictures from the family. Now, though, the smartphone is giving him headaches because he is frustrated by its features. "I think there is more that we need to understand about technology in this population," said Fitzpatrick. Her final point was to agree with the earlier comment that health literacy can address trust issues through its role in democratizing health information. "The reason for distrust in my experience is that we do not share the information, and we do not share it in a way that people can use it and understand it," she said.

Rudd commented on topics the workshop did not address, particularly the issue of death and dying and how it is a taboo subject for discussion among so many Americans. "I think we need some way of making it easier in our society to talk about it," said Rudd. In her opinion, health literacy, with its role in focusing on dignified conversations in which people feel free to ask questions and have the words to ask those questions, can help society develop the words to have those conversations.

After voicing her support for having the roundtable take on the end-of-life discussion in a future workshop, Linda Harris from the Office of Disease Prevention and Health Promotion said value-based care and payment, which were mentioned during the workshop, provide a great opportunity to invest in thinking about how to prepare the health care delivery system to incorporate health literacy into care delivery because health systems will be held responsible for something they do not know how to do yet, which is keep people healthy rather than treat them when they are sick. Health literacy can help build a market for user-friendly tools and conversations, and involve the community in the health care delivery system. The other point she made was about the notion of self-advocacy and how health literacy can help older adults and people with disabilities learn how to be self-advocates. She noted that children with disabilities learn how to advocate for themselves, and the lessons learned there should be used to help older adults learn self-advocacy.

Cindy Brach from the Agency for Healthcare Research and Quality said she heard some themes that the roundtable has focused on over the years, including the universality of limited health literacy and the multiple and exacerbated navigation challenges that people face when they get multiple chronic conditions, a common occurrence among the elderly. One thing the workshop did not address was some of the more acute problems this population faces, particularly regarding social determinants of health, such as housing. "In the elderly, housing and health care become overlapping and almost indistinguishable problems at the point where you cannot be independent and need support," said Brach. She said she had expected to hear something about the dual-eligible population and perhaps social health maintenance organizations or new Medicare communities that are thinking about how people live, are housed, and receive care across the age continuum.

Brach then said the workshop owes a debt to Dr. Stephen Thomas for encouraging moral outrage. "If we are judging our society by how we treat the most vulnerable, then looking at the elderly as a population and particularly those at the more disadvantaged spectrum, we are not doing very well," said Brach. She said she was also struck by the dichotomy of needing to talk to both the patient and the caregiver. She said,

> I realize that while a health literacy practice is to encourage bringing a friend or family member to help you remember and ask questions, I do not think that there is guidance for health care professionals of how to incorporate those caregivers or friends and family members into the conversation.

She thought the roundtable might consider that problem and how it might be able to help that dynamic.

Gem Daus from the Health Resources and Services Administration said he was happy to learn about the village network, for he did not realize it was so formalized. He noted that the concept is prevalent in ethnic communities as a means of caring for themselves, albeit with varying degrees of success. It is important, he said, to have places where everyone knows everyone's name, for those are the locations where people can communicate with one another and have conversations about health and social connections in a health literate manner.

Suzanne Bakken from Columbia University said from her perspective as a health informatician who works with populations in which health disparities are common, much of what was discussed at the workshop is intersectional in nature in that it occurs at the intersection of social determinants of health, health literacy, and age. Intersectionality, she said, is an important concept that leads to people being increasingly disadvantaged and requires creative solutions to address. She noted a project she has been involved with that has shown that technology-based interventions are more effective at triggering behavior change when they are combined with a human component. She commented, too, that social isolation is becoming like smoking in that its adverse effects among the elderly, many of whom are socially isolated, may be profound.

What she did not hear much about was technologies other than smartphone apps. She noted that a higher proportion of African Americans and Latinos use Twitter than do non-Hispanic whites. It is also a technology that older adults are using because of its similarity to text messaging. In fact, she has been studying how Latinos caring for older adults with dementia are using Twitter and believes these studies will provide interesting information about the content and structure of caregiving. One thing she has already learned is that two of the most overwhelming aspects of caring for an older adult with dementia in the Latino community are figuring out the financial logistics and how to deal with some of the symptoms of dementia.

Emma Andrews from Pfizer Inc. said she was struck by the role the community can play in addressing health disparities in clinical trials and communicating better about medications. Another takeaway she got was that although the health care enterprise is in the business of making and delivering medications that help prolong people's lives, the elderly often feel dismissed by the health care system. She, too, reiterated the need to make technology accessible and understandable by older adults. On a personal note, she said she was born in Uganda and her parents have retired there, but she does not have to worry about who will help care for them there because the community members take care of one another at every point in life. What she takes from that is that it may be possible to use the principles of health literacy to make sure that from an early age, children realize that everyone is important and that just because someone is older does not mean they should be dismissed. She noted that some countries in Europe are encouraging intergenerational living and even offering incentives to young adults to live in an elderly community. What they are seeing in these "arranged communities" is a positive change in behaviors and attitudes toward each other in both the young and the old.

Alicia Fernandez from the University of California, San Francisco, said that what struck her was that caring for an older parent or relative is hard under even the best circumstances and that society needs to place more value on the plain work of dressing, feeding, and caring for someone. "No amount of technology is going to change that and how most of that work is done by women, overwhelmingly by immigrants and poorly paid people who are themselves struggling with issues around the intersection of knowledge, literacy, and technology." The day's discussions, she said, made her want to see more models of how other countries care for older adults and how Medicaid came to pay for in-home support services so that she can start thinking about how to change the system.

Smith observed that it is often easier for families to cope with physical illness than cognitive decline, in his opinion. He noted that this is something he has observed throughout his career as a general internist: to him, this drives home the message that one patient is not like any others. "If we bundle them all into one lump, we will not actually make progress," said Smith.

Michael McKee from the University of Michigan Medical School spoke about how fragmentation of the U.S. health care system makes it difficult for patients and providers to connect. In his opinion, the medical profession needs to go back to its roots and be better at taking a patient's history as a means of communicating with patients and forming a good connection. As social animals, humans need connection. Technology can be a facilitator of that, but it can also be a barrier.

Annlouise Assaf from Pfizer Inc. noted how her extremely active 90-year-old mother broke her leg on vacation and is now experiencing much of what was discussed today in terms of relying on others to care for her and spend time with her. Assaf said her mother complains that she is lonely, even though Assaf, her sister, and the grandchildren spend more time with her than before her injury, probably because of her loss of independence. She recounted how her mother complains that her doctors do not see her and do not listen to her because she is old. When Assaf accompanied her mother to an appointment, the doctor started talking to her rather than her mother. Assaf corrected him, and once the doctor started talking directly to her mother, her mother seemed to take ownership of her recovery and her recovery proceeded more rapidly. Assaf said it struck her that many of the health literacy problems older adults experience are similar to those experiences by people of all ages and perhaps similar to those of racial and ethnic groups, but the problems are magnified because older adults are often "invisible." "The only way you can get someone to not be invisible is to make sure they are active partners in sharing their health care decisions with their health care provider," said Assaf. "We need to figure out how to do that in the best way."

Working at Pfizer after many years in academia, her experience has been that when she speaks to her colleagues about health literacy, they tell her she is preaching to the choir. That may be, she said, but even the best choirs need to practice. "Maybe that is the gap we need to fill, that we do not practice enough, and we do not understand what it means to have this issue about health literacy."

Lindsey Robinson from the American Dental Association said the workshop resonated with so many people because of their own experiences caring for older adults or navigating the health care system themselves. In her case, her mother, who passed away from pulmonary disease, had good interactions when her clinical care team asked her what her desires and needs were and what she wanted the outcomes to be rather than simply making decisions for her because she was in her mid-70s. Her worst interactions, though, were with clinicians who decided there was nothing to do for her mother, whose disease was terminal, and that they did not even try. This made her mother depressed and was disappointing for the family around her who were desperately trying to help her. The best interaction she had with the health care system was the day before she passed away, when the physician who saw her at the interstitial lung disease clinic at the University of California, San Francisco, looked at her, took her hands and told her that he could not cure her, but he could help her feel better. "I learned a lot from that experience," said Robinson. "It helped me be a better health care provider."

Robinson, too, appreciated the moral outrage that Thomas brought to the workshop, which reminded her of the first Roundtable on Health Literacy workshop she attended on oral health literacy in 2012. Congressman Elijah Cummings (D-MD), who delivered the workshop keynote address, was outraged and moved to action over the death of a 12-year-old boy who died from a preventable oral health disease in 2007. The boy, Deamonte Driver, died of a brain infection after a lack of accessible dental care allowed bacteria from a dental abscess to move into his brain.[3] Robinson noted her appreciation for the work Thomas is doing at the community level because it offers the best opportunity to reduce health disparities, though she wishes that a dentist or hygienist was included in the groups that visit barbershops and beauty salons, given the importance of dental health to chronic disease management.

---

[3] To read the workshop summary section of Congressman Cummings's keynote address, see www.nap.edu/read/13484/chapter/3 (accessed April 23, 2018).

Offering the final comments, Rosof said he found it interesting that while the discussion started to address health care delivery, it was really the health care team that was the focus of the day. “There is no one individual who provides health care,” said Rosof. “It is really the team, and the team includes the patient, the family, and the community. I think if we begin to think about that a little bit more seriously, we will recognize that we can improve health care by team function rather than perhaps what we think about as a single caregiver.”

References

AARP Foundation. 2014. *Framework for isolation in adults over 50*. http://www.aarp.org/content/dam/aarp/aarp_foundation/2012_PDFs/AARP-Foundation-Isolation-Framework-Report.pdf (accessed April 4, 2018).

Baker, D. W., J. A. Gazmararian, J. Sudano, and M. Patterson. 2000. The association between age and health literacy among elderly persons. *The Journals of Gerontology: Series B, Psychological Sciences and Social Sciences* 55(6):S368–S374.

Baker, D. W., J. A. Gazmararian, M. V. Williams, T. Scott, R. M. Parker, D. Green, J. Ren, and J. Peel. 2002. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health* 92(8):1278–1283.

Brougham, R. R. 2009. *New directions in aging research: Health and cognition*. New York: Nova Biomedical Books.

Chesser, A. K., N. Keene Woods, K. Smothers, and N. Rogers. 2016. Health literacy and older adults: A systematic review. *Gerontology & Geriatric Medicine*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5119904 (accessed April 23, 2018).

Cutilli, C. C., and C. T. Schaefer. 2011. Case studies in geriatric health literacy. *Orthopaedic Nursing* 30(4):281–287.

Favreault, M., and J. Dey. 2016. *Long-term services and supports for older Americans: Risks and financing research brief*. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services.

Forman, D. E., A. D. Berman, C. H. McCabe, D. S. Baim, and J. Y. Wei. 1992. PTCA in the elderly: The "young-old" versus the "old-old." *Journal of the American Geriatrics Society* 40(1):19–22.

Freedman, V. A., and B. C. Spillman. 2014a. Disability and care needs among older Americans. *Milbank Quarterly* 92(3):509–541.

Freedman, V. A., and B. C. Spillman. 2014b. *Disability and care needs of older Americans: An analysis of the 2011 National Health and Aging Trends study*. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services.

Gualtieri, L., S. Rosenbluth, and J. Phillips. 2016. Can a free wearable activity tracker change behavior? The impact of trackers on adults in a physician-led wellness group. *JMIR Research Protocols* 5(4):e237.

Hanoch, Y., and T. Rice. 2006. Can limiting choice increase social welfare? The elderly and health insurance. *Milbank Quarterly* 84(1):37–73.

IOM (Institute of Medicine). 2004. *Health literacy: A prescription to end confusion*. Washington, DC: The National Academies Press. doi: https://doi.org/10.17226/10883.

IOM. 2008. *Retooling for an aging America: Building the health care workforce*. Washington, DC: The National Academies Press. doi: https://doi.org/10.17226/12089.

Kobayashi, L. C., J. Wardle, M. S. Wolf, and C. von Wagner. 2016. Aging and functional health literacy: A systematic review and meta-analysis. *The Journals of Gerontology: Series B* 71(3):445–457.

Kopera-Frye, K. 2016. *Health literacy among older adults*. New York: Springer Publishing Co.

Kuye, I. O., R. G. Frank, and J. McWilliams. 2013. Cognition and take-up of subsidized drug benefits by Medicare beneficiaries. *JAMA Internal Medicine* 173(12):1100–1107.

Lindland, E., M. Fond, A. Haydon, and N. Kendall-Taylor. 2015. *Gauging aging: Mapping the gaps between expert and public understandings of aging in America.* Washington, DC: FrameWorks Institute.

Linnan, L., S. B. Thomas, H. D'Angelo, and Y. Ferguson. 2012. African American barbershops and beauty salons: An innovative approach to reducing health disparities through community building and health education. In *Community organizing and community building for health and welfare*. 3rd edition, edited by M. Minkler. New Brunswick, NJ: Rutgers University Press.

Morris, N. S., C. D. MacLean, L. D. Chew, and B. Littenberg. 2006. The single item literacy screener: Evaluation of a brief instrument to identify limited reading ability. *BMC Family Practice* 7(1):21.

NASEM (National Academies of Sciences, Engineering, and Medicine). 2016. *Families caring for an aging America*. Washington, DC: The National Academies Press. doi: https://doi.org/10.17226/23606.

O'Neil, M., and A. Haydon. 2015. *Aging, agency, and attribution of responsibility: Shifting public discourse about older adults.* Washington, DC: FrameWorks Institute.

Paccagnella, M. 2016. Age, ageing and skills: Results from the Survey of Adult Skills. *OECD Education Working Papers, No. 132*. Paris, France: OECD Publishing. https://doi.org/10.1787/5jm0q1n38lvc-en (accessed June 19, 2018).

Sorensen, K., S. Van den Broucke, J. Fullam, G. Doyle, J. Pelikan, Z. Slonska, and H. Brand. 2012. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health* 12:80.

Sweetland, J., A. Volmert, and M. O'Neil. 2017. *Finding the frame: An empirical approach to reframing aging and ageism.* Washington, DC: FrameWorks Institute.

Thomas, S. B., S. C. Quinn, J. Butler, C. S. Fryer, and M. A. Garza. 2011. Toward a fourth generation of disparities research to achieve health equity. *Annual Review of Public Health* 32:399–416.

UN DESA (United Nations Department of Economic and Social Affairs). 2005. *World population prospects: The 2004 revision.* http://www.un.org/esa/population/publications/WPP2004/WPP2004_Volume3.htm (accessed April 23, 2018).

Victor, R. G., K. Lynch, N. Li, C. Blyler, E. Muhammad, J. Handler, J. Brettler, M. Rashid, B. Hsu, D. Foxx-Drew, N. Moy, A. E. Reid, and R. M. Elashoff. 2018. A cluster-randomized trial of blood-pressure reduction in Black barbershops. *New England Journal of Medicine* 378(14):1291–1301.

Windh, J., A. Tumlinson, J. Mulcahy, J. L. Wolff, A. Willink, J. D. Kasper, and G. L. Atkins. 2017. *Medicare spending on older adults who need long-term services and supports*. Research Brief. Washington, DC: Long-Term Quality Alliance. http://www.ltqa.org/wp-content/themes/ltqaMain/custom/images//Medicare-Spending-for-Older-Adults-Who-Need-LTSS_Research-Brief_Final.pdf (accessed April 23, 2018).

Wolff, J. L., and C. M. Boyd. 2015. A look at person- and family-centered care among older adults: Results from a national survey [corrected]. *Journal of General Internal Medicine* 30(10):1497–1504.

Wolff, J. L., and D. L. Roter. 2008. Hidden in plain sight: Medical visit companions as a resource for vulnerable older adults. *Archives of Internal Medicine* 168(13):1409–1415.

Wolff, J. L., and D. L. Roter. 2011. Family presence in routine medical visits: A meta-analytical review. *Social Science and Medicine* 72(6):823–831.

Wolff, J. L., and D. L. Roter. 2012. Older adults' mental health function and patient-centered care: Does the presence of a family companion help or hinder communication? *Journal of General Internal Medicine* 27(6):661–668.

Wolff, J. L., and B. Spillman. 2014. Older adults receiving assistance with physician visits and prescribed medications and their family caregivers: Prevalence, characteristics, and hours of care. *Journals of Gerontology. Series A: Biological Sciences and Medical Sciences* 69(Suppl 1):S65–S72.

Wolff, J. L., C. M. Boyd, L. N. Gitlin, M. L. Bruce, and D. L. Roter. 2012. Going it together: Persistence of older adults' accompaniment to physician visits by a family companion. *Journal of the American Geriatrics Society* 60(1):106–112.

Wolff, J. L., D. L. Roter, J. Barron, C. M. Boyd, B. Leff, T. E. Finucane, J. J. Gallo, P. V. Rabins, D. L. Roth, and L. N. Gitlin. 2014. A tool to strengthen the older patient–companion partnership in primary care: Results from a pilot study. *Journal of the American Geriatrics Society* 62(2):312–319.

Wolff, J. L., M. L. Clayman, P. Rabins, M. A. Cook, and D. L. Roter. 2015. An exploration of patient and family engagement in routine primary care visits. *Health Expectations* 18(2):188–198.

Wolff, J. L., A. Berger, D. Clarke, J. A. Green, R. Stametz, C. Yule, and J. D. Darer. 2016a. Patients, care partners, and shared access to the patient portal: Online practices at an integrated health system. *Journal of the American Medical Informatics Association* 23(6):1150–1158.

Wolff, J. L., J. D. Darer, and K. L. Larsen. 2016b. Family caregivers and consumer health information technology. *Journal of General Internal Medicine* 31(1):117–121.

Wolff, J. L., J. D. Darer, A. Berger, D. Clarke, J. A. Green, R. A. Stametz, T. Delbanco, and J. Walker. 2017a. Inviting patients and care partners to read doctors' notes: OpenNotes and shared access to electronic medical records. *Journal of the American Medical Informatics Association* 24(e1):e166–e172.

Wolff, J. L., Y. Guan, C. M. Boyd, J. Vick, H. Amjad, D. L. Roth, L. N. Gitlin, and D. L. Roter. 2017b. Examining the context and helpfulness of family companion contributions to older adults' primary care visits. *Patient Education and Counseling* 100(3):487–494.

Zizza, C. A., K. J. Ellison, and C. M. Wernette. 2009. Total water intakes of community-living middle-old and oldest-old adults. *The Journals of Gerontology: Series A* 64A(4):481–486.

Appendix A

Workshop Agenda

Health Literacy and Older Adults:
Reshaping the Landscape: A Workshop
March 13, 2018

Keck Center, Room 100
500 Fifth Street, NW
Washington, DC 20001

8:30–8:40	**WELCOME AND WORKSHOP OVERVIEW** *Bernard Rosof, M.D., MACP, Chair, Roundtable on Health Literacy; Professor of Medicine, Zucker School of Medicine at Hofstra/Northwell; Chief Executive Officer, Quality HealthCare Advisory Group*
8:40–10:00	**PERSONAL LANDSCAPE** Moderator: Shannah Koss, M.P.P., President, Koss on Care, LLC
8:40–9:00	**Personal Experience** *Mary Ann Zimmerman, M.S., Founding Director, Silver Spring Village*
9:00–9:20	**Health Literacy and Older Adults—What Do We Know?** *Amy Chesser, Ph.D., Assistant Professor, Wichita State University*
9:20–10:00	**Discussion**
10:00–10:15	BREAK

10:15–12:00	**THE FAMILY AND COMMUNITY LANDSCAPE** Moderator: Terri Ann Parnell, D.N.P., M.A., RN, FAAN, Member, Roundtable on Health Literacy; Principal and Founder, Health Literacy Partners
10:15–10:35	**Giving Voice to Older Adults and Caregivers: Difficult Conversations and Decisions** *Jennifer Wolff, Ph.D., Professor, Johns Hopkins Bloomberg School of Public Health*
10:35–10:55	**Vulnerable Older Adults: Health Literacy as a Tool to Ease Disparities** *Stephen B. Thomas, Ph.D., Director, Maryland Center for Health Equity; Professor, Health Services Administration, University of Maryland School of Public Health*
10:55–11:15	**Community Living, Fostering Engagement, and Independence** *Nora Super, M.P.A., Director, Aging and Disability Business Institute, National Association of Area Agencies on Aging (n4a)*
11:15–12:00	**Discussion**
12:00–1:00	LUNCH
1:00–2:30	**THE HEALTH SYSTEM LANDSCAPE** Moderator: Deidra Crews, M.D., Sc.M., Associate Professor of Medicine, Johns Hopkins University School of Medicine
1:00–1:20	**Navigating Long-Term Services and Supports** *Anne Tumlinson, Anne Tumlinson Innovations; Founder, Daughterhood.org*
1:20–1:40	**Technology as a Facilitator or Barrier for Older Adults** *Lisa Gualtieri, Ph.D., Sc.M., Assistant Professor, Tufts University School of Medicine*
1:40–2:30	**Discussion**
2:30–2:45	BREAK

2:45–4:15	**REFLECTING ON THE DAY'S PRESENTATIONS** Moderator: Rima Rudd, Sc.D., M.S.P.H., Harvard T.H. Chan School of Public Health
2:45–3:30	*Mary Ann Zimmerman, M.S., Founding Director, Silver Spring Village* *Susan D. Goodman, Blogger, Acting Our Age: Women's Lives at 85+* *Yolanda Taylor Brignoni, M.P.A., Strategic Communications Director, AARP* *Z. Colette Edwards, M.D., M.B.A., National Medical Director, Associate Health and Well-Being, Humana*
3:30–4:15	**Discussion**
4:15–5:00	**REFLECTIONS FROM THE ROUNDTABLE**
5:00	**ADJOURN**

Appendix B

Biographical Sketches of Workshop Moderators, Speakers, and Panelists

Amy K. Chesser, Ph.D., began her academic career in public health and then worked as a faculty member in a clinical department. Dr. Chesser has a passion for older adults and teaches several courses in aging studies, such as Health Communication and Aging, Death and Dying, and Advanced Perspectives of Sociology of Aging.

Deidra Crews, M.D., Sc.M., is a board-certified nephrologist and associate professor of medicine in the Division of Nephrology and associate vice chair for diversity and inclusion of the Department of Medicine at the Johns Hopkins University School of Medicine. She is jointly appointed in the Johns Hopkins University School of Nursing, and holds faculty appointments with the Welch Center for Prevention, Epidemiology and Clinical Research, the Johns Hopkins Center for Health Equity, and the Hopkins Center on Aging and Health. Dr. Crews serves as chair on the American Society of Nephrology (ASN) Diversity and Inclusion Committee; as a member of the Centers for Disease Control and Prevention Chronic Kidney Disease Surveillance Team, and the Advisory Panel on Addressing Disparities of the Patient-Centered Outcomes Research Institute; and as an editorial board member of the *Clinical Journal of the American Society of Nephrology* and *Advances in Chronic Kidney Disease*. She represents ASN on the American College of Physicians' Council of Subspecialty Societies and has previously served as chair of the ASN Chronic Kidney Disease Advisory Group. Additionally, Dr. Crews is a member of the American Board of Internal Medicine Nephrology Board. She has received several awards for her research work, including the President's Research Recognition Award of the Johns Hopkins Urban Health Institute and the Ernest Everett Just Award in Medical and Public Health Research on African American Health and Quality of Life from the College of Charleston and the Medical University of South Carolina. She is a member of the National Academy of Medicine's (NAM's) Emerging Leaders Forum and was the inaugural Gilbert S. Omenn Anniversary Fellow of the NAM. She is a member of Alpha Omega Alpha Honor Medical Society. Dr. Crews received her undergraduate degree from the University of Virginia and her M.D. from Saint Louis University. A graduate of the Osler Medical Training Program, she completed a Nephrology fellowship and an Sc.M. in Clinical Epidemiology at Johns Hopkins University.

Z. Colette Edwards, M.D., M.B.A., provides clinical leadership to optimize the health and well-being of Humana's 45,000 associates. She plays a key role in the development and delivery of a strategy that includes a holistic view of benefits, the work environment, programs, and services. Additionally, she serves as an internal consultant, providing input, feedback, identification of opportunities and best practices, and an integrated view of data to deliver actionable insights. Humana has been a 2014, 2015, 2016, and 2017 Platinum Award winner in the National Business Group on Health's "Best Employers for Healthy Lifestyles" recognition program. In 2017, Humana ranked No. 3 on the list of the "Healthiest 100 Workplaces in America," compiled by Healthiest Employers to honor the companies most successful in achieving well-being through leadership, innovation, and engagement, and achieved Gold status in the American Heart Association's Workplace Health Achievement Index, which measures the comprehensiveness and quality of a company's workplace health program and the overall heart health of its employees. Dr. Edwards is an internist and gastroenterologist who received her B.A. from Harvard University, and her M.D. and M.B.A. from the Perelman School of Medicine and the Wharton School, respectively, at the University of Pennsylvania. She completed a residency in Internal Medicine from the Hospital of the University of Pennsylvania, followed by a fellowship in Gastroenterology from the University of California, San Francisco. Dr. Edwards has also completed a graduate certificate program in health and wellness coaching from Maryland University of Integrative Health, formerly Tai Sophia Institute.

Susan Goodman, M.Ed., has worked to create services and supports for older people for most of her professional life. Her interest was sparked by personal experience: After living with her family in a crowded home, her grandmother finally had the opportunity to live on her own. In her 70s, she moved into a studio apartment in senior housing, where she flourished. Her grandmother's transformation fueled her interest in helping older people retain both their independence and their dignity. Ms. Goodman's work experiences have enabled her to view the issues from a variety of standpoints. They have included setting up a shared-living arrangement in Cambridge, Massachusetts, for women previously living in nursing homes; developing congregate and home-delivered meal programs west of Boston; spearheading the regional elder services planning for a Massachusetts Area Agency on Aging; launching a national elder care network to assist older relatives of Fortune 500 company employees; allocating corporate dollars to develop in-home support services in locations throughout the country; and directing the communications for a provider of affordable senior housing to highlight the benefits of independent living within a caring community. Throughout her career, Ms. Goodman has valued the opportunity to forge relationships with older adults. With these relationships, a faceless crowd of older adults became unique individuals with gifts to offer. In 2016, Ms. Goodman started a blog, Acting Our Age: Women's Lives at 85+, to offer others a similar opportunity to learn from the perspectives, life experiences, and wisdom of amazing—yet ordinary—women who are approaching aging with grace, grit, and humor.

Lisa Gualtieri, Ph.D., Sc.M., is an assistant professor at the Tufts University School of Medicine in the Department of Public Health and Community Medicine, where she is the director of the Digital Health Communication certificate program. Her research focuses on the use of wearable activity trackers by older adults and on the integration of data from connected health devices into clinical care. Dr. Gualtieri is the founder of RecycleHealth.com, a nonprofit that collects and refurbishes used trackers and donates them to underserved populations, including older adults, developmentally disabled adults, and veterans. She serves on the Food and Drug Administration's General Hospital and Personal Use Devices Panel. Dr. Gualtieri has a B.A. in Mathematics from the University of Massachusetts, a Ph.D. in Computer Science from Harvard University, and an Sc.M. in Computer Science from Brown University.

Shannah Koss, M.P.P., is president of Koss on Care, LLC, and co-founder of Connected Health Resources, LLC, a service company supporting easy-to-understand clinical information and navigation of health and social services. Ms. Koss is a health policy and informatics expert and strategist who has supported federal and state government health agencies and private health care businesses and organizations for more than 30 years. She has held executive positions in health information technology and health policy for consulting and health services firms, including vice president of Avalere Health, senior vice president of I-Trax, vice president of Health Solutions for Voxiva, and Health Insurance Portability and Accountability

Act (HIPAA) national practice executive at IBM. Her recent work and volunteer activities include several community-based initiatives in the state of Maryland: a pilot project for low-income seniors and disabled individuals assisting with community-based services navigation; a multidisciplinary Montgomery County, Maryland, project called Health Partners, designed to improve services for underserved populations; and Silver Spring Village, where she helped with the initial development and operations and now provides ongoing health and services expertise and support. She has also served on the Maryland Health Information Exchange Policy Board since it was established in 2010. Ms. Koss received an M.P.P. in government and industry from Harvard Kennedy School of Government.

Terri Ann Parnell, D.N.P., M.A., RN, FAAN, is a nurse, a nationally recognized health literacy expert, and an award-winning author. She is principal and founder of Health Literacy Partners, a corporation that specializes in providing a tapestry of solutions to promote health equity by enhancing person-centered care, effective communication, and the patient experience. Her recent experience includes providing health literacy education and consultation to several New York State Delivery System Reform Incentive Payment Performing Provider Systems. Previously, Dr. Parnell was vice president for Health Literacy and Patient Education for the Northwell Health System, where she was responsible for the health literacy strategic plan and integrating concepts of health literacy, language access services, and cultural awareness into core activities across the system. Dr. Parnell is a member of the National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy and has served as a committee member on the American Nurses Association Care Coordination Quality Measures Panel. She is a fellow in the American Academy of Nursing and The New York Academy of Medicine, and has been selected for the 2016–2017 New York Academy of Medicine Fellow Ambassadors Program. In 2016, Dr. Parnell joined the TVR Communications Advisory Board as their chief nursing officer. Her second book, *Health Literacy in Nursing: Providing Person-Centered Care*, received an *American Journal of Nursing* 2015 Book of the Year Award in the category of Nursing Management and Leadership. Dr. Parnell is a graduate of St. Vincent's Hospital School of Nursing in New York City. She earned a B.S. in Nursing from Adelphi University, an M.A. in Health Administration from Hofstra University, and a D.N.P. from Case Western Reserve University.

Bernard M. Rosof, M.D., MACP, is at the forefront of national initiatives in the areas of quality and performance improvement. Following completion of a fellowship in Gastroenterology at the Yale University School of Medicine, Dr. Rosof practiced internal medicine and gastroenterology for

29 years. He is a past chair of the Board of Directors of Huntington Hospital (Northwell Health) in New York and a current member of the Board of Overseers of the Health System. He is a past member of the Board of Directors of the National Quality Forum (NQF), and the co-chair of the National Quality Partnership convened by the NQF to set national priorities and goals to transform America's health care by advising the Secretary of Health and Human Services on the development of the National Quality Strategy. Dr. Rosof is the immediate past chair of the Physician Consortium for Performance Improvement convened by the American Medical Association that continues to lead efforts in developing, testing, and implementing evidence-based performance measures for use at the point of care. He was a member of the Clinical Performance Measurement Committee of the National Committee for Quality Assurance, and the chair of the Physician Advisory Committee for the UnitedHealth Group. He has chaired committees for the New York State Department of Health (DOH) and the Institute of Medicine, and currently serves as chair of the National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy, as well as the DOH Committee on Quality in Office Based Surgery. Dr. Rosof is CEO of the Quality HealthCare Advisory Group, which provides strategic consultative services to the community of health care providers interested in improving the quality and safety of health care delivery in our nation. He is a professor in the Department of Medicine at the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell. Dr. Rosof is the recipient of the Laureate Award from the American College of Physicians and the Theodore Roosevelt Award for Distinguished Community Service. Dr. Rosof is also the recipient of the 2012 Stengel Award from the American College of Physicians (ACP) for outstanding service to the ACP and his influence in maintaining and advancing the best standards of medical education, medical practice, and clinical research, and received the New York University Alumni Leadership Award in 2016.

Rima Rudd, Sc.D., M.S.P.H., is the senior lecturer on health literacy, education, and policy at the Harvard T.H. Chan School of Public Health. Her work centers on health communication and on the design and evaluation of public health community-based programs. She has been teaching courses on innovative strategies in health education, program planning and evaluation, psychosocial and behavioral theory, and health literacy since 1988. Dr. Rudd focuses her research inquiries and policy work on literacy-related disparities and literacy-related barriers to health programs, services, and care, working closely with the adult education, public health, oral health, and medical sectors. Dr. Rudd wrote several reports that helped shape the agenda in health literacy research and practice. They include the health literacy chapter of the Department of Health and Human Services report

Communicating Health: Priorities and Strategies for Progress (2003) and the 2010 *National Call for Action*. She coded all health-related items in the international surveys for assessments of adult literacy skills enabling the United States, Canada, Australia, New Zealand, and other countries to assess national health literacy skills. She authored the Educational Testing Services Report *Literacy and Health in America* (2004) and contributed to other national assessments. Dr. Rudd provided two in-depth literature reviews (*Review of Adult Learning and Literacy*, volume 1 in 2000 and volume 7 in 2007). She served on the Institute of Medicine Committee on Health Literacy, the National Research Council Committee on Measuring Adult Literacy, the National Institute of Dental and Craniofacial Research Workgroup on Oral Health Literacy, and the Joint Commission Advisory Committee on Health Literacy and Patient Safety. Dr. Rudd contributed to the ensuing reports and white papers as well as to several publications of the Roundtable on Health Literacy. She has received national and international awards for her work in health literacy. Most recently, the University of Maryland named a doctoral scholar's award in her honor.

Nora Super, M.P.A., serves as the director of the Aging and Disability Business Institute at the National Association of Area Agencies on Aging (n4a). To respond to the growing demand for home- and community-based organizations (CBOs) in the evolving health care marketplace, CBOs have been increasing their business acumen and organizational capacity. Building on several years of support from The John A. Hartford Foundation, the U.S. Administration for Community Living, The SCAN Foundation, the Gary and Mary West Foundation, the Colorado Health Foundation, and the Buck Family Fund of the Marin Community Foundation, the Aging and Disability Business Institute (Business Institute) was created in 2016 to successfully build and strengthen contract-based partnerships between CBOs and the health care system. Led by n4a, in partnership with several leading aging and disability organizations, the Business Institute serves as a national resource center for agencies interested in acquiring the tools and resources to successfully adapt to a changing health care environment, enhance their organizational capacity, and capitalize on emerging opportunities to diversify funding. Prior to joining n4a, Ms. Super served as the executive director of the 2015 White House Conference on Aging, where she directed a nationwide effort to identify and advance actions to improve the quality of life of older Americans. Ms. Super has worked in a variety of leadership roles in the public and private sectors, including academia, and has served in government at the federal, state, and local levels, and as congressional staff. A native of New Orleans, Ms. Super studied Political Science at Tulane University and completed her M.P.A. with a concentration in Health Policy at George Washington University.

Yolanda Taylor Brignoni, M.P.A., is AARP's strategic communications director for health and healthy living. In this role, she works across AARP's 30+ communications channels and platforms to ensure the organization delivers effective and impactful health communications to its 38 million members and all consumers ages 50 and older. She brings with her more than 15 years of experience conceiving and executing strategic communications campaigns to motivate action and fuel social change domestically and globally. A versatile professional with crisis management and multimedia agency experience, Ms. Taylor Brignoni has directed health communications campaigns for government, corporate, and nonprofit clients. Prior to joining AARP, she was the communications director for the United Nations (UN) Foundation's Women & Population program, where she elevated and grew the program's executive and programmatic brand, and amplified the work of UN agencies, executive directors, and ambassadors. She has won several accolades for her work in communications and journalism, including awards from *PR News* and PRWeek on event public relations and multicultural communications, as well as awards from the Georgia Press Association for feature (health) and religion writing. Ms. Taylor Brignoni holds a B.A. in Newspapers and a B.A. in International Affairs from the University of Georgia, and an M.P.A. from George Washington University.

Stephen B. Thomas, Ph.D., is the director of the Maryland Center for Health Equity and professor of health services administration in the School of Public Health at the University of Maryland, College Park. Dr. Thomas is one of the nation's leading scholars on community-based interventions to eliminate racial and ethnic health disparities, including obesity, diabetes, hypertension, HIV/AIDS, and violence. He is principal investigator of the Center of Excellence on Race, Ethnicity and Disparities Research funded by the National Institutes of Health's (NIH's) National Institute on Minority Health and Health Disparities (NIMHD), includes teams of scientists conducting targeted research on obesity, vaccine acceptance, and men's health. Dr. Thomas is also principal investigator on the NIH NIMHD National Bioethics Research Infrastructure Initiative, "Building Trust Between Minorities and Researchers," which focuses on "plain-language" delivery of scientifically sound and culturally relevant research with racial and ethnic minority populations. He served as the Philip Hallen Professor of Community Health and Social Justice at the University of Pittsburgh's Graduate School of Public Health (2000–2010). He was awarded the 2005 David Satcher Award from the Directors of Health Promotion and Education for his leadership in reducing health disparities through health literacy and the improvement of health promotion and disease prevention programs for adults ages 50 and over. In 2004, he received the Alonzo Smyth Yerby Award from the Harvard T.H. Chan School of

Public Health for his work with people suffering poor health literacy and the health effects of poverty.

Anne Tumlinson is the founder of Anne Tumlinson Innovations and Daughterhood.org. She develops ideas to improve how we finance and deliver care to frail older adults. Ms. Tumlinson has testified before the U.S. House Energy and Commerce Committee, the U.S. Senate Aging Committee, the Congressional Long-Term Care Commission, and the Bipartisan Policy Center. Her testimony has consistently emphasized the need for care delivery redesign for frail older adults and long-term care financing reform. In support of this work, Ms. Tumlinson researches, writes, and speaks about innovation in aging services, contributing to *Health Affairs Blog*, *McKnight's Long-Term Care News*, Twin Cities PBS's *Next Avenue* blog, and MariaShriver.com. Ms. Tumlinson has also created a consumer website, daughterhood.org, to create community for families navigating the health and elder care systems on behalf of their loved ones. Among other affiliations, Ms. Tumlinson serves on the Board of Directors of the Caregiver Action Network and the Aetna Medicaid Advisory Panel, and on the conference planning committee for the National Investment Center for Seniors Care.

Jennifer Wolff, Ph.D., is a professor of health policy and management at the Johns Hopkins Bloomberg School of Public Health, with a joint appointment in the Division of Geriatric Medicine and Gerontology in the Johns Hopkins University School of Medicine. She also has an appointment as a core faculty member in the Johns Hopkins Center on Aging and Health. Dr. Wolff has more than 15 years of experience as a funded investigator in health services research and gerontology. Her research has focused primarily on late-life family caregiving and innovative models of care for older adults with complex health needs. Her most recent work has focused on developing interventions that more effectively involve family caregivers in older adults' primary care.

Mary Ann Zimmerman, M.S., retired in 2012 from a contractor position with the Department of State Bureau for Conflict and Stabilization Operations as senior training advisor. She is a civil engineering graduate from Purdue University, where she received the Distinguished Engineering Alumna Award (the first woman to be so named). Ms. Zimmerman has worked for the American Public Works Association and City of Chicago as a traffic engineer; at Cummins Inc. in a variety of technical management positions; and as a management consultant in more than 25 countries, primarily in sub-Saharan Africa and Eastern Europe. She has lived in downtown Silver Spring, Maryland, since 1993. Since retirement, Ms. Zimmerman has returned to her roots as an active participant in the Silver Spring community by serving on the founding Board of Directors of the Silver Spring Village, as well as two terms as secretary. She chairs the Board's Resource Development Committee. Other current local affiliations include the Silver Spring Citizen Advisory Board and the Kensington–Rockville (and previously Silver Spring) Branch of the American Association of University Women. Past affiliations include Washington Metropolitan Area Transit Authority Riders' Advisory Council, Silver Spring Town Center, Inc., First Night Montgomery, Silver Spring Urban District Advisory Board, and the Montgomery County Blue Ribbon Panel on Pedestrian and Traffic Safety. She is a graduate of Leadership Montgomery and the IMPACT Silver Spring community empowerment program.