Healthcare Navigation and Decision Making

Perspectives of Adults Aged 65 and Older and Family Caregivers

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Executive Summary

As adults age, the ability to navigate the healthcare system and make informed healthcare decisions is crucial. Family caregivers, likewise, often are called upon to navigate the healthcare system on behalf of those for whom they care. To better understand the perspectives and needs of older adults—those aged 65 and older—and family caregivers/care partners when making healthcare decisions and navigating the healthcare system, FAIR Health, a national, independent nonprofit organization, commissioned ENGINE Insights to conduct a study comprising two national surveys¹ that assessed perspectives of older adults and family caregivers/care partners on healthcare decision making (including shared decision making), the impact of healthcare costs on healthcare decisions, and challenges in navigating the healthcare system.

Key findings included the following:

- One in four older adults reported that they never know the costs of healthcare services before getting a bill.
- Though a significant proportion of older adults consider healthcare costs to be an important factor when making healthcare decisions, more than a third have difficulty getting such cost information.
- Among older adults, encountering difficulties in obtaining cost information may be an obstacle to accessing needed healthcare.
- More than one in four older adults reported putting off or skipping needed healthcare due to cost; those with lower household incomes were more likely to report forgoing needed care compared with older adults with higher household incomes.
- Family caregivers/care partners generally take part in shared decision-making discussions with their care receiver (the person for whom a caregiver provides care) and healthcare providers and/or teams.

¹ Support for the surveys was provided by The John A. Hartford Foundation. Based in New York City, The John A. Hartford Foundation is a national, private, nonpartisan philanthropy dedicated to improving the care of older adults. Established in 1929, the Foundation has three priority areas: creating age-friendly health systems, supporting family caregiving, and improving serious illness and end-of-life care. For more information, visit johnahartford.org and follow @johnahartford on Twitter.
Executive Summary

• When asked from where they learn about health and healthcare, family caregivers reported the following top three sources of information: healthcare providers, followed by websites/the web and family members.
• Family caregivers/care partners expressed an appetite and need for healthcare information, resources and tools that facilitate better decisions about their care receiver’s care.

These findings reveal the challenges and opportunities for supporting older adults and family caregivers/care partners in navigating the healthcare system. The findings underscore the appetite and need for resources and tools that provide objective cost information for healthcare services for older adults and caregivers/care partners to better navigate the healthcare system and make informed healthcare decisions. Tools that facilitate informed healthcare decision making, including shared decision making among patients, caregivers/care partners and healthcare providers, may help older adult patients and their caregivers/care partners navigate the healthcare system with greater ease.
Introduction

In recent years, healthcare consumers have had to navigate an increasingly complex healthcare system in order to make informed healthcare decisions that take their preferences into account. Patients aged 65 and older, especially those with multiple comorbidities, face significant additional barriers when navigating the healthcare system to access high-quality care and services. Barriers to high-quality care may be due to a lack of coordination between healthcare providers, conflicting recommendations from different healthcare professionals, inadequate guidance and the inability to understand insurance plans, often leading to fragmented care and higher treatment costs. Research suggests that patients prefer to know the cost of care before receiving it, but often do not discuss costs with their providers, despite evidence showing that cost-related conversations may decrease noncompliance with treatment plans due to financial distress. Similarly, family caregivers/care partners, who assume a wide range of responsibilities related to care coordination and direct care, may possess limited resources and training to help them navigate the healthcare system on behalf of their care receiver and manage the associated costs.


5 Lee et al., “Experiences of Older Primary Care Patients with Multimorbidity and Their Caregivers in Navigating the Healthcare System.”


Introduction

Shared decision making—the process by which healthcare providers, patients and caregivers/care partners decide the best treatment and care options based on clinical evidence, potential risks and outcomes and patients’ preferences and values—shows promise for reducing unnecessary spending⁹ and healthcare costs¹⁰ and for improving decision making without having an adverse effect on clinical outcomes.¹¹ This is especially important considering the growing issue of “financial toxicity”—the financial, emotional and mental burden patients experience with medical costs that can lead to diminished access to care and a reduced quality of life.¹²,¹³ Various studies have suggested an association between shared decision making and increased patient satisfaction,¹⁴ decreased symptom burden,¹⁵ increased knowledge, improved clinical interaction and communication between patients and their healthcare providers and clinicians,¹⁶ and reduced spending.¹⁷

Shared Decision Making

The process by which healthcare providers, patients and caregivers/care partners decide the best treatment and care options based on clinical evidence, potential risks and outcomes and patients’ preferences and values.

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¹⁵ Yahanda and Mozersky, “What's the Role of Time in Shared Decision Making?”


¹⁷ Lee and Emmanuel, “Shared Decision Making to Improve Care and Reduce Costs.
Introduction

Thus, there is a growing interest in shared decision making for older adults given its potential to improve the quality of healthcare for patients, particularly older adults who rely more heavily on healthcare services as they age. Shared decision making may not be limited to the clinician-patient dyad when a patient is an older adult with complex health needs. In these cases, “triadic decision making,” involving the healthcare team, caregiver/care partner and patient, may help assure that all views are accounted for and minimize discordance during the decision-making process.


Introduction

FAIR Health, a national, independent nonprofit organization, commissioned a study comprising two national surveys as part of “A National Initiative to Advance Cost Information in Shared Decision Making for Serious Health Conditions,” which is generously supported by The John A. Hartford Foundation. This initiative was designed to provide adults aged 65 and older, especially those with serious illnesses, and their caregivers/care partners with the information and resources needed to make informed healthcare decisions and better navigate the healthcare system. Building on the success of its award-winning consumer website, fairhealthconsumer.org in English and fairhealthconsumidor.org in Spanish, and prior shared decision-making initiatives, FAIR Health will pilot new shared decision-making tools and total treatment cost scenarios in the latter half of 2022 —accompanied by a rich array of educational content and resources—for conditions that commonly affect older adults. Survey findings in this report, supported by additional sources of information, will help shape the development of these tools and related educational offerings.
Methodology

To better understand the perspectives and needs of adults aged 65 and older and family caregivers/care partners when navigating the healthcare system, researching healthcare costs and making healthcare decisions, FAIR Health commissioned ENGINE Insights to field two national surveys: one with adults aged 65 and older and the other with family caregivers/care partners. The survey for adults aged 65 and older was fielded from November 2 to November 7, 2021. The survey for family caregiver/care partners was fielded from November 3 to November 10, 2021. The study utilized random sampling to select respondents in the continental United States. The older adult survey respondents were a random sample of 1,005 adults aged 65 and over, with a margin of error of +/- 3.1 percent at the 95 percent confidence level. The family caregiver/care partner survey included a random sample of 507 adults aged 18 and over who ever provided care for someone else, with a margin of error of +/- 4.4 percent at the 95 percent confidence level.

Both the older patient and family caregiver/care partner surveys were distributed nationwide and targeted populations meeting the above-mentioned criteria. To assure a true representative sample of the US population, both surveys were set to match the Current Population Survey (US Census). The survey data are representative of demographic factors that include race/ethnicity, age, gender, region, household income, current employment status, marital status and children in the household and community types (i.e., urban, suburban and rural). Respondents submitted their responses using devices that included desktops/laptops, tablets and smartphones.

ENGINE Insights is a research and data analytics company that utilizes its expertise in research strategy, data analytics and scientific insights to help organizations understand consumer behaviors.
Results

The surveys elicited responses from older adults and family caregivers and care partners related to the knowledge of healthcare costs and decision making, navigating the healthcare system, attitudes and practice of shared decision making, access to care and sources of information about health and healthcare. A summary of the findings follows.

*Healthcare Costs and Their Role in Healthcare Decision Making*

- **One in four older adults (aged 65 and older) never know the costs of healthcare services before getting a bill.** Although 32 percent of older adults reported that they “sometimes” know the costs of healthcare services before receiving their bill, 25 percent of older adults reported that they “never” know costs of healthcare services before receiving their bills, while 21 percent reported that knowing their healthcare costs in advance depended on whether the care was given by healthcare providers in their health plan network or not in their health plan network. (See Figure 1.) Among the respondents, a higher proportion of older Hispanic adults (27 percent), older adults with a high school diploma or less (29 percent) and those aged 76 and older (33 percent) reported never knowing the costs of the services they receive before getting their bill. (See Figures 2 through 4.)

![Pie chart showing survey responses on knowing healthcare costs](image)

**Figure 1.** When you seek healthcare, how often do you know how much it will cost before you get a bill?
Figure 2. When you seek healthcare, how often do you know how much it will cost before you get a bill? (Hispanic Ethnicity)
Results

Figure 3. When you seek healthcare, how often do you know how much it will cost before you get a bill? (Educational Attainment)

Figure 4. When you seek healthcare, how often do you know how much it will cost before you get a bill? (Age Groups)
Results

- A significant proportion of older adults consider healthcare costs to be an important factor when making healthcare decisions; more than a third have difficulty getting such cost information. Thirty-seven percent of older adults felt that healthcare costs are an “important” factor when making healthcare decisions, while 22 percent felt that it was the “most important” factor when making healthcare decisions. Sixteen percent of older adults reported that healthcare costs were “a thought” when making a healthcare decision, while 24 percent reported that they do not think about out-of-pocket cost when making a healthcare decision. (See Figure 5.) However, 35 percent reported that they found getting information about their healthcare costs to be “somewhat hard” or “very hard.” (See Figure 6.)

![Figure 5. How important to you is the cost of care when making a decision about your care—whether it is emergency, urgent or routine care?](image-url)
Results

Figure 6. How easy is it to get facts and see what your healthcare costs will be?

- Most older adults are comfortable with speaking to their healthcare providers and clinicians about the costs of care but rarely do so. Although 69 percent of older adults are comfortable speaking to their healthcare providers about the costs of care (see Figure 7), 77 percent of respondents reported that they “never” (28 percent) or “not very often” (49 percent) spoke about costs with their healthcare providers. Only 22 percent reported that they spoke about healthcare costs with their healthcare providers and/or healthcare teams (see Figure 8).

Figure 7. Are you comfortable with speaking to your healthcare providers and/or your healthcare team about the cost of care?
Results

A significant proportion of family caregivers/care partners also consider out-of-pocket costs an important factor when making healthcare decisions. Twenty-seven percent of caregivers/care partners felt that out-of-pocket costs are an “important” factor when making healthcare decisions, and 29 percent felt that they were the “most important” factor when making healthcare decisions. Thirty percent reported that they do not think about out-of-pocket costs when deciding about their care receiver’s care, while 13 percent reported that cost was “a thought” in decisions about their care receiver’s care. (See Figure 9.)
Results

• Family caregivers/care partners are more knowledgeable about their care receivers’ care.

Seveny-four percent of caregivers/care partners described themselves as “well informed” or “very well informed” about their care receivers’ health issue(s) and care. (See Figure 10.)

Figure 10. How informed are/were you about your care receiver’s health issue(s) and care?
Results

• The reported importance of healthcare costs in healthcare decision making varies slightly among family caregivers/care partners depending on certain factors such as the relationship to the person for whom they provide care, age of children in the household, income, gender, age, type of community setting, employment status and marital status. Caregivers caring for siblings (42 percent), those with children aged 17 and younger (42 percent), and those with a household income of $100,000 and above (42 percent) were significantly more likely to report that out-of-pocket costs are “most important” in deciding care and treatment plans. Likewise, male caregivers (33 percent), caregivers between the ages of 35 and 44 (47 percent), caregivers with a college degree and up (37 percent), caregivers residing in urban settings (42 percent), employed caregivers (38 percent) and married caregivers (36 percent) also cited healthcare costs as the “most important” factor in making healthcare decisions. Among the age cohorts, 43 percent of caregivers between the ages of 55 and 64, and 49 percent of caregivers aged 65 and older, “don’t think” about out-of-pocket costs when making decisions about their care receivers’ care. (See Figures 11 through 17.)
Results

Figure 11. How important are out-of-pocket costs to you (costs you pay with your own money) in decisions about your care receiver’s care? (Relationship to Care Receiver)
Results

Figure 12. How important are out-of-pocket costs to you (costs you pay with your own money) in decisions about your care receiver’s care? (Presence of Children in the Household)

Figure 13. How important are out-of-pocket costs to you (costs you pay with your own money) in decisions about your care receiver’s care? (Gender)
Results

Figure 14. How important are out-of-pocket costs to you (costs you pay with your own money) in decisions about your care receiver’s care? (Age Group)
Results

Figure 15. How important are out-of-pocket costs to you (costs you pay with your own money) in decisions about your care receiver's care? (Type of Community Setting)
Results

Figure 16. How important are out-of-pocket costs to you (costs you pay with your own money) in decisions about your care receiver’s care? (Employment Status)

Figure 17. How important are out-of-pocket costs to you (costs you pay with your own money) in decisions about your care receiver’s care? (Marital Status)
Results

- While a significant proportion of family caregivers/care partners consider costs to be an important factor in making decisions about their care receivers’ care, most do not discuss costs with healthcare providers. Thirty-four percent of caregiver respondents felt that healthcare costs should be an “important” factor to healthcare providers in decisions about their care receivers’ care, while 30 percent felt that it should be “most important” to their care receivers’ healthcare providers and/or teams. Twenty-four percent of caregiver respondents reported that they did not want the healthcare provider to think about out-of-pocket costs in decisions about their care receiver’s care, while 13 percent felt that costs should be “a thought” for healthcare providers in decisions about their care receivers’ care. (See Figure 18.) However, only 42 percent reported that they discussed those costs with their care receivers’ healthcare providers and/or teams. (See Figure 19.) Among the subset of caregiver respondents who reported that they do not discuss costs with their care receivers’ healthcare providers and/or teams, 64 percent would not like to engage in such discussions. (See Figure 20.)

Figure 18. How important should cost be to your care receiver’s healthcare provider in decisions about your care receiver’s care?
Results

Figure 19. Do/did you talk about costs of care with your care receiver’s healthcare provider or healthcare team?

Figure 20. Would you like to talk about costs of care with your care receiver’s healthcare provider? (Asked of subset of caregiver respondents who reported that they do not discuss costs with their care receivers’ healthcare providers and/or teams)
Results

- Educational levels among family caregivers/care partners correlated with differences in how important they feel healthcare costs are to making decisions about their care receivers’ care. Among caregiver respondents with a high school degree or lower (n=146), 52 percent indicated that healthcare costs were “most important” (25 percent) or “important” (27 percent) in healthcare decisions regarding their care receiver’s care. Comparatively, 63 percent of caregiver respondents with at least a college degree (n=165) indicated that healthcare costs were “most important” (37 percent) or “important” (26 percent) in healthcare decisions regarding their care receiver’s care. (See Figure 21.)

Figure 21. How important are out-of-pocket costs to you (costs you pay with your own money) in decisions about your care receiver’s care? (Educational Attainment) [Base: High school graduate or less = 146, Some college = 196, College graduate or above = 165]
Results

Attitudes toward Shared Decision Making

• Despite a strong interest in having shared decision-making discussions, just under a third of older patients report never having engaged in such conversations with their healthcare providers and/or healthcare teams. Forty-five percent of older adults are “interested” or “very interested” in having shared decision-making discussions with their healthcare providers and/or healthcare teams. (See Figure 22.) Moreover, 41 percent reported that they “always” or “often” take part in such discussions with healthcare providers. However, 29 percent reported that they have “never” engaged in shared decision making with their healthcare providers. (See Figure 23.)
Figure 23. Shared decision making (SDM) is the discussion between patients and their healthcare providers. SDM balances what’s most important to patients with information on the pros and cons of different care. These discussions are often helped by decision aids that show different choices. How often do you take part in SDM with your healthcare providers?
Results

• Family caregivers/care partners are interested in having shared decision-making discussions with care receivers and healthcare providers, believing that such discussions are preferred by those for whom they provide care. Almost 40 percent of caregivers/care partners reported that they believed that their care receivers would want to make healthcare decisions with them and/or their healthcare providers/teams, while 21 percent reported that their care receivers would want to share their thoughts but not make final decisions. (See Figure 24.) Moreover, a little more than half (54 percent) of the caregiver respondents expressed that they were “interested” or “very interested” in engaging in shared decision-making discussions with those for whom they provide care and their healthcare teams. (See Figure 25.)

Figure 24. In general, to what extent do you think your care receiver would like to be involved in decision making about their care?
Results

Figure 25. How interested are/were you in SDM with your care receiver and their healthcare provider(s)?
• **Family caregivers/care partners generally take part in shared decision-making discussions with their care receivers and their healthcare providers and/or teams.** Thirty-two percent of caregiver respondents reported that they “often” take part in shared decision making, while 28 percent reported that they engage in shared decision-making discussions “always” and 27 percent reported that they do so “every now and then.” (See Figure 26.)

**Figure 26.** Shared decision making (SDM) is the discussion between patients and their healthcare providers. SDM balances what’s most important to patients with clinical evidence about different types of care. These discussions are often helped by decision aids that show different choices. How often do/did you take part in SDM with your care receiver and their healthcare provider(s)?
Results

Family Caregiver Involvement in Decision Making

- When family caregivers were asked about their preferences regarding how involved they would like to be in decision making about their care receiver’s care, no single preference garnered a majority of support. Twenty-six percent of caregivers/care partners reported that they wanted to make these decisions with their care receivers. Twenty-three percent, however, reported that they wanted to engage in decision making with both their care receivers and healthcare providers. (See Figure 27.)

Figure 27. How involved would you like to be in decision making about the care of your care receiver?
Results

- Older adults with family caregivers/care partners rely on the assistance of their caregivers/care partners to help make decisions about their care. Of the 151 older adults who reported that they have someone to help them take care of themselves and accompany them to doctor’s visits, 23 percent reported that their caregivers/care partners “always” take part in their healthcare decision making, 32 percent reported that their caregivers/care partners take part “often” and 31 percent reported that they participate “every now and then.” (See Figure 28.)

![Figure 28. How often does your care partner take part in your healthcare decision making? (n = 151)](image-url)
Results

Healthcare Costs, Access and Utilization

- Among older adults, encountering difficulties in obtaining cost information may be an obstacle to accessing needed healthcare. In response to the question, “How easy is it to get facts and see what your healthcare costs will be?,” 35 percent said that it was “somewhat hard” or “very hard” to do so. Of this group, 27 percent reported that this difficulty got in the way of their ability to access needed care and 21 percent reported that it discouraged them. (See Figure 29.)

Figure 29. You mentioned it is “somewhat hard” or “very hard” to get facts and see what your healthcare costs will be. How does this change your ability to get needed care?
Results

- More than one in four (26 percent) older adults reported putting off or skipping needed healthcare due to cost. (See Figure 30.) Notably, 45 percent of older adult respondents with children in the household reported skipping needed care due to cost. (See Figure 31.) Older adults with lower household incomes were more likely to report forgoing needed care compared with older adults with higher household incomes: Thirty-two percent of older adults with household incomes below $50,000 reported that they skipped getting needed healthcare due to healthcare costs. This compared with 19 percent of older adults with household incomes between $50,000 and $100,000 and 16 percent of those with household incomes above $100,000. (See Figure 32.) Furthermore, among the age cohorts, adults between the ages of 65 and 75 were more likely to report that they skipped care (27 percent) than those aged 76 and older (18 percent). (See Figure 33.) However, among the older adult respondents, a higher proportion of older adults residing in rural areas (31 percent) and older women (30 percent) reported putting off or skipping much needed healthcare due to cost. (See Figures 34 and 35.)
Results

Figure 31. Have you ever put off or skipped needed healthcare due to cost? (Presence of Children in the Household)
Results

Figure 32. Have you ever put off or skipped needed healthcare due to cost? (Income)

Figure 33. Have you ever put off or skipped needed healthcare due to cost? (Age Group)
Results

Figure 34. Have you ever put off or skipped needed healthcare due to cost? (Type of Community Setting)

Figure 35. Have you ever put off or skipped needed healthcare due to cost? (Gender)
Results

- Among the different types of healthcare services presented, dental care was reported to be the most utilized service among older adults. Thirty-seven percent of older adults reported that they utilize dental care services twice a year. In comparison, only nine percent reported that they utilize healthcare services for life-long health issues/disabilities twice a year. (See Figure 36.)

Figure 36. How often do you use this care?
Results

Navigating the Healthcare System and Barriers to Informed Decision Making

• Many older adults attend doctor’s visits and manage their healthcare services without the help of a caregiver/care partner. Most older adults (63 percent)—regardless of gender, age group, race/ethnicity and household income—reported that they do not have caregivers/care partners who accompany them to doctor’s visits, suggesting that a significant proportion of adults aged 65 and older navigate the healthcare system by themselves. (See Figure 37.)

Figure 37. How often do you have someone who comes to healthcare visits with you?

“ How often do you have someone who comes to healthcare visits with you? ”
Results

- Most older adult respondents (57 percent) reported no barriers to making informed healthcare decisions. Those that did reported the following top three barriers to making informed decisions: the preferences of healthcare providers (16 percent), not enough time with healthcare providers (12 percent) and not being able to understand the medical language (9 percent). (See Figure 38.)

![Figure 38. What are the greatest barriers to making informed decisions about your health and care?](image)
Results

- Compared with older adults with at least some college, older adults with a high school diploma or less were more likely to cite as the top three barriers: can’t understand the medical language, don’t know where to look for information and too many medications to keep track of. (See Figure 39.)

Figure 39. What are the greatest barriers to making informed decisions about your health and care? (Top Three Barriers) (Educational Attainment)
Results

• While a significant proportion of family caregivers (29 percent) reported not having any roadblocks to making decisions about their care receiver's care, those who did reported the following top three barriers: Working full-time and not having time (14 percent), not enough time with healthcare providers (13 percent) and too many health issues to keep track of (11 percent). (See Figure 40.)

Figure 40. What is the greatest roadblock to staying informed when making or helping make a decision about your care receiver's healthcare?
Results

Need for Healthcare Resources and Tools for Family Caregivers/Care Partners

- When asked where they learn about health and healthcare, family caregivers reported the following top three sources of information: healthcare providers (59 percent), websites/the web (43 percent) and family members (41 percent). (See Figure 41.)

Figure 41. Where do you learn about health and healthcare?
Results

• Family caregivers/care partners have a significant need and appetite for healthcare information, resources and tools that help them make better decisions about their care receiver’s care. When asked about the kinds of information, resources and tools that would help them make better decisions about their care receivers’ care, most caregivers/care partners selected information about providing better care for their care receivers (42 percent) and costs of care (40 percent), followed by clinical information (35 percent), educational trainings to help care partners steer through the healthcare system (33 percent), information about different models of care that can coordinate different services (31 percent) and tools that outline different care choices with costs (30 percent). (See Figure 42.) Most caregivers/care partners would prefer to access such information, resources and tools via a website (63 percent); an app on a mobile device, like a phone or tablet (45 percent); and paper (hard) copies (39 percent). (See Figure 43.)

Most caregivers/care partners would prefer to access healthcare information, resources and tools via:

• 63% website;
• 45% an app on a mobile device, like a phone or tablet; and
• 39% paper (hard) copies.
Results

Figure 42. What types of resources, tools or support would help you make better decisions about your care receiver’s care?
Results

Figure 43. How would you like to get this information or training?
Discussion

FAIR Health’s study shed light on how older adults and family caregivers/care partners navigate the healthcare system and make healthcare decisions. Results highlighted the perceived importance and role of costs in healthcare decision making and care access. The study’s findings underscore challenges facing adults aged 65 and older and their caregivers, as well as potential solutions to address such issues, particularly in the context of the COVID-19 pandemic and its anticipated myriad long-term sequelaes. As the US population grows older—it is anticipated that by 2060 the number of adults 65 and older will grow by 69 percent\(^25\)—the findings’ micro- and macro-level implications may be helpful to improving how older adults and caregivers/care partners navigate the healthcare system.

Healthcare Costs, Navigation and Access

While 37 percent of older adults felt that healthcare costs are an “important” factor when making healthcare decisions and 22 percent felt that it was the “most important” factor when making healthcare decisions, a finding that accords with prior research,\(^26\) one in four older adults reported that they “never” know the costs of their healthcare services prior to receiving a bill. For 35 percent of older adult respondents, getting information about their healthcare costs was reported as “somewhat hard” or “very hard.” Among those who reported this difficulty, 27 percent noted that the inability to get facts about healthcare costs gets in the way of accessing needed care, and another 21 percent reported that it discourages them from doing so. More concerning, 26 percent of older adults reported delaying or forgoing needed care due to cost. Notably, this was more pronounced among older adults who fell into the following categories: those who reside in rural areas, those who were women, those with children in the household or those with incomes below $50,000.


Discussion

Indeed, economic and financial burdens pertaining to healthcare have weighed on US residents, particularly amid the COVID-19 pandemic. In a survey conducted by Gallup and West Health, just under a quarter of US adults reported that healthcare costs were a major financial burden for their families.27 With the majority of those 65 and older covered by Medicare—which currently does not cover dental, hearing, vision or long-term care services and whose high cost-sharing features have been noted28—the FAIR Health findings, which suggest that the ability to access care and navigate the healthcare system may be hindered by cost-related challenges, are especially noteworthy in the context of prior research. The Commonwealth Fund’s 2021 International Health Policy Survey of Older Adults found that, compared with those in other high-income countries, older adults in the United States pay more for healthcare and are more likely to delay or skip care due to cost-related reasons.29 Additionally, in 2020, just more than 35 percent of insured adults ages 60 to 64 paid $2,000 or more in out-of-pocket healthcare costs, compared to 20 percent of adults aged 65 and older.30 Another study found that higher levels of education were associated with lower likelihood of postponing or skipping care due to cost.31

29 Gretchen Jacobson et al., When Costs Are a Barrier to Getting Health Care: Reports from Older Adults in the United States and Other High-Income Countries, The Commonwealth Fund, October 2021, https://doi.org/10.26099/m7jm-2n91.
Discussion

Research conducted by the Kaiser Family Foundation has shown the potential for Medicare beneficiaries to encounter high out-of-pocket costs for hearing, vision and dental services. In a departure from these findings, a recent study that compared private and public insurance options found that individuals with employer-sponsored insurance were more likely to report higher costs of care, poorer access to care and medical debt than those on public insurance such as Medicare and Medicaid.

The finding that rural residents and women are more likely to report delaying or skipping care due to cost also is supported by existing research. Rural residents often experience poorer health and higher mortality rates than their urban counterparts, in part due to lower access to healthcare. An AARP study found that delayed or skipped care in adults aged 40 and older was common among approximately one-third of rural residents. Many rural areas have seen increasingly older, poorer, uninsured and underinsured patient populations.


Discussion

In 2016, 20 percent of Americans aged 65 and older lived in rural areas,\textsuperscript{37} suggesting that addressing healthcare-related issues among older adults in rural areas may be an important area of focus. Prior to the COVID-19 pandemic, more than a third of women in the United States were more likely to report skipping care due to cost, compared with other countries.\textsuperscript{38} A markedly higher proportion of women reported skipping even preventive care during the pandemic.\textsuperscript{39}

The finding that older adults with children in the household are more likely to report that they skipped or delayed care due to cost may be partly explained by recent shifts in household composition. A greater proportion of older adults live alone or without children in the household,\textsuperscript{40} and an estimated six percent of older adults live with school-age children.\textsuperscript{41} Older adults of color are more likely to live with school-age children.\textsuperscript{42} While the relationship between household composition and financial status requires further study, it may be that living with family members with school-age children may be driven by financial reasons, and hence may partly explain this finding.


\textsuperscript{42} Rae et al., \textit{Millions of Seniors Live in Households with School-Age Children}.
Discussion

Clearly, for a segment of older adults, access to healthcare cost information prior to receiving care, especially information discussed with a healthcare provider, plays an important role in healthcare navigation and decision making. FAIR Health's findings point to the importance of addressing older adults’ cost-related barriers to accessing care, especially for older adults living with multiple comorbidities. Due to the presence of multiple comorbidities, many older adults have increased care needs; these needs are further compounded for older adults with lower incomes, older adults who reside in rural areas and older women. Skipping or delaying care, which trended upwards during the pandemic, has been associated with poorer health downstream and may have major implications for population health nationwide. Providing cost-related information via healthcare cost engagement tools and shared decision making with healthcare providers may be one step for addressing healthcare challenges among older adults, with policy-level interventions to address these issues more widely.
Discussion

Older Adults and Dental Care

In the absence of Medicare coverage for dental services, attention has been paid to dental care coverage and costs for older adults. Despite health experts’ recommendation that patients visit their dentists twice a year as a preventative measure, less than half (37 percent) of older adult respondents to FAIR Health's surveys reported that they accessed dental services twice per year. Notably, adults 65 and older have a greater prevalence of oral disease, although they largely lack dental coverage and pay more out-of-pocket costs for dental care than younger adults. According to a 2019 report published by the Kaiser Family Foundation, 20 percent of older adults paid more than $1,000 out-of-pocket for dental care in 2018. With regard to dental care, findings from The Commonwealth Fund’s 2021 International Health Policy Survey provided additional context: one in six older adults in the United States—similar to the percentage reported by older adults in Australia, Canada, and New Zealand—skipped a dental visit in the past year due to cost. Previous research along with FAIR Health’s findings underscore the importance of access to information about dental services and costs, a foundation that may also serve as a basis for negotiating with dental providers, to help support older adults navigating dental care.

“One in six older adults in the United States...”

skipped a dental visit in the past year due to cost.


47 Jacobson et al, “Older Adults on Medicare and Those Near Medicare Age Face Cost Barriers to Care.”
Discussion

Disparities in Ability to Navigate the Healthcare System and Make Informed Decisions

While older adults largely reported that they navigate the healthcare system alone, most reported no barriers to making informed healthcare decisions. Those who did cited the following top three barriers: the preferences of healthcare providers—the opinions and choices that may depart from those of older adults—not enough time with healthcare providers and not being able to understand the medical language. However, those with a high school diploma or lower were more likely to report that not being able to understand the medical language, not knowing where to look for information and too many medications to keep track of served as barriers to navigating the healthcare system. Barriers to informed healthcare decision making among those with lower household incomes and lower levels of educational attainment support have also been documented in previous research, which has found that factors such as household income,\(^50\) healthcare costs,\(^49\) inability to understand medical language\(^50\) and limited time with healthcare providers\(^51\) may pose challenges to older adults and caregivers/care partners.


\(^{49}\) Jacobson et al., *When Costs Are a Barrier to Getting Health Care*.


Discussion

Consistent with the literature, FAIR Health survey findings revealed that older adults’ ability to navigate the healthcare system and make informed decisions corresponds with educational attainment, household income and ethnicity. Survey respondents were more likely to report difficulty in finding the costs of healthcare if they were Hispanic, had a high school diploma or lower and were aged 76 and older. These findings are consistent with those from previous studies, which suggest that low health literacy and health insurance literacy also are prevalent among older Hispanic adults, older adults with a high school diploma or lower, and adults aged 76 and older. Low health literacy—the capacity to obtain, process and understand basic health information and services needed to make appropriate health and healthcare decisions—\(^{52}\) is associated with delayed or forgone care and more difficulty accessing care.\(^ {53}\) Health insurance literacy is the ability to find and evaluate information about health plans, select the coverage best suited to one’s financial and health circumstances and use the plan knowledgeable once enrolled.\(^ {54}\) While low health insurance literacy and low health literacy generally include different domains, they are correlated with similar effects, including greater avoidance of preventive and non-preventive healthcare services\(^ {55}\) and worse health outcomes.\(^ {56}\)


Discussion

Low health insurance literacy is prevalent among American adults, especially those who are uninsured and from minority and lower-income backgrounds. Spanish-speaking, Hispanic/Latino groups generally have worse health insurance literacy than non-Hispanic groups in the United States and trail non-Hispanic whites by 30 percent in understanding health insurance terminology. This established research was underscored by FAIR Health's survey findings.

Healthcare engagement tools that offer information in easy-to-understand formats, along with support teams to help consumers, especially those with lower educational and income levels and language barriers, may greatly help those who require additional assistance when navigating the healthcare system.

60 Urban Institute Health Policy Center, Large Racial and Ethnic Differences in Health Insurance Literacy Signal Need for Targeted Education and Outreach.
Discussion

Opportunities to Advance Shared Decision Making

FAIR Health’s study revealed that most older adults feel comfortable discussing healthcare costs with their healthcare providers, but rarely have these conversations. Shared decision making has been found to be effective in scenarios involving preference-sensitive conditions (those “for which the clinical evidence does not clearly support one treatment option and the appropriate course of treatment depends on the values or preferences of the patient regarding the benefits, harms and scientific evidence for each treatment”)61 and end-of-life care.62 Generally involving evidence-based strategies and decision aids, shared decision making has been associated with lower medical costs, and fewer preference-sensitive procedures and hospital admissions.63 Using decision aids with information about treatment costs leads to cost discussions more often than using decision aids that do not.64 Research has further highlighted that implementing shared decision making with older patients leads them to feel respected and understood by their providers,65 and to experience less conflict in decision making, a better understanding of the risks and benefits of treatment options and improved knowledge about conditions and possible outcomes.66, 67

Discussion

Notably, 41 percent of adults aged 65 and older participate in shared decision-making discussions with healthcare providers, and 45 percent of older adults reported an interest in doing so. Shared decision making—facilitated by tools that outline both clinical and cost information for different care and treatment options—can serve as an effective strategy for engaging older patients in their healthcare decisions. This is especially important considering that older patients in the United States shoulder a significant portion of their healthcare costs but may not always receive the care they prefer. However, despite the potential benefits of shared decision making, responses from older adults indicate difficulties in integrating the process in clinical settings. Among the reported barriers to shared decision making, most older adult respondents cited healthcare providers’ preferences—in other words, providers’ opinions and choices that may depart from those of older adults—as the barrier preventing them from making informed decisions.

The survey findings revealed that a significant proportion of family caregiver survey respondents reported already taking part in shared decision-making discussions with their caregivers and their healthcare providers, suggesting that, where applicable, including caregivers in shared decision-making discussions may be effective. This supports the notion that there are opportunities to advance shared decision making among older adults and to include their caregivers/care partners where applicable.

“...there are opportunities to advance shared decision making among older adults and to include their caregivers/care partners where applicable.”

Discussion

Family Caregivers’/Care Partners’ Ability to Navigate the Healthcare System

Notably, just under a third of family caregivers/care partners reported having no roadblocks to making decisions about their care receiver’s care; however, among the respondents who cited roadblocks, these included time constraints due to “working full-time and not having time,” “not enough time with healthcare providers,” and “too many health issues to keep track of.” Caregiver survey respondents also placed great importance on out-of-pocket costs when making healthcare decisions with their care receivers and healthcare providers. A little more than a quarter of caregiver respondents (29 percent) reported that out-of-pocket healthcare costs are the “most important” factor when making healthcare decisions and reported being knowledgeable about the costs of their care receiver’s care. This perception was more pronounced among respondents in the following categories: male (33 percent), between the ages of 35 and 44 (47 percent), college graduate and up (37 percent), reside in urban settings (42 percent), employed (38 percent) and married (36 percent).

These findings are in line with data published in recent studies. Indeed, the challenges faced by family caregivers and care partners have been noted in the literature, with financial considerations being top of mind for caregivers.69 Financial strain is experienced by caregivers across all age groups. On average, family caregivers spend just over a quarter (26 percent) of their income on caregiving.70

Discussion

According to a 2021 AARP report on caregiving out-of-pocket costs, caregivers under the age of 50 report the highest out-of-pocket costs, with male caregivers spending slightly more than female caregivers. Among age cohorts, caregivers between the ages of 35 and 49 have the highest out-of-pocket costs. Similarly, findings from Crouch et al.’s 2019 study indicate that the burden of out-of-pocket costs keenly affect caregivers with children and those with some college education or less.

Caregivers caring for a sibling, and those with higher education levels, were more likely to report that healthcare costs were “most important” when making healthcare decisions. One potential explanation may be that those with higher levels of education, and therefore, higher levels of health insurance literacy, may have a greater understanding or awareness of how healthcare costs factor into healthcare decision making or perhaps may have more confidence in using healthcare cost information as a data point to make healthcare decisions.

Sharing and/or discussing the costs of care with older patients’ family caregivers/care partners may serve as an important strategy for engaging patients and caregivers in healthcare decision making. The FAIR Health study showed that family caregivers are an important part of the healthcare decision-making process and are therefore a key distribution channel to consider when sharing healthcare information with older adults.

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71 Skufca and Rainville, “Caregiving Can Be Costly—Even Financially.”
Discussion

Need for Consumer-Oriented Tools and Resources

With a significant proportion of older adult survey respondents (59 percent) and caregiver respondents (56 percent) reporting that costs of care are “important” or “most important” when making healthcare decisions, tools that offer cost information may be of great help to both audiences. Family caregivers/care partners expressed their support of information, resources and tools that would help them learn how to make better decisions about their care receivers’ care, understand healthcare costs and clinical information, outline different models of care and care choices with costs and assist them with healthcare navigation. While the need for such information is clear, findings that family caregivers/care partners most commonly learn about health and healthcare from healthcare providers suggest that healthcare providers serve as an important channel for distributing healthcare information—especially information about healthcare costs. Furthermore, providing in advance clear information about geographically specific healthcare costs—medical and dental—and options for financial assistance, in multiple modalities—website, mobile app and paper copies—may help address barriers to accessing care among a subset of consumers who find it difficult to access this type of information. Tailored interventions, delivered in diverse modalities and supported at all levels of influence,\(^7^3\) may also be effective in spreading such tools and information.

Discussion

Implications

The study findings suggest that solutions, applied at both micro and macro levels, may help improve healthcare navigation and decision making for older adults and family caregivers:

1. Where clinically applicable, integrate shared decision-making tools to facilitate shared decision-making discussions with patients and, where relevant, their caregivers. Supporting informed healthcare decision making, including shared decision making, through tools that offer healthcare cost information may help older adults and their caregivers/care partners navigate the healthcare system with greater ease.

2. Consumer-facing tools and resources that pertain to health and healthcare, including dental care, should be offered in a variety of modalities, including websites, mobile apps and paper copies that offer information about healthcare and healthcare costs. Such tools, and accompanying educational content and messaging, should be tailored to diverse older adult and family caregiver audiences.

3. Owing to the roles that they play in healthcare navigation and decision making on behalf of those for whom they care, target family caregivers/care partners when disseminating consumer-facing healthcare navigation tools and resources. Healthcare providers, likewise, serve as a significant source of health and healthcare information and can be important champions in dissemination campaigns that seek to reach older adults and family caregivers/care partners with healthcare navigation tools.

Educational dissemination campaigns that target all levels of influence—individual, interpersonal, organizational, community and policy levels—may help improve the ability and experience of older adults and caregivers in navigating the healthcare system and making informed decisions.
Discussion

4. Consumer-oriented tools and strategies that inform consumers about healthcare and associated costs—in other words, that promote health literacy and health insurance literacy—should be tailored to account for disparities in health insurance literacy, educational attainment, ethnicity and household income levels and any other factors that may be associated with impeded ability to navigate the healthcare system.

5. Organizational- and societal-level policies that support greater uptake of shared decision making for older adults and the diffusion of healthcare transparency tools may be helpful in advancing shared decision making and greater ability of older adults and family caregivers/care partners to navigate the healthcare system.
Conclusion

FAIR Health’s survey findings revealed how older adults and family caregivers/care partners navigate the healthcare system, the perceived importance of healthcare costs when making healthcare decisions, how healthcare costs may affect access to care, barriers to effective healthcare navigation and decision making, the role of family caregivers and care partners in healthcare decision making and the role of healthcare providers in providing healthcare information. Results also revealed the particular challenges related to costs of care facing lower-income individuals, rural residents and women. The findings make clear the need for consumer-facing tools that offer healthcare cost information and that facilitate healthcare navigation and decision making. Offering tools to family caregivers, who support having greater access to information about health and healthcare through web- and mobile-based tools and resources and paper copies, and who play a significant role in their care receivers’ care, likewise is supported by the findings. At the micro level, offering healthcare decision-making tools, including shared decision-making tools, with cost information—accompanied by tailored, multimodality educational content and messaging for audiences of varied levels of comprehension and familiarity with the healthcare system and different languages—can help older adults and their caregivers in navigating the complexities of the healthcare system. At the macro level, policy-level interventions that broaden the scope of and access to such tools and educational messaging may further help address the challenges that many older adults and family caregivers face in the context of making informed healthcare decisions and navigating the healthcare system.
About FAIR Health

FAIR Health is a national, independent nonprofit organization dedicated to bringing transparency to healthcare costs and health insurance information through data products, consumer resources and health systems research support. FAIR Health qualifies as a public charity under section 501(c)(3) of the federal tax code. FAIR Health possesses the nation’s largest collection of private healthcare claims data, which includes over 35 billion claim records and is growing at a rate of over 2 billion claim records a year. FAIR Health licenses its privately billed data and data products—including benchmark modules, data visualizations, custom analytics and market indices—to commercial insurers and self-insurers, employers, providers, hospitals and healthcare systems, government agencies, researchers and others. Certified by the Centers for Medicare & Medicaid Services (CMS) as a national Qualified Entity, FAIR Health also receives data representing the experience of all individuals enrolled in traditional Medicare Parts A, B and D; FAIR Health includes among the private claims data in its database, data on Medicare Advantage enrollees. FAIR Health can produce insightful analytic reports and data products based on combined Medicare and commercial claims data for government, providers, payors and other authorized users. FAIR Health’s free, award-winning, national consumer websites are fairhealthconsumer.org and fairhealthconsumidor.org.

For more information on FAIR Health, visit fairhealth.org.