Research Report

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A Framework for Integrating Family Caregivers into the Health Care Team

There are currently about 53 million family and friends providing care and assistance to loved ones in the United States, an increase of 9.5 million caregivers between 2015 to 2020 (AARP and National Alliance for Caregiving, 2020). These family members, hereafter "family caregivers" or "caregivers," are a crucial element of the long-term care system. They provide assistance with everyday activities, such as eating, bathing, dressing, driving, and taking medications (Amerigroup Corporation, 2014). The total value of long-term services and supports (LTSS)

KEY FINDINGS

- Integrating family caregivers into a patient's health care team has many benefits, yet these caregivers face significant barriers to communicating and coordinating care with the health care team.
- To better understand these barriers and identify ways to mitigate them, we reviewed the literature on the role of family caregivers in the coordination of care and conducted key informant interviews with 13 experts from diverse stakeholder groups.
- Barriers to integration fell under four themes: (1) identifying caregivers; (2) communication and information-sharing; (3) time limitations and competing demands; and (4) trust and cultural barriers.
- We also identified six policy areas in which initiatives could mitigate these barriers: (1) identify and record information on family caregivers; (2) incentivize providers to engage with family caregivers; (3) invest in programs that provide supportive services for family caregivers; (4) expand access to and funding for care coordinators to support caregivers and connect them to clinical information; (5) implement training programs for providers and caregivers to facilitate effective communication; and (6) develop, test, and improve caregiver access to technologies that foster caregiver-provider care integration and information-sharing.
- Future work is needed to expand and assess policy approaches through stakeholder-engaged consensus methods, assess the availability of evidence-based research, assess each approach on metrics of feasibility and impact, evaluate approaches for their cost effectiveness, and build consensus on how best to implement the most-promising choices.
- Our study is among the first to focus in depth on integrating family caregivers into the health care team by incorporating interviews with payers, providers, and caregiver advocates and experts. The report is intended to spur a conversation about potential ways to promote integration and provide a blueprint for the next steps to implementation.

for older adults, including the estimated economic value of typical unpaid family care, exceeded $400 billion in 2011. Care provided by family members and friends accounted for more than half of this amount (Congressional Budget Office, 2013).

Family caregivers have direct and frequent access to loved ones with caregiving needs: More than one-third of care recipients live with their family caregivers and 55 percent of caregivers visit their care recipients more than once a week (Weber-Raley and Smith, 2015). These regular interactions allow family caregivers to monitor changes in health and care needs on a more regular basis than would be possible for formal health care providers. It is thus not surprising that including family members in care collaboration improves patients' access to services and reduces patients' unmet needs (Griffin et al., 2017; Samus et al., 2014). Other established benefits in involving family caregivers include better quality of care, increased safety (Callahan et al., 2009; Meyer et al., 2018; Wolff et al., 2010) and improved quality of life for care recipients (Callahan et al., 2009; Samus et al., 2014) and also delayed patient institutionalization (National Academies of Sciences, Engineering, and Medicine, 2016; Samus et al., 2014).

Including family caregivers in the formal care team also offers benefits for the caregivers themselves, such as increased mastery of caregiving, confidence, and self-efficacy (Callahan et al., 2009; Guay et al., 2017; Hengelaar et al., 2018) and also a better quality of life, well-being, and mental health (Bass, Clark, et al., 2003; Bass, Judge, et al., 2013; Callahan et al., 2009; National Academies of Sciences, Engineering, and Medicine, 2016; Guay et al., 2017). Enhancing coordination between family caregivers and the formal care team can improve care planning by integrating caregiver expertise into patients' plan of care and preparing family caregivers to be surrogate decisionmakers at the end of life (Bruening et al., 2020; Wolff et al., 2016).

Recent changes in the U.S. health care system and payment models have increased opportunities to integrate family caregivers into care teams.

Despite these benefits, caregivers are often treated as secondary members of the care team (e.g., primarily communicating with health care teams through patients instead of having direct access to the team itself). Given the established benefits of collaboration between a family caregiver and the formal health care team, improved integration is warranted but is not currently common. Our study aims to start the conversation about ways to better integrate family caregivers into health care teams.

The goal of this study is to identify promising policy directions and provide a blueprint for assessing, developing, and implementing policies to improve the integration of family caregivers into health care teams. We focus on family members caring for adults who need help with everyday activities (e.g., veterans with disabilities, adults with intellectual disabilities or developmental disabilities, and adults with functional limitations or complex chronic conditions).

We broadly define *family caregiver integration*, which includes communication, collaboration, and coordination with providers, individuals, or organizations that deliver care or health care services or help coordinate care for people with caregiving needs. We define *health care team* as doctors, nurses, social workers, care coordinators, and private-sector health and care service providers.

Recent changes in the U.S. health care system and payment models have increased opportunities to integrate family caregivers into care teams. For example, the growth in value-based payment models (Muhlestein et al., 2018), which hold a health care delivery system and payers accountable for both the quality and cost of care, has led to a reassessment of which factors improve quality and provides new opportunities for recognizing the work of caregivers.

An increased focus on *patient-centered care* encourages patients' involvement in their own care and could be expanded to include family members in decisionmaking, yielding a more *family-centered care* focus (National Academies of Sciences, Engineering, and Medicine, 2016). Finally, the recent expansion of supplementary benefits in Medicare Advantage Plans to cover caregiver support demonstrates that payers are also recognizing the importance of family caregivers.

Other efforts are underway to better integrate family caregivers into health care teams. For example, a National Academies of Sciences, Engineering, and Medicine report on family caregivers has helped to raise awareness of caregivers' needs and potential ways to support them (National Academies of Sciences, Engineering, and Medicine, 2016). Most states have passed and implemented the Caregiver Advise, Record, Enable (CARE) Act, which requires hospitals to record the name of family caregivers for a patient in hospital records, to consult with caregivers when a patient is to be discharged from the hospital, and to provide instructions about medical tasks that the caregivers will need to assume after a patient's release. In addition, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, which became federal law in 2018, created a council of diverse informants charged with developing a national strategy and plan to support family caregivers.

This work is also timely because the coronavirus disease 2019 (COVID-19) pandemic makes receiving care in institutions or from formal personal caregivers or home health aides less feasible and potentially risky. The situation in nursing homes is particularly well known: COVID-19 has run rampant in nursing homes and other institutional settings, generating calls to revamp the formal system of LTSS with a combination of funding, regulation, and new strategies for care that supports a variety of institutional and home-based care options (Werner, Hoffman, and Coe, 2020).

One recommendation for increasing support for home-based care is self-directed LTSS, which would permit patients to employ family members as caregivers (Ujvari et al., 2020). Several state Medicaid programs are temporarily allowing family caregivers to receive payment for direct care services during the COVID-19 pandemic (Fox-Grage, Teshale, and Spradlin, 2020); the Centers for Medicare & Medicaid Services (CMS) began providing a waiver for homebound status during COVID-19 that allows for more coverage of home-based care (Volp, Diamond, and Shrank, 2020).

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Our Approach

Our work has three basic aims: (1) provide a more-targeted and in-depth analysis of issues around *care integration* between family caregivers and health care providers, including promising policy directions for improving family caregiver collaboration with the care team; (2) identify a set of policy areas relevant to multiple informants; and (3) provide recommendations for expanding, assessing, selecting, and implementing relevant policies. We used a mixed-methods approach: a review of topic-related literature, policy reports, and websites to identify relevant research, policy discussions, and programs; interviews with three important informant groups (caregiver advocacy organizations, payers, and providers); and case studies of existing efforts that support the integration of family caregivers into care teams. Figure 1 shows how we identified key themes and case studies from interviews and literature.

- **The literature review** provides an overview of relevant studies from the academic community and highlights policy discussions about the role of family caregivers in the coordination of care. The objectives of the review were to identify potential benefits from integrating family caregivers into the care team, identify barriers and facilitators to care coordination involving family caregivers, and identify innovative programs that connect family members to the health care team. The review was meant to be broadly inclusive. To that end, we took a two-pronged approach to identifying relevant literature. Internet searches using common search engines were conducted to identify relevant academic articles or reports. We also reviewed the reference list of two recent works that examine integrating caregivers into a formal care team to identify relevant academic articles and recent papers citing these foundational works (National Academies of Sciences, Engineering, and Medicine, 2016; Sperber, 2019).
- **Interviews** were conducted with 13 key informants selected to represent the perspectives of three groups: caregiver experts and representatives (five interviews); payers, i.e., insurance companies (four interviews); and both clinical and direct service providers (four interviews). We chose these informant groups because each would need to be engaged to institute effective policy to improve care coordination; thus, their views on the barriers and facilitators to care coordination with family caregivers are crucial. To choose the interviewees within each group, we reached out to key informant groups (e.g., well-known caregiving advocacy groups) and used contacts from long-term care experts at the RAND Corporation and contacts of the sponsor, Seniorlink. Informants were invited to participate via e-mail; more than 80 percent responded to our emails and agreed to be interviewed. Telephone interviews were conducted by interviewers using a semistructured discussion guide with a notetaker present. The interview guide covered a variety of topics aimed at each key informant group asking about: (1) current state of caregiver integration; (2) barriers to integration; (3) policy actions to enhance integration and facilitators to implementing them; and (4) benefits to patients of care integration. Interviews were audio-recorded with the subjects' consent, and eligible respondents received a $100 honorarium for their participation. The study was approved by the RAND Human Subjects Protection Committee.
- **Themes** were identified from the literature review and interviews. After completing the interviews, we analyzed the interview data and the information from the literature review. The barriers to integration fell naturally into four categories, as shown in Figure 2. We reviewed the interview notes and audio recordings to identify facilitators to overcoming each of the barriers. These facilitators were used as the basis for identifying

FIGURE 1
Analytic Approach

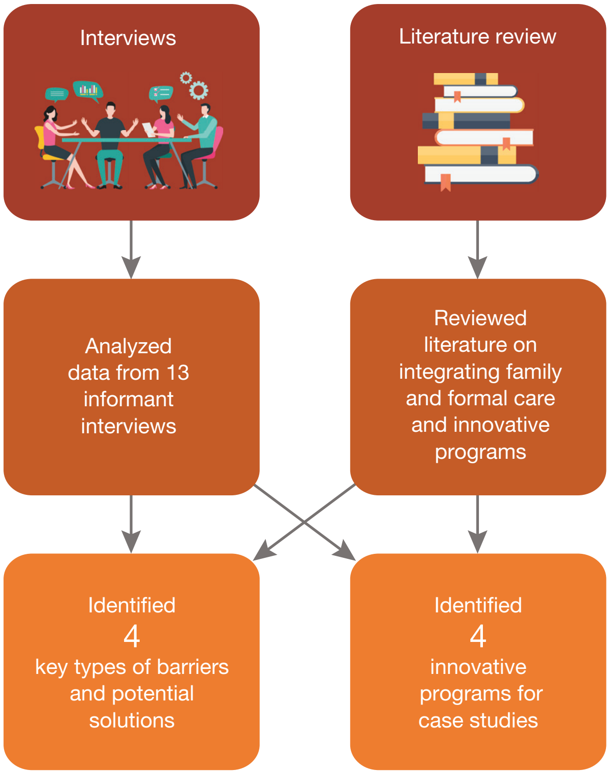

FIGURE 2
Barriers to Integrating Family Caregivers into Health Care Teams

Topic	Barriers
Identifying caregivers 	• Family members do not self-identify as caregivers. • Care recipients do not identify family members as caregivers. • Caregiver information is often missing from patient health records. • Information for multiple caregivers is not typically recorded.
Communication and information-sharing 	• Family caregivers do not have the information or education needed to carry out caregiving tasks. • Family caregivers do not have access to providers or patient health records. • Family caregivers do not understand medical terminology. • Clinical providers do not communicate with each other. • Privacy restrictions limit who has access to a patient's medical information.
Time limitations and competing demands 	• Clinical providers have limited time and resources to engage with caregivers. • Health care systems do not provide ways to reimburse providers for time spent coordinating care with family caregivers. • Family caregivers have limited time and resources to engage with providers.
Trust and cultural barriers 	• The health care team has difficulty interacting with family caregivers from different cultural backgrounds. • Terminology and language barriers in which family caregivers do not understand medical terminology and/or are non-native English speakers. • Certain communities lack trust in the health care system.

groups of potential policy areas. We did not require barriers and facilitators to be mentioned by a minimum number of key informants to be included in the analysis.

- **Case studies** were used to take a more in-depth look at four efforts that informants have implemented to promote the integration of caregivers. We selected these case studies because the programs explicitly promoted care collaboration between family caregivers and health care teams, and detailed information about each program could be obtained by searching webpages, from the interviews, and the academic literature. We selected a combination of programs to capture the diversity of informant groups engaged in these efforts. We included one provider program targeted to family caregivers of veterans, one program offered by a payer, one program targeted to family caregivers of patients with dementia run by an academic research community, and one private company effort that leverages technologies and other solutions to provide care and integrate caregivers.

We frame our discussion of results around the types of barriers reported in the informant interviews.

> “Often, even if there’s a place to put something in the medical record, there’s . . . only one space for one name; and the reality is, people have multiple caregivers.”

We begin by describing barriers to family caregiver integration. Next, we discuss potential ways to overcome these barriers and group them into six policy areas. We then describe other considerations that were raised in the interviews but fell outside the scope of the barriers and facilitators discussion. Next, we turn to the case studies and describe which barriers each program addresses and how it does so. We conclude by providing recommendations for next steps.

Barriers to Integration

To inform potential policy approaches, we began our analyses by grouping barriers to family caregiver integration. Barriers from both the interviews and the literature review were grouped in four primary themes: (1) identifying caregivers; (2) communication and information-sharing; (3) time limitations and competing demands; and (4) trust and cultural barriers. These barriers are summarized in Figure 2 and discussed in more detail in this section. The themes and specific barriers identified in the literature were similar to those noted in the interviews; however, informants provided richer context for understanding barriers and were the primary source for identifying potential solutions.

Identifying Caregivers

One of the fundamental barriers to integrating family caregivers into the formal care team is the difficulty that care teams faced in identifying caregivers. This barrier has been identified in an extensive body of work (National Academies of Sciences, Engineering, and Medicine, 2016; Grossman, Zak, and Zelinski, 2018; Meyer et al., 2018; Peterson et al., 2016; Reuben et al., 2013; Sperber et al., 2019), and it was also highlighted in our interviews. Key informants noted that the team needs to identify the caregivers to connect them with the care team. This is challenging for several reasons. Several informants noted that some individuals do not self-identify as caregivers; rather they view caring for a loved one as something they simply do as family members. Similarly, care recipients themselves may not think of their family members as caregivers. In addition, the health system itself has structural limitations, such as the lack of a standardized way to record caregiver information on patient health records and a limited ability to change this information over time. Another problem is that the system is not equipped for the complexity of caregiving arrangements. As noted in one interview, “Often, even if there’s a place to put something in the medical record, there’s . . . only one space for one name; and the reality is, people have multiple caregivers . . . so the ability to get a sense of that is really limited.” Another concern raised by the key informants comes from the patient’s perspective: Patients may resist having family members involved in their care. As one key informant explained, “The autonomy of the older adult, their desire to want to . . . be the captain of their own ship . . . can be a challenge or a barrier for health professionals to engage with family caregivers.” Six out of the 13 key informants discussed identifying caregivers as a barrier to integrating family caregivers into the care team: four caregiver experts/advocates, one payer, and one provider.

Communication and Information-Sharing

Another common theme emerging from both the literature and interviews relates to communication and information-sharing. The goal for integrating caregivers into the care team would be full integration in which communication can flow seamlessly in *all* directions—from the health care team to caregivers, from caregivers to the health care team, among caregivers, and among different types of providers. The literature notes that even health care teams that do include caregivers face barriers to fully coordinating a patient's care with their caregivers; these barriers include a lack of communication skills among both caregivers (Moore, 2008; Moore and Cook, 2011) and providers (Moore, 2008; National Academies of Sciences, Engineering, and Medicine, 2016; Schulz and Czaja, 2018; Sperber et al., 2019; Washington et al., 2011). The security of patient health information (Schulz and Czaja, 2018; Sperber et al., 2019) and compliance with the Health Insurance Portability and Accountability Act (HIPAA) (Nadash, Silverstein, and Porell, 2019) are also discussed in the literature as barriers that prevent effective communication and information-sharing between providers and family caregivers.

Key informants expanded on this theme by describing specific scenarios that prevented effective communication and information-sharing. For instance, when describing the ability of providers to communicate with family caregivers, informants described how caregivers may be bombarded with too much information and may not be equipped or have time to sort through all the resources to determine the most relevant information. Key informants also discussed medical terminology as a barrier for caregivers when trying to communicate with the care team. One informant said, "Health care providers, even when they are really focused and trained in health literacy, they still speak in health speak. . . . There's just this really different paradigm of language construction and communication [and] the caregiver has no visibility in that world." When describing the ability of family caregivers to communicate with providers, one key informant noted, "The most isolating experience that an older person and a family caregiver can have is when they feel they have no ability to communicate effectively with the health care delivery system."

With regard to information-sharing, several informants mentioned how family caregivers do not always have the means to share information with providers even though caregivers have firsthand knowledge of a patient's condition and may notice subtle changes in health that clinical providers could miss. As one key informant described, "There are things that the family caregiver is going to witness that [providers] will never have insight to that is directly impacting that person's health and their quality of life." Moreover, key informants described a lack of information or tools necessary to fully understand or carry out caregiving responsibilities. As one key informant explained, "Information and education . . . [are] the biggest tools that caregivers need." Family caregivers may not get the information they need about a loved one's diagnosis or treatments. One reason could be that they lack access to clinical providers or patient health records. Multiple informants discussed how the timing of information is also important. The types of information family caregivers need depend on a patient's condition, and providing what caregivers need when they need it can be challenging. As one informant said, "The timeliness of the interventions and supports . . . the sudden onset versus gradual—we should learn about those trajectories, and we should know when somebody's going to need the information and supports."

> "The most isolating experience that an older person and a family caregiver can have is when they feel they have no ability to communicate effectively with the health care delivery system."

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The interviews surfaced two key barriers to communication from the provider's perspective: (1) a fragmented health system in which providers do not always communicate with each other about a patient's care and (2) privacy restrictions and security standards from HIPAA. A fragmented health system means that providers may not be aware of all the treatments and health conditions of a particular patient, hampering a provider's ability to provide correct and necessary information to family caregivers. All informant groups cited privacy restrictions and security standards from HIPAA as barriers because they limit to whom providers can speak about a patient's care. These factors are especially problematic if patients cannot communicate their preferences about who should be involved with their care and who requires secure storage of protected health information. All 13 key informants mentioned communication difficulties and inadequate information as barriers to caregiver integration.

Time Limitations and Competing Demands

Both clinical providers and family caregivers have time limitations and competing demands. The literature focuses on this barrier from the perspective of providers, noting the lack of time for engagement with caregivers (Coleman, 2016; Peterson et al., 2016; Washington et al., 2011; Sperber et al., 2019) and the lack of compensation and financial incentives for engaging (Kaiser and Kaiser, 2017; Schulz and Czaja, 2018).

Informants independently identified this theme, describing it in more detail from both provider and caregiver perspectives. For instance, informants described the pressures on providers to address patient concerns as quickly as possible, which limits their time to engage with family caregivers. As one provider described:

> You can get this sinking feeling when you're having a busy day and you walk into a patient's room in the hospital and you see a bunch of family around and you're . . . worried it's going to take [too much] time. . . . [We need to think about] shifting that mentality . . . to [recognize] these are actually the people that are going to help you . . . this is your support as well.

Informants also noted that there have been shifts in the U.S. health care system to support interactions between providers and caregivers, such as the growth in value-based payment models and person-centered care and the addition of nonmedical benefits to Medicare Advantage Plans. However, these system-level changes that allow for better integration of family caregivers are slow, incremental, and vary across different health care delivery systems. Moreover, key informants felt that clinicians may bear too much of the responsibility for engaging with family caregivers. "There is probably an overreliance on physicians as being the lever . . . [and] they are not trained to engage in that kind of shared decisionmaking . . . we ask them to do a lot," one key informant said.

One way to identify caregivers is with a caregiver assessment, which is "a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the ability of the caregiver to contribute to the needs of the care recipient" (Feinberg and Houser, 2012). However, one key informant felt that it was unrealistic for clinicians to conduct caregiver assessments on all family members involved in a patient's care because current health care delivery systems do not have workflows or reimbursement mechanisms to allow for such interactions.

Family caregivers also have limited time to determine how to reach out to and talk with the health care team. The care system can be difficult for caregivers to navigate, and caregiving can be a full-time job. Caregivers often have competing demands, such as employment obligations, their own children, or their own health issues. As a result, finding time when providers and family caregivers are both available to discuss a patient's care could be difficult. Social determinants of health, such as a lack of housing or inadequate transportation on the part of the patient and family caregiver, can also serve as barriers. Eleven of the 13 key informants described time limitations and competing demands as a barrier: five caregiver experts/advocates, four payers, and two providers.

Trust and Cultural Barriers

The literature reviewed touches briefly on trust and cultural barriers to integrating caregivers into the formal care team. Some topics noted in the literature are disagreement among medical professionals about how much to involve family caregivers and the amount of time it takes to build trust between caregivers and the formal care team (Hengelaar et al., 2018).

Barriers falling under this theme were elaborated on in interviews. Multiple informants noted the diversity of family caregivers and the need for the health care team, including clinical providers, care coordinators, and other professionals assisting with care, to understand the cultural backgrounds of both patient and caregiver. For example, compared with white family caregivers, family caregivers in minority communities are more likely to experience strain and worry about making a mistake in care (Reinhard, 2019), indicating how important it is for this group to be supported. As one key informant stated, "The diversity piece is so critically important . . . particularly in some diverse communities that for really good reasons don't necessarily trust the health care system." Another key informant emphasized the importance for the formal health care team to communicate with family caregivers in a way that addresses "cultural sensitivity, thinking about the different cultural norms and how people treat their elders or how they view caregiver[s]." Language was cited as a two-sided barrier: Not all family caregivers are native English speakers or are familiar with medical terminology. These barriers can cause miscommunication between family caregivers and the health care team and make caregivers wary of reaching out if they feel that they cannot adequately express their needs or that the health care team does not understand their concerns. Trust and cultural barriers were noted by six out of the 13 key informants: three caregiver experts/advocates and three payers.

Identifying Policy Areas and Ways to Facilitate Implementing Policies

We also asked key informants about ways to address the identified barriers, including through policy, technology, or other potential action items that could facilitate the integration of caregivers into the health care team. In Figure 3, we list the facilitators identified from the interviews (bulleted information) and group them into six broad policy areas. We report informant-identified facilitators in the figure as they were described to us; we did not confirm that they were the optimal or even appropriate approaches for addressing barriers. At the end of this report, we

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FIGURE 3

Policy Areas and Facilitators Derived from Interviews

Policy Areas	Barriers Addressed	Stakeholders
1 Identify and record information on family caregivers. • Make asking for a patient's permission to speak to family members a routine part of care. • Find ways for providers to learn more about day-to-day life of patients and who provides care. • Leverage opportunities to identify caregivers during advanced care planning.	Identifying caregivers; communication and information-sharing	Policymakers, payers, providers, technology sector
2 Incentivize providers to engage with family caregivers. • Explore billing options to cover time engaging with caregivers. • Explore other reimbursement policies that would facilitate provider engagement with caregivers.	Time limitations and competing demands	Policymakers, payers
3 Invest in programs that provide supportive services for family caregivers. • Implement routine assessments. • Pay family caregivers for time performing caregiving tasks. • Increase family caregiver supports covered by supplemental benefits in Medicare Advantage Plans. • Promote paid leave policies.	Time limitations and competing demands	Policymakers, payers
4 Expand access to and funding for care coordinators to support caregivers and connect them to clinical information. • Expand access to all patients with care needs. • Provide opportunities for caregivers to connect with care coordinators to assess their own needs.	Communication and information-sharing; time limitations and competing demands; trust and cultural barriers	Policymakers, payers, providers, technology sector
5 Implement training programs for providers and caregivers to facilitate effective communication. • Implement training programs to improve communication between providers and caregivers. • Require sensitivity training for providers to enhance communication with diverse populations.	Communication and information-sharing; trust and cultural barriers	Policymakers, payers, providers
6 Develop, test, and improve caregiver access to technologies that foster caregiver-provider care integration and information-sharing. • Increase use of shared access features on patient portals. • Develop system to record family caregiver information in EHRs. • Provide access to asynchronous technologies, such as texting. • Increase use of telemedicine and virtual clinics. • Learn from and evaluate existing technologies that can promote care integration.	Identifying caregivers; communication and information-sharing; time limitations and competing demands	Policymakers, providers, technology sector

describe next steps for expanding, assessing, selecting, and implementing interventions in these policy areas.

We also identify which informants would be involved in implementing solutions:

- policymakers, which include individuals who influence policy (e.g., government officials, advocacy groups, the research community)
- payers, which include public and private payers, such as insurance companies, state Medicaid programs, and CMS
- providers, which include individuals or organizations that provide direct care or health care services or help coordinate care for people with caregiving needs (because this group is broad, in our discussion, we highlight the specific subgroups of providers for whom the policy area is most relevant)
- technology sector, which includes private companies that develop and implement technologies that could facilitate care coordination.

Policy Area 1. Identify and record information on family caregivers. One caregiver expert and advocate stated:

> I think a lot of the onus needs to be on the health care sector . . . the question always has to be asked, "Do you have someone that looks after you or cares for you or that you're in regular contact with who does things for you?" And then assume that that person is probably going to need some level of information, education, and perhaps some type of supports so that the caregiver does not somehow get left out of the equation and left holding the bag, so to speak.

Although it may seem standard procedure to identify caregivers, such an effort is not currently part of routine care and does not happen in all states or in all settings (with the CARE Act, this is now happening in hospitals in most, but not all, states). Additionally, opportunities to identify multiple caregivers are limited.

We heard several potential ideas from key informants about how to improve caregiver identification and make it part of routine care. For example,

- asking for a patient's permission to speak to family members and learning about the caregiving routine. This should be done along with capturing or confirming basic demographic information so that recording caregiver information does not become a burden on clinical providers.
- incorporating elements of caregiver assessment into a health care encounter (potentially to be conducted by members of an interdisciplinary team working with primary providers) that enable clinical providers and care coordinators to learn more about the day-to-day life of patients and their care routine. The goal is to inform providers about who is participating in a patient's care and what tasks each person is doing. "I'm sure we can improve upon the assessments that exist with regard to what a potential caregiver can do and what they want and are willing and able to do so that we can better home in on what role an individual might have as a member on that care team," one key informant said.
- leveraging opportunities during advanced care planning with primary care physicians by asking a patient whether someone in his

"I think a lot of the onus needs to be on the health care sector . . . the question always has to be asked, 'Do you have someone that looks after you or cares for you or that you're in regular contact with who does things for you?'"

or her family should be involved in those conversations.

Implementing these types of approaches would require having precautions in place to ensure that regulations related to patient privacy are met, allow patients to decide how much information to share with family members, and give patients the ability to easily rescind access to their patient health information if they so choose. This policy area addresses the barrier themes of identifying family caregivers and communication and information-sharing by finding ways to identify family caregivers that would also enable these caregivers to discuss with providers the treatments and care planning for their loved ones.

This policy area is relevant to all informants, including providers, payers, policymakers, and the technology sector. This policy area is relevant to policymakers who could require new procedures and practices to be put in place by payers and providers to identify and record family caregiver information. This policy area is also relevant to payers and providers who would have to institute these new policies. Finally, health information technology providers can partner with health systems in platform design to facilitate the ability to capture and use caregiver information.

Policy Area 2. Incentivize providers to engage with family caregivers. Informants described time constraints that make it difficult for providers to engage with caregivers in a meaningful way, and they suggested several potential solutions. One suggestion was implementing payment models that allow providers to bill for time spent engaging with caregivers. Several informants stated that systemwide reform would be needed to successfully integrate family caregivers into the care team because reimbursement mechanisms that reinforce integration do not currently exist and would need to be implemented. As one key informant stated when describing what it would take to integrate family caregivers into the care team, "I think it's hard to overstate what a fundamental change this is for the health care system. To do this really requires . . . redesign and not incremental change and really requires us to think about where and how we deliver care." Another stated that time-based codes to bill time spent with family caregivers would help to overcome perceived barriers from clinicians because they will feel their efforts are recognized.

One suggestion was implementing payment models that allow providers to bill for time spent engaging with caregivers.

However, another key informant perceived limited time rather than billing as the key issue, suggesting that providers might not welcome new billing options and that other reimbursement policies may be needed. This was echoed by another informant who felt that a more effective strategy to increasing provider collaboration with family caregivers would be to promote value-based health care delivery systems rather than create payment codes for time spent with caregivers in existing fee-for-service systems that reimburse providers on the quantity of care. Value-based health care systems reward providers on the quality of care, thereby incentivizing providers to coordinate care with family caregivers if doing so would improve patient health outcomes.

Actions in this policy area could be implemented by policymakers and payers. The actions are relevant to the barriers of time limitations and competing demands—in this case, the limited time (and ability to bill for such time) available to clinical providers.

Policy Area 3. Invest in programs that provide supportive services for family caregivers. Increasing supports for family caregivers can reduce the burden on caregivers and give them time to coordinate with the health care team. Increasing support for family caregivers can be done by increasing funding for existing programs that have been shown to be effective, supporting new research to determine the effectiveness of existing programs, or supporting the development of new programs. Other studies have recommended policy options to encourage more and better supports for family caregivers, mainly as a mechanism for reducing caregiver burden and facilitating better care (National Academies of Sciences, Engineering, and Medicine, 2016; Reinhard, 2019).

One of the key informants we interviewed said that another benefit to caregiver supports was "taking one more thing off of a caregiver's plate" and freeing up caregiver time—one of the critical barriers to caregivers' being able to collaborate with providers. Facilitators included

- implementing routine assessments of family caregivers to provide clinical providers and care coordinators with information about what family caregivers need and how to best support them
- expanding programs that pay family caregivers for their caregiving tasks, an approach already being taken for certain Medicaid and low-income populations (e.g., cash and counseling)
- increasing family caregiver supports covered by supplemental benefits in Medicare Advantage Plans to alleviate the caregiver workload
- promoting paid leave policies to help working family caregivers reduce potential income loss when they take time off to care for their loved ones.

This policy area is relevant to policymakers and payers. Actions in this policy area would address barriers related to time limitations and competing demands. The suggested solutions can help give caregivers the necessary time and resources to provide quality care.

Policy Area 4. Expand access to and funding for care coordinators to support caregivers and connect them to clinical information. Having a single designated person who connects caregivers to the training and clinical resources they need can provide valuable information, improve communication, and save time for both caregivers and the care team. As one key informant stated, "Probably the greatest nonmedical service that could be offered . . . is a care coordinator/care navigator that is a real person that somebody can call that is inside the health system and can really help the family caregiver navigate the world that their loved one is in." Care coordinators include care managers (who are focused primarily on clinical care coordination after an episode of care), care navigators (who work in a nonclinical setting), case managers (who work in a nonclinical or combination clinical and nonclinical setting), or a combination of these positions depending on the setting, employer, and role (e.g., Managed Care versus Dual-Medicaid and Medicare plans versus hospital discharge unit). According to one key informant, care coordinators serve as the "bridge and connection from the medical world back to daily living" for family caregivers and "having payers who fund meaningful care coordination and care navigation has a huge impact on a caregiver's life."

This policy area is relevant to both clinical and nonclinical coordinators of care. The payers we spoke with discussed how they have begun to use care coordinators to connect family caregivers to clinicians and health care information, but these care coordinators are generally available only for the highest-risk patients. Efforts in this policy area would expand access to care coordinators for all patients with care needs, provide opportunities for caregivers to connect with care coordinators separately to help meet their needs, and allow for interaction with clinicians and nurses as needed. Care coordinators would facilitate the caregiver's engagement with the health care team on behalf of and alongside clinical providers.

This policy area could also be expanded to cut across informant types. Although care coordinators tend to liaise between insurance companies and health care providers, care coordinators could also be employed by the private sector. For example, the

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Training programs on effective communication can give clinical providers and care coordinators the skills to convey complicated clinical information in ways that a family caregiver can easily understand.

technology sector has begun to provide access to care coordinators in the form of in-home case managers and virtual assistants. Because care coordinators can be made available in different settings (e.g., hospitals, nursing homes) and through different informants (such as insurance companies and providers), this policy area is relevant to policymakers, payers, the technology sector, and providers—provider institutions that might expand their use of care coordinators and clinical providers who might benefit from having care coordinators as key contacts for family caregivers. This policy area can potentially address several barriers mentioned in the interviews: improving communication and information-sharing among care team members; easing time limitations and competing demands for both clinicians and family caregivers; and offering the appropriate training for care navigators to help improve trust and reduce cultural barriers (which would promote cultural competence).

Policy Area 5. Implement training programs for providers and caregivers to facilitate effective communication. Training programs on effective communication can give clinical providers and care coordinators the skills to convey complicated clinical information in ways that a family caregiver can easily understand. Cultural and sensitivity training can help these providers better coordinate care with diverse family caregivers.

Even if opportunities for communication are improved, barriers can occur in the conversations themselves. One key informant emphasized the importance of "making sure providers are training their staff on family caregivers and making sure that they're including family caregivers into processes." Given the diversity of caregivers' cultural backgrounds and needs, it is essential for clinical providers and care coordinators to learn how to communicate with different types of caregivers. Training programs aimed at learning those communication skills need to be developed, and existing programs, such as the Department of Veterans Affairs' (VA's) Campaign for Inclusive Care described in the case study section (see Case Study Box 1), need to be assessed for efficacy.

This policy area is most relevant to providers—provider institutions that would need to implement solutions and clinical providers and care coordinators who would participate in the training. In addition, policymakers may be able to help develop programs and enforce adherence, and payers may be able to require providers to participate in these training programs. The themes of (1) communication and information-sharing and (2) trust and cultural barriers are among the barriers that could be addressed by initiatives in this policy area.

Policy Area 6. Develop, test, and improve caregiver access to technologies that foster caregiver-provider care integration and information-sharing. This policy area relates to increasing access to, improving, and developing technologies for both providers and caregivers. Family caregivers need access to patient health information and mechanisms for sharing information with clinical providers and care coordinators. EHRs are one way to share information, but family caregivers do not always have access to this information. Suggestions for addressing this barrier include increasing the use of shared access features on patient portals and developing a system to record information about family caregivers, such as documentation of caregiver name, relationship to caregiver, contact information, and primary caregiving responsibilities.

Expanding access to EHRs and such information as clinicians' notes could provide valuable information and opportunities for caregiver-provider communication. As one key informant stated, "When you give people information and allow them to log into an electronic health record . . . [it] improves their ability and their likelihood of interacting as part of the health care team."

On the caregiver side, key informants described the need to develop and test technologies that support caregivers and foster caregiver-provider care integration and information-sharing. One key informant noted that "we live in a smartphone world," and technology is the easiest way to communicate and share information. Technology could provide a platform for communication that could occur when family caregivers have downtime, such as through texting or asynchronous messaging.

Promising technologies discussed in our interviews and case studies involved apps and digital technologies that connect caregivers to one another and to care teams. One key informant suggested leveraging technologies that caregivers might already use and asking "those companies to build out caregiving workstreams" as opposed to developing new technologies that caregivers would have to learn to use. Moreover, one key informant suggested increasing the use of telemedicine and virtual clinics so that care team members, including family caregivers, could share information in a secure environment. Key informants also mentioned that some home care agencies use technologies that encourage professional caregivers (e.g., direct care workers or home health aides) to provide daily electronic reports about their patients so health changes can be monitored and interventions can be deployed when necessary.

This policy area is relevant to the technology sector, policymakers, and providers. The technology sector will need to develop and improve these technologies and facilitate the integration of caregiver and provider technologies. There is a need for technology and health care companies that are, or could be, developing care coordination tools to focus on the needs of end users and to include caregivers in the conversation as new tools are developed. The technology sector may also help to develop EHR functionality to include information about caregivers. It will also be crucial for policymakers to invest in evaluating these products to determine how they affect patient and caregiver outcomes and the costs of integrating these products across payers, providers, patients, and caregivers. Providers are also important informants, because these tools will need to be implemented by provider organizations and may be used to connect clinical providers and care coordinators to patients and caregivers.

New technology solutions can also be coupled with several of the policy suggestions noted earlier. They have the potential to improve communication and information-sharing for all informants, from caregivers to payers to providers. The right kinds of technologies, such as asynchronous communication methods, can also free up valuable time and resources for both caregivers and clinical providers. Technologies can also be used to improve caregiver identification and facilitate access to care managers.

Other Observations from the Interviews

Several important themes emerged in the interviews that relate to specific populations with unique needs.

> "When you give people information and allow them to log into an electronic health record . . . [it] improves their ability and their likelihood of interacting as part of the health care team."

“I think a lot of the younger caregivers have been left out of the conversation, so we don’t really have a lot of information about what kind of supports they need.”

Several key informants suggested investigating what could be learned from pediatrics. The pediatric model always includes a caregiver (i.e., a parent or legal guardian) in conversations about a patient’s care and decisionmaking and could have valuable lessons for how to facilitate caregiver integration among older or disabled adults with family members involved in their care.

Key informants also mentioned caregivers with unique needs, such as youths. As one informant noted:

> I think a lot of the younger caregivers have been left out of the conversation, so we don’t really have a lot of information about what kind of supports they need. We talk a lot about that middle-aged caregiver, that sandwich generation that’s taking care of a parent and also a child, and taking care of that aging population, but we don’t know a lot about [youth caregivers]—and we know they’re out there, we know a lot of kids are taking care of their parents, and that’s with school-aged kids—so there’s just a lot of questions around, “Where do we even start? What do they need from us?”

Many of the suggestions to improve caregiver integration would still pose barriers for youth caregivers. One key informant cited a case where a youth was the primary caregiver but could not be noted as such on the records because she was a minor, creating added difficulties with communication. Other caregivers with unique needs are those caring for family members with rare genetic diseases, in which case providers may have less knowledge of the illness or patient’s needs than do caregivers. Relatedly, caregivers can be care recipients at the same time. It is vital for the formal health care team to recognize this and develop care plans accordingly, ideally with both the family caregivers and the people to whom they provide care in mind.

We interviewed organizations representing direct care workers (e.g., direct care aides who provide care in home-based settings and institutions), but we only touch on those discussions in this report even though these workers are an integral part of the care team. The direct care workforce face many of the same barriers as family caregivers in communicating with medical professionals and, according to key informants, are generally not integrated into health care teams. They also face additional challenges communicating with family caregivers. Family caregivers and direct care workers often perform similar work in their caregiving roles, creating misunderstandings and sometimes tensions over what caregiving tasks are needed, how to meet those needs, and how to divide caregiving responsibilities. Family caregivers and direct care workers may also have competing expectations. Because direct care workers may be the primary coordinators in the formal care team who family caregivers encounter, they sometimes receive the bulk of caregiver stress and frustration with the formal care system. Many of the policy areas and discussions that relate to providers and medical professionals are also applicable to direct care workers. To fully integrate both family caregivers and direct care workers into a care team, it will be important to recognize their unique contributions.

Finally, several informants discussed Medicaid waivers as ways to support family caregivers. However, the extent to which this can be done is unclear, and each state separately negotiates with CMS for permission to offer such services. To make it easier for states to include family caregiver supports and services as part of Medicaid, CMS could provide guidance for states on standard family caregiver support services available through Medicaid waiver programs that have been shown to be successful and on the best way to implement these programs. Although this was not raised specifically in the interviews, this policy approach could be applied to payers more broadly and also to specific payers that offer Medicare Advantage Plans. Beginning in 2019, supplemental benefits for Medicare Advantage Plans were expanded to cover caregiver support programs (e.g., adult day care, respite care, counseling) and, as of March 2020, 125 Medicare Advantage Plans covering almost 900,000 enrollees offered support for caregivers as a supplemental benefit (ATI Advisory, 2020). As more Medicare Advantage Plans consider offering caregiver supports, it will be important to establish best practices for implementing these programs.

Case Studies of Promising Programs

Finally, we highlight four efforts that address some of the barriers identified and exemplify the types of solutions that could be implemented across sectors to explicitly promote care collaboration between family caregivers and the health care team.

VA Campaign for Inclusive Care (see Case Study Box 1). The VA Campaign for Inclusive Care was launched in January 2020 to provide Veterans Health Administration (VHA) health care providers with training and tools to better equip them to identify, engage, and communicate with caregivers of veterans. The program, which supports VA clinicians, nurses, and social workers, is organized by the Elizabeth Dole Foundation in collaboration with the VA and with support from United Service Automobile Association (USAA).

The program designs and deploys tools and training for VHA providers through an online portal called the Academy for Inclusive Care. The portal contains training videos, educational materials, and other resources to help providers learn how to integrate caregivers in care coordination. The training videos cover such topics as steps to take to bring together providers, veterans, and their caregivers; information about the roles of veteran caregivers; information about stressors that veteran caregivers encounter; best practices for communicating with caregivers; VHA privacy regulations; and understanding the caregiver journey.

The tools and training were created as part of a multistep research-based project that included an examination of previous literature, interviews with providers, advisory board discussions, and expert feedback. Preliminary work to develop the definition of inclusive care identified key challenges, including providers' lack of time and the complexity and diversity of caregivers' roles and expectations (Sperber et al., 2019).

This program addresses the barrier of identifying caregivers by making it standard practice to include a family member in a care team if a family caregiver is available. The program also addresses trust and cultural barriers by training providers to better understand and communicate with veterans and their caregivers. It mitigates barriers associated with time by providing videos and tools that can be used at one's leisure to learn more about how to care for this population.

VHA is divided into 21 Veterans Integrated Service Networks (VISNs). The program is currently at three VISNs, with plans to expand to 12 VISNs by the end of 2020. As part of the program, data will be collected to measure the impact of the program,

Case Study Box 1

VA Campaign for Inclusive Care

Date Established

January 2020

Barriers Addressed

Identifying caregivers; trust and cultural barriers; time limitations and competing demands

Key Features

- Provides training to providers on how to include caregivers in care coordination
- Offers access to the Academy for Inclusive Care online portal, which contains training videos, educational materials, and other resources

Target Population

VHA health care providers

including tracking provider usage of the Academy for Inclusive Care, provider skills assessments, and surveys of caregivers.

Optum Care Navigator (see Case Study Box 2). UnitedHealthcare Dual Complete® is a Dual Special Needs Medicare Advantage Plan (DSNP) serving members who are covered by both Medicare and Medicaid. The Optum at Home program is an integrated care delivery program that coordinates clinical care for members in their home for certain regional DSNP plans. The Optum Care Navigator, launched in January 2019, is part of Optum at Home. The Optum Care Navigator provides proactive outreach to members and promotes outreach between the member and a care navigator from the program by giving members one consistent contact. The program goals are to ensure the member's access to care; mitigate social determinants of health; close gaps in care; and help members navigate a health care system, including coordination with Medicaid.

The program gives all members access to a care navigator who can address concerns and coordinate their care. The care navigators typically have a medical or professional background (e.g., social workers, licensed professional nurses) and receive ongoing training on how to engage with members and how to assess their needs across multiple dimensions aligned with the social determinants of health. When the care navigator first engages with a member, he or she tries to identify a caregiver by asking whether a family member should be part of the conversation, and, if so, includes that person in discussions about the member's care plan. Care navigators also serve as a resource that caregivers can reach out to with questions and concerns about the member's care plan. Currently, family caregivers and members communicate with the care navigators exclusively by phone. Members deemed high risk are also assigned a clinician who does a home visit as often as once a month.

This program addresses the barrier of identifying caregivers by making it routine practice to ask about family caregivers. The program also addresses the barrier of communication and information-sharing by connecting patients and family caregivers to care navigators who can provide relevant information tools and access. Care navigators can also save time for family caregivers by researching relevant information for them and connecting them to resources so that they do not need to track down the information themselves.

Case Study Box 2

Optum Care Navigator

Date Established
January 2019

Barriers Addressed
Identifying caregivers; communication and information-sharing; time limitations and competing demands

Key Features

- All members are assigned a care navigator
- High-risk members are assigned a care navigator and a clinician who does regular home visits
- Family caregivers communicate with care navigators and clinicians to address concerns and coordinate care

Target Population
Adults covered by both Medicare and Medicaid and their caregivers

The program has not yet been formally evaluated, but there are plans to examine its impact on such outcomes as customer satisfaction, member quality of life, and ability for members to get the right care at the right time. Future plans are to explore other communication methods among the care navigator and members and family caregivers, including texts and apps.

UCLA Alzheimer's and Dementia Care Program (see Case Study Box 3). The UCLA Alzheimer's and Dementia Care (ADC) program was created in July 2012 through a CMS innovation grant and with support from philanthropy and the UCLA Health system. The program was created to address gaps in dementia care, including the lack of support and training for family caregivers. To participate in ADC, the patient must have a referral from a UCLA physician. The program provides a 90-minute in-person visit with a nurse practitioner who serves as a dementia care specialist, a personalized care plan developed with the referring physician, and follow-up calls or in-person visits to make sure that the care plan is implemented appropriately. During the visit, the needs of both the patient and caregiver are assessed and potential services and programs applicable to the patient and caregiver are discussed.

Caregivers also have access to assistance and advice 24 hours per day, seven days per week, 365 days per year through the program's dementia care specialists and on-call geriatricians. Dementia care specialists provide patients and caregivers with information about community-based resources that address their needs. This program addresses barriers related to communication and information-sharing by connecting patients and caregivers to medical providers and around-the-clock clinical and care information.

This program has been shown to have high levels of caregiver satisfaction (Tan, Jennings, and Reuben, 2014) and improved clinical outcomes for both the patient and caregiver (Reuben et al., 2019). Reported challenges with implementing the UCLA ADC program included difficulties establishing clinical boundaries for the dementia care specialist and lack of commercially available software to support data collection, documentation, and communication for this type of program (Reuben et al., 2013). The study team at UCLA is conducting new evaluations to examine how these health center–based interventions affect patient and caregiver outcomes compared with community-based interventions.

Case Study Box 3

UCLA Alzheimer's and Dementia Care Program

Date Established
2012

Barriers Addressed
Communication and information-sharing

Key Features

- Each patient is assigned a nurse practitioner who serves as a dementia care specialist
- A personalized care plan is developed with the referring physician
- Family caregivers have access to assistance and advice 24/7, 365 days a year through its dementia care specialists and on-call geriatricians

Target Population
People with dementia and their family caregivers

Seniorlink (see Case Study Box 4). Seniorlink is a tech-enabled private health services company founded in 2000 that promotes home care for adults with complex chronic conditions by providing support to their family caregivers. Seniorlink leverages its proprietary HIPAA-secure technology, Vela, and evidence-based protocols with clinical oversight from care teams comprising a nurse and a care manager. In its home-based model, Seniorlink partners with state Medicaid payers or health plans to offer a cost-effective alternative to nursing home care. They also partner with health plans to augment their case management capabilities and offer both care managers through Seniorlink clinical teams and access to Vela. Through the Vela app, care managers connect with members and their family caregivers.

Vela was designed to include social media functions that a typical caregiver already uses (e.g., group chatting, sharing of pictures/videos) to make it user-friendly. Family caregivers, members, and other care team partners can use Vela to report incidents (e.g., falls, hospitalizations) and share documents, pictures, and videos that are then automatically saved for easy access later, creating a longitudinal record. Vela provides care managers access to Care Paths, built by Seniorlink. These are institutionalized best practices that give care managers conversational scripts to use with members and family caregivers on how to manage clinical, social, and behavioral aspects of care. The scripts can be customized for health plans as needed.

The care managers in Vela have health or professional backgrounds (e.g., social workers, nurses) and may be employed by Seniorlink or the payer. These solutions address the barrier of communication and information-sharing by enabling family caregivers to ask questions and provide updates about their loved ones while receiving support from their professional health care team. It also saves time by providing opportunities through its asynchronous communication feature to share information in real time and offers a centralized point of contact for family caregivers.

Members enrolled in the home-based model of care from Seniorlink have been found to experience fewer hospitalizations and emergency room visits compared with Medicare beneficiaries with similar complex conditions (Patel and Tumlinson, 2017).

Case Study Box 4

Seniorlink

Date Established
2000

Barriers Addressed
Communication and information-sharing; time limitations and competing demands

Key Features

- Leverages both one-on-one support through a care team—consisting of a nurse and a care manager—and a proprietary HIPAA-secure app called Vela
- Vela was designed to include communication functions that a typical caregiver already uses and provides the ability to share documents that are automatically saved for easy access later
- Care teams use Care Paths, which are institutionalized best practices, to communicate with family caregivers about clinical, social, and behavioral aspects of care

Target Population
Adults with complex chronic conditions or disabilities covered by both Medicare and Medicaid and their family caregivers

Seniorlink plans to expand operations to additional states and is conducting pilots with national health plans, including Medicare Advantage Plans, to test ways to improve collaboration among certain populations, such as family caregivers of people diagnosed with Alzheimer's or dementia and family caregivers of Medicare Advantage members who have multiple chronic conditions and are frequently hospitalized and struggle with activities of daily living.

Recommendations for Next Steps

Using the facilitators suggested in the key informant interviews, we identified six policy areas in which activities could help to integrate the family caregiver into the formal care team. However, pursuing these opportunities first requires several critical steps.

- **Systematic review of evidence-based programs.** Our literature review identified some evaluations of programs to improve integration of family caregivers into the health care team, but a more global, systematic review focused only on relevant programs is still needed to identify the evidence base for program implementation in the policy areas we identified and areas where evaluation and research are still needed. For example, Policy Area 3 (invest in programs that provide supportive services for family caregivers) would benefit particularly from this form of evaluation. There are many programs available to support caregivers. A systematic review of those that produce successful outcomes is needed to identify the best ways to support family caregivers and to determine which programs are cost-feasible for government agencies, employers, or payers to implement.
- **Expand the current study and include informant consensus-building methods to assess facilitators on a variety of metrics and identify a comprehensive list of action items for policy implementation.** Given that this study involved a small number of interviews, a natural next step is to convene a larger group of informants, either through an expert panel, focus groups, or more interviews, to see if there are other facilitators or action items to consider. Once a more comprehensive set is identified, they could be evaluated on several dimensions. In other RAND work, researchers assessed policy options for LTSS for dementia on the domains of feasibility, impact, and equity (Shih et al., 2014). We recommend doing the same for the final set of facilitators, ideally by developing evaluation metrics through a large and diverse group of informants and consensus methods.

  This method would help identify high-impact, feasible approaches that are ripe for implementation versus those that may need further development before they are ready to be implemented. For instance, Policy Area 2 (incentivize providers to engage with family caregivers) would particularly benefit from an informant assessment of the feasibility of different types of facilitators, because we received inconsistent information in our interviews on the feasibility of this option. Although it surfaced in several interviews as a viable solution, one informant suggested that providers would not welcome new billing options.

- **Cost-effectiveness analyses.** Policies are unlikely to be implemented without evidence of cost-effectiveness showing that the benefits (e.g., better patient health, lower health care costs) outweigh the costs (e.g., policy implementation costs). Formal cost-effectiveness analyses of the comprehensive set of facilitators will be essential for selecting and implementing the most beneficial policies.
- **Potential pilot options.** A next step would also be to pilot potential interventions to obtain data on effectiveness. Piloting combinations of approaches could also be beneficial. Initiatives in Policy Areas 1 and 3, for instance, may have greater impact if considered in tandem. Programs to support family caregivers (Policy Area 3) can be best implemented if caregivers are identified in a systematic way (Policy Area 1).

Conclusions

Family caregivers perform critical roles within the health care team. Although the role of family caregivers has begun to gain more recognition, integrating family caregivers as partners in the health care team is not standard protocol. There are many reasons why family caregivers should be included in the care team. They tend to have intimate knowledge of the care recipient's needs and wishes, giving them a unique ability to monitor and provide care. They also know the patient best, can provide valuable information to care providers, and are, as one expert put it, "the true eyes and ears—together with paid caregivers—it's the people who are in the home all the time who really understand what is possible and what isn't, [and are] able to think creatively about what the solutions ought to be [for supporting the patient]." As noted in the literature and our interviews with experts, there are also established benefits to the care recipient from receiving care that is well coordinated between the family caregivers and a formal care team.

The central role of family members as care providers has become even more pronounced in the context of the COVID-19 pandemic. Family members may be reluctant to use personal care and home health aides to care for their loved ones. Nursing homes are also a less viable option for care as disease spread has been rampant in them and in other institutional settings (Barnett and Grabowski, 2020). COVID-19 has exposed many of the flaws in the current long-term care system and facilitated new supports for home-based care (Fox-Grage, Teshale, and Spradlin, 2020; Volp, Diamond, and Shrank, 2020; Werner, Hoffman, and Coe, 2020). In this way, COVID-19 could disrupt the existing LTSS system while providing new opportunities for integrating family members into care teams in the future. For instance, new waiver options to pay family members in lieu of formal caregivers could serve to grow the pool of family caregivers and provide even greater motivation for improving their role as care team partners.

Although other work (National Academies of Sciences, Engineering, and Medicine, 2016) has already described caregiver needs and made recommendations for caregiver supports, our study is unique in that it focuses explicitly on integrating caregivers into the formal health care team by interviewing experts across a variety of sectors (e.g.,

> "[I]t's the people who are in the home all the time who really understand what is possible and what isn't, [and are] able to think creatively about what the solutions ought to be [for supporting the patient]."

caregiver advocates and experts, payers, providers) and identifying potential solutions and promising efforts applied in different settings.

We identified barriers to integration falling under four key themes: (1) identifying caregivers; (2) communication and information-sharing; (3) time limitations and competing demands; and (4) trust and cultural barriers. We also identified six policy areas in which initiatives could surmount these barriers: (1) identify and record information on family caregivers; (2) incentivize providers to engage with family caregivers; (3) invest in programs that provide supportive services for family caregivers; (4) expand access to and funding for care coordinators to support caregivers and connect them to clinical information; (5) implement training programs for providers and caregivers to facilitate effective communication; and (6) develop, test, and improve caregiver access to technologies that foster caregiver-provider care integration and information-sharing.

Finally, we offer case studies that provide a snapshot of existing programs that are addressing some of these barriers. We recommend expanding our approach through informant-engaged consensus methods; assessing the feasibility and impact of alternative approaches; determining cost effectiveness; assessing policy approaches on metrics of feasibility and impact; evaluating cost effectiveness; determining the availability of evidence-based research on program outcomes; and building consensus on how best to implement the most-promising approaches.

The policy area of developing, testing, and improving the use of technologies to connect caregivers to a care team is particularly crucial now, when people are hesitant to visit health care providers in person and employ formal caregivers from outside the home because of the risk of contracting COVID-19. Telemedicine is being used by health care professionals in lieu of office appointments. Technology to support caregivers and connect them to the care team is also critical for ensuring that care needs are being sufficiently met. This shift toward telemedicine and technology use for caregiver integration could persist even after the pandemic.

Data for this report were collected prior to the COVID-19 pandemic so we did not ask in our interviews what the pandemic implied for integrating caregivers into the formal care team. This connection should be explored in future work.

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About This Report

There are about 53 million family and friends providing care and assistance to loved ones in the United States. Although family caregivers provide a significant portion of health and support services to individuals with serious illnesses, they are often overlooked by the U.S. health care system. Fundamental changes are needed in the way we identify, assess, and support family caregivers. Recent changes in the U.S. health care system and payment models have increased the opportunities to integrate family caregivers into care teams.

In this report, the authors reviewed the literature on the role of family caregivers in the coordination of care and conducted key informant interviews with 13 experts from diverse stakeholder groups to better understand the barriers to integrating family caregivers into a patient's health care team and ways to mitigate these barriers. The authors identified promising policy directions and provide recommendations for next steps for assessing, developing, and implementing policies to improve the integration of family caregivers into health care teams.

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