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Perspective
EXPERT INSIGHTS ON A TIMELY POLICY ISSUE

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The Coronavirus Pandemic Highlights Why Family Caregivers Need to Be Integrated into the Health Care Team and Shows Us How to Make it Happen

We all know someone who is helping a loved one with daily care. These family caregivers might be supporting a parent, a disabled child, or a spouse with a chronic illness by assisting with everyday activities, such as eating, bathing, dressing, driving, and taking medications. There are currently 53 million family members in the United States providing care to loved ones (AARP and National Alliance for Caregiving, 2020). Recent changes in health care practices, such as shorter hospital stays, increasingly complex disease management, and more frequent management of chronic illnesses at home, have shifted the responsibility for many medical tasks to these family caregivers. It is also common for family caregivers to assist with medical tasks. In a recent survey, half of family caregivers said that they perform at least one type of medical or nursing task (e.g., managing medications, wound care, pain treatment, or incontinence care; handling medical equipment) for a loved one (Reinhard, 2019).

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Although family caregivers need to coordinate and communicate with what can be a large number of health care and social service providers, they are not treated as core members of the health care team. Family caregivers cannot easily share important clinical or social information with other care providers or receive the necessary information to effectively support their loved ones. Trying to provide care in this environment can create burdens for family caregivers and detract from more productive work, breeding frustration for all parties, undermining the quality of care provided, increasing unmet care needs, and generating adverse physical and mental health consequences for both caregivers and care recipients (Callahan et al., 2009; Griffin et al., 2017; Meyer et al., 2018; Samus et al., 2014; Wolff et al., 2010).

How COVID-19 Has Affected Family Caregiving

Coronavirus disease 2019 (COVID-19) has dramatically altered caregiving nationwide. To reduce the risk of COVID-19 infection, homes have become the default setting for both medical care and long-term care, and family members have become frontline workers. Formal caregiving has become less accessible because of the risk of infection posed by personal care and home health aides, many of whom provide services to multiple clients. In addition, many home- and community-based care organizations are experiencing shortages in the supply of care as aides opt out of the workforce to protect their own health. As a result, even individuals who want assistance from a paid caregiver might find it hard to obtain such help. Exacerbating the situation, other support services, such as respite and adult day centers, have shut down, creating more work for family caregivers and increasing the risk of burnout.

Potential Approaches to Integrating Family Caregivers into the Care Team

In light of COVID-19, it is more crucial than ever to support family caregivers who may be assuming increasingly heavy responsibilities, including providing medical care. However, helping family caregivers without involving the care team can have only limited benefits, especially for the many adults with complex health care needs.

In our related report, we highlight six policy areas in which further action could be taken to mitigate barriers

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to integrating family caregivers into the formal care team (Friedman and Tong, 2020). We conducted a comprehensive review of the scientific literature on the barriers and facilitators to integrating caregivers into the formal care team, and we supplemented this review by interviewing key informants, such as caregiver experts and representatives, clinical and direct service providers, and payers (e.g., insurance companies). We synthesized this information to identify barriers to integrating family caregivers into formal care teams. We grouped the barriers into common themes: difficulties identifying family caregivers; barriers to effective communication between providers and caregivers and lack of information-sharing; time limitations and competing demands that keep both providers and family members from effectively coordinating care; and trust and cultural barriers that limit communication.

We also asked key informants about the ways to address the barriers and grouped their suggested solutions into six policy areas: (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.

Although we completed this analysis before COVID-19 began to dominate public health concerns in the United States, the suggested solutions to integrating family caregivers into the care team are even more salient now. COVID-19 is altering what medical practice looks like, and some of these changes have been positive and could be enduring. These lessons can be leveraged to improve integration of family caregivers into the care team even after the pandemic is under control. A prominent example is the enhanced role of technology through which caregivers provide care and interact with the formal care team. This virtual approach has become mainstream and could persist as a common method of communication. Other solutions that have been adapted or expanded during COVID-19 also could—and maybe should—persist beyond the pandemic. To that end, we offer the following recommendations.

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Permanently Implement Some of the Temporary Policies in Support of Family Caregivers and Home-Based Care

Some of the policies enacted temporarily to address the challenges of family caregiving in the COVID-19 environment

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should be made permanent. When the immediate threat of COVID-19 diminishes, caregiving challenges will remain.

For example, temporary policies have been put in place to support health care provided at home. Coverage of telehealth services for Medicare beneficiaries, for instance, has been expanded temporarily during the pandemic, and Medicare has expanded the range of services covered by telehealth and the types of health care professionals who can bill Medicare for telehealth services (Centers for Medicare & Medicaid Services, 2020b). Telehealth services directly affect the family caregiver: A recent survey of caregivers indicated that 50 percent have used telehealth and virtual care visits with a health care provider to provide ongoing assistance to a family member or friend since the COVID-19 outbreak began in early 2020 (Associated Press-NORC Center for Public Affairs Research, 2020). Expanding remote services may give family caregivers more opportunities to participate in telehealth and virtual visits even after the pandemic ends, especially if complementary policies and practices are also instituted to ensure that these remote technologies are accessible and easy to use. An example of complementary policies and practices includes Medicaid section 1915(c) waiver Appendix K filings by states to allow case management to be done by phone or other IT platforms (Centers for Medicare & Medicaid Services, 2020a). Furthermore, beginning in late March 2020, the Centers for Medicare & Medicaid Services also began providing a waiver for homebound status during COVID-19 that allows for more home-based care and creates new opportunities for clinical models of care at home (Volpp, Diamond, and Shrank, 2020). These models of care will be needed even after the pandemic ends to support people in the setting that they most desire and provide person-centered and family-centered care.

Another temporary policy that merits permanence is paying family members for providing care. Because of the critical caregiving responsibilities of family members, especially during COVID-19, such roles are becoming more formalized, with new opportunities to permit patients to employ and pay family members as their 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 through a Medicaid section 1915(c) waiver Appendix K filing (Fox-Grage, Teshale, and Spradlin, 2020). Once the urgent threat of COVID-19 eases, this type of support can be continued as a way to recognize and support family members as integral members of the care team.

Assess Technological Solutions for Connecting Caregivers to the Formal Care Team

Caregivers are increasingly using digital technology to work more effectively, better manage their tasks, and interact more consistently with other caregivers and their loved ones. Digital tools also have the potential to bridge the gap between caregivers and formal care teams—for example, by increasing shared access features on patient portals (e.g., Epic MyChart), allowing caregivers to send secure electronic messages to health care or social service providers, providing caregiver-focused educational information, or giving caregivers access to clinical notes. Additional digital functionality could be built into patient portals—such as tools to assist with managing medications, task management to track caregiver roles, and a translator to convert clinical notes from medical jargon to a common language—to help family caregivers care for their loved ones. Electronic health records could document key information about family caregivers to raise their visibility and to give health care providers points of contact—for example, caregiver name, relationship to care recipient, contact information, advanced directives, and caregiving responsibilities, among other information.

OpenNotes, a movement to share clinical notes through patient health portals, is one example of using an electronic tool to allow doctors, nurses, therapists, and other health care professionals to share clinical visit notes with patients and their caregivers. Advocates of OpenNotes have been developing new capabilities so that both caregivers and patients can log in and view records and potentially even contribute to records, while ensuring that patient privacy is retained (OpenNotes, undated).

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Several digital technology companies have also begun to develop novel software tools for caregivers. For example, Seniorlink, a company that provides services, support, and technology that engages family caregivers (and highlighted as a case study in our earlier report), promotes home care for adults with complex chronic conditions through its care teams, consisting of a nurse and care manager, supported by proprietary Health Insurance Portability and Accountability Act (HIPAA) secure technology called Vela. Care managers and family caregivers connect through

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Vela, which provides communication functions and the ability to share documents and information. Since the COVID-19 pandemic began, Seniorlink has transitioned more than 6,500 families to an all-remote model of care management. Via Vela, these teams have been able to coach caregivers based on real-time feedback from families so that priority needs are met, including the emotional and behavioral health needs of both caregivers and those for whom they care. Care teams have discussed various topics with caregivers. Over the course of the pandemic, care teams have begun covering topics on accessing resources and supporting emotional and behavioral health needs to address the new and increased challenges that caregivers and individuals are facing during the pandemic.

Examples of successful efforts to use technology to integrate family caregivers into the care team notwithstanding, key informants in our study described how technological tools are still largely disconnected from the information platforms of health care providers and social services. Efforts to integrate with these services inevitably encounter challenges, such as limitations and variations in the capabilities of existing provider software systems and unclear expectations for how the provider will interact with the caregiver via the electronic system. The necessary next steps are to determine how to best integrate existing technologies with health care and social services and to develop more powerful tools to facilitate collaborations among caregivers, providers, social workers, and care settings.

Concluding Thoughts

The COVID-19 epidemic has dramatically affected every aspect of caregiving in the United States, but perhaps none more so than in family caregiving. The effect on caregivers who are family members may be especially pronounced because they are not typically viewed by health care professionals as core members of the health care team, despite their extraordinary contributions to the well-being of those for whom they care. This can compromise both the quality of care they provide and their own well-being.

Changes to caregiving and associated policies in the era of COVID-19 have highlighted the potential for policy and technology to promote care at home and better integrate family caregivers into the care team. Technology can be a tool to provide needed information and facilitate communication between family caregivers and the health care team.

The pandemic has provided a new perspective on how to address core challenges in family caregiving. Those challenges are not unique to COVID-19—the pandemic only served to raise their profile. COVID-19 has required dramatic changes in multiple areas of health care, including new approaches to communication and new ways to pay for and use technology. These innovations are being subjected to rigorous real-world testing as providers use technology to provide a wider variety of services.

No one would have chosen a pandemic to demonstrate the value of technology in health care delivery. However, we can seize the opportunity to learn and profit from what it has taught us. Those lessons will still have value—perhaps increased value—once COVID-19 is tamed.

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About This Perspective

This Perspective builds on a recent RAND report, entitled *A Framework for Integrating Family Caregivers Into the Health Care Team*, and reexamines findings from that work in the context of the coronavirus disease 2019 (COVID-19). In this Perspective, we describe why, in light of COVID-19, it is more crucial than ever to integrate family caregivers into the health care team, and we highlight several solutions for accomplishing this goal.

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