



# Perspectives on Rural Caregiving Challenges and Interventions

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## Key Findings

- Forty-one key informants across multiple sectors identified challenges, recent changes to rural caregiving, and strategies related to supporting informal (unpaid) caregivers in rural areas.
- Main challenges relate to access to resources, transportation, culture, demography, and isolation.
- Recent changes to rural caregiving relate to technology, demographic shifts, financial pressure, and changes in awareness and information.
- Possible strategies to support rural caregivers include increasing funding, developing a national strategy, and expanding access to resources.

## Purpose

Unpaid, informal caregivers provide the vast majority of all long-term care in the United States. However, little is known about specific challenges they face in rural areas or what can be done to support them. This brief presents findings from key informant interviews describing challenges and opportunities related to supporting informal caregivers in rural areas. A [related policy brief](#), “Resources for Caregivers in Rural Communities,” provides details about specific programs serving caregivers in rural areas.

## Background and Policy Context

Currently, the vast majority of all long-term care needs, broadly defined as an individual needing help with personal care and performing daily activities, is provided by informal (unpaid) caregivers.<sup>1</sup> In fact, recent estimates suggest that 80-90% of all long-term care needs are met by informal caregivers, usually family members, and more than 44 million Americans are currently providing unpaid care to a loved one, with the majority of care recipients being older adults.<sup>1,2</sup> The value of unpaid caregiving has been estimated at nearly \$500 billion annually, yet it receives far less research attention than institutional care or home health services. Caregiving, especially without appropriate support, is associated with various poor health outcomes for the caregiver.<sup>3</sup>

The entire U.S. is aging quickly, leading to increased need for caregiving.<sup>4</sup> Rural areas have an older population structure than urban areas and face shortages in the formal long-term care workforce,<sup>5</sup> pushing even more of the burden of care to unpaid caregivers. Additionally, rural residents anticipate that they will need more assistance from caregivers with activities of daily living as they age than urban residents.<sup>6</sup> Despite this, caregiver support programs are no more prevalent in rural areas, and are scarcer for some populations, including employed caregivers, who have fewer workplace supports available to them.<sup>7,8</sup> This leaves rural caregivers who may need help most at the greatest risk of not receiving it.

There are multiple ways in which policy can impact the health and wellbeing of caregivers and their care recipients; however, there is limited research on either the specific challenges faced by rural caregivers or policy levers to support their needs, specifically in a rural context. This brief identifies potential strategies for supporting rural caregivers using information from key informant interviews from experts in informal caregiving across the country.

## Approach

Data for this study come from 41 key informants across 34 interviews (some interviews had multiple informants participate). We identified key

informants for inclusion based on expertise in rural health and caregiving issues and then used a snowball technique, asking key informants to nominate other potential respondents to participate. We included key informants from across the country, covering all four Census regions, from a variety of sectors, including academia and research (n=12), grant management and technical assistance (n=5), state agencies (n=4), advocacy (n=6), business (n=3), and direct service (n=11).

We reached out to potential key informants by email with an invitation to participate. Participants were given the option of completing the interview by telephone (n=36), email (n=2), or in-person (n=3). Interviews were conducted between October 2017 and February 2018, lasted approximately 20-25 minutes each, and included questions on what is unique about caregiving in rural areas, how rural caregiving has changed (if at all) in the past 10 years, and what policy and programmatic interventions respondents would recommend. We also asked key informants to identify specific programs supporting unpaid caregivers in rural areas (the results of which are included in an [accompanying policy brief](#) entitled “Resources for Caregivers in Rural Communities”), as well as for any recommendations for other key informants we should speak with. We used content analysis to identify themes from the interviews, with both researchers coding all interviews independently and then working together to find consensus across codes.

## Results

We identified themes within three broad areas related to informal caregivers in rural areas: challenges, changes in caregiving, and strategies to support rural caregivers. These are detailed below. For illustrative quotations, see tables 1-3, pages 5 and 6.

### Challenges

When asked about challenges related to informal caregiving in rural areas, key informants listed issues around five main themes. These were all endorsed by multiple respondents, and are listed below in the order of how frequently they were mentioned.

*Access to resources.* This most-commonly endorsed theme included observations that rural areas had fewer resources generally to support rural caregivers, including fewer formal support programs; more restricted access to health care; workforce shortages; and less access to home care and respite services. Respondents also noted that if a supportive service fell through, there was less likely to be

a backup plan available. Key informants noted that small populations in rural areas meant that there were fewer available resources and fewer back-up options if one type of service fell through. As a result, they noted that informal caregivers may face additional pressure to provide care without much help.

*Transportation.* Key informants noted the long distances between caregivers and health care and supportive services, as well as potential distances between caregivers and non-resident care recipients. Respondents also noted the financial constraints related to transportation, including gas and private vehicles being expensive, as well as difficulty accessing non-medical transportation. Additionally, because of long distances and because of limited public transportation, key informants noted that it can take a prohibitively long time to run even a simple errand. Because many rural caregivers do not have a back-up system of care available, this leaves them unable to travel for those errands, as they cannot leave their care recipient alone for that long.

*Rural culture.* Several lamented that it can be difficult to get caregivers in rural areas to ask for help, perhaps because of stigma attached to the idea of not being able to solve one’s own problem. However, several key informants also mentioned the strength of rural communities, in that they cared for and looked out for one another. One key informant noted that because formal health care staff tend to be from the area they serve, they might be more likely to look out for informal caregivers and their needs. Another noted that rural areas have particularly strong informal networks and people will support each other, including pitching in to help provide care.

*Demography.* An aging rural population creates greater demand for caregiving and also means that caregivers themselves are getting older, on average. We also heard about increasing rates of disability and need for care, as well as higher rates of poverty and lower incomes in rural areas. Additionally, one key informant noted that because rural communities have lower population densities, they also have fewer resources available to them. Another noted that because of economic pressure, younger adults have been leaving rural areas and are no longer there to provide care when needed.

*Isolation.* Long distances lead to more social isolation among caregivers, which may make it difficult for them to access help and supportive services when they need it. Caregivers who cannot leave their care recipient alone often lose ties to their previous social, occupational, and civic activities. One key informant noted that this can

put both caregivers and care recipients at higher risk of depression and anxiety. Further, being physically isolated may make it more difficult for individuals to access services – or even to become aware of the availability of supportive services that could help them.

See Table 1 for illustrative quotations related to this theme.

### Changes in Caregiving

When asked how caregiving in rural areas has changed in the past decade, key informants listed changes, both positive and challenging, related to four main themes:

*Technology.* Comments related to this theme, the most-frequently-mentioned in this category, focused on increased access to personal computers and smartphones,

as well as the ability to connect with loved ones remotely via communication technology. Most respondents were hopeful that these changes would reduce social isolation, but some noted disparities in access to these technologies, expressing concerns that some rural caregivers without access to broadband or the ability to afford devices could become further isolated. Key informants also described changes in technology in health care, including telehealth and telemedicine, as well as increased availability of on-line caregiving resources and information, hoping such changes would increase access to care and supportive services for rural caregivers and care recipients.

*Demographic shifts.* Similar to the challenge listed above, key informants expressed concerns about changes in the age structure of rural communities, noting that

**Table 1: Illustrative Quotations for Challenges Related to Informal Caregiving in Rural Areas**

Theme	Illustrative Quotations
<b>Access to resources</b>	<ul style="list-style-type: none"> <li>• There are fewer resources in rural communities because of smaller populations and less support to keep them going.</li> <li>• Less redundancy of formal health services in rural areas, so that if one option fails, there isn't a back-up one.</li> <li>• There aren't as many providers (respite, companion care, adult day services)—and people who live on farms or ranches can't leave their care recipient at home, so a lot of them take their care recipient with them as they plow the fields, and leave them in a truck to wait—which is dangerous. It's a huge struggle if there isn't a respite or care center to go to, and those [care centers] need special licenses so aren't that many.</li> </ul>
<b>Transportation</b>	<ul style="list-style-type: none"> <li>• Most communities have a bus system, but it can still take several hours for someone to run a simple errand. For caregivers who can't leave their care recipient alone for that long, it's not workable.</li> <li>• There's a caregiver shortage everywhere, but it's felt more in rural areas because there are situations where local companies won't travel out to someone's home for fewer than 4 hours because the transit is cost-prohibitive for them. But, if a caregiver only needs help for 1 hour, they might not be able to afford care for that long and then they go without altogether.</li> </ul>
<b>Rural culture</b>	<ul style="list-style-type: none"> <li>• On the positive side—staff in rural programs tend to be from the area they serve and are incredibly committed, passionate, and knowledgeable about the area. It's not just a job for them.</li> <li>• While in small towns there is some stigma, there is also non-familial support of the community.</li> <li>• Rural areas have stronger networks—informal networks—and will look to friends, family, and faith communities, while urban areas depend on formal services and supports. Rural people are more equipped and willing to come together and provide a safety net, and they're more self-reliant.</li> </ul>
<b>Demography</b>	<ul style="list-style-type: none"> <li>• There is a family caregiver support program that provides funding for a certain number of hours of care, but there's no one to provide the care in rural areas.</li> <li>• In rural areas, if there are no jobs, then the younger people are leaving and there are fewer people to provide care.</li> </ul>
<b>Isolation</b>	<ul style="list-style-type: none"> <li>• There are even areas that aren't covered by any services at all, because they're too far away.</li> <li>• Isolation is also a really big issue. It's a problem for both caregivers and care recipients—for caregivers, if they want to go to town for a quick break, they often can't, because there isn't someone living next door who can come over and help them. The isolation can lead to depression and anxiety. Many older adults used to be social and go into town a lot, but then health problems make it harder for them to do so.</li> </ul>

increases in longevity, disability, dementia, and acuity of disease have the potential to put more strain on caregivers. They added that out-migration of younger and middle-aged adults left some older adults without available caregivers, and some also discussed lower marriage rates and lower birth rates, both of which lead to a pool of fewer available caregivers in the short- and long-term.

*Financial pressure.* Rural areas have recovered more slowly from the Great Recession in the late 2000's and some have eroding tax bases. One key informant observed that the recession has meant that fewer men are employed in rural areas; as a result, there are more available to provide care for their loved ones. (Indeed, research supports this, showing that men had a consistently higher unemployment rate than women during the Great Recession and men have had a sharper decline in labor force participation than women since.<sup>9</sup>)

*Changes in awareness and information.* Several observed greater public awareness of caregivers and the need for supportive services, owing in part to increased demand for such care, and in part to recent educational and awareness campaigns. Several also mentioned that information is easier to access online.

See Table 2 for illustrative quotations related to this theme.

### Strategies to Support Caregivers

Finally, when key informants were asked about potential policy and programmatic interventions to better support informal caregivers in rural areas, they provided a variety of suggestions, largely falling under the following three themes:

*Increase funding.* Many directly named the need to increase funding for caregiver support programs, including through existing programs like the Older Americans Act or by creating new state or federal initiatives. Some noted the need to be creative with funding, including assessing whether or not U.S. Department of Agriculture (USDA) funding could support caregivers, and identifying flexible sources of funding that are not tied to only one population (e.g. individuals with dementia). Several key informants also emphasized the importance of supporting individual caregivers through stipends and of increasing access to health insurance (e.g., through Medicaid) to make health care more affordable for caregivers and care recipients alike. One key informant noted that the cost of health care has put a strain on farming families and their availability to provide care to one another. Because the cost of health insurance and health care has risen, one spouse from a farm often needs to travel to town to work (for the health insurance benefits); this makes it difficult to also provide unpaid care to ailing family members on or near the farm.

**Table 2: Illustrative Quotations for Changes Related to Informal Caregiving in Rural Areas**

Theme	Illustrative Quotations
<b>Technology</b>	<ul style="list-style-type: none"> <li>• <i>The availability [ability] to communicate with loved ones [from a distance]; for caregivers who aren't close or [who need to travel to] work, technology helps if they're making long trips to care.</i></li> </ul>
<b>Demographic Shifts</b>	<ul style="list-style-type: none"> <li>• <i>Increases in both longevity and acuity have led to greater stressors for caregivers.</i></li> <li>• <i>As people live longer and have more chronic conditions, it becomes more of a problem to have enough providers. The trend was always there for rural, but it is becoming more predominant as the population changes.</i></li> <li>• <i>Seeing more older people taking care of older people. We've come to understand the sandwich generation and wrap our minds around their issues, but what is new is that those who are older than the baby boomers are caring for each other.</i></li> </ul>
<b>Financial pressure</b>	<ul style="list-style-type: none"> <li>• <i>It's always more difficult caregiving in rural areas—the money [for supporting unpaid caregivers] goes to where the population is, and there is not a large population in rural areas, so because of limited [federal] money, rural gets less. It also costs more to deliver services in rural areas. Money is stagnant, and that's a constant problem.</i></li> </ul>
<b>Changes in awareness &amp; information</b>	<ul style="list-style-type: none"> <li>• <i>Social media and internet are huge, and while people may not be able to get all of the services they see [online, targeting informal caregivers], they at least have a greater awareness.</i></li> <li>• <i>Rural areas have given more thought to aging and have realized that older adults are critical citizens, and communities know they need to make an effort to get them to stay.</i></li> </ul>

*Develop a national strategy.* Key informants noted the need for more public attention to the issue of informal caregiving, as well as policies and programs to better support caregivers, in both rural and urban areas. They mentioned that individual communities are doing good work in this area, but felt there should be more concerted efforts by federal and state policy makers and members of the public to raise awareness and better support caregivers across the country. One suggested utilizing state and local radio programming to increase awareness in rural areas about caregiving and the importance of support services.

*Expand access to resources.* Many key informants cited a need to increase the availability and accessibility of caregiver-support resources, including by addressing access to existing programs and expanding the number and type of available programs. This includes formal health care services as well as supportive services and information, which might include transportation, respite care, educational materials, and workplace supports ([see the accompanying brief](#), “Resources for Caregivers in Rural Communities,” for specific examples.) Suggestions to increase access to services included hosting events in rural

communities so that caregivers can reach supportive programs locally. These efforts might be led by community members, health care providers, policy makers, and other concerned stakeholders.

See Table 3 for illustrative quotations related to this theme.

## Discussion and Implications

In this brief, we used information from 41 key informants to identify challenges, recent changes, and strategies to support informal caregivers in rural areas. These interviews highlighted the complex nature of informal caregiving, particularly in rural areas, where resources are more limited. They also highlighted the critical work that informal caregivers are doing to meet the needs of rural residents across the country.

The key informants identified some potential strategies to support informal caregivers in rural areas. There are also multiple policy levers that have been used to support caregivers across the country. Some examples that have been shown to improve quality of life and caregiver well-being include:

**Table 3: Illustrative Quotations for Strategies Related to Supporting Informal Caregiving in Rural Areas**

Theme	Quotation
<b>Increase funding</b>	<ul style="list-style-type: none"> <li>• <i>Improve (not lower or cut) Medicaid services, which too many families are currently lacking.</i></li> <li>• <i>Caregiving can put you in a spiral toward poverty. I think it's better to directly pay caregivers than to provide tax relief.</i></li> <li>• <i>Address health care and housing costs. When those are so high, it's difficult for people to also provide informal care or to volunteer for caregiving programs. In farming families, one spouse often has to work in town now to get health care benefits— didn't used to be the case, and it makes it harder for adult children to provide care to their older parents if they're [the adult children] working in town.</i></li> </ul>
	<ul style="list-style-type: none"> <li>• <i>Recognizing that we have a fragile system in rural areas, which relies on people stretching themselves further. Anything else that stretches them will leave holes in the safety net.</i></li> <li>• <i>There is a broader lack of awareness and education to the role of caregiving. We need to do a better job communicating about caregiving, particularly in the workplace, and communities like churches, to be able to recognize caregivers and help them.</i></li> </ul>
	<ul style="list-style-type: none"> <li>• <i>Making services more accessible or that go to homes [providing in-home care and assistance] is such a concern for caregivers and effects caregivers' wellbeing and ability to care for their loved ones.</i></li> <li>• <i>Caregivers should be comfortable, prepared, and confident—family caregivers are often afraid they are going to harm the care recipients, and there has to be a way to improve confidence and preparation, and if skilled tasks are where the need is, then we need to focus on that.</i></li> <li>• <i>Expanding broadband internet, universal broadband access—to provide the infrastructure to be able to provide technology services to rural caregiving families. It would broaden connections, and allow for things like remote in-home monitoring technology and telemedicine.</i></li> </ul>
<b>Expand access to resources</b>	

- state policies requiring caregiver training before a care recipient is discharged from the hospital;<sup>1</sup>
  - Medicare regulations requiring more thorough discharge planning as it relates to identifying, training, and supporting caregivers;
  - improved access to care coordination services;
  - Medicaid Home and Community-Based Services Waiver demonstration programs to assess caregiver needs;
  - funding for the National Family Caregiver Support Program (under Title III-E of the Older Americans Act) and the Lifespan Respite Care Act (Public Health Service Act);<sup>5</sup>
  - expanded family leave policies;
  - clinical protocols for screening for caregiver depression/isolation/burden;
  - transportation programs to allow care recipients to attend respite care programs, allowing caregivers a short reprieve; and
  - expanded economic incentives for caregivers, including tax credits, providing working “credits” in the Social Security program, and offering subsidies for providing care.
- More work is needed to understand how these programs would specifically address the needs of rural caregivers.
- Regardless of the specific policy or programmatic approach used to support informal caregivers in rural areas, it is essential that policy-makers, researchers, and practitioners alike recognize the value of informal caregivers and find ways to support and sustain them.

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### Rural Health Research & Policy Centers

Funded by the Federal Office of Rural Health Policy  
[www.ruralhealthresearch.org](http://www.ruralhealthresearch.org)

Support for this study was provided by the Office of Rural Health Policy, Health Resources and Services Administration, PHS Grant No. 5U1CRH03717.

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