Working Caregivers in Rural Minnesota: A New Model
Working Caregivers in Rural Minnesota: A New Model

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Minnesota Gerontological Society Conference
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Agenda

• Background
• Rural-urban differences in caregiver supports, including for employed caregivers
• Key informant interview results
• Discussion and implications for serving rural caregivers
Acknowledgements

• Our colleagues at RHRC:
  – Katy Kozhimannil, PhD, MPA
  – Michelle Casey, MS

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Rural Health Research Center Grant

• Mission:

We conduct policy-relevant research to improve the lives of rural residents and families, to advance health equity, and to enhance the vitality of rural communities.
Caring for Caregivers Project

• Goals:
  – Identify rural-urban differences in caregiver experiences
  – Describe rural-urban differences in available supports for caregivers, including employed caregivers
  – Examine unique challenges and opportunities related to supporting unpaid caregivers in rural settings
Why Care about Caregiving?

• More than 80% of all long-term care is provided by informal/unpaid caregivers
• More than 44 million Americans are currently providing care to a loved one
  – In Minnesota, an estimated 585,000 people are caregivers
• The value of unpaid caregiving has been estimated at nearly $500 billion annually
• Without support, caregiving can be associated with high burden and poor health outcomes
Caregiving in a Rural Context

- Limited research on rural-urban differences in unpaid caregiving
- This, despite fact that rural areas:
  - Are older, on average, than urban areas;
  - Have fewer economic and health care resources;
  - Face practical challenges related to transportation, distance, and infrastructure;
  - Experience unique barriers to formal long-term care services
How do rural and urban caregivers, including employed caregivers, differ in their use of and access to supportive services?
Quantitative Analysis

• Caregiving in the U.S. survey
  – 2015 survey of 1,563 unpaid caregivers across the U.S.
  – Web-based survey sponsored by AARP and the National Alliance for Caregiving
• Weighted analysis to identify rural-urban differences in caregiver experiences, health, and supportive services
• Sub-group analysis of employed caregivers to identify rural-urban differences in workplace supports
Rural-Urban Differences in Caregiver Experiences and Preferences

- Rural-urban differences in caregiver experiences, health, use of supports, and preferences for supports
## Demographic Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Urban caregiver</th>
<th>Rural caregiver</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>58.7%</td>
<td>59.8%</td>
<td>0.778</td>
</tr>
<tr>
<td>Age (Mean; Range: 18-89)</td>
<td>53.6 (18.5)</td>
<td>54.4 (19.2)</td>
<td>0.621</td>
</tr>
<tr>
<td>Educational attainment</td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Less than high school</td>
<td>6.4%</td>
<td>10.3%</td>
<td></td>
</tr>
<tr>
<td>College or more</td>
<td>38.7%</td>
<td>27.1%</td>
<td></td>
</tr>
<tr>
<td>Household income</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>&lt;15,000</td>
<td>10.2%</td>
<td>11.1%</td>
<td></td>
</tr>
<tr>
<td>15000-29,999</td>
<td>14.8%</td>
<td>21.6%</td>
<td></td>
</tr>
<tr>
<td>10000+</td>
<td>23.7%</td>
<td>12.9%</td>
<td></td>
</tr>
<tr>
<td>Employed in past year (while providing care)</td>
<td>54.7%</td>
<td>44.3%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Good, very good, excellent health</td>
<td>82.5%</td>
<td>86.6%</td>
<td>0.148</td>
</tr>
</tbody>
</table>
## Caregiving Experiences

<table>
<thead>
<tr>
<th></th>
<th>Urban caregiver</th>
<th>Rural caregiver</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver strain (Mean)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical strain (Range: 1-5)</td>
<td>2.5 (1.3)</td>
<td>2.4 (1.1)</td>
<td>0.226</td>
</tr>
<tr>
<td>Emotional strain (Range: 1-5)</td>
<td>3.0 (1.3)</td>
<td>3.0 (1.3)</td>
<td>0.685</td>
</tr>
<tr>
<td>Financial strain (Range: 1-5)</td>
<td>2.2 (1.3)</td>
<td>2.3 (1.3)</td>
<td>0.671</td>
</tr>
<tr>
<td><strong>Caregiving intensity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hours of care provided per week (Mean; Range: 0.5-98)</td>
<td>26.2 (30.7)</td>
<td>22.8 (27.5)</td>
<td>0.112</td>
</tr>
<tr>
<td><strong>Distance to care recipient</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In household</td>
<td>37.70%</td>
<td>39.60%</td>
<td>0.978</td>
</tr>
<tr>
<td>Within 20 minutes</td>
<td>38.90%</td>
<td>38.10%</td>
<td></td>
</tr>
<tr>
<td>20-60 minutes</td>
<td>13.10%</td>
<td>11.70%</td>
<td></td>
</tr>
<tr>
<td>1-2 hours</td>
<td>3.70%</td>
<td>3.90%</td>
<td></td>
</tr>
<tr>
<td>More than 2 hours</td>
<td>6.70%</td>
<td>6.80%</td>
<td></td>
</tr>
</tbody>
</table>
Caregiver Service Use by Location

Number of caregiver services used; services included respite care, transportation, paid help, home modifications, information on financial help

- Urban
- Rural

- 0 services: 31% Urban, 34% Rural
- 1 service: 31.2% Urban, 29.4% Rural
- 2 services: 17.9% Urban, 18.3% Rural
- 3 services: 11.5% Urban, 10.3% Rural
- 4 services: 6.9% Urban, 6.7% Rural
- 5 services: 1.4% Urban, 1.4% Rural
## Preferences for Services and Policies

<table>
<thead>
<tr>
<th>Policies that would be helpful:</th>
<th>Urban caregiver</th>
<th>Rural caregiver</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requiring providers to include caregiver name on care recipient's chart</td>
<td>51.40%</td>
<td>49.40%</td>
<td>0.061</td>
</tr>
<tr>
<td>Requiring hospitals to keep caregiver informed of major decisions</td>
<td>43.20%</td>
<td>39.00%</td>
<td>0.279</td>
</tr>
<tr>
<td>Requiring hospitals/facilities to instruct caregiver on nursing tasks</td>
<td>43.70%</td>
<td>43.40%</td>
<td>0.931</td>
</tr>
<tr>
<td>Having respite services available</td>
<td>35.20%</td>
<td>27.60%</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Requiring providers to ask caregiver about what he/she needs to take care of self</td>
<td>26.70%</td>
<td>22.90%</td>
<td>0.28</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Need more help/information about:</th>
<th>Urban caregiver</th>
<th>Rural caregiver</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keeping care recipient safe at home</td>
<td>42.50%</td>
<td>37.40%</td>
<td>0.189</td>
</tr>
<tr>
<td>Management challenging behaviors</td>
<td>13.60%</td>
<td>9.70%</td>
<td>0.119</td>
</tr>
<tr>
<td>Managing emotional/physical stress</td>
<td>42.80%</td>
<td>38.10%</td>
<td>0.232</td>
</tr>
<tr>
<td>Making end-of-life decisions</td>
<td>22.60%</td>
<td>21.50%</td>
<td>0.762</td>
</tr>
</tbody>
</table>
Do caregivers employed outside of the home have different access to workplace supports for caregiving, depending on rural-urban location?
## Caregiver Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Urban caregiver</th>
<th>Rural caregiver</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary caregiver</td>
<td>59.10%</td>
<td>62.20%</td>
<td>0.622</td>
</tr>
<tr>
<td>Level of care burden index</td>
<td>2.7</td>
<td>2.4</td>
<td>0.23</td>
</tr>
<tr>
<td>(range 1-5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average strain (range 1-5)</td>
<td>2.5</td>
<td>2.4</td>
<td>0.538</td>
</tr>
<tr>
<td>Hours of caregiving per week</td>
<td>20.5</td>
<td>15.6</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Average hours worked per week</td>
<td>35.8</td>
<td>34.4</td>
<td>0.326</td>
</tr>
<tr>
<td>Supervisor knows about</td>
<td>60.80%</td>
<td>67.80%</td>
<td>0.295</td>
</tr>
<tr>
<td>caregiving responsibilities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Workplace Supports</td>
<td>Urban caregiver</td>
<td>Rural caregiver</td>
<td>P value</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>----------------</td>
<td>----------------</td>
<td>---------</td>
</tr>
<tr>
<td>Flexible work hours</td>
<td>54.70%</td>
<td>49.30%</td>
<td>0.416</td>
</tr>
<tr>
<td>Telecommuting or working from home allowed</td>
<td>24.90%</td>
<td>9.70%</td>
<td>&lt; .01</td>
</tr>
<tr>
<td>Supportive programs (EAP, information, referrals)</td>
<td>25.80%</td>
<td>15.20%</td>
<td>&lt; .01</td>
</tr>
<tr>
<td>Paid leave available</td>
<td>34.10%</td>
<td>17.70%</td>
<td>&lt; .01</td>
</tr>
<tr>
<td>Paid sick time available</td>
<td>52.70%</td>
<td>45.60%</td>
<td>0.274</td>
</tr>
<tr>
<td>Count of workplace benefits</td>
<td>1.89</td>
<td>1.34</td>
<td>&lt; .001</td>
</tr>
</tbody>
</table>
Key Findings: Quantitative Analysis

• Rural caregivers face socioeconomic disadvantages, relative to urban.

• Rural and urban caregivers have similar levels of strain and service usage, with ~1/3 of all caregivers using NO supportive services.

• In the workplace, employed rural caregivers have significantly fewer supports available to them.
What unique challenges and opportunities must be considered when designing models to support rural caregivers?
Qualitative Analysis

• Semi-structured interviews with key informants with expertise in rural caregiving (n=41)
• National sample, across all four Census regions
• Variety of sectors: 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)
• Themes identified by research team using content analysis
Perspectives on Rural Caregiving Challenges and Interventions

Carrie Hemmens-Smith, PhD
Morgan Uhr, MPH

Key Findings
- Forty-one key informants across multiple sectors identified challenges, recent changes to rural caregiving, and strategies related to supporting informal rural caregivers in rural areas.
- Key findings from key informant interviews describing challenges and opportunities related to supporting informal caregivers in rural areas. A supplementary file, “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 caregivers. In fact, 80% of all long-term care needs are met by informal caregivers, usually family members, and more than 90 million Americans are currently providing unpaid care to a loved one, with the majority of care recipients being older adults. The value of unpaid caregiving has been estimated at nearly $500 billion annually, as it is received, and research shows that informal caregivers are three times more likely to be caregivers for more than one person simultaneously. In addition, informal caregivers in rural areas are more likely to be women, lone parents, and family members.

The role of U.S. aging policy in leading to increased need for caregiving. Rural areas have an older population structure than urban areas and face shortages in the formal long-term care workforce, 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 by age 85 or older. Despite this, caregiver support programs are not as prevalent in rural areas, and are scarcer for some populations, including employed caregivers who have fewer workplace supports available to them. This leaves rural caregivers who may need help at the greatest risk of not receiving.

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 the specific challenges faced by rural caregivers and potential solutions. This policy brief highlights key findings from key informant interviews and offers potential strategies for supporting rural caregivers.

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

Resources for Caregiving in Rural Communities

Morgan Uhr, MPH
Carrie Hemmens-Smith, PhD

Introduction
Estimates suggest that informal caregivers provide the vast majority of all long-term care (80%–90%) to family members and friends in need of assistance. This unpaid caregiving has been associated with poor health outcomes, like increased depression, and a decrease in physical health, particularly for caregivers who lack support. Fortunately, these impacts on health can be mitigated by the use of supportive services, and numerous research studies have shown that informal caregivers are more likely to provide services and support for caregivers. However, research shows that, despite the potential benefits of caregiver support, programs are not as prevalent in rural areas, and are scarcer for some populations, including employed caregivers who have fewer workplace supports available to them.

This policy brief provides an overview of available resources for caregivers in rural areas, including government, community-based, and faith-based organizations. The policy brief is focused on those that provide services targeted to caregivers of adults with long-term care needs, and emphasizes those programs available to rural caregivers. While many programs are national in scope, the resources included here may include many that have been implemented in rural communities and states with large rural populations, as well as resources that are available online (either directly or via telephone), and even inclusive access to rural caregivers.

This resource guide is not an exhaustive list of available programs and focuses on resources for caregivers of older adults and adults with functional impairments. There are many other organizations that focus on supporting caregivers of other groups of individuals (e.g., children); these resources are not included here.

Resources for Caregivers

Providing caregivers with proper training, knowledge of resources available to them in their area, tools for managing difficult behaviors or whose own areas are critical to their caregivers and their personal mental and physical health. Programs providing support to caregivers can be run at the state or local level, and are organized by non-profits, corporations, or faith-based organizations. Supportive services range from providing information to counseling and case management.

We included resources that offer support to caregivers and their care recipients in rural areas. These resources can include programs that support caregivers directly through training, programs for care recipients (such as respite care) that improve daily life for caregivers, or programs that are broader than that may be offered at various organizations who want to improve or expand the services they provide to caregivers in their local communities. We also attempted to select resources that are more proactive to assist.

We have compiled a list of resources and supporting care programs and related information available for caregivers in rural areas in the state of Minnesota, including government and community-based resources.

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Challenges to Rural Caregiving

- Themes (in order of frequency):
  - Access to resources
  - Transportation
  - Rural “culture”
  - Demography
  - Isolation
Theme 1: Access to Resources

• Fewer caregiving-specific resources
• Limited health care; workforce shortages
• Less access to home care and respite services
• Few, if any, back-up options available
“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.”
Theme 2: Transportation

- Long distances
- Financial constraints (owning vehicles, gas and maintenance, etc.)
- Limited public transportation
- Difficulty accessing non-medical transportation
Transportation Quotes

• 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.

• 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.
Theme 3: Rural Culture

• Reluctance to ask for help
• Strength of rural networks
Rural Culture Quotes

• 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.

• 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.
Theme 4: Demography

- Aging population; greater demand for care
- Caregivers also getting older
- Increasing rates of disability
- Higher rates of poverty/lower incomes in rural areas
- Fewer people means fewer services
Demography Quotes

• There are less resources in rural communities because of smaller populations and less support to keep them going.

• In rural areas, if there are no jobs, then the younger people are leaving and there are fewer people to provide care.
Theme 5: Isolation

• Long distances create increased risk of social isolation for caregivers
• Caregivers lose ties to previous social, occupational, and civic activities
• More difficult to learn about and access services
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.
Strategies to Support Rural Caregivers

• Key informants offered recommendations for continuing and new models to support rural caregivers

• Themes:
  – Increase funding
  – Develop a national strategy
  – Expand access to resources
Strategy 1: Increase Funding

• Increase funding through existing programs/policies, like the Older Americans Act
• Partner with other agencies, like USDA
• Identify flexible sources of funding
• Support individual caregivers through stipends and access to health insurance
Strategy 2: Develop a National Strategy

• Need for more public awareness and attention
• Utilize existing channels of information, such as radio in rural areas

Quote:
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.
Strategy 3: Expand Access to Resources

• Expand knowledge of/access to existing resources
• Expand the number and type of available options
  – Might include: transportation, health care services, supportive services, information/education, respite care, and workplace supports
• Reach caregivers locally, in their communities
Where to From Here?

• Build on existing efforts to support caregivers
• Address rural-specific needs, constraints, and opportunities
• Research ways in which state and federal efforts address the needs (or not) of rural caregivers
Policy Implications

• With a complex problem comes a variety of avenues to intervene. Specific policies might include:
  – Recognition and education of caregivers in clinical settings
  – Expand access to broadband Internet and transportation in rural settings
  – Broaden family leave and sick time policies in workplaces
  – Financial support for caregivers
  – Continued/expanded Funding for National Caregiver Support Program and Lifespan Respite Care Act; Medicaid HCBS Waiver programs; etc.
Build on Existing Programs

• Programs and policies exist on the national, state, local, and organization levels to support caregivers
  – Detailed in “Resources for Caregiving in Rural Communities” policy brief (2018)

• More is needed to fully meet the needs of rural caregivers, especially employed rural caregivers
A New Model for Supporting Employed Caregivers in Rural Areas
Comprehensive Person Pulse

Healthcare Providers
- Health Systems
- Community Paramedics
- Care Clinics

Employers
- Transportation Provider
- Maintenance Services
- Food Bank

Neighbors
Friends
Family
Faith Groups

Autonome Solutions
Discussion
• What is working well in your community?

• Where do gaps remain?

• Do we need a “new model” or should we build on what we already have? Both?
Gateway provides easy and timely access to research conducted by the Rural Health Research Centers

ruralhealthresearch.org

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- Fact Sheets
- Policy Briefs
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