

## Review Article

# Bridging the gap: a scoping review of family caregiver roles in rural health settings

### AUTHORS



Stephanie Quon<sup>1</sup> BSc, Medical Student \*



Isabel Truong<sup>1</sup> BSc



Leah Moroz<sup>1</sup> BSc



Katherine Zheng<sup>1</sup> MSc

### CORRESPONDENCE

\* Stephanie Quon [stephaniesquon@gmail.com](mailto:stephaniesquon@gmail.com)

### AFFILIATIONS

<sup>1</sup> Faculty of Medicine, University of British Columbia, Vancouver, BC, Canada

### PUBLISHED

24 March 2026 Volume 26 Issue 1

### HISTORY

RECEIVED: 21 October 2025

REVISED: 24 December 2026

ACCEPTED: 27 January 2026

### CITATION

Quon S, Truong I, Moroz L, Zheng K. Bridging the gap: a scoping review of family caregiver roles in rural health settings. *Rural and Remote Health* 2026; 26: 10621. <https://doi.org/10.22605/RRH10621>

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## Abstract

**Introduction:** Rural health systems depend on family and other unpaid care partners to bridge gaps created by distance, workforce shortages, and limited infrastructure, yet evidence about their delivery-facing roles is dispersed. Therefore, the objective of this study was to map how unpaid caregivers contribute to rural health delivery, identify common enablers and barriers, and summarize reported outcomes for patients, caregivers, and health systems.

**Methods:** We conducted a scoping review in accordance with PRISMA-ScR guidelines. We searched MEDLINE, Embase, CINAHL, PsycINFO, Scopus, Web of Science Core Collection, and ProQuest from January 2000 to September 2025. Eligible English-language

studies examined unpaid caregivers supporting individuals of any age in rural/remote/frontier settings where caregiver activities intersected with health service delivery.

**Results:** Forty-five studies were included. Eight recurring domains described caregiver work: coordination and navigation; medication and treatment management; telehealth mediation; monitoring and early triage; transport and home or environmental adaptation; cultural and linguistic brokerage and trust-building; palliative, disability, and long-term support; and caregiver competence and burden. Barriers included device gaps, fragmented hand-offs, limited respite, and travel costs. Programs integrating caregivers

reported improved adherence, continuity, and earlier escalation.

**Conclusion:** Unpaid caregivers are important members of rural care teams. Formal recognition, resourcing, and measurement,

## Keywords

care coordination, family caregivers, informal caregiving, rural health services, telehealth.

## Introduction

Family and informal caregivers, including relatives, friends, and community members who provide unpaid support, are indispensable to rural health systems, forming the foundation of long-term and daily care for older adults and individuals living with chronic illness or disability<sup>1-3</sup>. In many rural communities, the scarcity of healthcare professionals, geographic isolation, transportation challenges, and limited access to specialty care expand the scope of caregiving responsibilities, often requiring families and informal caregivers to assume complex roles that extend beyond basic assistance to include care coordination, health advocacy, and technology facilitation for telehealth<sup>1,3-5</sup>. These factors position caregivers not only as critical partners in care but also as de facto extensions of the rural health workforce, bridging gaps that formal systems are unable to fill<sup>5,6</sup>.

Rural caregivers often face distinct and multifaceted challenges arising from geographic dispersion, service limitations, and socioeconomic barriers that influence access to both formal and informal supports<sup>4,5,7</sup>. Long travel distances to healthcare facilities, reduced availability of respite or home care services, and the need to manage care independently contribute to elevated caregiving intensity and stress<sup>3,4,8</sup>. Studies have shown that rural caregivers are more likely to provide 20 or more hours of care per week (total weekly caregiving hours) compared to urban caregivers, reflecting both higher dependency of care recipients and limited formal service integration<sup>3,8</sup>. The reliance on unpaid family labor is particularly pronounced in rural regions where publicly funded programs and professional home care services are scarce, reinforcing rural–urban inequities in caregiving support<sup>2,5</sup>.

Despite these structural barriers, rural caregivers demonstrate remarkable adaptability and resilience, frequently mobilizing community-based social capital to sustain caregiving networks<sup>4,6</sup>. Neighbors, extended kin, and local volunteer groups often fill care gaps left by overstretched health systems, creating informal webs of support that enhance continuity of care<sup>4,6</sup>. However, these informal systems cannot fully mitigate the cumulative burden borne by caregivers, who experience disproportionately high levels of physical strain, emotional distress, and financial insecurity<sup>3,9</sup>. Evidence also highlights elevated risks of chronic disease, obesity, and poor self-rated health among rural caregivers, particularly those engaged in long-term or palliative caregiving<sup>3,10</sup>. Caregiver fatigue and limited access to mental health and respite services exacerbate the cycle of caregiver burnout, compromising both caregiver wellbeing and patient outcomes<sup>4,10</sup>.

Emerging models aimed at supporting rural caregivers underscore the importance of locally tailored interventions that address contextual barriers while strengthening the sustainability of rural health systems<sup>3,4,6</sup>. Strategies such as integrated care coordination, mobile health units, telehealth expansion, and community-based respite programs have demonstrated potential to reduce caregiver strain and enhance system efficiency<sup>3,10</sup>. Digital health innovations,

alongside investments in coordination infrastructure, broadband, respite, and financial supports, are essential for sustainable and equitable rural care.

in particular, have been leveraged to bridge geographical divides and facilitate collaboration among dispersed providers and caregivers, although challenges in connectivity, digital literacy, and trust remain significant obstacles<sup>4,5</sup>. By recognizing and investing in the central role of caregivers, rural health systems can move toward more equitable and sustainable care delivery models<sup>3,6</sup>.

Yet, despite the growing recognition of caregivers' essential role in rural care, evidence on what families and informal caregivers do, how they interact with rural providers and systems, and where specific supports and policy interventions are most needed remains fragmented<sup>1,3,4</sup>. To address these gaps, we conducted a scoping review following the PRISMA-ScR framework to systematically map the roles, activities, facilitators, barriers, and outcomes associated with family and informal caregivers in rural health delivery across diverse clinical contexts and geographic regions<sup>11</sup>. Specifically, this review asks, What roles do family and informal caregivers play in rural healthcare delivery, how do they interact with health systems and providers, and what barriers, facilitators, and outcomes are associated with caregiving in rural contexts?

## Methods

This scoping review was conducted in accordance with the PRISMA-ScR framework<sup>12</sup> and followed the methodological framework outlined by Arksey and O'Malley<sup>13</sup>, with refinements by Levac and colleagues<sup>14</sup> to enhance rigor, transparency, and stakeholder relevance.

## Eligibility criteria

Studies were included if they examined family or informal caregivers providing unpaid support to individuals of any age living in rural, remote, or frontier settings, accepting authors' definitions of rurality. Eligible studies described caregiving activities that contributed directly to health service delivery, such as monitoring, triage and decision support, medication management, care coordination or navigation, telehealth facilitation, transport and logistics, or cultural brokering. Contexts encompassed community, primary care, home care, long-term care, and care transitions, including rural hospitals or clinics when caregiver roles intersected with service delivery. Eligible study designs included quantitative, qualitative, and mixed-methods research, as well as program evaluations and relevant grey literature such as reports, theses, and policy briefs. Publications were limited to English-language studies published between January 2000 and September 2025. Exclusion criteria included studies focusing solely on urban settings, paid or professional caregivers, editorials or commentaries without empirical or implementation content, and articles in which caregiving was incidental, with no link to care delivery activities.

## Information sources and search strategy

Comprehensive searches were conducted across MEDLINE (Ovid), Embase, CINAHL, PsycINFO, Scopus, Web of Science Core Collection, and ProQuest Dissertations and Theses. Grey literature sources included OpenGrey, government and non-government organization websites such as rural health commissions and aging councils, and conference proceedings from the National Rural Health Association and the World Organization of Family Doctors Rural Health conferences. A sample MEDLINE search strategy included terms for rurality ('rural', 'remote', 'frontier', 'small town', 'underserved area') combined with caregiver-related terms ('caregiv\*', 'family care\*', 'unpaid care\*', 'carer\*', 'kin care\*') and health delivery concepts ('health service\*', 'telehealth', 'care coordination', 'primary care', 'medication management', 'palliative', 'rehabilitation').

## Screening and selection

A total of 3004 records were identified, including 2781 from databases and 223 from grey literature sources (Supplementary figure 1). After removing 824 duplicates, 2180 records were screened by title and abstract. Of these, 1968 were excluded for reasons such as urban-only context, inclusion of paid staff only, lack of relevance to care delivery, and non-empirical format (eg editorials). Full texts of 212 studies were reviewed in detail, with 167 excluded for reasons including inability to separate rural data ( $n=54$ ), caregiver role being incidental to delivery ( $n=48$ ), absence of empirical or implementation data ( $n=38$ ), and being a conference abstract without sufficient data ( $n=27$ ). A total of 45 studies were included in the final synthesis (42 peer-reviewed and 3 grey literature sources). Screening at both stages was conducted independently by two reviewers, with disagreements resolved through discussion or arbitration by a third reviewer. Inter-rater reliability for title and abstract screening was  $\kappa=0.74$ , indicating substantial agreement.

## Data extraction

Data extraction captured information on study region and country, rural definition, care setting, population and health condition, caregiver type, specific care delivery roles, enablers and barriers, outcomes (including patient clinical and utilization outcomes, caregiver burden, cost, and equity impacts), study design, and indicators of implementation quality. Consistent with scoping

review methodology, formal critical appraisal or risk-of-bias instruments were not applied. Instead, study quality was considered pragmatically during data extraction and synthesis by examining methodological transparency, appropriateness of study design to the research question, clarity of caregiver role definitions, and relevance to care delivery contexts. Charting was performed in duplicate, with calibration exercises conducted on an initial subset of 25 studies to ensure consistency. The synthesis used an inductive thematic analysis guided by a constant comparative approach. Constant comparative techniques were applied pragmatically to iteratively compare data across studies, caregiver roles, and contexts during coding and theme development, allowing emerging concepts to be refined, merged, or differentiated as new evidence was incorporated. This approach was used to enhance analytic rigor and coherence across heterogeneous study designs, rather than to generate theory, and was not intended to reflect formal grounded theory methodology. Findings were mapped to multi-level implementation determinants across patient, interpersonal, organizational, community, and policy domains. Quantitative data were narratively summarized due to heterogeneity in outcome measures, and no meta-analysis was undertaken.

## Ethics approval

Ethics approval was not required for this study, as it involved analysis of publicly available literature and did not include human participants or primary data collection.

## Results

We included 45 studies spanning home/community care, primary care, palliative/home hospice, rehabilitation/post-acute, and maternal-child contexts across diverse rural regions<sup>1-10,15-49</sup>. Synthesized findings clustered into eight delivery-facing themes: care coordination and system navigation; medication and treatment management; telehealth mediation and digital brokering; clinical monitoring and early triage; transportation, logistics and environmental adaptation; cultural/linguistic brokerage and trust-building; palliative, disability, and long-term support roles; and caregiver health, competence, and burden (Table 1). Together, these domains map how family and informal caregivers function as de-facto extensions of rural care teams, while also revealing concentrated pressure points where targeted supports are most needed.

**Table 1: Overview of included studies**

Authors, year	Setting	Population	Caregiver type	Design	Delivery-facing caregiver roles	Key outcomes reported
Michaels and Meeker, 2024 <sup>1</sup>	NR	Older adults	Family caregiver	Qualitative (grounded theory)	Coordination/navigation; transport/logistics; monitoring/triage; caregiver burden	Caregiver experience/burden; continuity themes
Miller et al, 2023 <sup>2</sup>	Community	Older adults with disability	Family/unpaid	Quantitative (observational)	Care support substitution; coordination	Use of family versus formal care; disparity patterns
Boswell et al, 2025 <sup>3</sup>	NR	Unpaid caregiving (general)	Unpaid caregivers	Quantitative (population survey/observational)	Burden; coordination	Geographic disparity outcomes
Choi et al, 2025 <sup>4</sup>	NR	Rural caregiving (general)	Family/unpaid	Qualitative	Coordination; transport; community support; burden	Challenges/resilience; caregiver wellbeing
Holland, 2022 <sup>5</sup>	Home/community	NR	Family caregiver	Qualitative	'Invisible health work': coordination; medication; home adaptation; burden	Hidden labor; system substitution

Campbell-Enns et al, 2023 <sup>6</sup>	NR	Dementia	Family/unpaid	Qualitative systematic review	Dementia support; coordination; burden; training needs	Needs, barriers, service gaps
Hussain et al, 2018 <sup>7</sup>	Community	Rural carers (general)	Family/unpaid	Quantitative (survey/observational)	Transport/logistics; burden	Employment, isolation, wellbeing
Cohen et al, 2022 <sup>8</sup>	Community	Informal caregiving	Informal caregivers	Quantitative (survey/observational)	Burden; support access	Health-related quality of life; rural-urban differences
Cohen et al, 2024 <sup>9</sup>	Community	Caregiving/support services	Family/unpaid	Quantitative (national survey)	Support service use; burden	Caregiver health; service access
Patano et al, 2024 <sup>10</sup>	Palliative/end-of-life	End-of-life caregiving	Family/unpaid	Scoping review	Palliative/long-term support; transport; burden	Social determinants of health plus emotional wellbeing outcomes
Burgdorf et al, 2022 <sup>15</sup>	Home health	Older adults (home health)	Family caregiver	Qualitative (multisite)	Training/competence; coordination	Barriers/facilitators to training
Fox et al, 2022 <sup>16</sup>	Transitional care	Recently discharged rural patients	Family caregiver	Multi-method	Coordination; monitoring/triage; training; telehealth support (if applicable)	Acceptability of interventions
Shepherd-Banigan et al, 2021 <sup>17</sup>	NR	Inclusive care (general)	Family caregiver	Mixed/qualitative (NR)	Coordination; communication/handoffs	Alignment of needs/expectations
Alkhalidi et al, 2025 <sup>18</sup>	NR	Long-term conditions	Informal carers	Systematic review	Medication/treatment management; coordination	Medication outcomes; role description
Roter et al, 2018 <sup>19</sup>	Home/community	Adult prescription use	Family caregiver	Quantitative/observational	Medication management	Adherence/medication use facilitation
Kiiski et al, 2025 <sup>20</sup>	Home visits	Older care recipients	Family caregiver	Qualitative	Medication management; coordination/navigation	System engagement challenges
Dowling and Manias, 2025 <sup>21</sup>	Transitions of care	Rural aged care residents	Family caregiver	Qualitative	Medication communication during hand-offs; coordination	Safety/communication outcomes
Wolff et al, 2016 <sup>22</sup>	Community	Older adults needing help with health activities	Family/unpaid	Quantitative (national profile)	Medication/treatment; coordination	Caregiving activity prevalence
Seuren and Shaw, 2024 <sup>23</sup>	Video consulting (home)	Physio/heart failure/cancer	Informal carers	Qualitative (linguistic ethnography)	Telehealth mediation/digital brokering; coordination	Access/feasibility; workload
Masterson Creber et al, 2023 <sup>24</sup>	Telehealth (system)	Older adults with heart failure	Care partners (role)	Scientific statement	Telehealth mediation; equity supports	Recommendations; equity outcomes
Behrman et al, 2021 <sup>25</sup>	Rural health (system)	COVID-19 rural health	NR	Position/statement	Broadband/device barriers; access enablers	Policy recommendations
Kitko et al, 2020 <sup>26</sup>	Heart failure care	Heart failure	Family caregiver	Scientific statement	Monitoring; medication; coordination; burden	Caregiver impacts; recommended supports
Gusdal et al, 2016 <sup>27</sup>	NR	Heart failure	Family caregiver	Qualitative (focus groups with nurses)	Monitoring/triage; caregiver burden; training	Perceptions of caregiver situation
Piamjariyakul et al, 2024 <sup>28</sup>	Home/community	Heart failure and vascular dementia	Family caregiver	Mixed-methods	Monitoring; medication; long-term support; burden	Preparedness; burden outcomes
Graven et al, 2024 <sup>29</sup>	Community	Heart failure dyads	Patient/caregiver dyads	Qualitative	Self-care support; monitoring; coordination	Self-care problems/strategies
Mcharo et al, 2023 <sup>30</sup>	Hospital	Heart failure admitted patients	Family caregiver	Qualitative	Inpatient support; coordination; burden	Caregiver experiences
Alharrasi et al, 2025 <sup>31</sup>	NR	Heart failure	Family caregiver	Quantitative	Monitoring; adherence support	Self-care behavior outcomes
Robinson-Barella et al, 2025 <sup>32</sup>	NR	Ethnically minoritised carers	Informal caregivers	Qualitative	Cultural/linguistic brokerage; trust-building; coordination	Access/experience outcomes
Racine et al, 2022 <sup>33</sup>	NR	Indigenous dementia caregiving	Indigenous informal caregivers	Integrative review	Cultural brokerage; dementia support; trust-building	Experience themes; service use
Gazaway et al, 2024 <sup>34</sup>	NR	Ill older adults	Rural family caregivers	Qualitative (likely)	Cultural values in decisions; coordination	Decision-making outcomes
Roberto et al, 2022 <sup>35</sup>	Community	Dementia	Family caregiver	Quantitative/mixed (NR)	Navigation; service use; cultural/sociocultural decision model	Service use; care decisions
Lombo-Caicedo et al, 2025 <sup>36</sup>	Rural caregiving program	Rural caregivers	Family/unpaid	Intervention/program evaluation	Training/competence; burden mitigation; coordination	Capacity-strengthening outcomes

Lalani et al, 2024 <sup>37</sup>	Community	Serious chronic illness (older adults)	Family caregivers	Mixed/qualitative (NR)	Palliative support; preferences; coordination	Needs/preferences outcomes
Breivik et al, 2024 <sup>38</sup>	NR	End-of-life caregiving	Family caregivers	Meta-ethnography	Palliative/long-term; burden; transport barriers	Experience synthesis outcomes
Mogan et al, 2024 <sup>39</sup>	Community	Last year of life	Family carers	Qualitative	Palliative support; coordination; transport; telehealth (if used)	Support gaps; isolation
Mason and Hodgkin, 2019 <sup>40</sup>	Community	Palliative caregiving	Family carers	Qualitative (phenomenological)	Palliative support; preparedness/training	Preparedness outcomes
Johnston et al, 2024 <sup>41</sup>	Community	Cancer caregiving	Rural caregivers	Qualitative	Navigation; support-seeking; burden	Caregiver wellbeing; access outcomes
Tran et al, 2025 <sup>42</sup>	Community	Dementia caregiving	Family caregivers	Quantitative	Burden; health outcomes	Mental/physical health outcomes
Bardach et al, 2021 <sup>43</sup>	Telemedicine	Dementia/Alzheimer's disease and related dementias caregiving	Rural caregivers	Mixed/qualitative (telemedicine questions)	Telehealth mediation; info needs; coordination	Informational needs outcomes
Miyawaki et al, 2024 <sup>44</sup>	Community	Alzheimer's disease and related dementias caregiving	Family caregivers	Quantitative (multi-site)	Service needs; navigation	Unmet service needs
Bryan and Asghar-Ali, 2020 <sup>45</sup>	Online training	Dementia caregiving training	Caregivers/clinicians	Curriculum development/evaluation	Training/competence	Preparedness/self-efficacy outcomes
Vipperman et al, 2023 <sup>46</sup>	Community	Dementia caregiving	Family caregivers	Quantitative/qualitative (NR)	Navigation; respite/service barriers; burden	Overload/service use outcomes
Howe et al, 2024 <sup>47</sup>	Community	Older adults care	Caregivers	Quantitative (NR)	Communication; training; coordination	Connectedness/training outcomes
Fox and Butler, 2023 <sup>48</sup>	Post-discharge/home	Recently hospitalized	Rural caregivers	Qualitative descriptive	Monitoring/triage; preparedness; escalation planning	Readmission risk response outcomes
Serchen et al, 2025 <sup>49</sup>	Rural health (system)	Rural communities	NR	Position paper	Infrastructure supports; caregiver integration (system-level)	Policy recommendations

NR, not reported.

### Care coordination and system navigation

Families and informal caregivers in rural contexts function as core coordinators who book appointments, chase referrals, complete insurance or coverage paperwork, and transfer key information across dispersed providers, activities driven by limited local availability and long travel distances, which amplify administrative burden in rural systems<sup>1,4,5,7</sup>. Because many rural networks lack robust, interoperable health information systems, caregivers routinely bridge communication gaps by hand-carrying summaries, repeating histories, and clarifying medication changes to avoid fragmentation during cross-provider interactions<sup>1,5,15</sup>. Their coordinating role peaks during transitions, such as hospital discharge, interfacility travel for specialty visits, and movement between home and outpatient services, where families and informal caregivers provide the 'glue' through logistics, advocacy, and real-time updates to multiple clinicians – roles that rural systems often rely on almost exclusively due to thin formal infrastructure<sup>2,15-17</sup>.

Despite centrality, caregivers face complex forms, inconsistent points of contact, and unclear accountability, all of which raise the risk of missed follow-through and caregiver strain in low-resource areas<sup>6,7</sup>. Studies consistently recommend embedding caregiver navigation into structured pathways, standardizing hand-offs, and creating clear lines for rural provider-to-caregiver communication to reduce duplication and error<sup>1,2,4</sup>. Where such supports are absent, families and informal caregivers compensate through

informal networks and persistence, but at the cost of time, travel, and emotional load, underscoring the need for formal recognition and tailored assistance in rural coordination models<sup>4,6</sup>.

### Medication and treatment management

Medication management is a high-stakes responsibility in rural caregiving, encompassing daily dosing, adherence strategies, and surveillance for adverse effects amid limited pharmacy and clinician access<sup>1,4,18,19</sup>. Families and informal caregivers frequently reconcile prescriptions following distant specialty appointments and must clarify changes with local providers or rural pharmacies in the absence of integrated records, a process vulnerable to discrepancies and duplication<sup>1,19,20</sup>. Pharmacy deserts, supply shortages, and travel costs compel caregivers to coordinate alternative access routes or undertake long trips, increasing inequities in continuity and safety for chronically ill rural patients<sup>1,4</sup>.

Communication gaps during transitions leave many families and informal caregivers monitoring side effects without timely clinical backup, reinforcing calls for proactive, caregiver-inclusive communication and clear, written medication plans tailored to rural constraints<sup>20,21</sup>. Interventions that position caregivers as partners, such as pill organizers, reminder systems, telephonic pharmacist consults, and telepharmacy, improve adherence and reduce errors when paired with accessible counselling and plain-language instructions<sup>18,20,22</sup>. Collectively, the literature emphasizes that medication safety in rural areas depends on recognizing

caregiver expertise, equipping them with actionable guidance, and creating direct pharmacist and prescriber touchpoints to offset infrastructure limits<sup>18,20,22</sup>.

### *Telehealth mediation and digital brokering*

As telehealth expands to mitigate distance, rural caregivers act as digital brokers who set up devices, troubleshoot connectivity, position cameras, and coach patients through remote encounters, roles that are essential where broadband and digital literacy are limited<sup>1,4,23</sup>. They also perform digital scribing, such as entering histories, vitals, or medication updates into portals, and relay clinician instructions during virtual exams, effectively extending clinical reach into the home<sup>23,24</sup>. Policy and practice statements highlight that successful telehealth for older adults and people with cognitive or physical limitations hinges on caregiver support, recommending routine assessment of caregiver readiness and provision of technical assistance in rural programs<sup>24,25</sup>.

However, these tasks add cognitive load and time pressure, particularly when connectivity is unreliable or platforms are not caregiver-friendly, leading to stress that is seldom accounted for in planning or reimbursement<sup>1,24</sup>. Studies call for caregiver-inclusive telehealth design, targeted digital literacy training, and investment in rural broadband to reduce repeated troubleshooting and visit failures<sup>4,25</sup>. When supported, caregivers' digital mediation improves access and safety, but lack of structural recognition risks entrenching hidden labor and widening digital inequities in remote regions<sup>1,23,24</sup>.

### *Clinical monitoring and early triage*

Limited local services mean rural caregivers routinely track symptoms, maintain logs for conditions like heart failure and diabetes, share wound photos, and decide when to escalate care despite long distances to facilities<sup>1,4,26-28</sup>. Daily monitoring supports early detection and guided interventions but is constrained by variable health literacy, equipment access, and confidence in recognizing red flags, reinforcing the value of concise tools and clear parameters<sup>16,29,30</sup>. Evidence indicates that engaged caregiver monitoring improves adherence and reduces potentially preventable hospitalizations when paired with feedback and easy escalation pathways<sup>31</sup>.

Remote technologies can strengthen monitoring and information exchange, yet digital divides and ad-hoc communication channels limit consistency and timeliness in many rural communities<sup>1,50</sup>. Protocols, checklists, and written action plans tailored to rural realities, such as who to call, when to travel, and what thresholds matter, bolster caregiver confidence and safety during deterioration events<sup>16,27</sup>. Nurse-led education, follow-up touchpoints, and community support groups address preparedness gaps and mitigate isolation and distress that accompany intensive home-based monitoring for complex conditions like heart failure and dementia<sup>16,28,30</sup>.

### *Transportation, logistics, and environmental adaptation*

Family caregivers in rural health delivery play a pivotal role in overcoming geographic and infrastructural barriers to care. They frequently assume responsibility for driving long distances to medical appointments or referral centers, a recurring challenge in regions with sparse local services and limited public transportation<sup>4,7,9</sup>. For patients requiring specialist follow-up or

hospital-based interventions, caregivers often coordinate multi-hour travel and overnight stays near urban centers, bearing both logistical and financial strain<sup>4,7</sup>. These demands are intensified by unpredictable appointment times, limited parking, and weather-dependent road conditions that heighten travel risk and uncertainty.

Rural caregivers also manage weather-contingent planning for emergencies and routine care, making advance arrangements during severe winters, floods, or wildfire seasons when travel becomes unsafe<sup>4,7</sup>. In parallel, they adapt the home environment to sustain safety and access for patients: installing ramps, ensuring adequate heating and water, maintaining generators, and modifying layouts for medical equipment or mobility aids<sup>5</sup>. These environmental adaptations constitute an essential yet under-recognized form of 'health system work' that substitutes for unavailable home modification and maintenance services.

The cumulative burden of travel, planning, and environmental adaptation contributes to financial stress, fatigue, and emotional exhaustion, especially for caregivers managing complex conditions without formal assistance<sup>10,28</sup>. Nonetheless, caregivers exhibit notable resilience by mobilizing informal networks such as friends, neighbors, and local volunteers to share travel duties and exchange resources<sup>4-6</sup>. The literature underscores that sustainable rural health delivery requires policy measures to offset travel costs, improve infrastructure, and formally recognize these logistical and environmental contributions as integral to rural health care<sup>4,9,10</sup>.

### *Cultural/linguistic brokerage and trust-building*

Family caregivers also serve as essential cultural and linguistic brokers within rural healthcare systems, translating not only language but also values, traditions, and worldviews between patients and providers. In multilingual and multicultural rural communities, caregivers frequently interpret medical information, ensuring that patients with limited English proficiency can understand diagnoses and care plans<sup>10,32</sup>. This interpretive role extends beyond language to encompass cultural navigation, where caregivers contextualize biomedical recommendations within family beliefs and community norms to enhance understanding and compliance<sup>32,33</sup>.

Among Indigenous and ethnically diverse populations, caregivers bridge the gap between Western medical systems and holistic community traditions, promoting relational, respectful, and culturally safe care<sup>33-35</sup>. They often mediate sensitive decisions around end-of-life care, chronic disease management, and spiritual practices, helping reconcile cultural expectations of family involvement, reciprocity, and collective decision-making<sup>32,33</sup>. In doing so, caregivers actively advocate for approaches that integrate traditional healing and community leadership into care delivery, reinforcing trust in systems that have historically marginalized their communities.

These trust-building functions are particularly vital in rural settings where institutional discrimination, geographic isolation, and histories of colonialism have eroded confidence in formal care systems<sup>4,10,36</sup>. Caregivers advocate for dignity and inclusion, navigating structural barriers and educating providers on cultural protocols and sensitivities<sup>6,36</sup>. Their work not only improves communication and uptake of services but also strengthens long-

term relationships between rural communities and health institutions, emphasizing that caregiver partnership is essential for achieving culturally grounded, equitable health care.

### *Palliative, disability, and long-term support care*

Family caregivers in rural areas are central to the provision of palliative, disability, and long-term care, managing tasks that span symptom control, equipment operation, respite coordination, and bereavement support<sup>10,37,38</sup>. In settings where palliative care and home health resources are scarce, caregivers frequently administer medications, monitor pain, and manage respiratory or feeding equipment with minimal professional guidance<sup>1,10</sup>. They troubleshoot oxygen concentrators, hospital beds, and infusion pumps, ensuring continuity of care across long distances from tertiary facilities.

Because formal respite programs are rare or unaffordable, rural caregivers depend on informal arrangements with family, neighbors, and community volunteers for relief<sup>4,38,39</sup>. This limited respite increases burnout risk, particularly during prolonged or end-of-life care when fatigue and sleep disruption are common<sup>10,40</sup>. Following death, bereavement is often experienced in isolation, with minimal psychological support or follow-up contact from healthcare providers<sup>10,40</sup>.

Despite these deficits, community connectedness offers protective value, providing emotional and logistical assistance through local networks, faith groups, and mutual aid<sup>6,38,39</sup>. Telehealth and remote palliative consults have begun to bridge access gaps, but there are persistent issues such as poor connectivity, low health literacy, and lack of training limit scalability<sup>1,39,41</sup>. The evidence underscores that strengthening palliative and disability supports in rural health systems requires integrating caregiver needs into planning, funding home-based equipment programs, and providing bereavement and respite infrastructure that acknowledges the depth of informal care work.

### *Caregiver health, competence, and burden*

Rural caregivers often experience considerable physical, emotional, and financial strain as they shoulder primary responsibility for long-term and complex care<sup>1,6,8,10</sup>. Time poverty, out-of-pocket costs, and safety risks from physically demanding tasks such as lifting and transferring patients are pervasive<sup>7,10,28</sup>. Limited respite options and ongoing exposure to patient suffering contribute to chronic stress, fatigue, and depressive symptoms that are more prevalent among rural caregivers than their urban counterparts<sup>10,42</sup>.

Training gaps amplify this burden. Caregivers frequently report needing education on dementia behavior management, wound care, mental health crisis response, and telehealth communication<sup>6,43</sup>. In dementia care, knowledge gaps surrounding behavioral symptoms and safety planning increase anxiety and risk of injury<sup>6,15</sup>. Similarly, lack of instruction in wound care and body mechanics predisposes caregivers to musculoskeletal injury<sup>28</sup>, while mental health crisis response training remains limited despite caregivers' exposure to acute agitation, self-harm, or psychosis episodes<sup>10,42</sup>. The growing reliance on virtual care also necessitates new competencies in telehealth etiquette and technology operation to facilitate safe, private, and effective communication<sup>1,43,44</sup>.

Evidence supports that structured, nurse-led education and online training modules significantly improve caregiver preparedness, competence, and self-efficacy<sup>28,45</sup>. Tailored, condition-specific training paired with peer support reduces burnout and enhances care quality<sup>15,46</sup>. Expanding rural access to such programs, alongside integrated mental health and financial supports, is essential to reduce overload and sustain caregivers' long-term wellbeing<sup>10,15,44</sup>.

### *Outcomes*

Family caregivers in rural health delivery are closely tied to improved patient and clinical outcomes, serving as key contributors to continuity and safety within constrained systems. Their involvement enhances appointment adherence, medication management, and timely escalation for clinical deteriorations, particularly when even minimal training or support is provided<sup>16,47</sup>. Studies demonstrate that programs explicitly integrating caregivers into telemonitoring or transitional care pathways lead to more consistent follow-through and symptom surveillance, although the benefits depend heavily on the clarity of caregiver roles and communication from providers<sup>16,47</sup>. When adequately supported, caregivers enable earlier recognition of 'red flag' symptoms and facilitate smoother care transitions, helping mitigate rural access barriers<sup>16,48</sup>.

Evidence on health system utilization outcomes is mixed but encouraging. Interventions that actively include caregivers, such as home-based telemonitoring and structured care coordination, show suggestive reductions in avoidable emergency department visits and unplanned readmissions, particularly for chronic diseases like heart failure and chronic obstructive pulmonary disease<sup>16,47</sup>. However, sustainability depends on caregiver acceptability and ongoing access to supervision or consultation, as burden increases when digital or monitoring tasks are added without compensation or relief<sup>1,8</sup>.

Caregiver outcomes themselves remain characterized by moderate to high burden. While digital tools can reduce travel fatigue by minimizing long-distance visits, they often extend daily responsibilities through increased time spent troubleshooting, documenting, or assisting with virtual care<sup>1,47</sup>. The invisible workload, including administrative coordination, household adaptation, and care logistics, continues to go largely unrecognized by health systems<sup>5,9</sup>. Equity impacts are similarly nuanced: caregivers' roles as cultural and linguistic brokers improve engagement among Indigenous and linguistically diverse communities, yet these responsibilities heighten stress and reinforce inequitable, unpaid reliance on families<sup>10</sup>. At the system level, families and informal caregivers substantially offset workforce shortages but risk perpetuating structural dependence on unpaid labor if policies fail to establish safeguards, training, and financial recognition<sup>2,5,9</sup>. Collectively, the evidence underscores the urgent need to formalize caregiver inclusion, build culturally responsive supports, and ensure that family labor complements rather than replaces professional care<sup>4,6</sup>.

### *Enablers and barriers*

The effectiveness of family caregivers in rural health delivery is shaped by a balance of enablers that facilitate engagement and barriers that constrain capacity. Key enablers include brief, structured training and nurse-led preparedness programs that

improve caregiver confidence and reduce anxiety, particularly for conditions such as heart failure, dementia, and post-stroke recovery<sup>15,28</sup>. Continuous access to a 24-hour nurse line or community health worker offers real-time reassurance and guidance, fostering safety and emotional support in geographically isolated regions<sup>15,28</sup>. Caregiver-inclusive discharge plans and clearly written instructions enhance continuity, while equipment provision and data-free telehealth platforms mitigate technology and travel inequities<sup>39</sup>. Financial supports, such as travel stipends and mileage reimbursement, and locally organized respite care further alleviate burden and improve retention of caregivers within the system<sup>7,10</sup>.

Despite these facilitators, significant barriers persist. Broadband and device gaps continue to impede telehealth participation, with many caregivers reporting poor connectivity and limited technical resources<sup>39</sup>. Discharge instructions are often fragmented or incomplete, leaving caregivers uncertain about follow-up requirements and increasing risk for medication errors or preventable readmissions<sup>15,16</sup>. Limited formal respite care and escalating travel-related costs, such as fuel, lodging, and lost income, amplify financial and emotional strain<sup>7,10</sup>. Role ambiguity remains a core challenge: caregivers frequently encounter unclear expectations, inconsistent communication, and a lack of formal recognition, leading to overload and burnout<sup>1,46</sup>.

Despite these obstacles, rural caregivers demonstrate adaptability and resilience through informal community networks that compensate for systemic gaps<sup>4,6</sup>. However, long-term sustainability demands systemic investment in infrastructure, communication pathways, and financial and emotional support. Strengthening caregiver education, expanding rural broadband, and formalizing caregiver roles within care teams are critical to improving patient outcomes and maintaining equity in rural health systems<sup>4,6,41</sup>.

## Discussion

This scoping review maps how families and informal caregivers function as de-facto extensions of rural care teams across eight delivery-facing domains, including care coordination, medication management, telehealth mediation, clinical monitoring, transportation/logistics, cultural brokerage, palliative and long-term support, and caregiver competence/burden. Collectively, the evidence shows that families and informal caregivers sustain continuity, access, and safety in systems characterized by distance, workforce scarcity, and infrastructural gaps, while shouldering substantial administrative, technical, and emotional work<sup>1,2,4,5</sup>. These findings reaffirm caregivers' indispensability to rural health delivery and make visible the specific operational tasks that health systems routinely offload to households.

Compared with prior reviews that emphasize burden or condition-specific caregiving (eg for dementia, cancer) and treat rurality as a subgroup, our synthesis foregrounds delivery-facing activities and situates caregiver work within system performance (continuity, access, safety)<sup>4,5</sup>. Two contributions stand out. First, telehealth mediation emerges as a distinct domain post-pandemic, with families and informal caregivers troubleshooting connectivity, positioning devices, and digitally scribing to make virtual encounters feasible in low-bandwidth settings<sup>23-25</sup>. Second, the synthesis underscores how distance and workforce shortages reconfigure family support into quasi-professional coordination

and monitoring roles, aligning with and extending earlier observations about rural caregiver substitution for formal services<sup>2,49</sup>.

On outcomes, signals are consistent: when caregivers receive even brief, targeted preparation and are actively integrated into pathways or telemonitoring, then appointment adherence, medication continuity, and timely escalation improve<sup>16,48</sup>. Evidence for utilization is mixed but suggestive of reduced avoidable emergency visits and readmissions in programs that include families and informal caregivers as structured partners, particularly in chronic disease management<sup>16,47</sup>. These gains, however, depend on clear role definition, responsive clinical backup, and tools that simplify monitoring and hand-offs; without such supports, added digital or administrative tasks may increase burden and undermine sustainability<sup>1</sup>.

Equity considerations are prominent. Cultural and linguistic brokerage by caregivers strengthens engagement and trust among Indigenous and linguistically diverse residents, aligning care with local norms and holistic worldviews<sup>10,32-34</sup>. Yet the same practices shift invisible labor and emotional load onto families, intersecting with socioeconomic constraints and gendered caregiving patterns to reproduce disparities in health and financial security<sup>6,9</sup>. Addressing equity therefore requires recognizing, supporting, and resourcing the brokerage work that households currently provide.

Implementation levers were remarkably consistent across settings. Brief, nurse-led training and preparedness, 24-hour clinical backup or community health worker support, caregiver-inclusive discharge plans, and low-data telehealth options enable safe participation and reduce uncertainty<sup>15,28,39</sup>. Conversely, broadband/device gaps, fragmented hand-offs, limited respite, and travel-related costs remain persistent barriers that magnify stress and risk<sup>7,10,15</sup>. Policy tools, such as travel stipends, home modification and equipment support, broadband expansion, and formal role recognition, are central to converting caregiver effort from an emergency substitute into a supported, sustainable component of rural delivery<sup>4,41</sup>.

Strengths of this study include a comprehensive, PRISMA-ScR-guided approach across regions, settings, and conditions, duplicate screening, and a multi-level synthesis that connects caregiver activities to system performance. Limitations include English-language restriction, heterogeneity that precluded meta-analysis, reliance on authors' rural definitions, and uneven depth in grey literature. Future work should standardize caregiver-inclusive outcome measures (including caregiver-reported outcomes), test implementation strategies in pragmatic trials, evaluate economic and equity impacts of caregiver supports (stipends, respite, broadband), and examine intersectional patterns (eg gender, income, Indigeneity) with longitudinal designs.

## Conclusion

Family and informal caregivers are indispensable to rural health delivery, performing coordinated, clinical, digital, logistical, and culturally anchored work that upholds access, continuity, and safety in under-resourced contexts. When health systems explicitly prepare and support caregivers, patient outcomes improve and avoidable utilization may decline, and when support is absent, risk and cost are shifted to households, widening inequities. Sustainable rural care therefore requires formal recognition,

resourcing, and measurement of caregiver contributions alongside investments in coordination, broadband, respite, and financial supports.

## Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

## Conflicts of interest

The authors declare no conflicts of interest.

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## AI disclosure statement

No generative artificial intelligence tools were used in the screening, data extraction, or analysis processes. AI-assisted language tools were used solely for minor language refinement and editing support during manuscript preparation, with all intellectual content, analysis, and final decisions made by the authors.

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