The Essential Role of Caregivers in Pulmonary Hypertension: A Patient Advocacy Perspective on Support, Resources, and the Unique Challenges Facing Families

Seth Hall, MBA, RRT, RRT-ACCS, RRT-NPS

Abstract

Pulmonary hypertension (PH) is a group of rare, progressive, and debilitating conditions that impose substantial burdens on both patients and their caregivers. This article examines the critical yet often overlooked role of caregivers in the management of PH, synthesizing evidence from patient advocacy organizations alongside peer-reviewed scientific literature. The physical, emotional, social, and financial dimensions of caregiver burden are explored, while highlighting the unique challenges faced by caregivers managing supplemental oxygen therapy. Special attention is devoted to the sandwich generation phenomenon, in which middle-aged adults simultaneously provide care to aging parents with PH while raising their own children. Additionally, this article examines the increased burden experienced by caregivers in rural communities, who face significant barriers including long travel distances to specialty care centers, time away from employment, and substantial out-of-pocket expenses for transportation and lodging. The article highlights awareness of caregivers as essential members of the care team and the importance of developing targeted solutions that address their specific needs.

Introduction

Pulmonary hypertension (PH) is a group of rare, progressive conditions characterized by elevated blood pressure in the pulmonary arteries, leading to progressive right heart failure and diminished quality of life (Galie et al., 2015). Classified into five distinct groups by the World Health Organization, PH varies in etiology and treatment approach but universally demands complex therapeutic regimens that may include continuous intravenous infusion, inhaled delivery, or careful oral medication management, along with frequent medical monitoring and often supplemental oxygen therapy as disease severity progresses (Humbert et al., 2022). The disease burden imposed on patients has been compared to that of chronic obstructive pulmonary disease, renal failure, and treatment-resistant cancer (Ferrari et al., 2015).

The impact of PH extends far beyond the individual patient, creating what researchers have termed a “ripple effect” that touches family members, particularly those who assume caregiving responsibilities (Hwang et al., 2011). For caregivers, the specific classification of their loved one’s PH may be less salient than the shared realities of managing a progressive, life-limiting illness. Symptom monitoring, medication management, coordination of specialty care, and emotional support represent universal caregiving demands regardless of the diagnostic category. Despite their critical role, caregivers remain a frequently overlooked population whose needs warrant focused attention from healthcare systems, communities, and policymakers.

This article provides an examination of the caregiver experience in PH, drawing upon scientific literature to advocate for enhanced recognition, support, and resources for this critical population. By centering patient advocacy principles, this article identifies pathways toward family-centered care models that recognize caregivers not simply as background support but as key partners in the care process.

The Burden of Caregiving in Rare Disease

Physical and Practical Demands

Caregivers of individuals with pulmonary hypertension assume substantial physical and practical responsibilities that evolve as disease severity progresses. International survey data revealed that 57 percent of caregivers found the demands of caregiving physically draining, with caregiving activities affecting their other daily responsibilities (Ferrari et al., 2012). Practical tasks commonly assumed by caregivers include medication administration (54 percent), household chores (61 percent), transportation to medical appointments, and assistance with personal care activities.

Patient advocacy resources specifically address practical considerations for caregivers, noting that responsibilities may include helping patients prevent infections, recognizing early signs of illness, and knowing when to restrict visitors or avoid crowded environments. These resources emphasize that caregivers must be prepared to assume responsibilities that patients may no longer be able to manage independently, requiring anticipatory planning and ongoing role adaptation.

Emotional and Psychological Impact

The psychological toll of caregiving in rare disease contexts has been extensively documented. A systematic literature review examining psychosocial impacts on caregivers of individuals with rare diseases found consistent patterns of increased psychological distress, lower quality of life, and elevated caregiver burden (Anderson et al., 2024). In the PH-specific context, Hwang et al. (2011) found that lower levels of social support were associated with increased depressive symptoms in

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Seth Hall is a Senior Director, Advocacy with Medical Affairs at Liquidia Corporation in Morrisville, NC.

at least 14 percent of caregivers, with emotional support deficits playing a particularly significant role in caregiver wellbeing.

The International PH Patient and Carer Survey documented that two-thirds of caregivers reported feeling fearful about the future, while 22 percent frequently felt stressed by caregiving demands (Ferrari et al., 2015). Additional concerns included uncertainty about appropriate patient care (19 percent), worry about inadequate care provision (21 percent), and self-doubt regarding caregiving competence (20 percent). Both patients (55 percent) and caregivers (approximately one-third) reported social isolation stemming from limited public understanding of PH, compounding emotional burden with social disconnection.

Financial Burden

The economic impact of pulmonary hypertension on families represents a significant yet often underappreciated aspect of caregiver burden. Research from multiple countries has documented substantial financial strain affecting both patients and caregivers. A Chinese national survey found that both patients and caregivers reported major impacts on family finances and employment, with the financial burden of treatment often overwhelming family resources (Zhai et al., 2017). The study highlighted that financial difficulties were especially pronounced, affecting work conditions for more than half of participants.

A recent Scientific Reports study examining rare disease caregiving found that financial well-being significantly moderated the relationship between caregiver burden and quality of life, with caregivers reporting greater financial security experiencing reduced burden impact on their perceived quality of life (Kowalczyk et al., 2025). This finding highlights the importance of addressing financial support needs as part of caregiver intervention strategies.

Rural Healthcare Access: The Hidden Burden on Caregivers

The challenges facing caregivers of pulmonary hypertension patients are complicated in rural communities, where geographic isolation can create serious barriers to accessing specialty care. Pulmonary hypertension, as a rare and complex disease, requires management by specialized PH centers, often located exclusively in metropolitan academic medical centers. For families residing in rural areas, this geographic distribution of expertise translates to significant travel burdens that compound the already substantial demands of caregiving.

The Travel Burden: Distance and Time

Rural caregivers frequently face round-trip journeys spanning hundreds of miles to reach PH specialty centers. In regions of the United States such as Central Appalachia, patients and their caregivers may travel three to four hours or more each way for routine appointments, transforming what would be a half-day commitment in urban settings into multi-day expeditions. Research on healthcare access barriers in rural communities has documented that these distances create layered challenges: the physical demands of long drives on patients already experiencing dyspnea and fatigue, the need for caregivers to navigate unfamiliar urban environments, and the logistical complexity of transporting oxygen equipment over extended distances.

The time investment required for these journeys extends far beyond driving hours. Caregivers must allocate time for pre-appointment preparation, including ensuring adequate oxygen supplies, packing medications, and arranging for any mobility assistance devices. Post-appointment recovery time may also be necessary, as the physical toll of travel on patients with compromised cardiopulmonary function can worsen symptoms and require rest before the return journey. For caregivers managing employment alongside their caregiving role, these time demands often necessitate using paid or unpaid time off, reducing hours, or in some cases, leaving the workforce entirely.

Employment and Income Loss

The intersection of caregiving responsibilities and employment represents a critical pressure point for rural PH caregivers. Each specialty appointment may require one to two full days away from work, with patients typically requiring quarterly visits during stable periods and more frequent monitoring during treatment adjustments or disease progression. For hourly workers without paid leave benefits, a common employment situation in rural communities, these absences translate directly to lost income. Even for salaried employees, the cumulative effect of repeated absences may jeopardize job security or advancement opportunities.

The Family and Medical Leave Act (FMLA) provides job-protected leave for qualifying caregivers, but this protection applies only to employers with 50 or more employees, a threshold that excludes many rural employers. FMLA leave is also unpaid, meaning that even protected caregivers face income reduction during absences. Research has shown that caregivers with lower income are more likely to provide financial support to their care recipients, creating a difficult situation in which those least able to absorb income loss are most likely to experience it (Lei et al., 2022).

Out-of-Pocket Expenses: Gas, Lodging, and Meals

Beyond lost wages, rural caregivers incur substantial direct expenses associated with medical travel. Fuel costs for roundtrips exceeding 200 to 400 miles can amount to $100 or more per appointment at current fuel prices, a significant burden when multiplied across multiple annual visits. For appointments requiring early morning arrival or spanning multiple days for testing, overnight lodging becomes necessary, adding $100 to $200 or more per night depending on proximity to medical centers. Meal expenses during travel further compound these costs.

Consider a representative scenario: a caregiver from rural Appalachia traveling 180 miles each way to a PH specialty center for a patient’s quarterly appointment where they also are scheduled for a right heart catheterization. Sometimes the procedure may require an overnight stay for pre-procedure preparation and post-procedure monitoring. Direct costs might include fuel ($80 to $120 round trip), two nights of hotel accommodation ($200 to $400), meals for two people over two days ($80 to $120), and parking at the medical center ($10 to $30). This single appointment could cost the family $400 to $700 in direct expenses, not including lost wages. Across four quarterly visits, annual out-of-pocket travel costs alone may exceed $2,000 to $3,000, resulting in a substantial burden for families.

Systemic Implications and Advocacy Opportunities

The geographic barriers facing rural caregivers represent a healthcare equity issue deserving focused advocacy attention.

Patient advocacy organizations have begun addressing these disparities through initiatives such as telemedicine advocacy, travel assistance programs, and support for satellite clinic development. Existing networks of specialty care centers, while concentrated in metropolitan areas, provide a model for distributed specialty care that could be expanded to reduce travel burden. Policy interventions that could meaningfully reduce rural caregiver burden include expanded telehealth reimbursement allowing for remote monitoring and follow-up visits, travel reimbursement programs through Medicaid and Medicare, support for mobile health units bringing specialty care to underserved regions, and incentive programs encouraging PH specialists to practice in rural areas.

The Sandwich Generation: Dual Caregiving Responsibilities

Among the most vulnerable caregiver populations are those belonging to the "sandwich generation," a term describing middle-aged adults simultaneously providing care to aging parents while raising their own children. According to the Pew Research Center, nearly half of adults aged 40 to 59 find themselves in this dual caregiving role (Pew Research, 2022). The National Study of Caregiving found that approximately 24 percent of adult child caregivers also care for minor children, representing an estimated 2.5 million individuals in the United States alone (Lei et al., 2022).

Research published in the Journal of the American Geriatrics Society documented that sandwich generation caregivers were more likely to report substantial financial difficulty (23.5 percent vs. 12.2 percent) and more likely to report substantial emotional difficulty (44 percent vs. 32 percent) compared to caregivers without minor children (Lei et al., 2022). Despite these heightened burdens, sandwich generation caregivers provided similar hours of care to their older adults (approximately 75 hours monthly) while simultaneously managing childcare and maintaining higher rates of workforce participation (69 percent vs. 54 percent).

The Mental Health America organization notes that sandwich generation caregivers face unique challenges in managing competing priorities, often experiencing guilt about divided attention and difficulty meeting their own standards for either caregiving role (MHA, 2024). A qualitative study examining coping strategies among sandwich generation caregivers identified three primary approaches: diversifying responses to meet varied needs, self-soothing through spiritual practices and enjoyable activities, and strategic distancing from caregiving situations to preserve psychological well-being (Mohammadi et al., 2024).

When the care recipient has pulmonary hypertension, the complexity intensifies. The unpredictable nature of PH symptoms, the need for vigilant monitoring, and the potential for rapid decompensation create additional stress layers for caregivers already stretched between generations. The Caregiver Action Network emphasizes that 60 percent of sandwich generation caregivers are women, who on average spend 45 additional minutes daily on caregiving tasks compared to male counterparts (CAN, 2024).

The rural dimension further compounds sandwich generation challenges. A caregiver managing both aging parents with pulmonary hypertension and school-aged children might have to coordinate long-distance medical travel around school schedules, arrange childcare during multi-day absences, and manage the competing financial demands of children's educational expenses and parents' medical costs. The combination of sandwich generation status, rural residence, and rare disease caregiving creates a set of overlapping burdens that calls for targeted research and intervention development.

Managing Oxygen Therapy: A Critical Caregiver Responsibility

As pulmonary hypertension progresses, many patients develop hypoxemia that requires supplemental oxygen therapy. Clinical guidance explains that people with PH need their heart and lungs to work harder to obtain adequate oxygen, leading to symptoms such as fatigue and breathlessness that supplemental oxygen can help alleviate. Data from the REVEAL registry demonstrated that 57 percent of patients used supplemental oxygen, with usage associated with more advanced disease and worse prognostic factors (Farber et al., 2018).

For caregivers, oxygen management is a significant practical and logistical responsibility. The American Thoracic Society clinical practice guidelines emphasize that patients and their caregivers should receive instruction and training on the use and maintenance of all oxygen equipment, along with education regarding oxygen safety, including smoking cessation, fire prevention, and tripping hazards (Jacobs et al., 2020). The guidelines specifically acknowledge the substantial body of evidence regarding patient and caregiver burden associated with ambulatory oxygen use, including managing equipment weight and bulk, embarrassment and perceived stigma, fear of cylinders running out, and reduced ability to travel outside the home.

Types of Oxygen Equipment

Caregivers must become proficient with multiple oxygen delivery systems. Standard oxygen concentrators, weighing approximately 50 pounds and typically mounted on wheels, represent the most common home-based option, filtering room air to deliver concentrated oxygen. Portable oxygen concentrators, under 20 pounds and battery-powered, enable greater patient mobility but require charging management and battery monitoring. Compressed gas cylinders offer portability but present weight challenges and require careful supply management, with cylinder duration being limited by the patient's liter flow of oxygen.

Safety Considerations and Rural Challenges

Patient advocacy resources provide guidance regarding oxygen therapy access and safety, noting that patients may face challenges obtaining appropriate equipment that fits their lifestyle. Caregivers must understand that oxygen cylinders should remain at least five feet from open flames, heat sources, or electrical devices, and that smoking presents significant fire risk in oxygen-enriched environments. The nasal mucosa may become dry with prolonged use, potentially causing nosebleeds, while skin irritation around masks or cannulas requires monitoring.

For rural caregivers, oxygen management presents additional challenges. Oxygen supply companies may have limited delivery areas or infrequent delivery schedules in remote regions, requiring caregivers to maintain larger stockpiles or travel to pick up supplies. During long-distance medical appointments, caregivers must calculate oxygen needs for the entire journey, accounting for delays and ensuring backup supplies. Power outages, more common in rural areas with aging infrastructure, can disable oxygen concentrators, making emergency backup plans and battery-powered alternatives necessary.

The Role of Patient Advocacy in Caregiver Support

Patient advocacy organizations serving the pulmonary hypertension community have developed extensive support infrastructure for caregivers. These organizations provide a range of resources including support groups, peer mentoring programs, dedicated caregiver support lines, and centralized resource portals offering guidance for newly diagnosed patients and their families. Many maintain large networks of both in-person and online support groups to accommodate geographic constraints, while providing educational materials covering treatment options, disease management, and resource navigation that benefit both patients and their caregivers.

Targeted caregiver programs offered by these organizations include guides on effective caregiving practices, the importance of self-care, and strategies for sustainable long-term caregiving. Help centers provide patients, caregivers, and healthcare providers with current medical information, support service availability, and resource connections. Virtual support groups specifically designed for caregivers to enable participation regardless of geographic location, a feature of particular importance for rural families.

Some organizations raise awareness and funding for PH research through community engagement events, offering caregivers unique avenues for emotional expression and community connection that transform feelings of helplessness into purposeful advocacy. Others use digital media platforms, including podcasts and social media campaigns, to share caregiver stories and build online communities of support that reach across geographic barriers. For caregivers managing patients with connective tissue disease-associated PH, specialty organizations provide educational resources and advocacy initiatives addressing the unique intersection of autoimmune disease and pulmonary hypertension, helping caregivers navigate the complex care coordination required between multiple specialties.

Collectively, these advocacy organizations continue building infrastructure to reach underserved populations, expanding networks of care centers, and developing digital tools to connect isolated caregivers with the support they need.

Advocacy Organization Resources

The following are examples, not an exhaustive list, of organizations that provide resources, support, and advocacy for patients with pulmonary hypertension, pulmonary fibrosis, scleroderma, and related conditions, as well as their caregivers and families.

Pulmonary Hypertension Association (PHA)
https://phassociation.org

PHA Europe
https://www.phaeurope.org

PHA Canada
https://www.phacanada.ca

PHA UK
https://www.phauk.org

phaware Global Association
https://www.phaware.global

Team PHenomenal Hope
https://www.teamphenomenalhope.org

Pulmonary Fibrosis Foundation (PFF)
https://www.pulmonaryfibrosis.org

European Pulmonary Fibrosis Federation (EU-PFF)
https://www.eu-pff.org

National Scleroderma Foundation
https://scleroderma.org

World Scleroderma Foundation
https://worldsclerofound.org

Scleroderma Research Foundation
https://srfcure.org

Sociedad Latina de Hipertensión Pulmonar (SLHP)
https://sociedadlatinahp.org

Pulmonary Hypertension Association Australia (PHAA)
https://phaaustralia.com

Lung Foundation Australia
https://lungfoundation.com.au

Pulmonary Vascular Research Institute (PVRI)
https://pvrinstitute.org

Conclusion

Caregivers of individuals with pulmonary hypertension fill an essential yet frequently invisible role in disease management. Whether navigating complex medication regimens, managing oxygen therapy logistics, advocating for appropriate specialty care, or simply providing emotional support through the uncertain trajectory of a progressive illness, these individuals make possible the quality of life that therapeutic advances promise. When caregivers are also managing responsibilities to younger generations, residing in rural communities far from specialty centers, or confronting financial constraints that limit access to support, their burden can become unsustainable without targeted intervention.

Patient advocacy organizations have demonstrated leadership in recognizing and addressing caregiver needs, developing resources that acknowledge caregivers not as peripheral support but as central partners in the therapeutic journey. The continued expansion of these resources, combined with healthcare system changes that formalize caregiver inclusion and policy modifications that address structural barriers such as geographic access and financial strain, offers a pathway toward truly family-centered PH care.

As the field advances therapeutic options for pulmonary hypertension, parallel attention to the people who support patient care, the caregivers, becomes increasingly important. Their wellbeing directly influences patient outcomes, treatment adherence, and quality of life. Investing in caregiver support is not only compassionate but also clinically sound. The path forward requires collaborative effort among healthcare providers, researchers, advocacy organizations, industry partners, and policymakers, all working toward a vision where no caregiver feels alone in their journey and every family affected by pulmonary hypertension has access to the support they need to thrive.

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