The Invisible Burden: Mental Health Challenges Facing Caregivers of Patients with Pulmonary Hypertension

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Background

- Pulmonary hypertension (PH) is a rare, progressive disease requiring complex medical management that significantly impacts both patients and their informal caregivers
- The 2015 and 2022 European Society of Cardiology/ European Respiratory Society (ESC/ERS) guidelines recommend psychological support for patients with PH (Class I, Level C recommendation),[1,2] yet caregiver mental health remains underexplored and inadequately addressed in clinical practice

Objective

- To synthesize existing evidence on the mental health burden experienced by caregivers of individuals with PH and identify gaps in current support resources

Methods

- A narrative review was conducted searching PubMed, Google Scholar, and Cochrane Library using terms including "pulmonary hypertension caregiver," "pulmonary hypertension caregiver burden," "pulmonary hypertension caregiver depression," and "pulmonary hypertension caregiver anxiety"
- The primary source was the first systematic review on PH caregivers[3]
- Additional literature was identified through reference list review and resources from patient advocacy organizations including the Pulmonary Hypertension Association (PHA) and Pulmonary Fibrosis Foundation (PFF)

Results

- The systematic review by Rawlings et al. (2022) synthesized evidence from 8 primary studies[4-11] encompassing 456 caregivers across 10 countries, revealing **substantial psychological burden among PH caregivers**

8 studies
456 caregivers
10 countries

Psychological burden among PH caregivers

14% **Moderate-to-severe depressive symptoms**
Lower social support was significantly associated with greater depression **(r = −0.50, p = 0.002)**[2]

International survey data[5]
66% **Fear** about the future
22% **Stress** related to caregiving demands

Chinese national survey data[6]
88% Felt **stressed**
59% **Health suffered** due to caregiving responsibilities

Caregiver burden increases as patient quality of life decreases[7]

Higher burden reported among[4]
- Female caregivers
- Unemployed caregivers

Caregivers of patients receiving complex infusion therapies experience **intense pressure** and ongoing **struggles balancing caregiving with personal needs**[8]

"their life is in my hands"

Caregivers actively **seek connection and information** online. Common themesinclude[9]:
- **Fear and frustration**
- **Questions about disease management**
- **Need for someone to listen**

Caregivers report significant **information gaps** and **feelings of vulnerability** associated with **disease uncertainty**[10]

Caregivers serve as **essential sources of emotional and practical support**, yet **often lack adequate guidance** from healthcare professionals[11]

Four key themes identified in qualitative research[3]

Unmet mental health needs in PH

<25% of individuals with mental disorders in the PH population receive psychological or pharmacological treatment[12]

No evidence exists evaluating interventions specifically designed for PH caregivers[3]

Despite documented need, a critical gap remains in evidence-based support for the psychological well-being of PH caregivers

Conclusions

- Caregivers of individuals with PH experience significant psychological distress, warranting clinical attention
- It is important to incorporate routine caregiver mental health screening, with particular attention to social support assessment, given its strong correlation with depressive symptoms
- Patient advocacy organizations offer a valuable support infrastructure that could be expanded to address identified gaps
- Future research should evaluate targeted interventions for PH caregivers, with emphasis on high-risk subgroups, including those with limited social support networks

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