# Supporting Caregiver Well-being in Chronic Lung Disease: Why It Matters for Pulmonary Rehabilitation.

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People living with chronic lung disease, particularly as the disease progresses, may be supported at home by a family member or friend who provides care without payment or formal training.[1,2] The responsibilities of caregivers are considerable: managing oxygen and inhaled therapies, assisting with activities of daily living, arranging transportation to appointments, and helping manage respiratory exacerbations.[1] In pulmonary rehabilitation (PR), caregivers often help with transportation to PR centre, assist with PR sessions, and aid with home exercises.[3,4] Lack of transportation and support from caregivers have been recognized as barriers to PR uptake and attendance.[3] In a cohort of 282 adults with moderate to severe COPD in the United States (US), 90% reported having a family caregiver, and those with a caregiver had an 11-fold higher odds of participating in PR than those without a caregiver.[5]

Caregiving in chronic lung disease has measurable effects on caregivers' well-being.[6] In a US national health survey conducted from 2015 to 2018, caregivers of individuals with COPD reported more days with poor mental health (relative risk 1.6) and low physical health (relative risk 1.2) compared to non-caregivers, and their health-related quality of life was compromised comparable to that of caregivers of individuals with dementia or cancer.[7]

Caregiver burden increases with disease severity. Caregivers of individuals with more symptomatic COPD and frequent exacerbations (GOLD group D) report higher subjective burden, including physical, psychological, social, and financial strain, than caregivers of

individuals with fewer symptoms and exacerbations (GOLD group A).[8] In a cohort of 138 caregivers of patients with severe COPD (mean FEV1 39%; 59% on long-term oxygen therapy) referred to a home-based PR program, 41% of caregivers screened positive for anxiety and 12% for depression based on the Hospital Anxiety and Depression Scale (score of 11 or greater).[9] The care demands in chronic lung disease are largely symptom-driven. Thus, worsening dyspnea, cough or sputum, respiratory infections, and oxygen needs can be unpredictable, contributing to a state of increased vigilance.[1] Time for the caregiver's own physical activity, routine meals, and sleep is often reallocated to the patient, potentially contributing to fatigue and low mood that can make the caregiving role harder to sustain.[10]

Caregiver's well-being is important for PR outcomes since caregiver capacity shapes patient participation. Individuals with COPD who live with a physically active partner or family member are more physically active themselves.[11] These associations are observational and do not establish direction, but they suggest that declining caregiver health may limit a patient's ability to attend, complete, and maintain the benefits of PR. Home-based and telerehabilitation models are increasingly common, and they often rely on caregivers for assistance with equipment setup and exercise oversight.[4,12] Given this reliance, the well-being of caregivers warrants attention.

Interventions for caregivers of those with chronic lung disease have been limited and mainly educational.[1,9,13] Programs have provided disease education, self-management, action plans for exacerbations, or psychosocial support in the form of counselling or group-based cognitive behavioural approaches. Further, these interventions have generally been delivered to the patient and caregiver simultaneously rather than focusing solely on the caregiver. To our knowledge, no program has provided exercise training or nutritional support that is focused on the caregiver specifically.[13] In one study of an 8-week home-based PR program of 241 patients with severe COPD, 138 caregivers participated in the program and received the same educational, behavioural, and self-management content as the patient.[9] Caregiver burden, anxiety, depressive symptoms, and fatigue improved over the program, although the study had no control group, and the program was designed around the patient's needs. The authors proposed a trial comparing patient-directed, caregiver-directed, and dyad-directed approaches,[9] which has not been undertaken to-date. Two ongoing studies have begun to involve caregivers in PR: a non-randomized study comparing caregivers' health when the patient completes home-based versus centre-based PR, in which carers may join the patient's exercise sessions,[14] and a planned randomized trial of caregiver-inclusive PR in which caregivers attend education and psychosocial support sessions.[15] Neither study offers exercise training or nutritional support designed for the caregiver.

The American Thoracic Society and European Respiratory Society define PR as a comprehensive intervention based on thorough assessment, followed by tailored therapies that include exercise training, education, and behaviour change, intended to improve the physical and psychological condition of people with chronic respiratory disease and to promote long-term adherence to health-enhancing behaviours.[16] A caregiver program could follow the same model, but with the assessment and goals centred around the caregiver. Such program would combine personalized exercise training, nutritional counselling, and stress management with education and support for behaviour change. In caregivers of adults with chronic conditions, physical activity interventions have been shown to improve mental health and quality of life,[17] although they have not been assessed in chronic lung disease.

The delivery structure of a caregiver multimodal program may matter as much as its program content. Home-based caregiver programs may suit caregivers who find it difficult to leave the patient, while others may value in-person sessions and time away from home. Thus, a flexible format and scheduling may be more appropriate for unpredictable care demands compared to a fixed schedule. The Canadian Caregiver Coalition supports tailored, multicomponent approaches over single-component programs for this reason.[18] A large umbrella review found that, for caregivers of older adults with chronic disease, multicomponent interventions tailored to the individual caregiver appear to be most effective.[19] Timing is also relevant: burden is higher in advanced disease,[1,8] and support offered once caregiver burnout is clinically apparent may be too late. As one example, at the University Health Network, we are conducting a feasibility randomized controlled trial of an 8-week individualized, home-based multimodal program of exercise, nutritional counselling, and stress management for caregivers of patients with advanced cardiac or lung disease followed in outpatient palliative care clinics.[20]

Caregivers of individuals with chronic lung disease experience measurable effects on their physical and mental health due to the unpredictable nature of care demands. These caregiver demands can displace their own sleep, physical activity, and nutritional habits. Caregiver support and well-being are also related to whether patients take part in and complete PR, and home-based programs often rely on caregiver support. Programs offered to caregivers have been predominantly educational. Thus, multimodal programs that include exercise, mental health, and nutritional support designed for caregivers should be developed and evaluated, with outcomes measured in both caregivers and patients. Supporting caregiver health may, in turn, help patients start, complete, and maintain the benefits of PR (Figure 1).

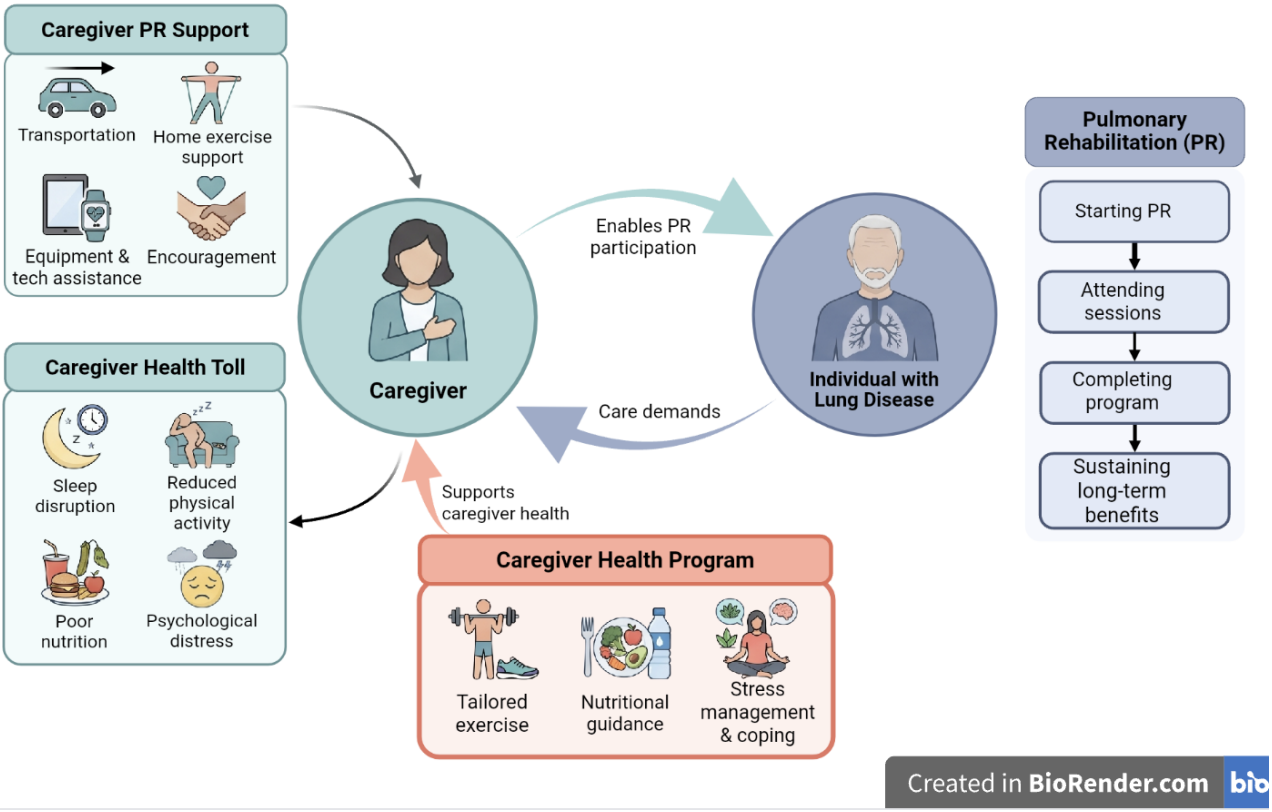



**Figure 1. Framework of Caregiver Support in Chronic Lung Disease in Pulmonary Rehabilitation.** Caregivers support the individual with lung disease to start, attend, complete, and sustain PR through transportation, home exercise support, equipment and technology assistance, and encouragement. Care demands may affect caregiver sleep, physical activity, nutrition, and psychological well-being. A caregiver health program of tailored exercise, nutritional guidance, and stress management may support caregiver health and, in turn, their capacity to support PR. Created in https://BioRender.com.

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