

Socioeconomic Impact of Pulmonary Arterial Hypertension on Patients and Their Caregivers in the Czech Republic

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Introduction

- Pulmonary arterial hypertension (PAH) is a rare, progressive disorder leading to right heart failure and, if left untreated, ultimately to death (1)
- The symptoms associated with PAH significantly impair patients’ health-related quality of life (HRQoL), can be hugely devastating and negatively affect all aspects of life: physical, social, and emotional (2,3)
- PAH also places a considerable burden on caregivers – typically the patient’s partners and close family members (2,4,5)
- The disease often impacts patients’ but also caregivers’ ability to work, leading to reduced household income, and causing financial stress (2,3,5)

Objectives

- The study aimed to evaluate the direct, indirect, and societal costs of PAH in the Czech Republic and to assess the burden of the disease from patient/family/society perspective
- We assessed quality of life, work productivity and PAH patients’ time burden associated with managing the disease
- We explored work productivity, time burden and overall disease burden on caregivers

Methods

- This study was a single arm, non-interventional, multicentric, cross-sectional hybrid study conducted in 2 centers specialized in PAH treatment in the Czech republic from June 26 to October 7, 2024.
- Prevalent PAH patients age 18+ with WHO-FC status II-IV were eligible if WHO-FC has been stable for at least 6 months and investigator could access at least 12-month clinical records related to PAH.
- Adult caregivers of patients in the study were also recruited to participate.
- Data was collected from:
  - clinical records (demographics, medical history, current disease status),
  - patients (EQ-5D-5L and WPAI questionnaires), PAH-related time burden and direct and indirect costs
  - caregivers (WPAI and ZARIT burden questionnaires)
- The Work Productivity and Activity Impairment (WPAI) questionnaire measures productivity loss on a scale from 0 to 1 (or 0 to 100), where zero indicates no impairment and 1 (100) represents complete loss of productivity in work and daily activities (6)
- The EQ-5D questionnaire assesses health-related quality of life on a utility score, values range from 0 (death) to 1 (full health) (conversion of five dimensions of EQ-5D descriptive system) and visual analogue scale, where values range from 0 (Worst imaginable health state) to 100 (Best imaginable health state) (7)
- The Zarit Burden Interview (ZBI) is a validated and internationally recognized tool for assessing caregiver burden (9). It consists of 22 items, each with four response options, yielding a total score ranging from 0 to 88, where 0 means no caregiver burden and 88 means maximum caregiver burden.
- Patients and caregivers were asked to estimate how much time on average per month they spend on PAH management activities.

Results

Patients Demographic and Clinical Characteristics (Table 1)

- 80 patients were included in the final analysis
- Median (IQR) time since diagnosis: 5.14 (2.36;11.47) years
- Idiopathic PAH: 99% of patients
- Mean (SD) NT-proBNP: 752 pg/mL (±1094.93), 6-minute walk distance: 376 meters (±201.20)

Caregivers Demographic (Table 2)

- 19 caregivers, all of them were close relatives of the patients enrolled in the study and willing to fill-in the study questionnaires

Table 1. Demographic and Clinical Characteristics of Patients (N=80)

	N (Value)
Sex	
Female	59 (73.8%)
Male	21 (26.3%)
Age	
Mean (years) [SD]	80 (53.5) [±16.2]
Under 65	53 (66.3%)
WHO FC groups	
WHO FC II	16 (20.0%)
WHO FC III	64 (80.0%)
PAH clinical classification	
Idiopathic	79 (98.8%)
Association with connective tissue disease	1 (1.2%)
Current PAH therapy	
Prostacyclin infusion therapy**	24 (30.0%)
Monotherapy	28 (35.0%)
Double therapy	36 (45.0%)
Triple therapy	16 (20.0%)
Long-term home oxygen therapy**	15 (18.8%)

\*\*Prostacyclin infusion therapy and Long-term home oxygen therapy can be occurring at the same time as Monotherapy, Double therapy and Triple therapy

Table 2. Demographic of Caregivers (N=19)

	N (Value)
Sex	
Female	10 (52.6%)
Male	9 (47.4%)
Age	
Mean (years) [SD]	19 (54.8 [±14.9])
Under 65	11 (57.9%)
Relationship to patient*	
Close relatives	19 (100.0%)
Distant relatives	0 (0.0%)
No family relationship	0 (0.0%)
Patient’s WHO FC class of whom the caregiver takes care of	
WHO FC II class	5 (26.3%)
WHO FC III class	14 (73.7%)
Proportion of patients who are being taken care of by caregiver	
WHO FC II class	5 (31.3%)
WHO FC III class	14 (21.9%)
Working status	
Student	1 (5.3%)
Working	11 (57.9%)
Retired	7 (36.8%)

\*Close relatives: wife/husband, father/mother etc., distant relatives: cousin, aunt/uncle, friend etc.

Patients’ sociodemographic data

- **Figure 1** presents the highest completed education level
- Among the 53 patients of working age, only 11 are employed full-time (**Figure 2**)
- Notably, 43 patients (53.8%) receive disability pensions (**Figure 2**). When considering only patients of productive age (<65 years), this proportion rises significantly to 81.1% (43 out of 53 patients)
- Out of 40 patients receiving disability pension due to PAH, 68% of them (27 patients) are classified with the most severe disability (**Figure 3**)

Figure 1. Patients’ highest level of education

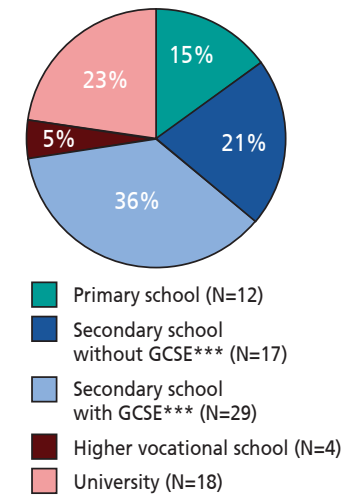
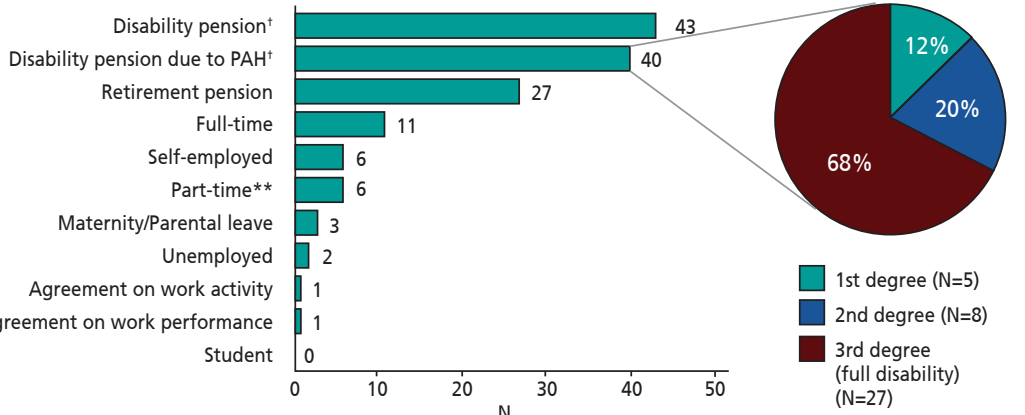
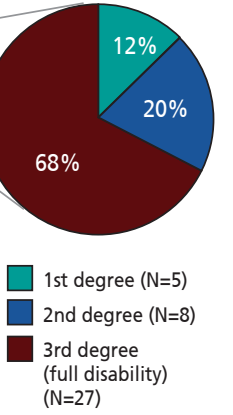


Figure 2. Type of employment\* (N)



\*Multiple choice  
\*\*Average number of working hours per week is 15  
\*\*\*General Certificate of Secondary Education  
†Disability of 1st degree is defined by Law as a decrease in working productivity by 35–49%, 2nd degree by 50–69% and 3rd degree by 70–100%

Figure 3. Disability pension due to PAH†



Loss of productivity based on WPAI\*

Patients

- The overall work impairment among 18 patients, who filled in the WPAI questions on work impairment, was 30.5%, indicating that working patients experienced a 30.5% reduction in productivity (**Figure 4**)
- The activity impairment – reflecting limitations in daily non-work related activities among 73 patients, who filled in the WPAI activity impairment question, was 46.2% overall (**Figure 4**)

Caregivers

- The overall work impairment among 9 caregivers, who filled in the WPAI questions on work impairment, was 30.8% (**Figure 5**)
- Similar to patients, this was mainly due to presenteeism. However, absenteeism was notably higher among caregivers, likely due to their need to accompany patients to medical appointments and assist with daily tasks such as cooking, dressing, housekeeping, transportation, and medical support (**Figure 5**)
- The activity impairment among 18 caregivers, who filled in the WPAI activity impairment question, was also significantly impaired with 38.3% reduction in activities

\*In WPAI questionnaire, all patients/caregivers could answer the question related to activity impairment, only working patients/caregivers could answer the questions related to work impairment

Figure 4. WPAI Patients (% of impairment)

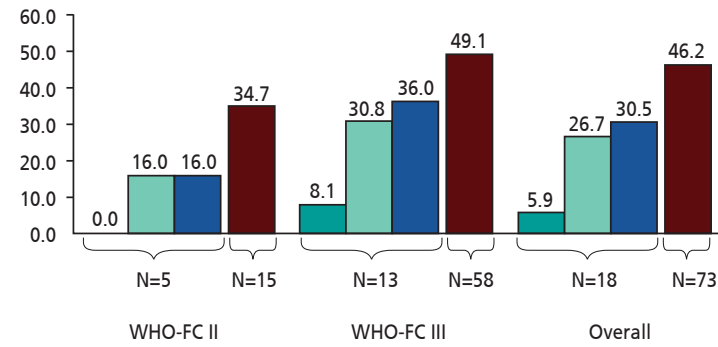
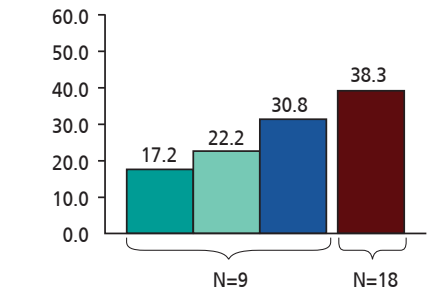


Figure 5. WPAI Caregivers (% of impairment)



Patients’ quality of life (EQ-5D)

- Mean EQ-5D-5L score on a scale from 0 (death) to 1 (full health) is 0.64 (WHO-FC II: 0.67 and WHO-FC III: 0.63)
- General population\* – average EQ-5D-5L score in this age group is approximately 0.85 (8)
- Mean EQ-5D-5L VAS score, ranging from 0 (Worst imaginable health state) to 100 (Best imaginable health state), is equal to 68.41 (WHO-FC II: 69.69 and WHO-FC III: 68.09)
- General population\* – average EQ-5D-VAS score in this age group is 0.90 (12)

\*UK value set in the absence of CZ value set in line with CZ HTA guidelines

Figure 6. Patients Quality of life EQ-5D-5L domains

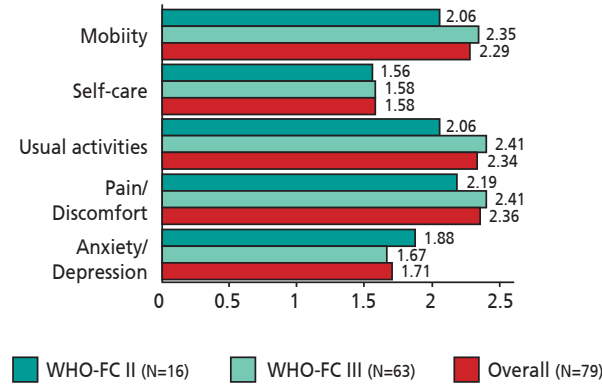
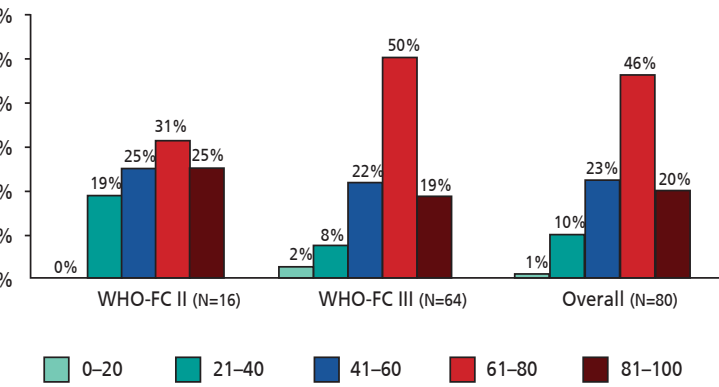


Figure 7. Patients’ EQ-5D VAS score



Monthly disease-related time burden

- Patients with PAH face a significant time burden due to disease management (**Figure 8**)
- Caregivers also experience a substantial time commitment, averaging 66 hours per month for PAH related patient care (**Figure 9**), mainly due to cooking, dressing and housekeeping (**Figure 10**)

Figure 8. Time burden patients

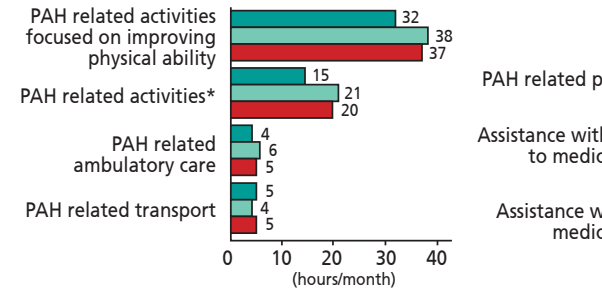


Figure 9. Time burden caregivers

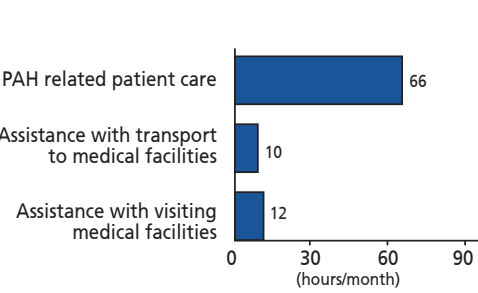
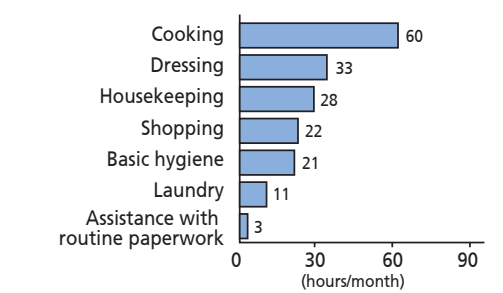


Figure 10. Time burden caregivers – activities

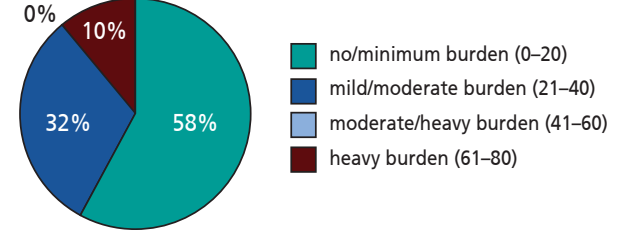


\*e.g., preparation of medicines, preparation of special diet...

Caregivers’ ZARIT burden

- The mean ZBI score among caregivers was 24.28, indicating a mild to moderate level of burden with a pronounced heterogeneity when 10 % and 32 % of caregivers report heavy and mild/moderate burden respectively and 0% moderate/heavy burden (**Figure 11**)
- This level of caregiver strain is comparable to that reported in caregivers of patients with advanced cancer (10,11), underscoring the significant impact of PAH not only on patients but also on their support networks

Figure 11. ZARIT burden interview caregivers



Limitations

- As in all observational studies, there may be a selection bias; the investigators were instructed to enroll all suitable patients who attended planned medical visits during the enrollment period.
- In addition, patient willingness to participate might create a bias; patients willing to enroll in the study might differ from the general PAH population. However, the high sample size decreases this risk.

Conclusions

- This study clearly demonstrates that PAH has a profound impact on the daily lives of both patients and their caregivers in the Czech Republic, while also imposing a significant burden on society.
- PAH is associated with a wide range of challenges stemming from both the disease itself and its treatment. It significantly affects patients’ quality of life, their ability to work and their capacity to perform everyday activities.
- In addition, PAH places a considerable strain on healthcare and social support systems, highlighting the need for comprehensive management strategies that address not only clinical outcomes but also the broader human and societal impact.

Disclosures

- PJ has received fees and grants from Janssen, AOP Orphan, Bayer Healthcare, MSD, Arena Pharmaceuticals, Gossamer Bio, Altavant Sciences GmbH. He has served on advisory boards for MSD AOP Orphan, outside presented work.
- LM has received honoraria from MSD and AOP Orphan for scientific lectures.
- JA, TM and JZ are employees of MSD, Czech republic and may own stock and/or stock options in Merck & Co., Inc., Rahway, NJ, USA.
- TD and KD are employees of Value Outcomes, paid consultants to MSD.

Acknowledgements

This study was funded by MSD Czech Republic.

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