



## Quality of Life in Families of Children with Pulmonary Hypertension: A Cross-Sectional Study

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### Background

- Pediatric pulmonary hypertension (PH) is a rare, life-threatening condition, requiring complex, multidisciplinary care.
- Advances in diagnostics and targeted therapies have improved survival, so **health-related quality of life (HRQoL)** has become a key outcome in pediatric PH guidelines.
- HRQoL is multidimensional, covering physical, emotional, social and role functioning.
- Previous studies show that:
  - Children with PH have significantly lower HRQoL than healthy peers and than children with other chronic conditions (congenital heart disease, cancer).
- Lower child HRQoL is strongly linked to increased parental stress and poorer parental adjustment.
- Evidence specifically focusing on **families and caregivers of children with PH** remains limited, especially in Europe.

### Results

- **Global HRQoL:** Mean SF-36  $\approx$  31/100 – markedly reduced.
- **Most affected domains:** physical functioning, role-physical, general health, role-emotional.
- **Clinical factors:**
  - Worse HRQoL in caregivers of older children.
  - Lower scores with greater exercise limitation, more dyspnoea, more frequent hospitalizations.
- **Family and social context:**
  - Lowest HRQoL in single-parent families (especially single fathers).
  - Higher HRQoL in two-parent families with additional support from grandparents.
- **Emotional and social burden:**
  - Nearly all caregivers: strong/very strong emotional burden.
  - Anxiety, sadness, despair, feeling that PH hinders life goals and lack of social support → significantly lower SF-36 scores.

### Conclusions

- Caregivers of children with PH experience severely impaired quality of life.
- Poorer HRQoL is linked to disease severity, older child age, single-parent family structure, financial/occupational burden and lack of social support.
- Emotional distress of both child and caregiver plays a key role.
- Comprehensive PH care should routinely include:
  - HRQoL monitoring in caregivers,
  - psychological and social support for families, organizational solutions (flexible work, community and family support).

### Aim

- To assess HRQoL in caregivers of children with PH.
- To identify socio-demographic and clinical factors related to poorer HRQoL.

### Material and methods

- Design: Cross-sectional questionnaire study.
- Setting: Specialized pediatric cardiology centre in Poland.
- Participants: 28 child–caregiver dyads; children 4–17 years with confirmed PH.
- **Tools:**
  - Author-designed caregiver questionnaire (socio-demographic data, family structure, finances, emotions, social support).
  - Clinical data (symptoms, exercise limitation, hospitalizations, cardiac surgery).
  - SF-36 Health Survey for caregivers' HRQoL (8 domains, physical and mental components).
- Analysis: Descriptive statistics, Shapiro–Wilk test, non-parametric group comparisons, correlations;  $p < 0.05$ .

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