SUMMARY

PH Global Patient Survey: Physical and Psychosocial Impact on Health-Related Quality of Life

The Pulmonary Vascular Research Institute (PVRI) published The Pulmonary Hypertension Global Patient Survey: Physical and Psychosocial Impacts on Health-Related Quality of Life, presenting data from 3329 patients from 88 countries.

The paper organises the data into seven themes:

1. Daily functioning

People were asked if pulmonary hypertension (PH) affected dressing/showering, walking short distances or climbing stairs, performing household chores, leisure activities, and sex. Over three quarters said PH negatively affects at least one of those functions “often” or “very often”.

2. Emotional wellbeing

Over half of the respondents “often” or “very often” felt low self-esteem, isolation, fear/fright, anger/frustration, misunderstood, or guilty/embarrassed/hopeless because of their pulmonary hypertension. Isolation, loneliness, and sadness were recurrent themes.

3. Physical wellbeing

Two thirds said pulmonary hypertension “often” or “very often” affected their physical wellbeing including sleep quality, diet, concentration, memory, or restlessness.

4. PH treatment and side effects

Half of patients reported side effects due to pulmonary hypertension medications, most commonly headaches and nausea. People with treatment side effects reported a negative impact on work.

5. Employment and disability

Almost three quarters of the pulmonary hypertension patients reported that pulmonary hypertensions affected their work and just over half were officially registered as disabled. In about 40% of cases, disability registration could lead to more financial support. Employers were largely (80%) aware of their employee’s PH and generally supported them.

6. Contraception and pregnancy

Women with pulmonary hypertension are told pregnancy is a health risk, so over four in five women of child-bearing age worried about pregnancy at least sometimes. Contraception and abortion access could be a challenge.

7. Patient Reported Outcome Measures (PROMs)

Nearly 90% had heard of Patient Reported Outcome Measures, but only one in five responders reported ever completing them. Of those few, only a quarter received feedback from their pulmonary hypertension team.

Regional variations

Patients' responses varied across the ten geographical regions.

North America

- Lowest emotional impact
- Highest rate of employer supportiveness

Central America & Caribbean

- Lowest rate of employer supportiveness

South America

- Lowest physical wellbeing
- Highest rate of concern about potential pregnancy

Central and Eastern Europe

- Highest rate of concern about potential pregnancy

Northern Europe

- Lowest emotional impact
- Highest physical wellbeing
- Highest use of Patient Reported Outcome Measures

Southern Europe

- (No highs or lows)

Western Europe

- (No highs or lows)

Asia

- Highest rate of patients experiencing any side effect

Africa

- Highest negative impacts on daily functioning
- Highest rate of assessed treatment side effects
- Lowest use of Patient Reported Outcome Measures

Oceania

- (No highs or lows)

What's next?

Because it is an "invisible" disease, pulmonary hypertension results in high emotional burdens as well as difficulties accessing support.

Several of these survey findings were included in the PH Call to Action list of tangible goals:

- 3. Patient Reported Outcomes Measures (PROMs) should be used to evaluate quality of life and guide holistic care, including psychological and rehabilitative services
- 4. Patients should be empowered to engage in shared-decision making in partnership with their clinicians, including managing side effects
- 6. Patients with PH should be assisted in applying to adjust employment or applying for disability support