Psychosocial issues in paediatric pulmonary hypertension using a Multidisciplinary approach

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Paediatric Pulmonary Arterial Hypertension (PAH)

Pediatric PAH is a rare disease
Incidence: 3 million children
Prevalence: 20 cases/million diagnosed with PAH

iPAH 0.7/million
PAH/CHD 2.2/million
other PAH/CTD PAH/HIV
Porto-pulmonary PAH PVOD

Availability of new medications
More knowledge, experiences and research
But little is known about the impact of PAH on children/families

*van Loon R L E et al. Circulation 2011;124:1755-1764

Worldwide consensus:

Specialized centers to provide optimal care

Diagnosis
Treatment
Care

National Network in the Netherlands

National Network for Pulmonary hypertension in childhood

7 University Medical Centers
2 Paediatric Cardiology Center
1 National Expertisecenter

Standard Diagnosis and Treatment of Pulmonary Hypertension in Children

Psychosocial problems and Optimal care

At diagnosis and during follow up:
Feeling overwhelmed
Worry / anxiety / uncertainty

Difficulties:
Medical treatment
Child's symptoms and/or disability
Family function

Rare disease Complex care Need for Multidisciplinary approach


Dedicated Health Care Team Expertise center

Pediatric medical specialists cardiologist/ pulmonologist and other specialists
PICU
Transplantation team

Achieving diagnosis
Treatment plan
Overall responsibility for patient care
Follow up
Research
Clinical trials
Education health professionals

Child with PAH and Family

Nurse practitioner
Follow up
Coordination patient care
Support child and parents
Patient education
Liaison with home care nurses/professionals
Education nurses
Research activities

Child with PAH and Family

Social worker
Interaction with family
Identification of social and practical problems / requirements
Support for children, parents / siblings
Improve problem solving skills
Encouraging positive coping mechanisms

Child with PAH and Family
**Dedicated Health Care Team Expertisecenter**

- Nurse practitioner
- Social worker
- Consultant education sick pupils

**Child with PAH and Family**

- Information home school
- Transform medical advice into practical possibilities
- Educational plan appropriate for physical and cognitive abilities
- Appropriate modifications and accommodations

**Educational plan appropriate for physical and cognitive abilities**

**Nurse practitioner** and **Family abilities**

**Appropriate modifications and accommodations**

**Social worker**

**Consultant education sick pupils**

**Play therapist**

**Psychological examination**

- Treatment of the child
- Cognitive behavior therapy
- Problem solving therapy (PST)
- Fear diminishing training
- Needle photos
- Advice parents
- Referral to local psychologist

**Psychological support**

**Psychologist**

**Sick pupils**
Adult PH center

- VU Medical Center Amsterdam
- University Medical Center Groningen
- University Medical Center Maastricht
- St. Antonius Hospital Nieuwegein
- University Medical Center Nijmegen
- University Medical Center Rotterdam

Case presentation:

The child newly diagnosed with paediatric PAH and his/her family

Ria Bakker / Sira Baars / Mirjam van Gent

Case presentation:

A child with severe PAH on the PICU and screening for lungtransplantation

B. Wijnberg-Williams / G. Wildeboer

Case presentation:

Transition of an adolescent with PAH

B. Coleman
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