

# Adolescence-Young patients with Pulmonary Hypertension « Transition »

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# What is transition ?

- Transition from a pediatric clinic to an adult clinic!
- Transition should not be an event but a process
- Needs
  - Physician understanding and education
  - Patient education
  - Parents education
  - Hospital staff and administration education

# Transition

- A health care priority
- Currently almost no science behind this process
- Only very few studies

# Congenital heart disease

- Pioneer transition plans
- Well established in many centers around the world
- Highlights the need for a team approach , the nurse being an important factor
- Adult CHD with or without PAH!!??

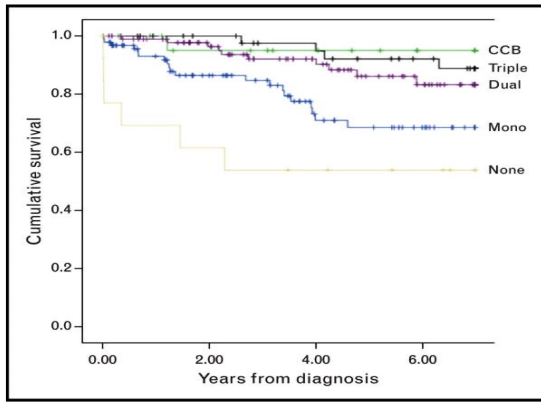
# Other etiologies

- >90% of the pediatric patients with chronic disease reach adulthood!!
  - CHD
  - Cystic fibrosis
  - Cancer
  - Sickle cell
  - Etc...

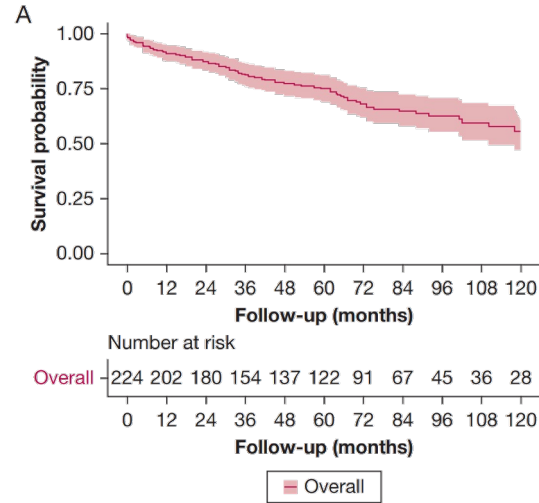
# Transition for PAH

- Survival is improving and more and more pediatric patients are transitioned to adult care
- Example of adult congenital heart disease (ACHD)
- When and how to transition to avoid problems
- Adolescence is a very vulnerable period!!

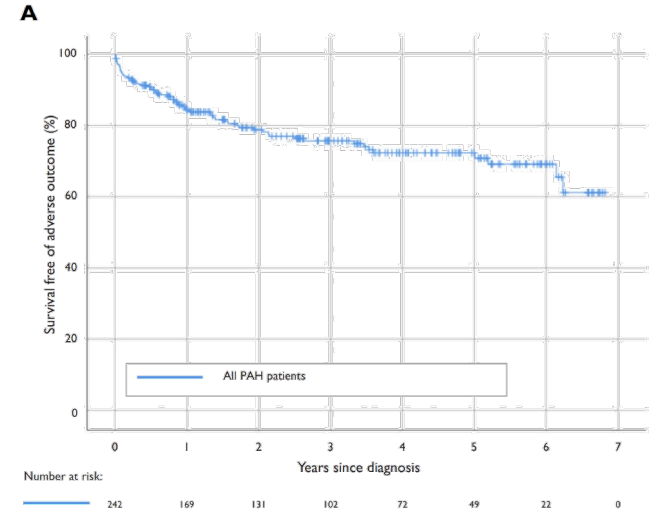
# Current survival in pediatric PAH



Zijlstra WMH, et al. JACC 2014



China multicenter cohort . Qian Y et al. Chest. 2023 Jun;163(6):1531-1542



Int TOPP-registry. Ploegstra MJ et al. Eur Heart J Qual Care Clin Outcomes. 2023

# Transition: ACHD

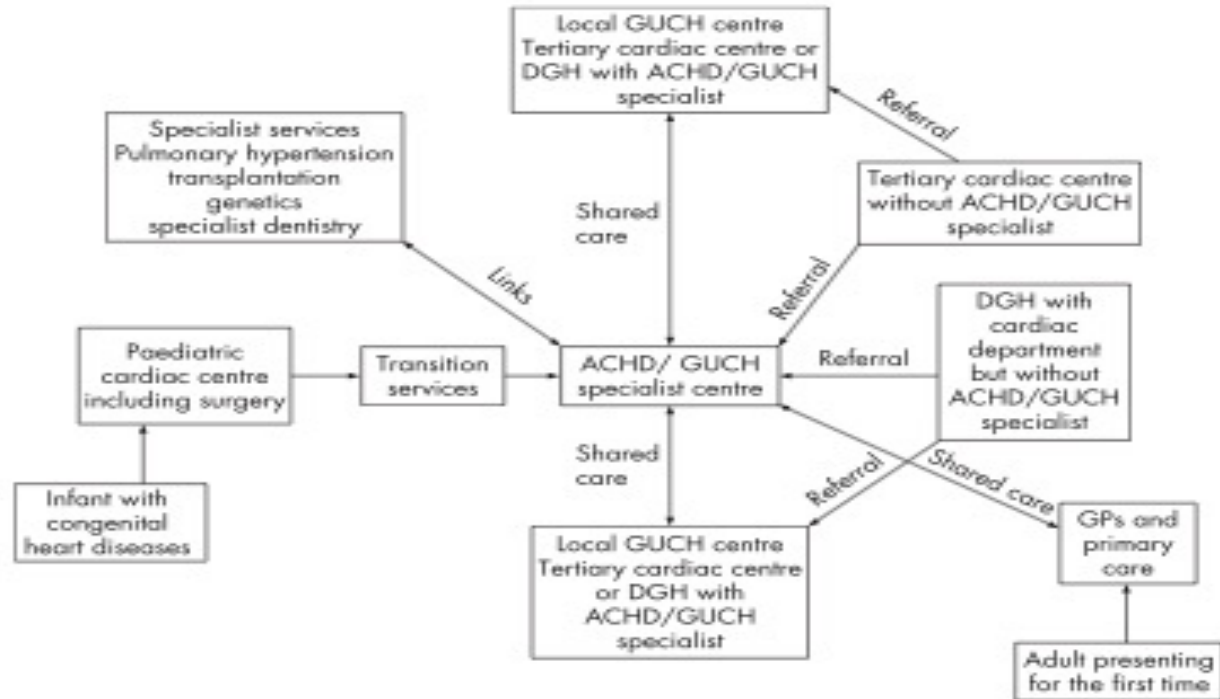


Figure 1 A service model for adults with congenital heart disease.<sup>10</sup>

# What is transition ?

- There is no gold standard
- Try to give recommendations but each center has its own practice and problems that requires an adaptation
- Example.
  - Pediatric and adult clinics in the same hospital or not....

# When is transition successful

- When you send the patient to the adult clinic???
- No!!!!
- When the patient attend the adult clinic regularly

# Why is transition difficult ?

- Patients are attached to their pediatrician
- Pediatrician are attached to their patient....
- Both feel unsecure to cut the umbilical cord...it is like a 16-18 years gestation or like a child living the parents home....



# Why is transition difficult ?

- Adolescence can represent a challenging period of physical, cognitive, and psychological development
- For children with pulmonary arterial hypertension (PAH), having a chronic and life-limiting disease is likely to create greater obstacles and adversities that may delay their ability to meet age-appropriate developmental milestones **OVERPROTECTION!!!**
- Difference between a diagnosis during adolescence or during infancy!

# Differences adults children

Adult	Pediatric
<p>Patient centered care</p> <ul style="list-style-type: none"><li>• Patient is the focus of all discussions</li><li>• Patient gives the consent</li><li>• Assumed that the patient understand the medical condition and informations</li></ul> <p>Focus on the disease</p>	<p>Family centered care</p> <ul style="list-style-type: none"><li>• Partial or complete involvement of the caregiver</li><li>• Caregiver is the primary decision maker</li><li>• Child may not be part of the decision process...</li></ul> <p>Focus on the disease and development</p>

# What helps success

- Proximity of pediatric and adults clinics
- Pediatrician is proactive and support transition
- Adolescents who start to come alone at the peds clinic.....

# Prior to transition

- Assess and evaluate adolescent patient's cognitive and psychosocial development
- Screen patient and caregiver for depression or any other psychosocial problems
- Prepare progressively for transition
  - Assess regularly the patient knowledge of the disease and care

# Initiation of transition

- Discuss concept of transition of care with the patient (12-14 years of age) and also with caregivers
- Discuss the concept of adults and self care!
- Clearly define roles and role expectations for the patient, caregiver, and pediatric provider
- Educate caregivers
- Provide educational materials, if available
- Interval assessment and review of age and developmentally appropriate expectations and goals (developmental delay i.e. trisomy 21....)

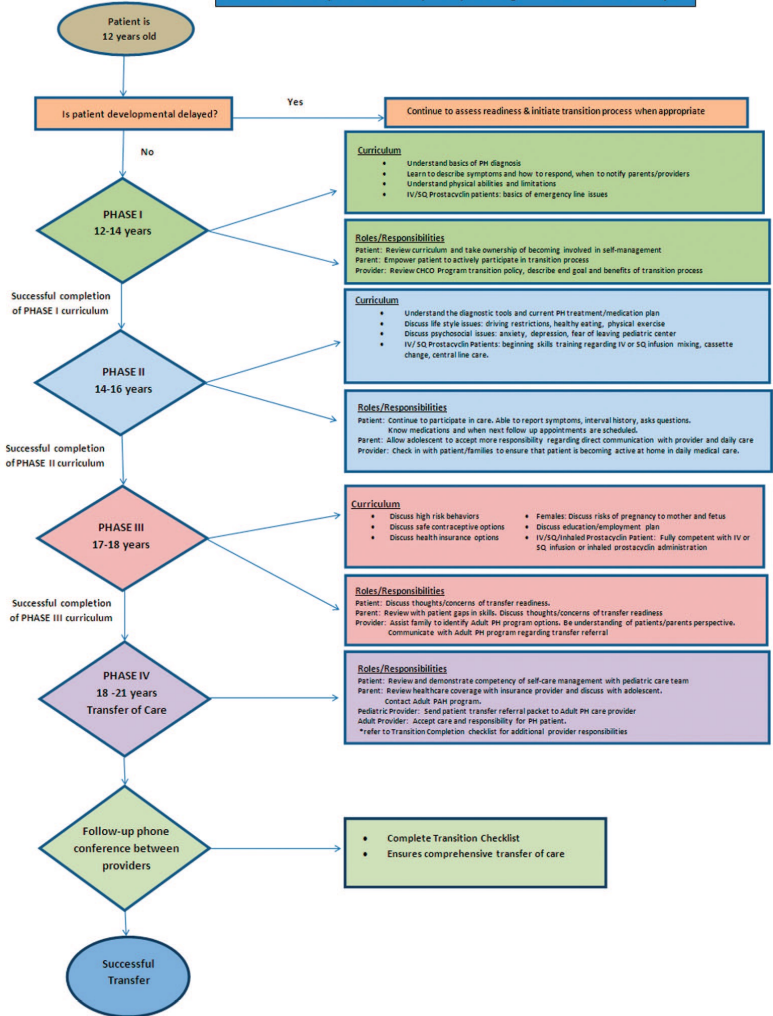
# Goals to met before transition

- Understanding of diagnosis and medical history
- Knowledge of medical therapies (medications—doses, frequency, and purpose)
- Additional medical knowledge:
  - Need for specific monitoring and anesthesia care, if applicable
  - Endocarditis prophylaxis, if applicable
  - Pregnancy risk and contraception
  - Drug and alcohol abuse
  - Self-management of care
  - Self-administration of oral medications
  - Self-administration of IV/SQ medication (interim steps to master—observe caregiver preparation, complete under caregiver supervision, self-preparation)
  - Central venous catheter care
  - Knowledge of purpose and adherence to diagnostic studies, including serum lab tests (eg, LFTs, INR)
- School/work plans—adaptation of school or work to disease and treatment
- Secure health insurance coverage as adult

# Last clinic visits before transition

- Arrange joint visit including patient, caregiver, pediatric and adult care team in pediatric setting
- Review medical summary during joint visit
- Provide formal written summary to patient and adult care team or full chart record!
- Discuss timing for initial visit at adult practice and frequency of visits
- If possible « Tour » the adult center
- Identify adult care team members, provide contact information (designated point person, nurse or physician?)

**Children's Hospital Colorado (CHCO) PH Program Transition Roadmap**



# The DENVER/colorado program

# Transfer check list

## Transfer Checklist



- Patient/ family and pediatric PH provider determine readiness to transition

- Patient has successfully completed Phases I through VI of transition curriculum

- Adult PH provider identified and notified of transfer referral

- Adult PH Provider has accepted referral and has received transfer referral packet

- Patient has scheduled and completed first Adult PH Clinic visit

- Patient and parents have the Adult PH Program's contact information
- Including contact process for emergency issues

- Telephone care conference between pediatric and adult providers to discuss issues.
- Confirm transfer of care complete and hand off successful.

- Patient has contacted all pharmacies, home health, and equipment providers with new PH provider information for future prescription management and care orders.

# 1st adult clinic

- Arrange overlap visit pediatric provider attends initial clinic visit
- Redefine roles and role expectations for the patient, parent, and adult provider

# Conclusion

- Current practices to transition care of adolescent patients with a chronic disease demonstrate that health care providers must improve their practice to meet the needs of these patients.
- Understanding the factors that impact the development of adolescents with PAH and implementing the essential components of transitional care into practice may help to provide these patients with the knowledge and skills necessary to independently and safely manage their own care.
- The demands of PAH therapies, and the complex and serious nature of this disease warrant health care providers to prioritize the implementation of an effective transition program in order to truly provide comprehensive care that meets the medical and psychological needs of these adolescents.

# Conclusion

- A good transition needs:
  - A lot of effort and time
  - To never underestimate the needs and the problems
  - Continuous education of patients, staff and administration
  - To stimulate the hospitals to support this process
  - CHD and PAH requires even more attention due to dual disease and sometimes clinics....