

Transitioning Pediatric Cardiac Patients to Adult Congenital Care: When, Why and How?



Angela Li, MD

Department of Cardiology

UCI/Rady Children's



Disclosures

- I have nothing to disclose

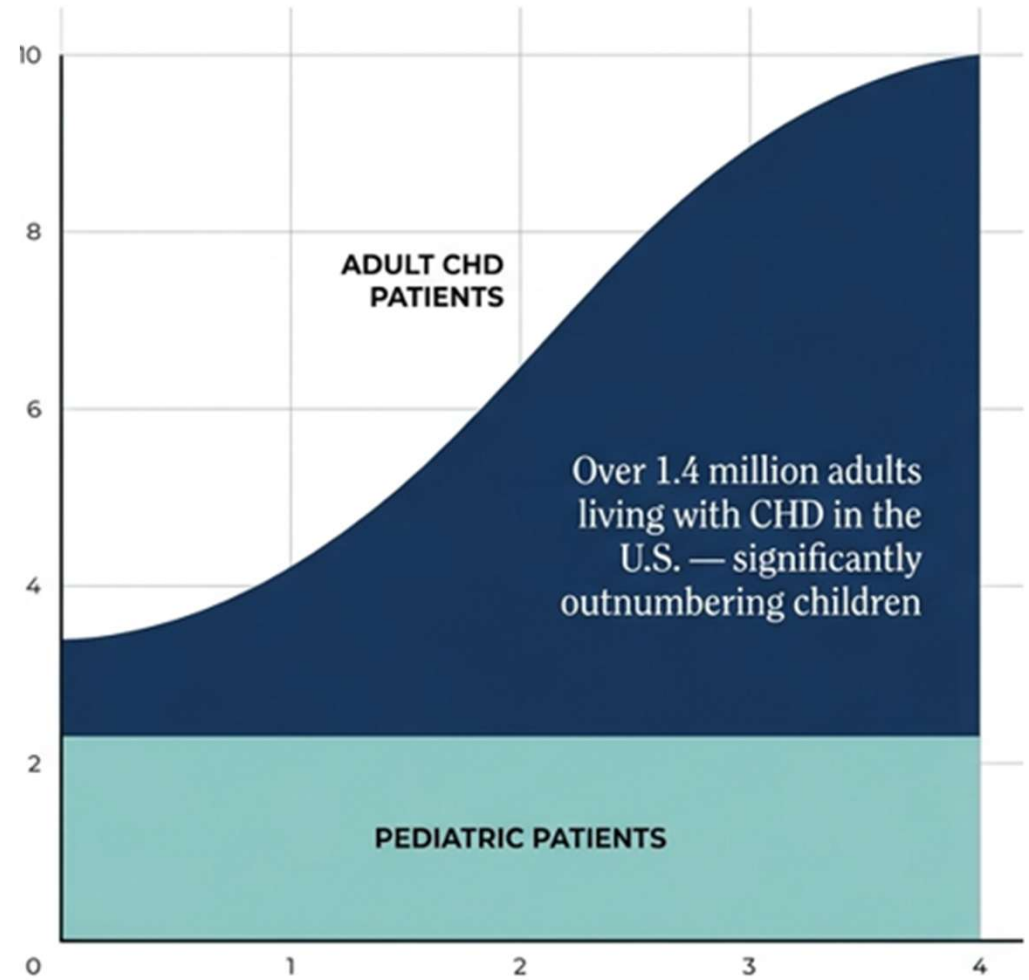


Learning Objectives

1. Understand the difference between transition and transfer of care between pediatric cardiology and adult congenital heart disease (ACHD)
2. Highlight common topics that are addressed in congenital cardiology as patients reach young adulthood
3. Discuss the components that make up an effective transition to ACHD

Background

- CHD = 1% of births in US
 - > 90% survive into adulthood
 - 2/3 of all CHD patients are now adults



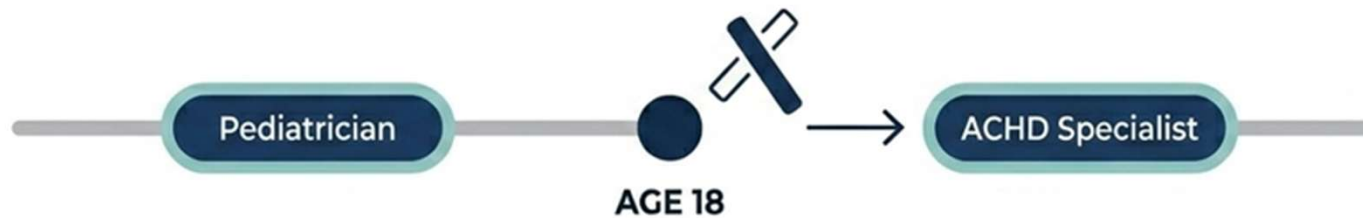
Transfer vs. Transition



Moons et. al

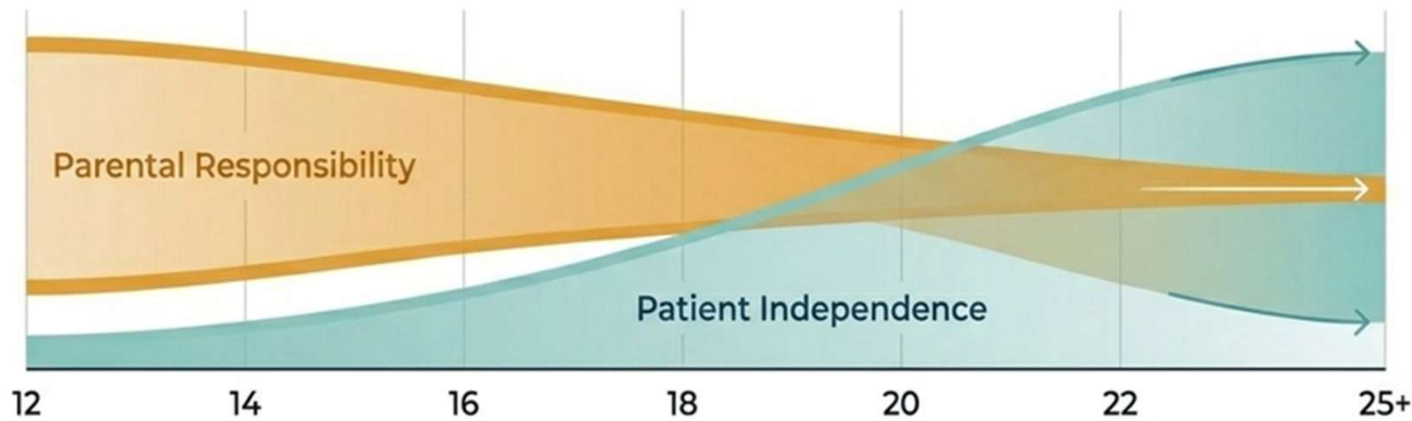
Transfer vs. Transition

TRANSFER



Transfer is an administrative event.

TRANSITION

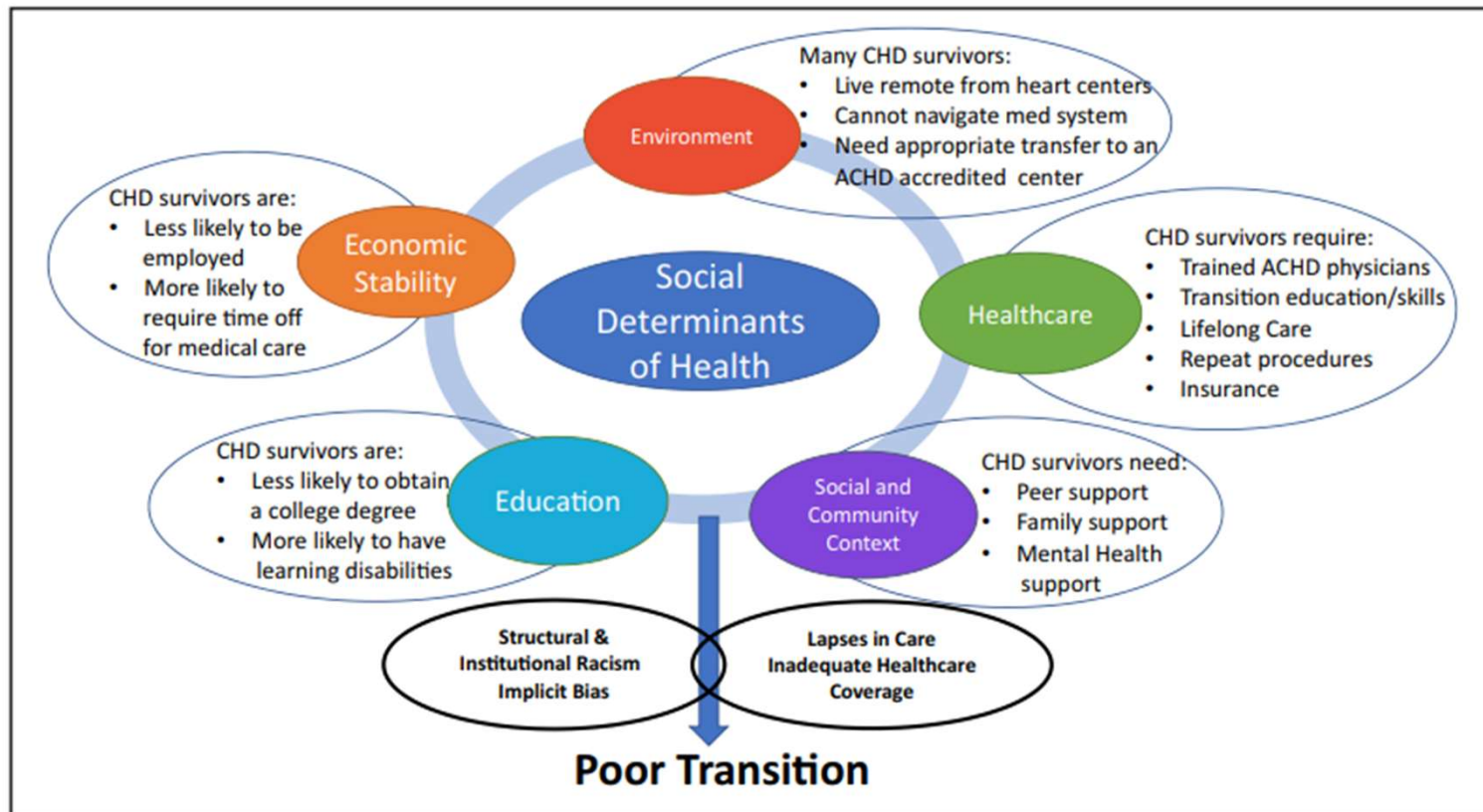


Transition is a longitudinal, developmental process of gaining independence and maximizing lifelong functioning.

Transfer vs. Transition

	Transfer (The Event)	Transition (The Process)
Timeframe	Point-in-time administrative event	Longitudinal process beginning in early adolescence (Age 12-14)
Focus	Purely medical handover of records	Holistic preparation (Medical, psychosocial, vocational)
Clinical Action	Handing over a patient file	Actively building patient capacity and health literacy
Patient Posture	Passive recipient of pediatric care	Empowered self-manager of adult chronic disease

Social Determinants of Health and Transition



Importance of Dedicated and Timely Transition

42%

of patients experience significant gaps in specialized cardiac care during the transition to adulthood.

Lapse in care: interruption in care for > 2-3 years

Loss to follow up: no documented cardiac follow up for > 3 years

Prevalence of loss of follow-up in congenital heart disease



Bassareo et. al

Importance of Dedicated and Timely Transition

The Overall Leak: A pooled proportion of **~26.1%** of patients are entirely lost to follow-up during the transition period.

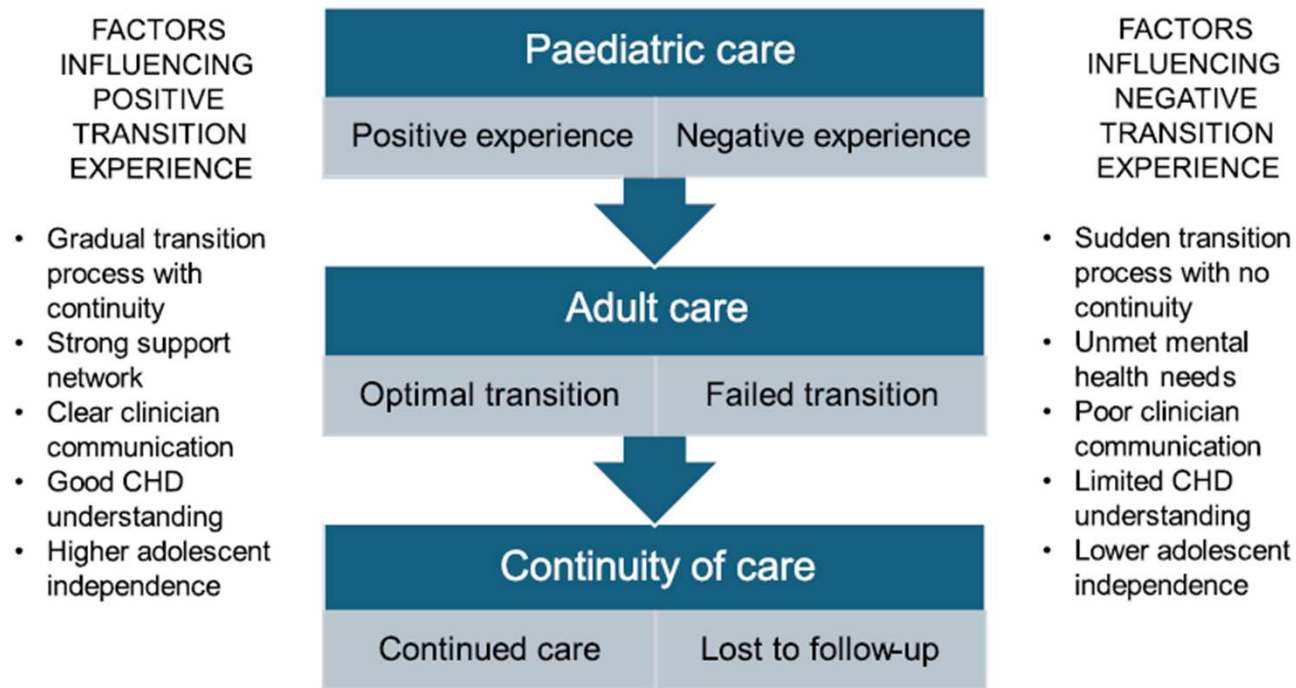
Pediatric Care

Adult Care

Smallest Leak: Complex Lesions (22.3% lost). These patients are highly symptomatic and deeply tethered to the medical system.

Largest Leak: Simple Lesions (25.7% lost).

Importance of Dedicated and Timely Transition



Ruban et. al

Importance of Dedicated and Timely Transition

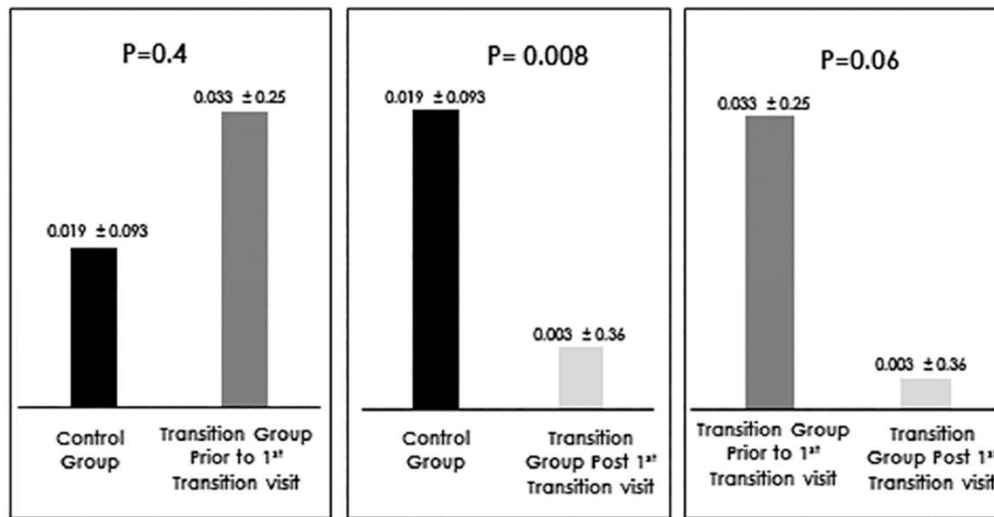


Fig. 1. Rates of unplanned cardiac hospitalizations in the transition group and control group. (A) Control and transition groups prior to first meeting with the transition team. (B) Control and transition groups after first transition meeting. (C) Transition group pre- and post- first meeting.

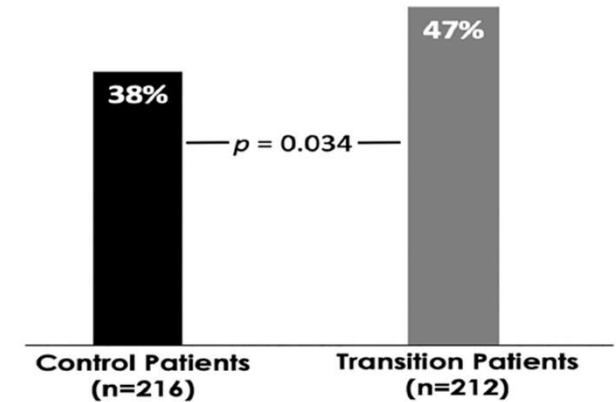
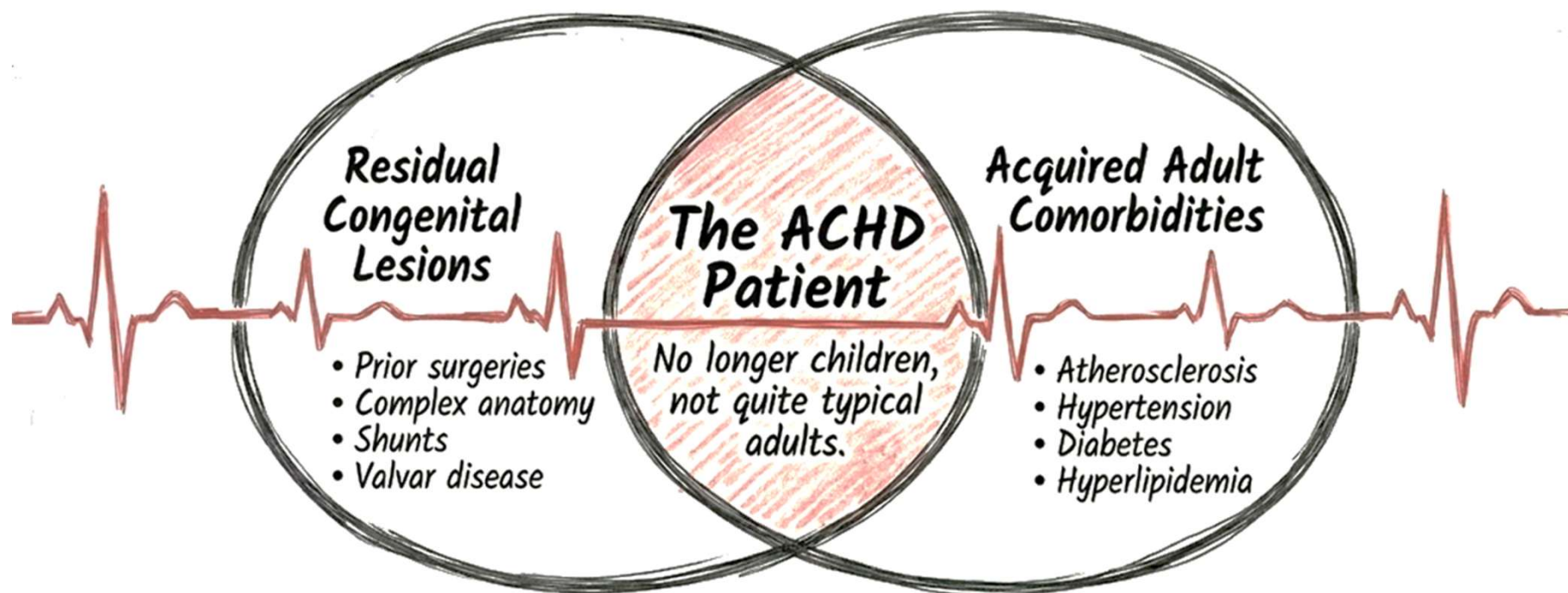


Fig. 2. Rate of transfer from pediatric to adult care in control group vs. transition group.

Bushee et. al

The ACHD Patient



The ACHD Patient

Table 2. Clinical problems in adults with congenital heart disease

Cardiac-related issues
Mortality, morbidity, QOL, occupation
Residua, sequelae, complication after initial repair, cardiac surgery, redo surgery
Catheter intervention, ablation
Arrhythmia, cardiac failure, sudden death
Pulmonary hypertension
Infective endocarditis
A multisystem systemic disorders in cyanotic CHD
Noncardiac issues
Reproductive issues, inheritance
Noncardiac surgery
Influence of aging and metabolic syndrome, smoking, alcohol drinking habit
Exercise, recreational sports
Travel by aircraft, driving license
Transition issues
Psychosocial considerations
Social security (health and life insurance, physically handicapped, pension)
Liver disease (hepatitis, liver cirrhosis, hepatic cancer)

Niwa et. al

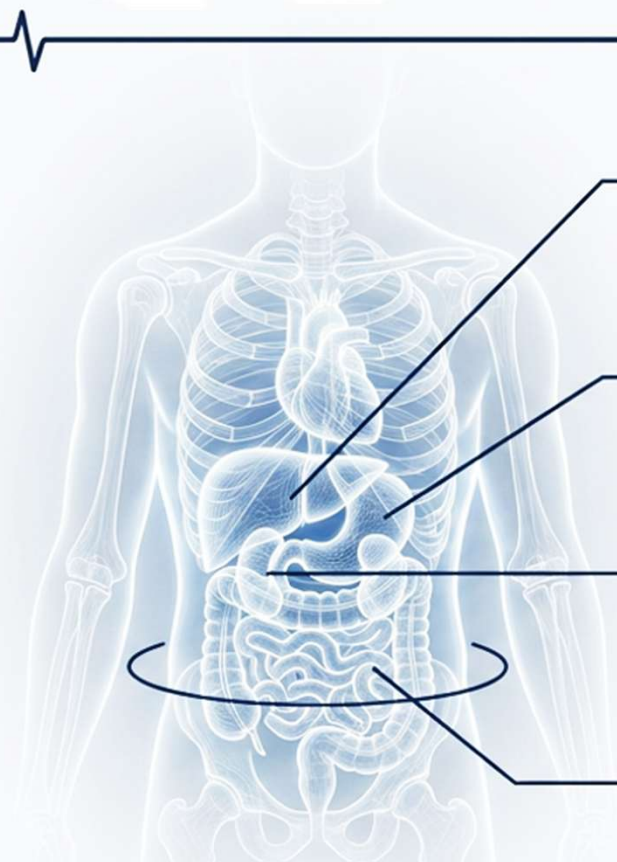


The ACHD Patient

Comorbidity		Impact on CHD outcomes
Cardiovascular disease	Arrhythmia Atherosclerotic disease Heart failure	Hospitalization ^{68,69} Functional status ^{12,69} Mortality ⁶⁹ Need for re-intervention ⁶⁸ Quality of life
Hepatic	Congestive hepatopathy Hepatitis C	Fontan-associated liver disease ^{70,71} Mortality
Neoplasms	Catheter- and imaging-related radiation	Mortality
Psychosocial	Anxiety Depression Neurocognitive delays Post traumatic stress disorder	Maintenance of care ⁷² Medication adherence ⁷³ Quality of life ^{12,72,74,75} Neurocognitive decline ⁴³
Pregnancy	Contraception-related CV Risks Maternal CV risks Obstetric risks Offspring risks	Fetal mortality ^{11,76-78} Premature birth ^{11,76-78} Small-for-gestational-age infants ^{11,76-78} Mortality ¹¹ Neonatal CHD Thromboembolic events ¹² Cardiovascular events ^{11,76-79} Hospitalization, quality of life
Pulmonary	Restrictive lung disease	Functional status Mortality ⁸⁰
Renal	Renal failure	Hospitalization ⁶⁸ Mortality ^{81,82}



The ACHD Patient



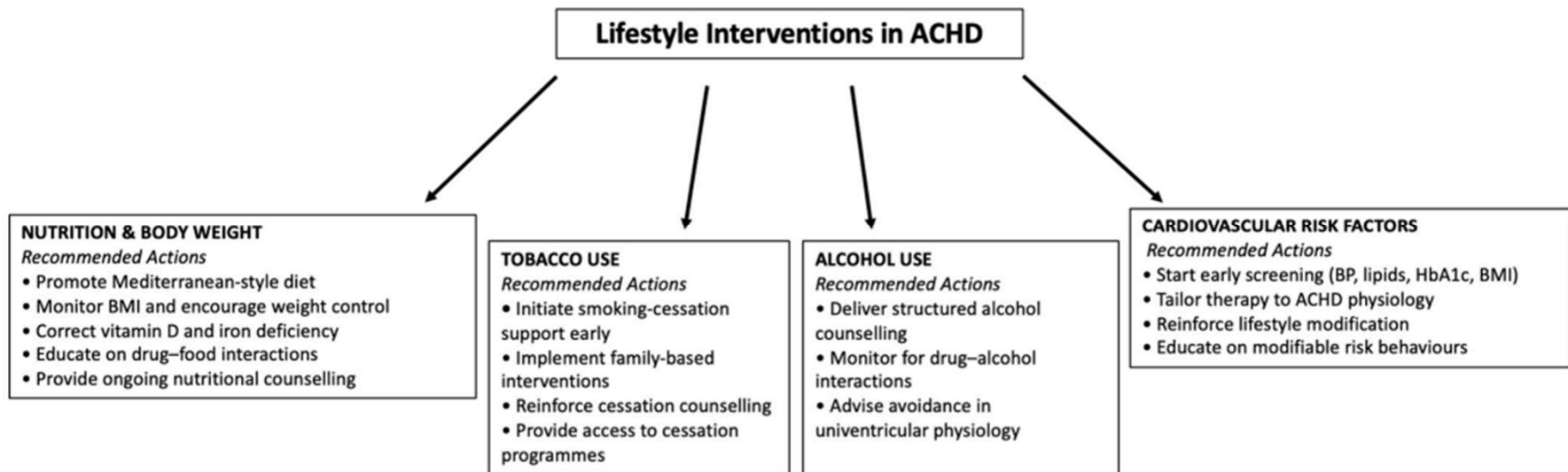
Liver: Fontan-associated liver disease (FALD) driven by decades of elevated central venous pressure.

Intestines: Protein-losing enteropathy resulting in severe malnutrition and immunodeficiency.

Kidneys: Progressive renal dysfunction secondary to chronic hypoxia and altered hemodynamics.

Systemic: Heightened vulnerability to acquired adult diseases, including accelerated atherosclerosis and cirrhosis.

Preventative Care in ACHD

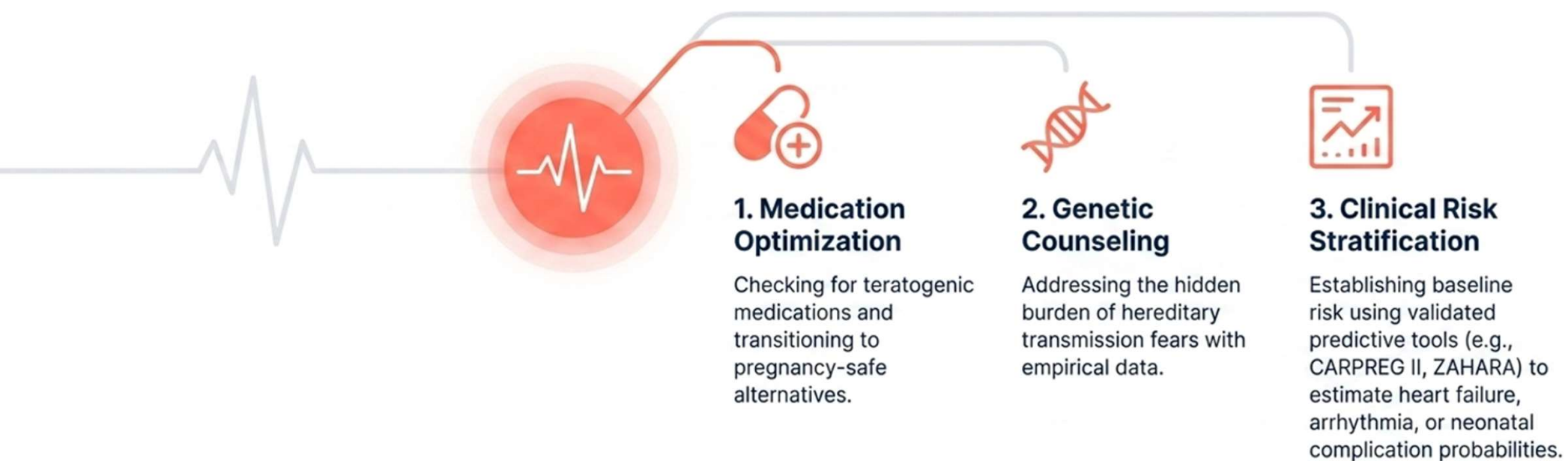


Boccuto et. al

Sexual Health and Family Planning in ACHD

	Estrogen-Containing	Progestin-Only	Non-Hormonal (IUDs)
Cyanotic Heart Disease	✗	✓	✓
Mechanical Valves	✗ Severe Thrombotic Risk	✓	✓
Fontan Circulation	✗	✓	✓

Sexual Health and Family Planning in ACHD



Transition Goals

Factors favouring a smooth transition:

- Start talking about transition at an appropriate time
- Transition clinical nurse specialist involvement
- General practitioners involvement
- Structured transition programme
- Joint appointments with paediatric cardiologist and ACHD specialist
- Good communication skills
- Increasing patients' self advocacy and knowledge on their disease
- Psychologist involvement
- High technology support
- Publicity campaigns on media



Paediatric cardiology

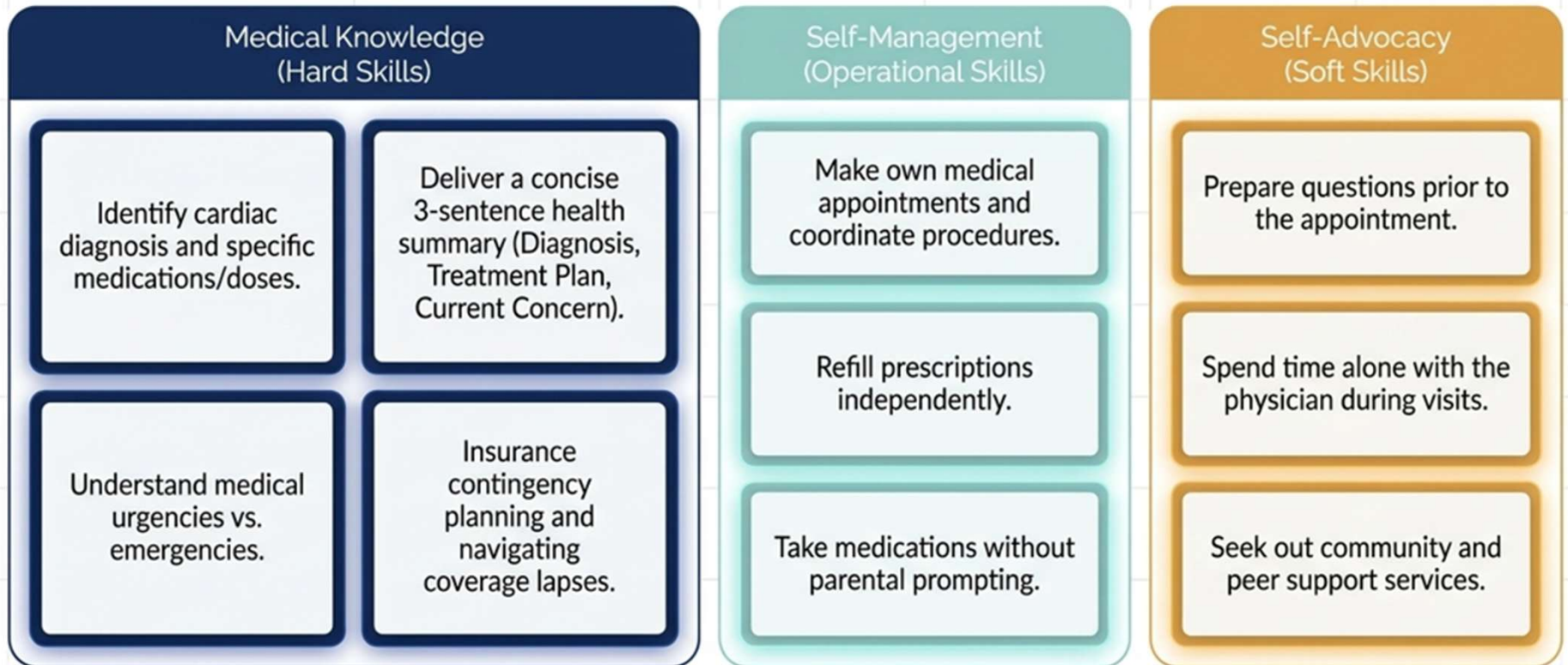


ACHD care



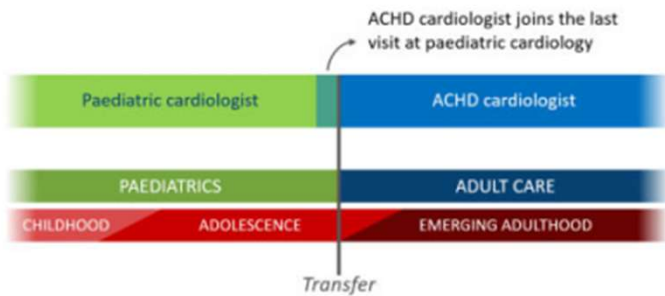
Bassareo et. al

Transition Goals

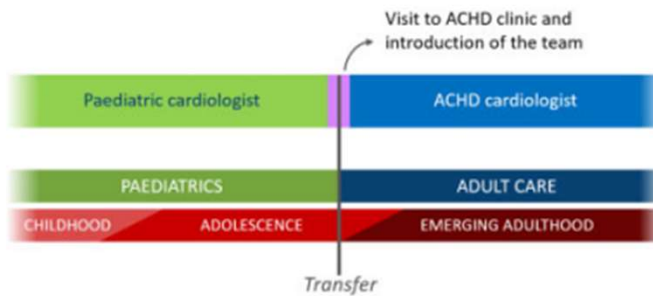


Sample Transition Models

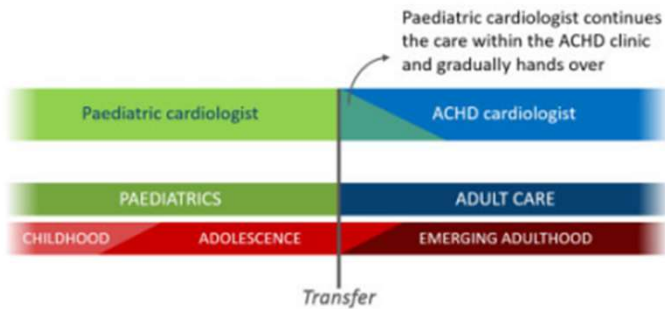
Joint clinic model



Introductory model



Paediatrician-in-adult-care model



Transition coordinator model

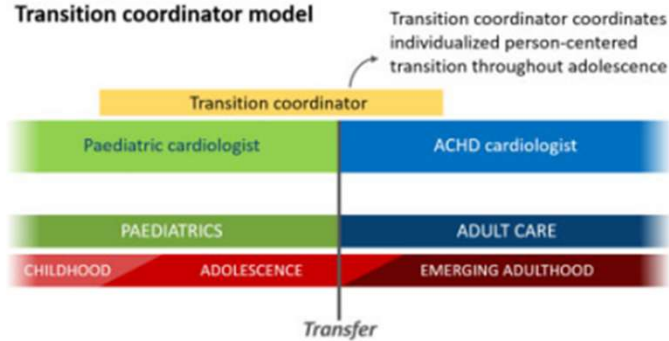
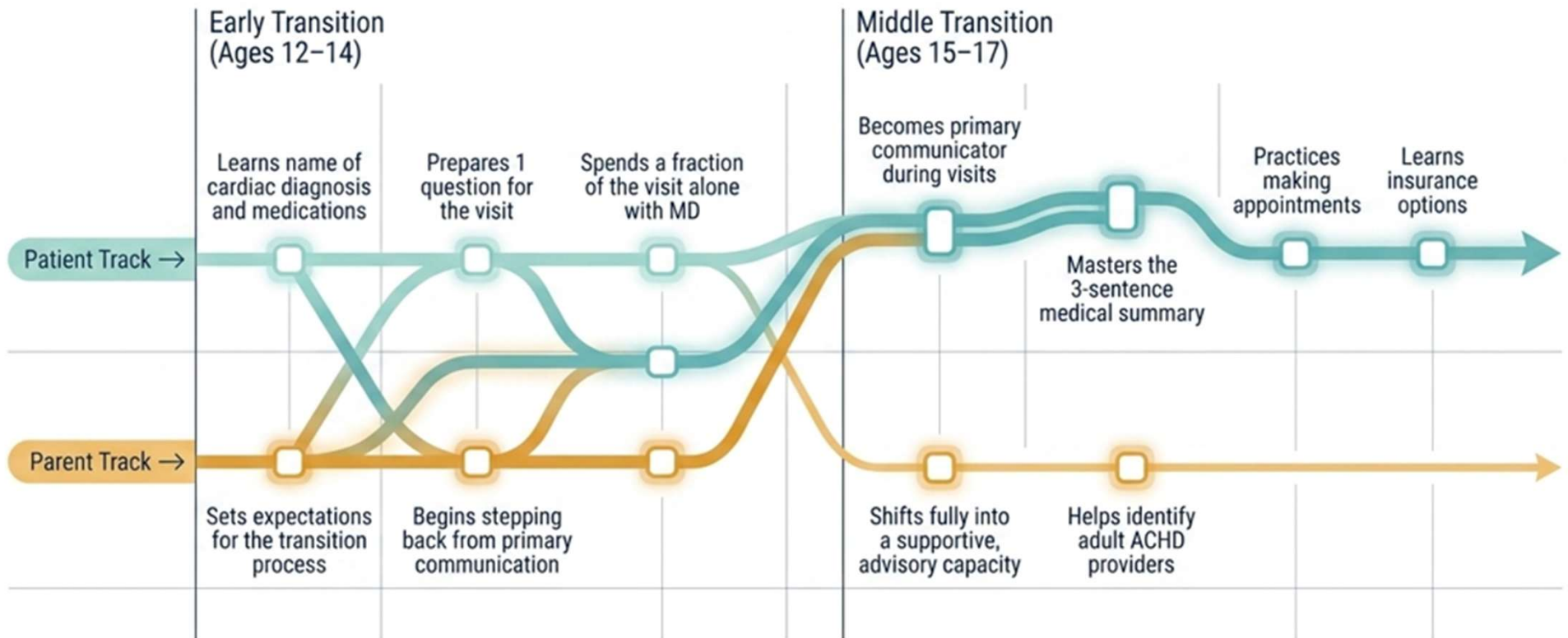


Figure 3 Models for transition.

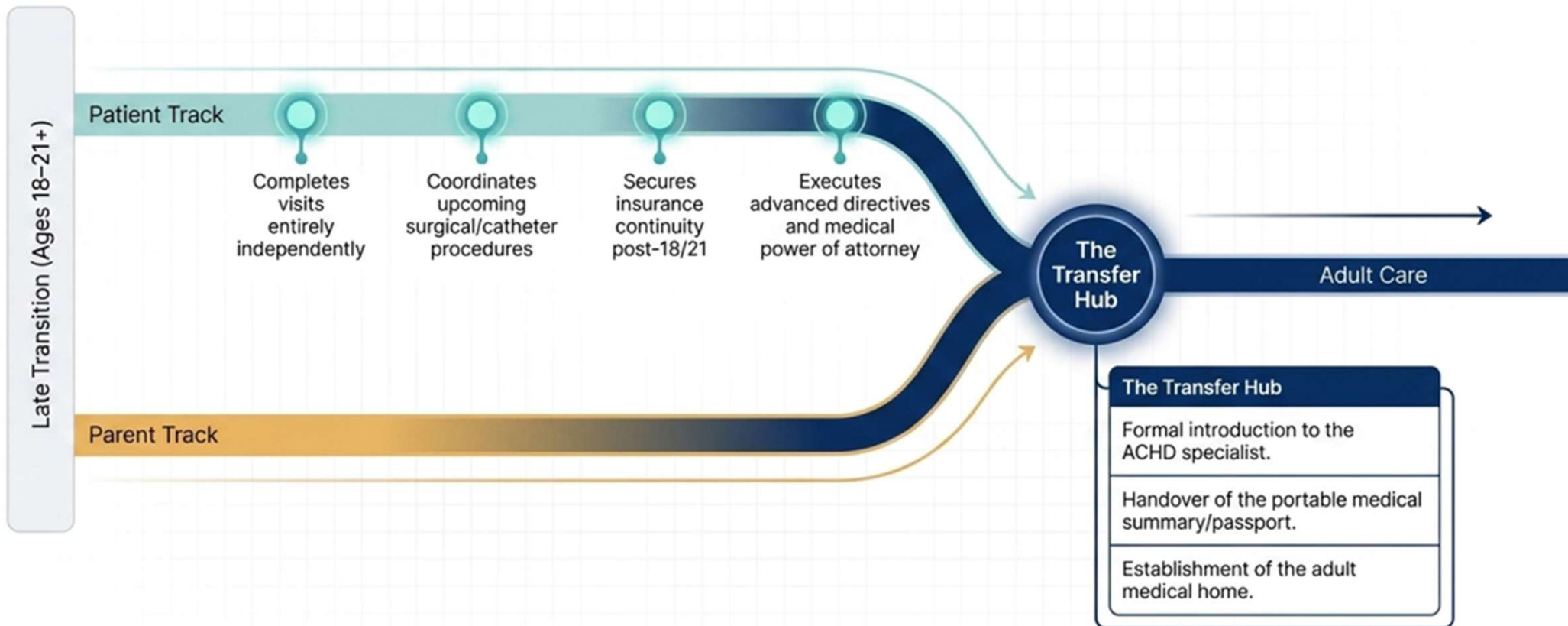
Sample Transition Models

	Resource Level	Core Modalities	Proven Outcomes
Nurse-Led, Clinic-Based Education	Low/Moderate	1-hour structured patient education sessions led by nursing staff.	Significant boosts in CHD knowledge; better understanding of symptoms; reduced time before first adult clinic visit.
Multidisciplinary Transition Clinic	High	Dedicated clinic visits with a social worker, nurse care manager, and ACHD physician.	Dramatic reduction in loss to follow-up (drops from 26% historical baseline to 7%).
Comprehensive Program (e.g., STEPSTONES)	Very High	Dedicated transition coordinator, peer information days, parental guidance, and continuous text/app support.	Increased patient empowerment; high patient satisfaction regarding confidentiality and sensitive discussions.



Transition Timeline



Transition Timeline

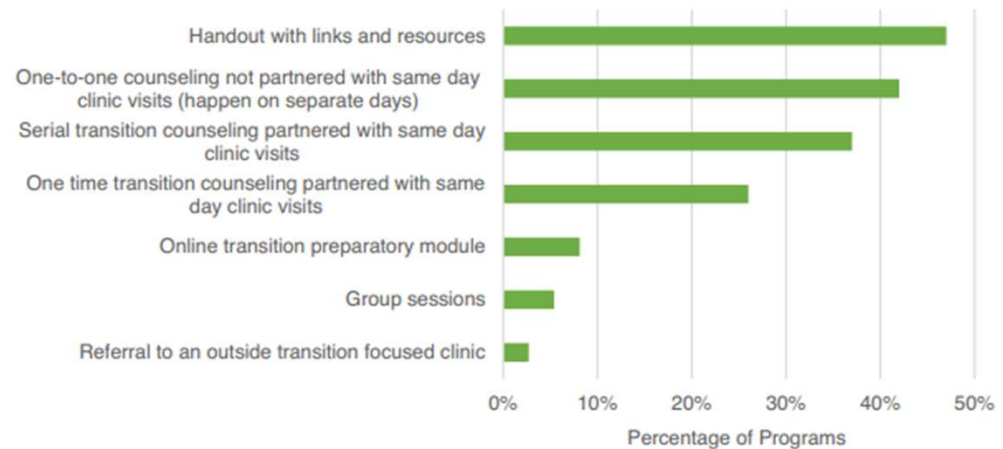
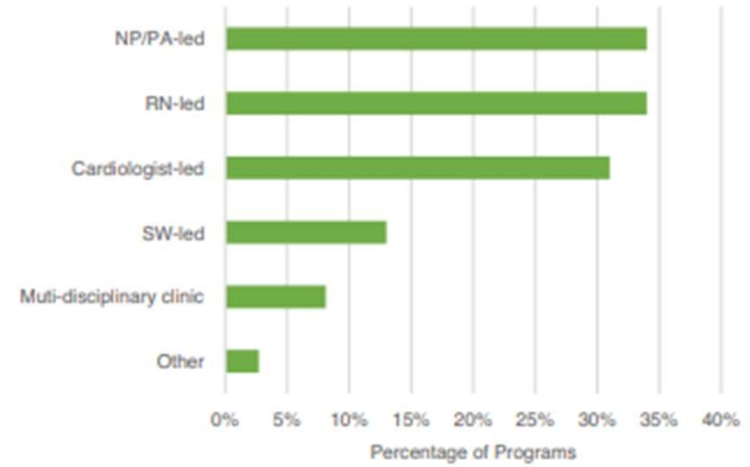
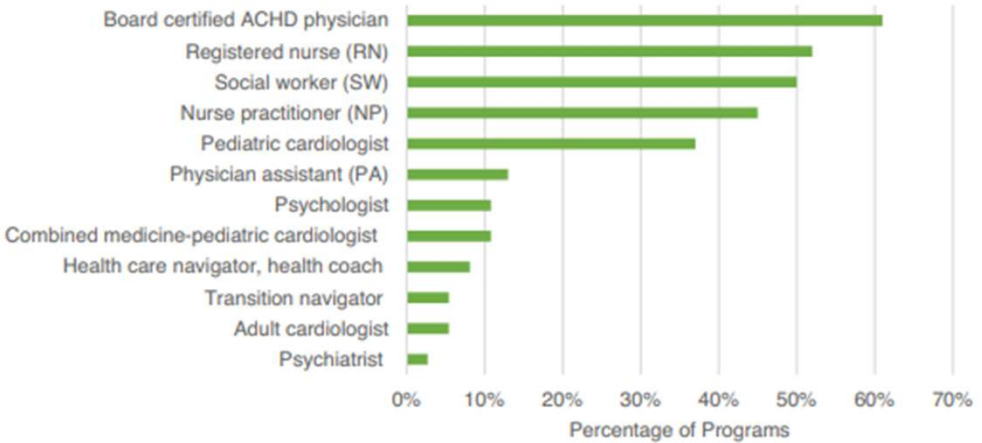


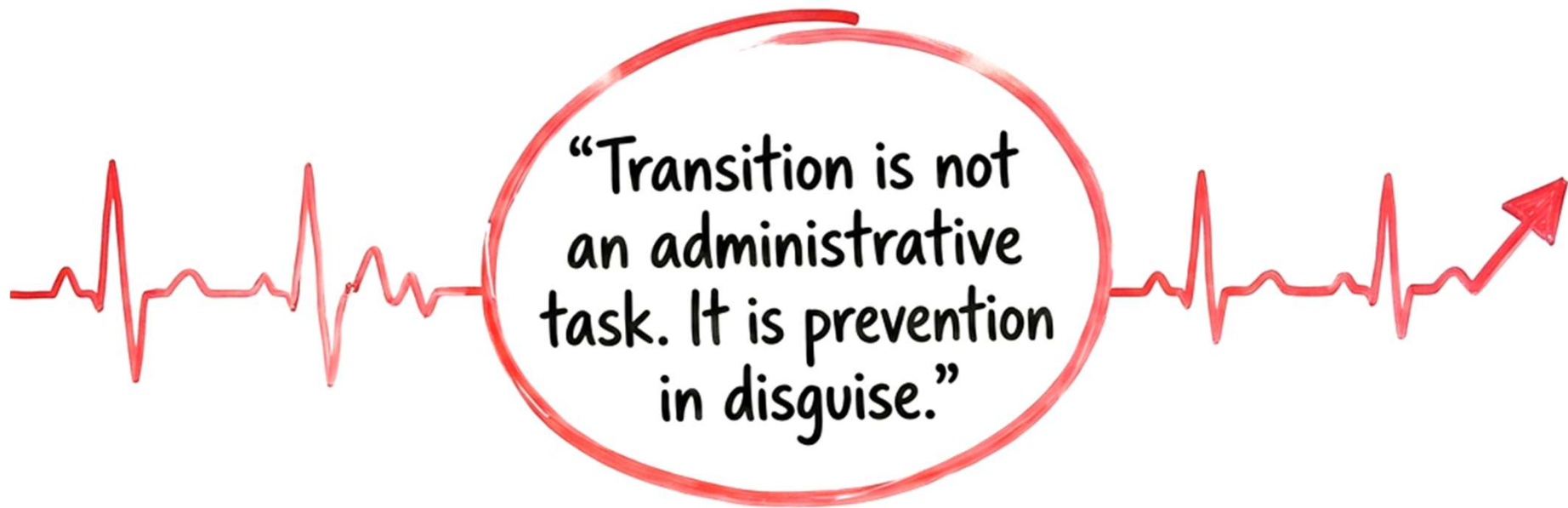
Sample Transition Passport

CHOC Congenital Heart Disease Passport			 	Checklist to graduation: <input type="checkbox"/> Anatomy – typical vs CHD <input type="checkbox"/> Tests/medications <input type="checkbox"/> Symptoms	<input type="checkbox"/> Navigating health system <input type="checkbox"/> Planning for the future
Name:	Usual oxygen saturation:	Emergency contact:			
Date of birth:	Usual blood pressure:				
Heart disease:	Allergies:	Cardiologist name and contact information:			
	Check BP from: <input type="checkbox"/> Left arm <input type="checkbox"/> Right arm				
Surgeries:	My medications:			Special considerations:	
Catheterizations:					



Data in the US





“Transition is not an administrative task. It is prevention in disguise.”

- ✓ Survival into adulthood is not a cure.
- ✓ Structured transition programs are a life-saving clinical necessity.
- ✓ Our goal is not just transfer, but maximizing the lifelong potential of every CHD patient.



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Questions?

Angela.Li1@choc.edu

