Transition within a chronic disease setting – the Congenital Heart Disease experience

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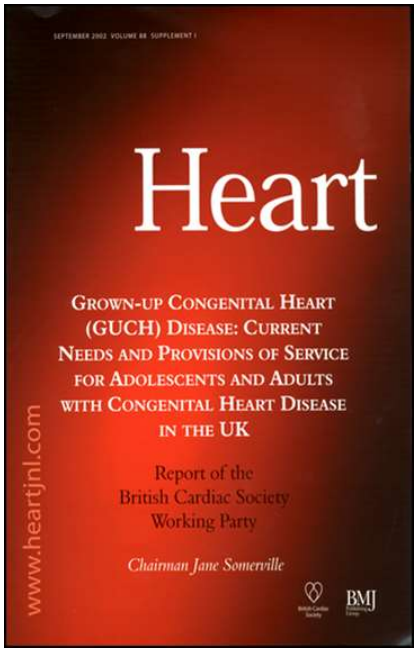
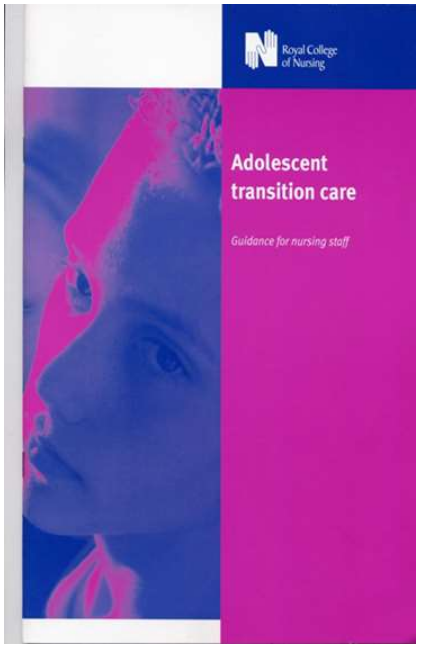
- First adolescent unit opened at the National Heart Hospital in 1975.
- Few ACHD services in the early 2000s – Transition was not ideal.
- Patients were often lost in FU or seen by paed cardiologists until the age of 25.
- Guidelines (BCS, 2002 & ESC, 2003) published on the provision & management of ACHD.





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British Heart Foundation

Setting up clinical nurse specialist services: what does our research tell us?

Jill Pattenden *and* ***Hanif Ismail*** *review the British Heart Foundation evaluations of cardiac nursing services and the lessons they hold for establishing new services*

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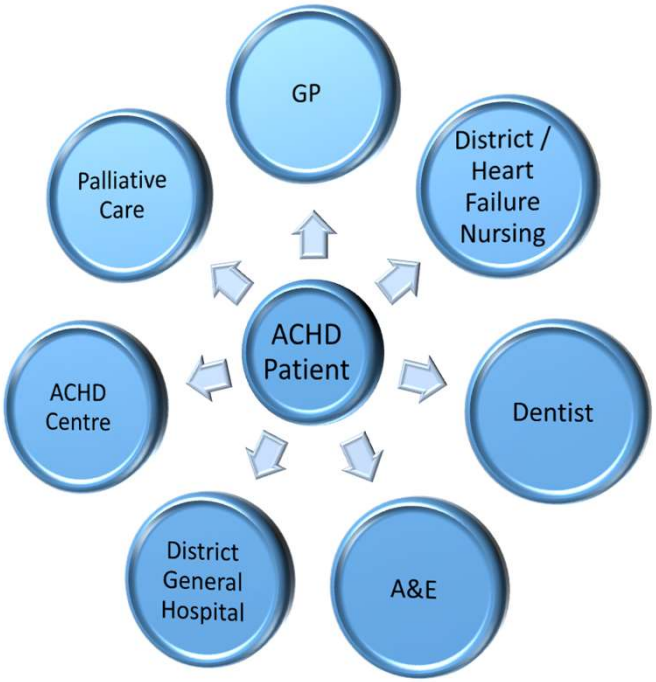
The Patient Pathway



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Quality

- At the centre of all service planning should be Quality!
- The Institute of Medicine 1990 illustrated how healthcare should be delivered.
- This is a simplistic diagram and this needs to be carefully thought through as with any change management changes in one area will produced a butterfly effect causing and effect in another area.
- These effects need to be predicted to make changes and maintain a quality service.

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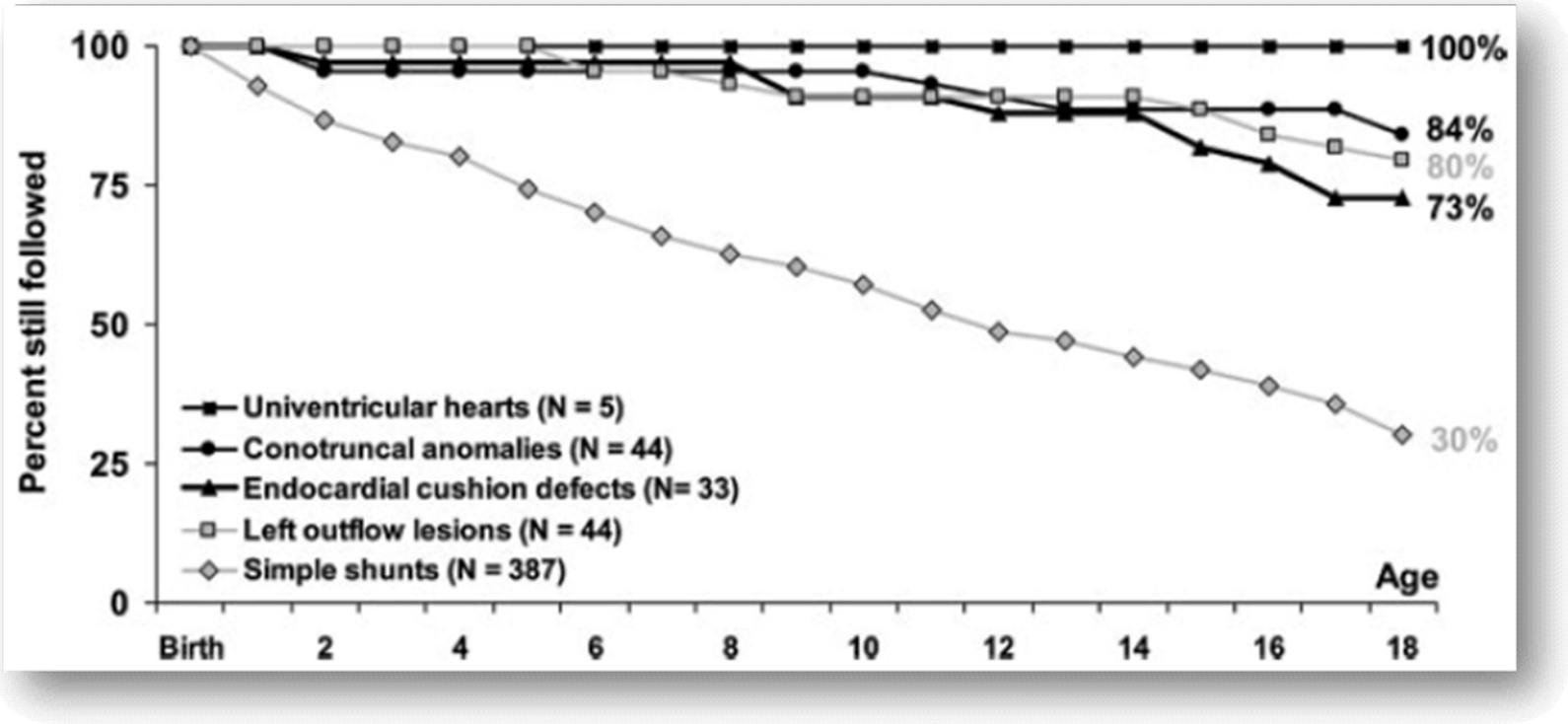
It is not uncommon, for adolescents and young adults with CHD to hold the misperception that they have been “cured” or “fixed.”

Lost to Follow-up



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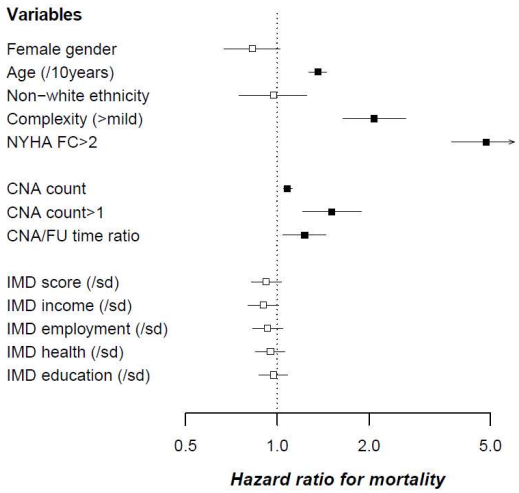

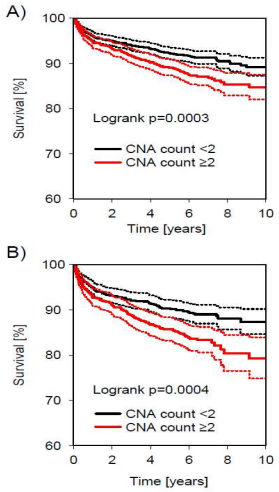

- 4461 ACHD pts examined with median age 26.4yrs between 1991-2008
- Overall 23% of scheduled clinic appts were not attended
- Main predictors of non-attendance were younger age, non-Caucasian ethnicity, lower economic socioeconomic status, number of previous missed appts, and lack of planned investigations on same day as appt i.e. ECHO
- Both the number of missed appts and the ratio of missed appts to follow-up period emerged as predictors of mortality independent of patients age, disease complexity, functional class and socioeconomic status
- Authors concluded attendance at appts in specialist centre is associated with better survival

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When should Transition Begin?

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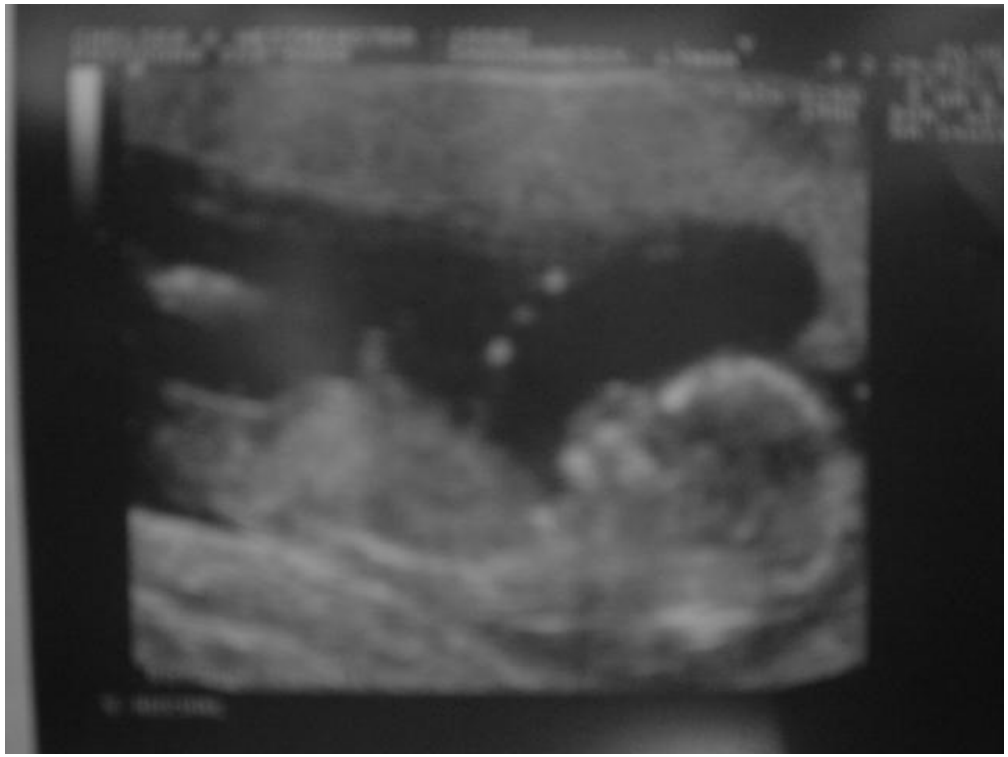
At the beginning!



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The Purpose of a Transition Program

To enable the Young person to take over the responsibility for their condition being able to make independent decisions taking into account their knowledge of their condition

Parent Perspective

Patient's Perspective

Medical team perspective

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Choosing the Right Model

There are many different transition processes described but it is important to establish a service that works for the individual centre

There is no ‘one size fits all’-approach

One of the most important requirements is to provide a transition service addressing the needs of the patients and their families. It should be supported to involve young people in the design of transition services guaranteeing to meet patients’ needs and expectations.

Royal College of Paediatrics and Child Health. Bridging the gaps: Health Care for Adolescents. London, UK: RCP&CH; 2003.

Adolescent Clinic Model

Adolescent clinics where all the patients attending the clinic are seen by adolescents team.

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Joint Clinic Model

Where joint clinics are organised by both paediatric and adult teams seeing the patients together (sometimes this is a one off handover clinic other times this can be a regular appointment.

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Traditional Medical Model

	Joint Consultation	Individual Consultation
Advantages	• Both Paediatric and Adult Cardiologists present • Direct communication between Paediatric and Adult Cardiologist • Can be less streeful for the patient and family knowing the two teams are working together	• One Doctor taking responsibility • More time for education to the patient and family • Easier for the adult doctor to establish a relationship with the patient
Disadvantages	• Needs two doctors – not cost effective • Less time for education • Division of responsibility	• More Stressful for the patient and the family • No direct handover with patient present from paediatric to adult doctor • Needs a solid transition program

Nurse-led model

Nurse-led model, where a team of clinical nurse specialists coordinates the transition process and meet the patients whilst they are in the pediatric department.

Within such a model, the transition coordinator stays with the patients when moving through to the adult department.

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Group Education

Group education involves inviting a number of adolescents to attend for a group transition session where they learn information about lifestyle issues, diet, exercise, endocarditis etc…

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What is covered on the day?

Series of talks & workshops covering: the normal heart; endocarditis; lifestyle; promoting independence; sexual health; transition preparation and psychosocial support

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What is covered on the day?

- Q&A sessions, expert panel and patient representatives
- ‘Marketplace’ of cardiac specific and general adolescent charity stalls during lunch

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Meeting Others!

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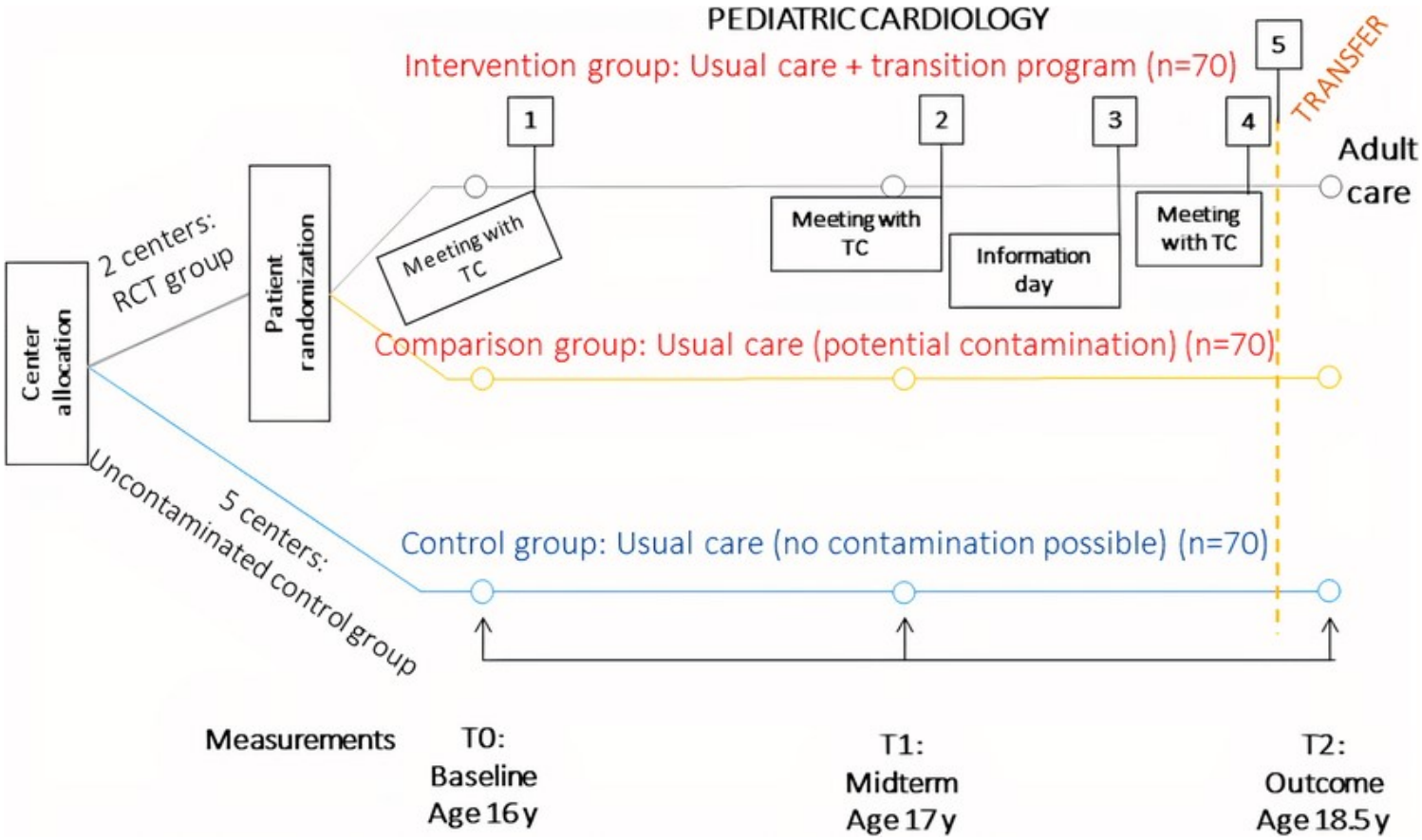

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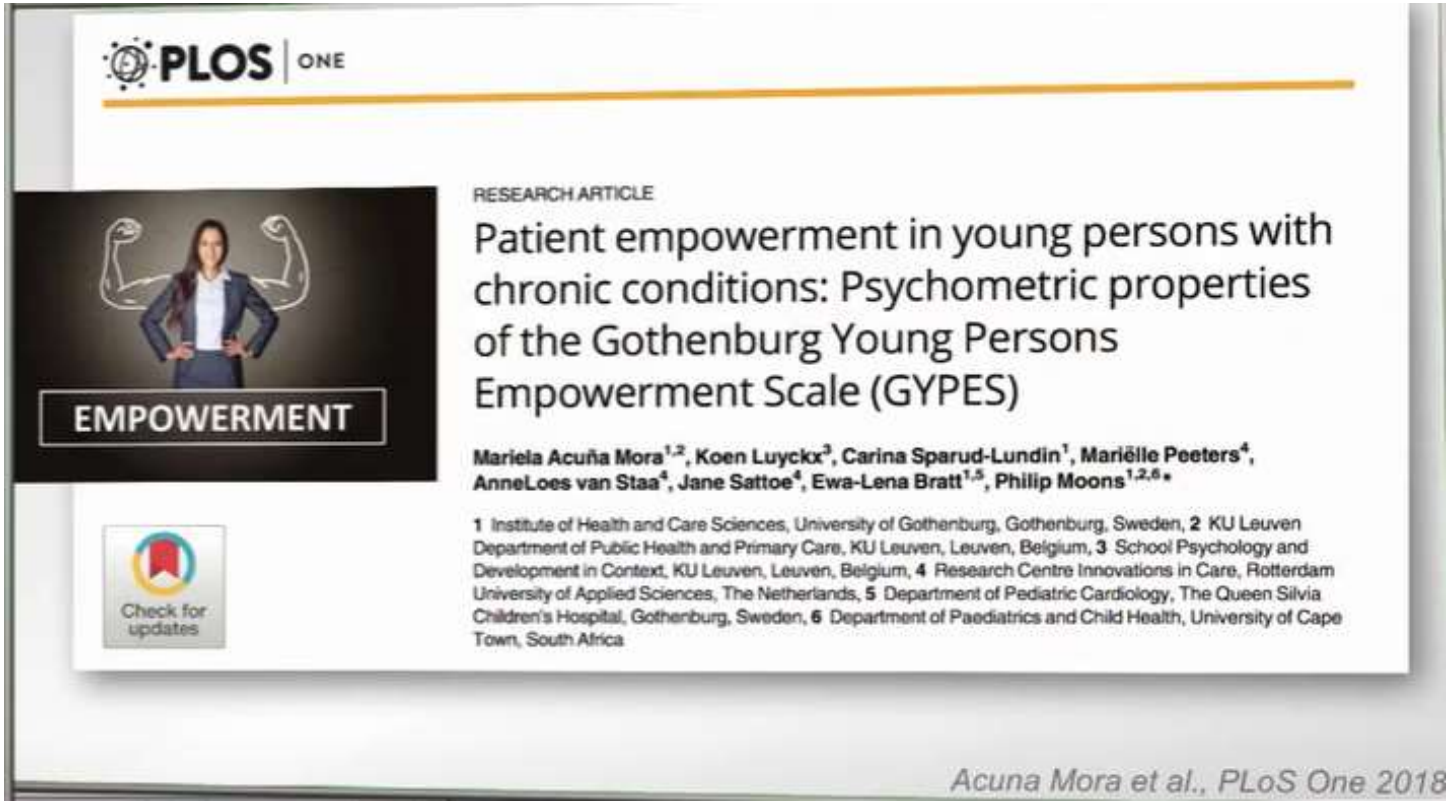

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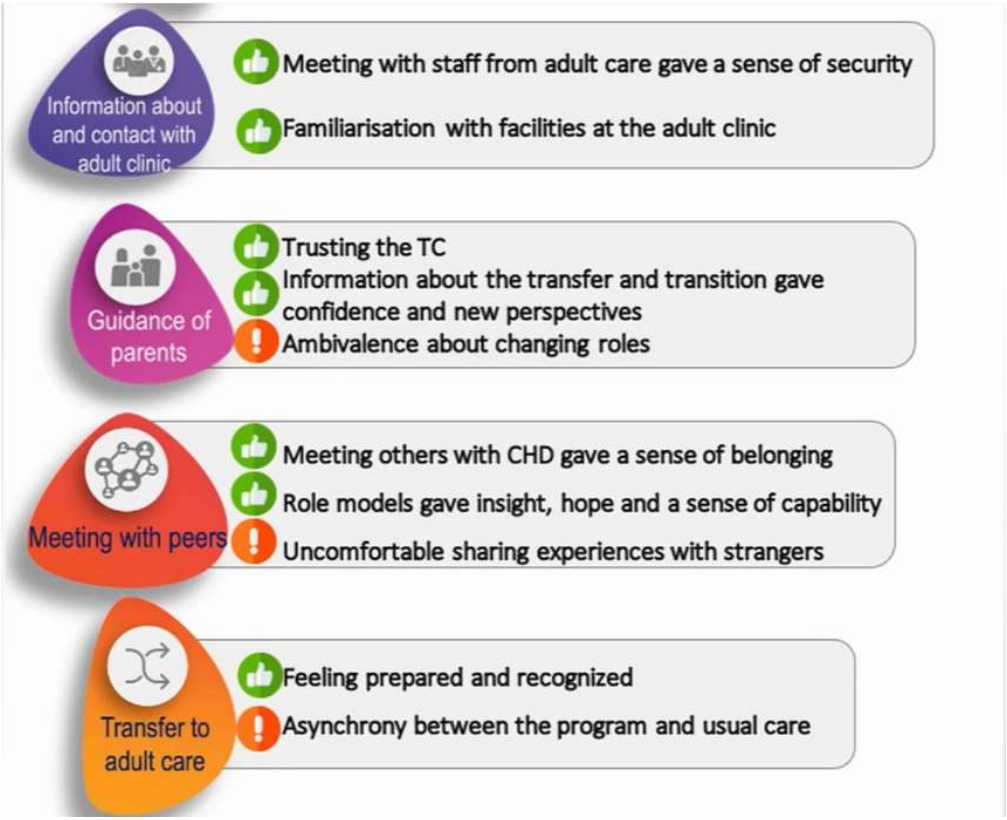
Transition coordinator
Being seen as a unique person in a safe space
Meeting in an equal caring relationship enhanced control
Need for additional tailoring
Written person-centered transition plan
The personal narrative was a useful tool but somewhat unclear
Goal setting was motivational and supportive
Information and education
Getting to learn in their own way and with others
Talking about sensitive issues was challenging but important
Talking about CHD and health behaviors led to an increased insight
Availability by telephone and email
Availability facilitated a safe caring relationship with the TC
Calling and texting was a convenient way of getting in touch



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ESC European Society of Cardiology

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SPECIAL ARTICLE

Transition to adulthood and transfer to adult care of adolescents with congenital heart disease: a global consensus statement of the ESC Association of Cardiovascular Nursing and Allied Professions (ACNAP), the ESC Working Group on Adult Congenital Heart Disease (WG ACHD), the Association for European Paediatric and Congenital Cardiology (AEPC), the Pan-African Society of Cardiology (PASCAR), the Asia-Pacific Pediatric Cardiac Society (APPCS), the Inter-American Society of Cardiology (IASC), the Cardiac Society of Australia and New Zealand (CSANZ), the International Society for Adult Congenital Heart Disease (ISACHD), the World Heart Federation (WHF), the European Congenital Heart Disease Organisation (ECHDO), and the Global Alliance for Rheumatic and Congenital Hearts (Global ARCH)

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The End!

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