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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)

* Corresponding author. Tel: +32 16 373315, Fax: + 32 16 336970, Email: philip.moons@kuleuven.be

Philip Moons[1,2,3,4]*, Ewa-Lena Bratt[2,5,6], Julie De Backer[7,8,9], Eva Goossens[1,4,6,8,10], Tim Hornung[11,12], Oktay Tutarel[9,13,14], Liesl Zühlke[3,15,16,17], John Jairo Araujo[18,19] Edward Callus[20,21,22], Harald Gabriel[9,23], Nauman Shahid[24], Karen Sliwa[25,26,27], Amy Verstappen[24], Hsiao-Ling Yang[28,29], and Corina Thomet[1,4,30,31]

[1]KU Leuven Department of Public Health and Primary Care, KU Leuven, Kapucijnenvoer 35, Box 7001, B-3000 Leuven, Belgium; [2]Institute of Health and Care Sciences, University of Gothenburg, Sweden; [3]Department of Paediatrics and Child Health, University of Cape Town, South Africa; [4]ESC Association of Cardiovascular Nursing and Allied Professions (ACNAP); [5]Department of Paediatric Cardiology, Queen Silvia's Children's Hospital, Gothenburg, Sweden; [6]Association for European Paediatric and Congenital Cardiology (AEPC); [7]Department of Cardiology and Center for Medical Genetics, Ghent University Hospital, Belgium; [8]Research Foundation Flanders (FWO), Brussels, Belgium; [9]ESC Working Group on Adult Congenital Heart Disease (WG ACHD); [10]Faculty of Medicine and Health Sciences, Centre for Research and Innovation in Care, Division of Nursing and Midwifery, University of Antwerp, Antwerp, Belgium; [11]Paediatric and Congenital Cardiology Service, Starship Children's Hospital, Auckland, New Zealand; [12]Cardiac Society of Australia and New Zealand (CSANZ); [13]Department of Congenital Heart Disease and Paediatric Cardiology, German Heart Centre Munich, TUM School of Medicine, Technical University of Munich, Munich, Germany; [14]DZHK (German Centre for Cardiovascular Research), partner site Munich Heart Alliance, Munich, Germany; [15]Division of Paediatric Cardiology, Red Cross War Memorial Children's Hospital, Cape Town, South Africa; [16]Division of Cardiology, Department of Medicine, Groote Schuur Hospital, University of Cape Town, Cape Town, South Africa; [17]Pan-African Society of Cardiology (PASCAR); [18]Department of Pediatric and Adult Congenital Heart Disease, Somer Incare Cardiovascular Center, Medellin, Colombia; [19]Inter-American Society of Cardiology (IASC); [20]Clinical Psychology Service, IRCCS Policlinico San Donato, Milan, Italy; [21]Department of Biomedical Sciences for Health, Università degli Studi di Milano, Milan, Italy; [22]European Congenital Heart Disease Organisation (ECHDO); [23]Department of Cardiology, Medical University of Vienna, Austria; [24]Global Alliance for Rheumatic and Congenital Hearts (Global ARCH); [25]Hatter Institute for Cardiovascular Research in Africa, University of Cape Town, South Africa; [26]CHI, Faculty of Health Sciences, University of Cape Town, South Africa; [27]World Heart Federation (WHF); [28]School of Nursing, College of Medicine, National Taiwan University, Taipei, Taiwan; [29]Asia-Pacific Pediatric Cardiac Society (APPCS); [30]Center for Congenital Heart Disease, University Hospital Inselspital, Department of Cardiology, University of Bern, Switzerland; and [31]International Society for Adult Congenital Heart Disease (ISACHD)

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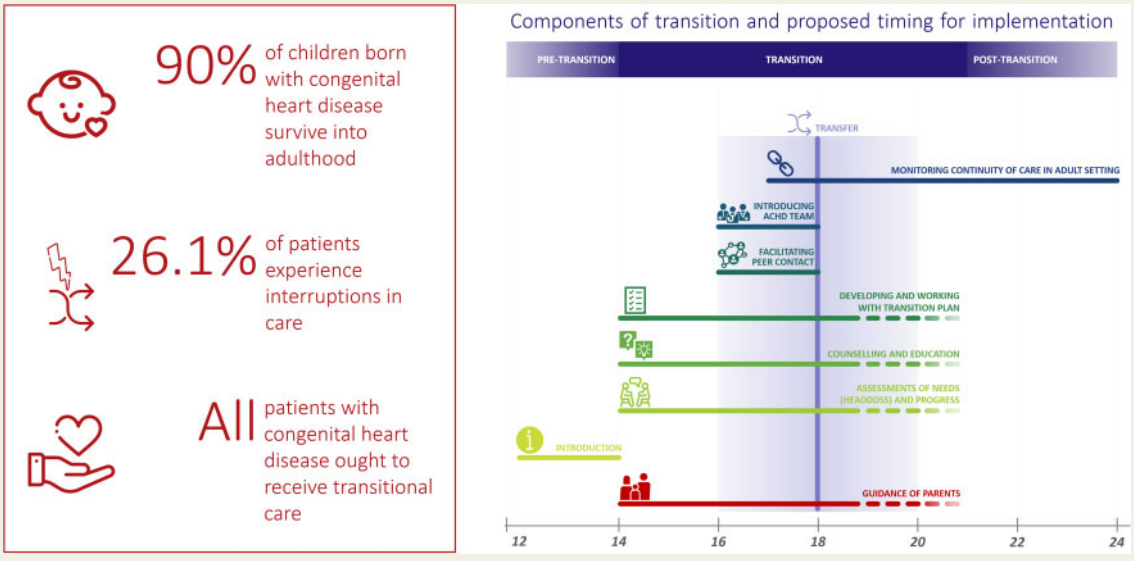
The vast majority of children with congenital heart disease (CHD) in high-income countries survive into adulthood. Further, paediatric cardiac services have expanded in middle-income countries. Both evolutions have resulted in an increasing number of CHD survivors. Expert care across the life span is necessitated. In adolescence, patients transition from being a dependent child to an independent adult. They are also advised to transfer from paediatrics to adult care. There is no universal consensus regarding how transitional care should be provided and how the transfer should be organized. This is even more challenging in countries with low resources. This consensus document describes issues and practices of transition and transfer of adolescents with CHD, accounting for different possibilities in high-, middle-, and low-income countries. Transitional care ought to be provided to all adolescents with CHD, taking into consideration the available resources. When reaching adulthood, patients ought to be transferred to adult care facilities/providers capable of managing their needs, and systems have to be in place to make sure that continuity of high-quality care is ensured after leaving paediatric cardiology.

Graphical Abstract



Transfer and transition in congenital heart disease.

Keywords Heart defect, congenital • Transition • Transfer • Continuity of care • Emerging adulthood • Adolescence

1. Introduction

Congenital heart disease (CHD) is the most common birth defect, with a global birth prevalence of 8.2 per 1000 newborns.[1] In high-income countries, 90% of afflicted children can reach adulthood.[2,3] Although CHD survival continues to be rare in low-income countries, increasing access to paediatric cardiac surgery in middle-income countries has resulted in a small but growing number of teens and adults living with moderate and complex CHD. Consequently, patients and families need to be prepared for the emerging adulthood. Adolescence is an important transitional phase for all young persons, and especially for those with chronic medical conditions, because on top of the normal developmental processes, they need to acquire knowledge and skills to independently manage their health.

Treatment and follow-up of children with CHD are performed by paediatric cardiology teams in paediatric settings. When patients are growing older, transfer to a setting that is age- appropriate and developmentally suited is advocated. This care is ideally provided in a specialty adult congenital heart disease (ACHD) programme to ensure sufficient expertise in the needs of adults with CHD.

Studies indicated that the transfer to adult care in CHD is often associated with interruption in cardiac follow-up[4] and that patients are insufficiently supported during their transition to adulthood.[5,6] Most middle-income countries are still developing paediatric cardiac care systems, and ACHD programmes and/or clinicians are rarely available.[7] However, the association between ACHD care maintenance and better outcomes is well-established, and all settings should aspire to an organized and co-ordinated process that prepares congenital heart patients to independently manage their life-long care needs (*Graphical abstract*)

The aim of this consensus document is to discuss issues and practices of transition and transfer of adolescents with CHD, which can be adapted as needed for use in high- and low-resource settings.

2. Terminology and definitions

When addressing transition in adolescents, several terms are of relevance. To have a uniform understanding, the conceptual definitions of adolescence, emerging adulthood, transition, transfer, transitional care, and transition programme are given in *Box 1*.[8–13]

3. Adolescents with congenital heart disease and their needs

3.1 The adolescent brain and mastering developmental tasks

Brain development in children and adolescents shows a regional and sex-specific course. Sensory and motor brain areas develop first, followed by a posterior to anterior maturation.[14] As a consequence, during adolescence, there is an imbalance between the limbic system, which is the driver for emotions, motivation, and behaviour, and the prefrontal control.[15] Cortical development in girls occurs earlier than in boys, due to differences in types and timing of sex hormones. Trophic changes in medial temporal regions explain higher risk-taking behaviours in boys.[16]

Alongside these physical changes, societal demands and expectations also increase during adolescence. Adolescents need to master specific developmental tasks, in order to establish a personalized identity.[17,18] *Figure 1* represents common developmental tasks of adolescence.[19,20] Adolescents with CHD have the same developmental tasks as healthy peers. However, having a heart defect and dealing with the condition in day-to-day life are extra stressors.

People with intellectual disabilities form a specific group in the CHD population, and present with special needs. When transitioning adolescents with intellectual disabilities, it is even more important to adopting developmental and systems perspectives in transitional care. Healthcare providers should be aware of specific developmental challenges that both patients and their families experience during this phase in life.[21] Especially, in these patients and families, transition is an overwhelming process.[22] Parents are critical to make the transition happening, and therefore they need support from the healthcare professionals to make it bearable.[22]

3.2 Behavioural factors

Risk behaviour in adolescents will often pose more threats to those affected with CHD. Overall, health behaviours in adolescents with CHD seem to be better than in similarly aged peers.[23,24] Yet, counselling patients on health behaviours is key to further improving their outcomes.[25] However, keeping the balance between avoiding complications without unnecessarily burdening patients with feelings of being different is vital.[26]

3.3 Continuous cardiac care

With a few exceptions, patients with CHD are in need of life-long follow-up. However, interruptions in care occur in 3.6–62.7% of young patients with CHD[4] and are associated with increased morbidity and urgent reinterventions.[27] Demographic, patient-specific, socio-economic, and healthcare system factors play a role in the occurrence of care gaps and require proper management.[28] It is suggested that the frequency and care level of follow-up is determined in consultation with a CHD expert centre.[29]

4. Transitional care: what does the evidence show?

International expert panels have identified multiple outcomes of transitional care, corresponding with the goals of transition (*Figure 2*).[30,31] Transition interventions ought to be developed and implemented with these goals in mind. These outcomes can be the primary or secondary endpoints, when evaluating the effects of transitional care.

The body of evidence on transfer and transition in adolescents with chronic conditions is extensive.[32] However, the level of evidence is rather low, with only a few studies investigating the effectiveness of transitional care using (quasi)-experimental designs.[32,33] Evidence is especially lacking from low- and middle-income countries.[32] In CHD, the results of two trials on the effects of transition have been published so far. The Chapter 1 (Congenital Heart Adolescents Participating in Transition Evaluation Research) study found that a 1-h nurse-led transition intervention resulted in improved self-management and cardiac knowledge.[34] In the Chapter 2 study, two nurse-led sessions were held with a 2-month interval.[35]

Figure 1 Developmental tasks of adolescence. Adapted from Havighurst[19] and Lerner and Galambos.[20]

In the intervention group, the delay in ACHD care was lower and CHD knowledge as well as self-management skills improved.[35]

A further important step in providing evidence is the STEPSTONES project.[36,37] This is an ongoing project testing the effectiveness of a transition programme, combined with process and economic evaluations. STEPSTONES is the first transition programme that is constructed using the methodology of intervention mapping.[38]

Although the evidence on the effectiveness of transition programmes in CHD is limited, there is evidence on the effects of particular transitional care interventions. For instance, it has been shown that interventions are able to improve the knowledge,[39–42] self-management,[41] continuity of care,[43,44] and functional status of people with CHD.[43] This evidence, together with findings from other chronic conditions,[32,33] give a proof of concept that transitional care is effective.

5. Empowering patients and families

An important goal of the transition is to empower patients and families.[45] Empowerment can be defined as 'an enabling process or outcome arising from communication with the healthcare professional and a mutual sharing of resources over information relating to illness, which enhances the patient's feelings of control, self-efficacy, coping abilities and ability to achieve change over their condition'.[46] Patient empowerment aims at increasing autonomy, patient participation, awareness, and consciousness, as well as the development of relevant psychosocial skills.[47] As a consequence, a higher level of patient empowerment is associated with improved quality of life, well-being, and clinical outcomes.[48] In CHD, empowerment is associated with transition readiness and improved communication with healthcare providers.[49] Therefore, empowerment can be a target for intervention in transition, and it can be seen as an intermediate outcome, which indirectly improves the ultimate transition outcomes (*Figure 2*).

6. Different transition models

There are different models for transition in CHD, each having particular characteristics (*Figure 3*). The 'joint clinic model', 'paediatrician-in-adult-care model', and 'introductory model' are rather 'transfer models' because the focus is on handing over the adolescent from paediatrics to adult care, and little room is given to the developmental process that is inherent to transition to adulthood.

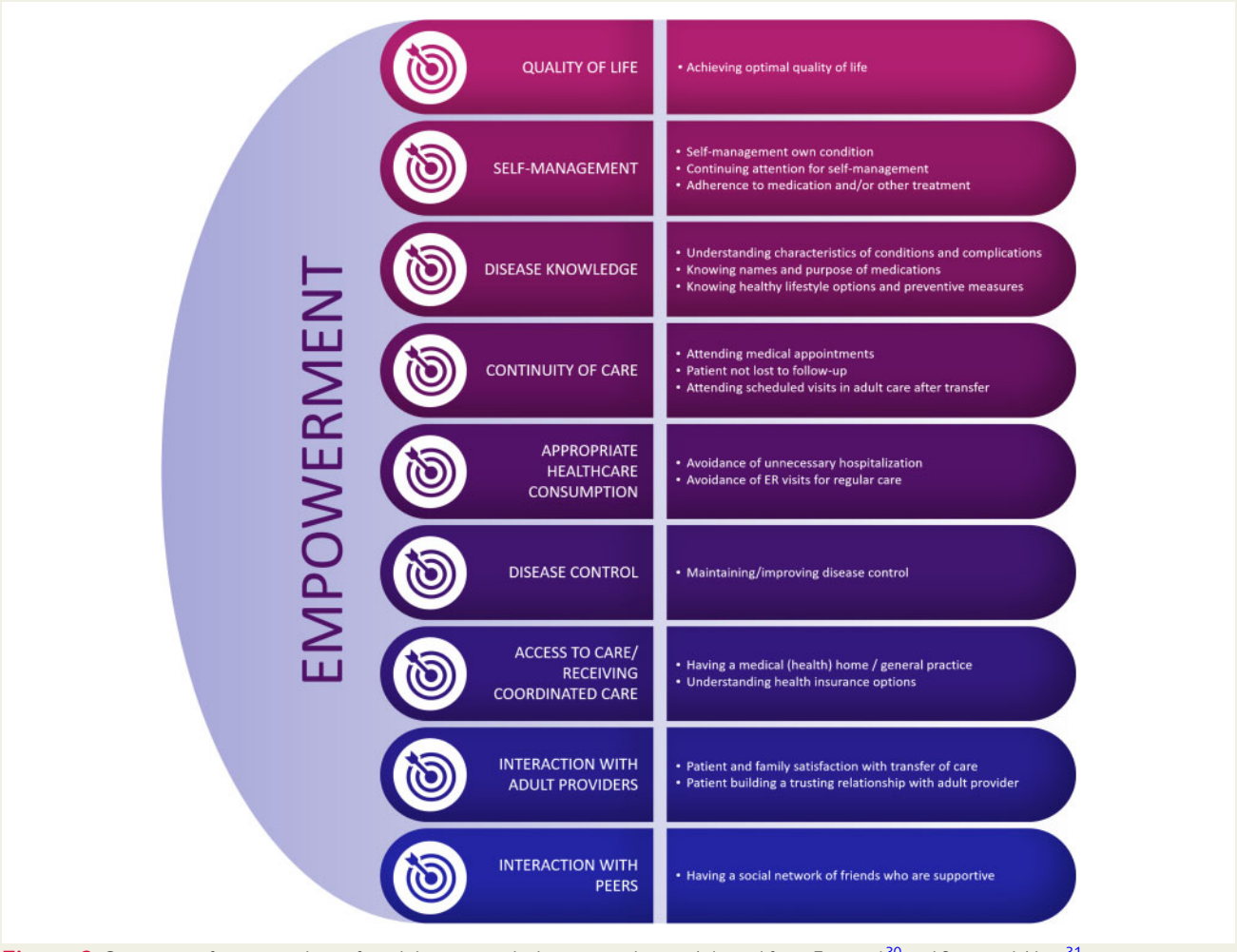


Figure 2 Outcomes of transitional care for adolescents with chronic conditions. Adapted from Fair *et al.*[30] and Suris and Akre.[31]

Alternatively, the 'transition coordinator model' is taking the developmental process as the core, accompanies the adolescent in the transition to adulthood, and provides comprehensive transitional care. In this model, the transition is not necessarily stopping when the patient is transferred.

The 'transition coordinator model' is the preferred model, because it comprehensively addresses the challenges of transition. Of course, the choice of model depends on the resources and competencies available in the country and the centre. The lack of trained ACHD providers, especially in low- and middle-income settings[7] requires some centres to keep patients under paediatric surveillance.[50] In such cases, the adoption of an adult-centred approach within the established paediatric care setting is important.[51]

7. How to transition and transfer adolescents with heart disease

Transitional care should start in early adolescence and continues into emerging adulthood (see definitions in *Box 1*) (*Figure 4*). It is to be provided in three distinct phases: pre-transition, transition, and post-transition. It is advocated that the pre-transition phase starts in early adolescence, to have the highest impact.[51] At specific ages, certain key interventions have to be implemented and milestones have to be achieved.[51] However, to individualize transitional care towards the developmental stage of the patient and to account for the possibilities of the centre, there is flexibility in the ages at which the milestones have to be achieved. By compiling these key interventions in a structured way, a transition programme is constructed (see definition in *Box 1*).

7.1 Pre-transition introduction

Around the age of 12 years, the planned transition process and the transfer policy need to be introduced to the patient and parents/guardian (*Figure 4*).[51] This introduction can be given during a scheduled outpatient visit or by sending an introduction letter to the parents (see example: Supplementary material online, *Document S1*).

7.2 Assessment of needs and progress

As of the age of 14 years, the needs of the adolescent should be comprehensively assessed. The structure of the HEADDDSS psychosocial interview guide for adolescents can be applied. HEADDDSS

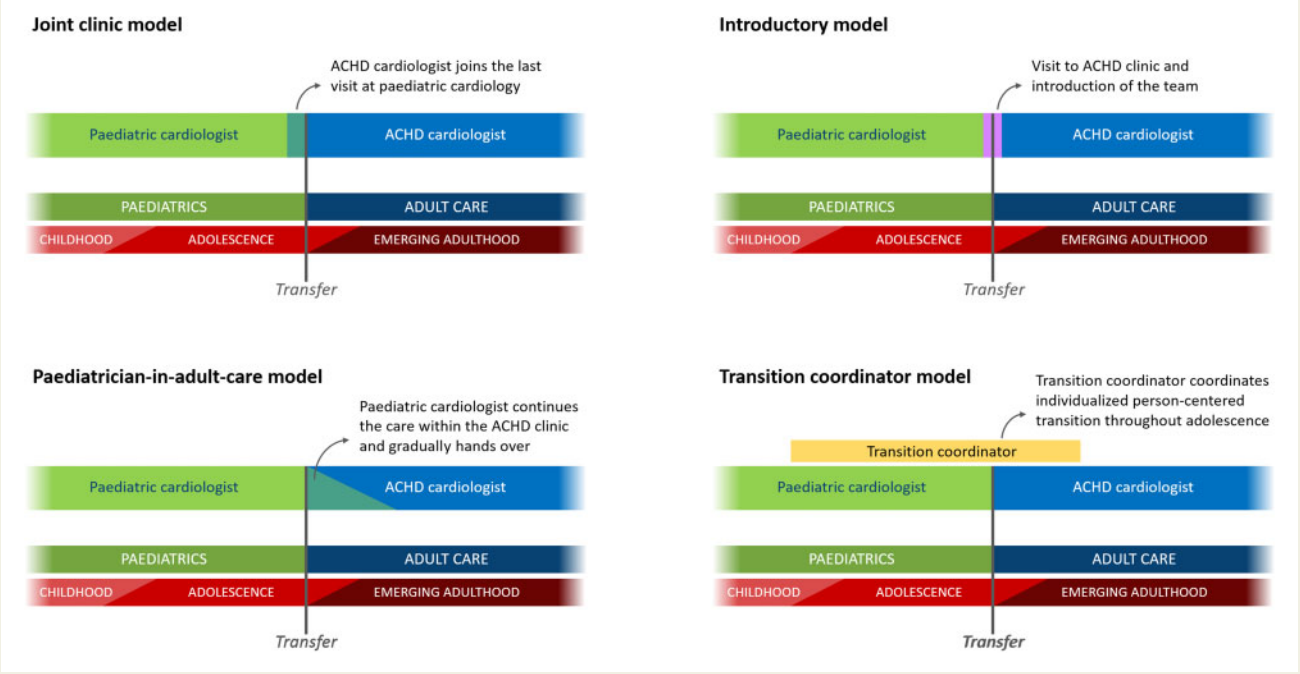


Figure 3 Models for transition.

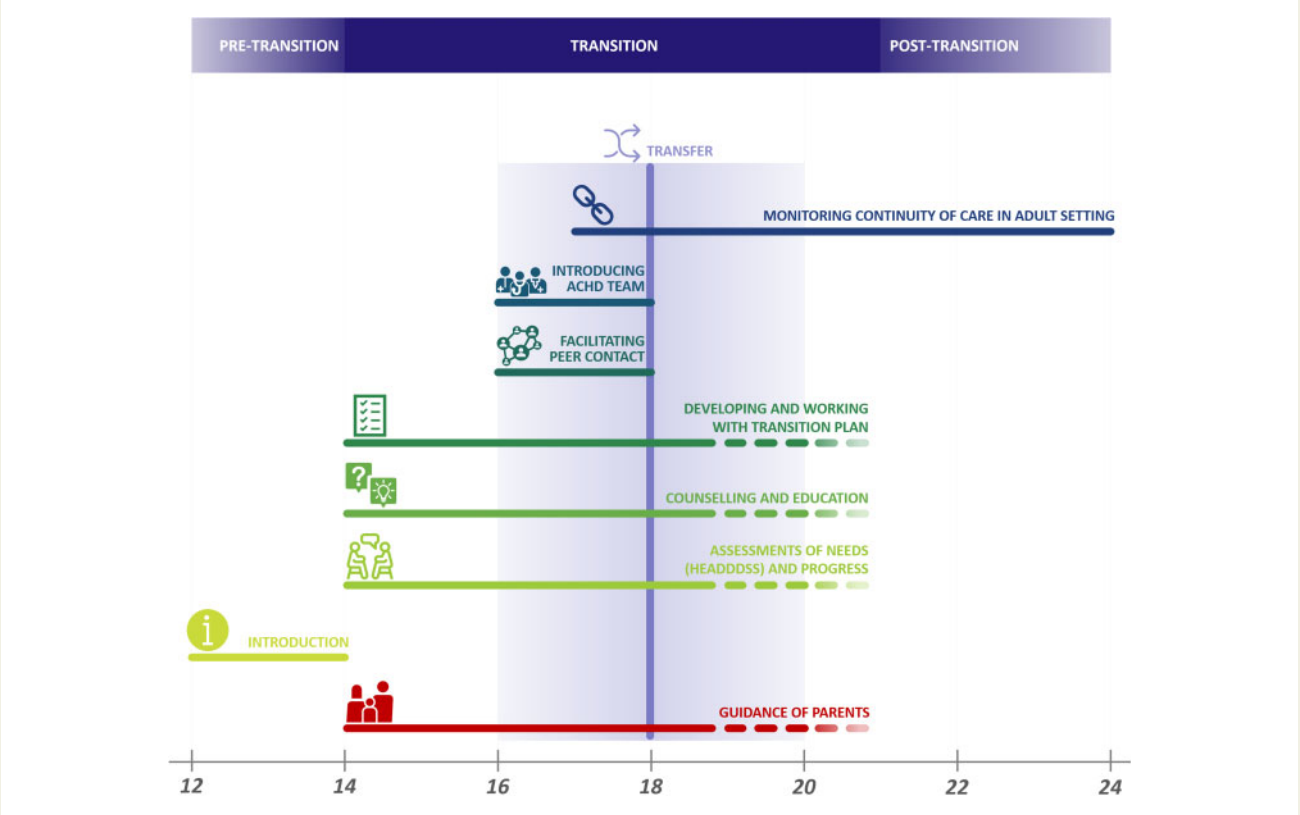


Figure 4 Components of transition and proposed timing for implementation.

Box 1 Glossary of terms

Adolescence is a developmental period ranging from age 10 to 24 years that is characterized by biological growth and social role transitions.[8]

Emerging adulthood is a phase of the life span between adolescence and full-fledged adulthood, which encompasses late adolescence and early adulthood and ranges from age 18 to 29 years.[9,10]

Transition is a passage from one life phase, physical condition, or social role to another, resulting in a temporary disconnectedness of the normal way of living, which demands an adjustment of the person and the environment.[11,12]

Transfer is an event or series of events through which adolescents and young adults with chronic physical and medical conditions move their care from a paediatric to an adult healthcare environment.[13]

Transitional care is the provision of interventions that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from being a dependent child towards an independent adult, with the aim to prepare the adolescents to take charge of their lives and their health in adulthood.

Transition programme is a set of co-ordinated transitional care interventions that are provided in a structured albeit individualized way, in order to support the process of the transition to adulthood and achieve the outcomes of transition.

Transition policy is a written document that sets out principles, standards and practices of how transition is managed at the centre.

Transition plan is a working document that records findings of assessments, describes the progress in transition, and outlines planned actions to achieve predefined goals.

stands for Home, Education, Activities, Diet, Drugs, Depression, Sex, and Safety.[52] This health interview gives insights into the living circumstances and lifestyle of the adolescent and allows an understanding of the capacities and problem areas of the adolescent. Supplementary material online, *Table S1* gives first-line and follow-up questions for each of the domains of HEADDDSS. These questions should not to be addressed in an exhaustive way, but they should rather guide the interview. During the transition, the progress of the needs and capacities has to be followed up. This progress is sometimes called transition readiness.[53]

7.3 Counselling and education

Based on the information obtained from the assessments, patients should actively and repeatedly be involved in education and counselling activities. Education and counselling have to adopt adolescent-friendly communication styles[54] and they should cover medical, psychosocial, and behavioural topics: CHD management and the need for life-long medical follow-up; healthy lifestyle choices (e.g. alcohol consumption, smoking, substance use); reproductive issues (e.g. recurrence risk and family planning); physical activity; vocational advice; endocarditis prevention and prophylaxis; and advance care planning as appropriate.[55–58] Discussions of sexuality and contraception should be responsive to the cultural and religious beliefs of the patients and families. In some countries, counselling regarding military service has to be included. Several formats and tools, such as cardiac diagrams, medical summary, patient-tailored health passport, smartphone application, written booklets, and web-based education programmes, can be applied in practice.[59–61] Goal-setting and the use of shared management[62] are specific strategies to empower patients and enabling them to function well in daily life.[63–65]

7.4 Developing and working with a transition plan

Both the assessment and the counselling efforts should be documented in a transition plan (see definition in *Box 1*). Components to be included in such a transition plan are summarized in *Box 2*. This transition plan is a working document and is to be completed throughout the transition process (see example in Supplementary material online, *Document S2*).

7.5 Facilitating peer contact

Adolescents with chronic conditions often want an opportunity to meet and talk with peers who are in the same situation.[66–68] If possible, it is important to facilitate such peer contact. Some centres work with youth ambassadors or local patient organizations to support peers,[69,70] whereas others organize annual adolescent days[36,71] or summer/weekend camps.[72] In areas in which stigma prevents in-person meetings, connecting with peers via social media or instant messaging tools can be encouraged.

7.6 Introducing the adult congenital heart disease team

A critical component of transition is that patients and families are introduced to the ACHD team, the outpatient clinic, and the flow of an ACHD outpatient visit.[66,73,74] This first contact is decisive for successful transfer.[73] Such an introduction can be done by a guided visit at the ACHD outpatient clinic, a personal meeting with the ACHD team, a brochure/flyer, or a virtual presentation on slides or video.

7.7 The transfer to adult care

At a certain moment, patients need to be transferred to adult care. In areas in which ACHD care is available, an active referral to an ACHD team is strongly preferred over merely informing the patient about the nearest ACHD centre. A transfer letter including a complete medical summary should be given to the patients and the taking-over ACHD team. It is argued that all patients should be seen at least once in a specialized ACHD centre.[29] In regions of the world where these do not exist, patients should be referred to physicians with some training in ACHD.[75] The ACHD team will then decide upon the level of care and follow-up intervals.[29] The optimal age for transfer is 18–19 years, because this is associated with improved outcomes.[76] However, patient preferences showed that an earlier transfer at 16–17 years may be appropriate as well.[73,77] Irrespective if a predefined age is used to transfer patients to adult care, the developmental competencies of the adolescents should be taken into consideration. For

Box 2 Essential components of a transition plan

- Demographic information of the patient
- Contact information to caregivers
- Persons of importance to the adolescent
- Need of special support and ongoing care
- Degree of parental involvement in the transition plan/process
- Brief report of current medical status
- Preparations for the visit with the transition co-ordinator
- Recommendations regarding prognosis, physical activities, drugs, family planning, endocarditis prevention, future need of interventions and follow-up, choice of profession, travelling, and driving license
- Reporting of the HEADDDSS (Home, Education, Activities, Diet, Drugs, Depression, Sex, and Safety)
- Goals for transition, own resources, and capacities and need of support as expressed by the patient
- Reporting of accommodations designed for learning and functioning, discussed with schools and comprehensive disability services

some adolescents, an earlier transfer could be appropriate, whereas for others, the transfer should be delayed to give them the chance to further develop the required knowledge and skills. Whatever age the patient is transferred, the transition process should not finish with transfer to adult care. The continuation of transitional care then is the responsibility of the ACHD team, together with the transition co-ordinator. It is, therefore, important that ACHD programmes bring in expertise in transitional care to ensure the continuation of transition and to help patients to integrate in adult life and care.

7.8 Monitoring continuity of care

To keep patients in follow-up, it is advised that the paediatric team defines the timing of the next visit to the ACHD team and an invitation is sent to the patient.[78] If patients miss their first transfer appointment, the ACHD team should have a reminder system in place because adherence to the first appointments in adult care is a predictor for continuity of care.[28] Short text message reminders, for instance, have been demonstrated to increase healthcare appointment attendance.[79] In case of no-show, dedicated administrative staff ought to be vigilant and ensure that these patients receive a new invitation.

7.9 Guidance of parents

Transition is often more challenging for parents than for the adolescents.[73,80] Indeed, parents are required to change their behaviours and become accustomed to their changing role.[63,80] Specific support for parents during transition is key and will not only reduce parental stress and anxiety but may also result in better transition outcomes for the adolescents because parents are better equipped to empower their child. Information provided to parents should be available in appropriate languages and formats. Given that parents may come from culturally diverse backgrounds, additional material that is culturally appropriate and adapted to their health literacy level is required. Guidance of parents during the transition should address the topics described in Supplementary material online, *Box S1*.

8. Structural requirements/ composition of teams

8.1 Human resources

Paediatric and ACHD cardiologists have a pivotal role, since the paediatric team initiates the transition process and adult care providers carry on with the process. As the 'transition coordinator model' is the preferred model to provide comprehensive transitional care, a transition co-ordinator is a critical player.[81] Although no specific professional/educational requirements are formulated, advanced practice nurses are well placed to be transition co-ordinators[55,82,83] because they are trained to perform health interviews, address psychosocial issues, and offer education.[84–86] Furthermore, such masters-prepared nurses have organizational skills that are essential in this role.[86] It is important that transition co-ordinators receive specific training in adolescent health.[51] Depending on patients' needs, other disciplines may be involved: psychologists, social workers, occupational therapists, physical therapists, or speech and language therapists.

Administrative support for the transition programme is indispensable. In centres where there is no transition co-ordinator available, administrative services may review the process[87] and at least make sure that continuity of care is monitored and patients are kept in follow-up. Which structures come into use will depend on the organization and personnel resources of the centre. Small or low-resource centres may not be able to allocate all desirable human resources. As an example of transition in a middle-income country, the case of South Africa is presented in Supplementary material online, *Box S2*.

Although transition in CHD entails specialized care providers, also primary care providers have an important role in the transition.[51,88] Working collaboratively with CHD specialists, primary care providers are in a unique position to provide care across the age span and be a consistent presence for the patients as they leave paediatric care and enter the adult-oriented healthcare system. They can also ensure successful transfer and retention in ACHD care by monitoring ACHD clinic attendance.

8.2 Structural requirements

Structural elements of healthcare programmes encompass physical, organizational, and other system characteristics.[89] The following documents are important structural elements:

- A written transition policy, which is a document that sets out principles, standards, and practices of how the transition is managed at the centre, which incorporates (i) management agreements between paediatric and ACHD care; (ii) description of patient population and criteria of inclusion; (iii) intensity of transition intervention; (iv) family inclusion; (v) competencies of staff, (vi) teaching aids; (vii) liaison with schools and comprehensive disability services for those in need; (viii) possibilities for telehealth; (ix) billing; and (x) monitoring systems.

- A transition plan, which is a working document that records findings of assessments, describes the progress in transition, and outlines planned actions to achieve predefined goals. Components that should be included in a transition plan are described in *Box 2*. The Ready-Steady-Go project in the UK (www.uhs.nhs.uk/readysteadygo) developed a generic transition plan. It comprises assessments about knowledge and skills over time, and progress notes can be made (see Supplementary material online, *Document S2*). These Ready-Steady-Go can serve as an example and a basis for developing CHD-specific transition plans.

9. Conclusion

Transitional care and the transfer to adult care settings are important for all adolescents with CHD. Available resources will determine which components of transition programmes can be implemented, and who will be able to perform this. Regardless, systems must be in place to ensure that continuity of care is ensured after leaving paediatric cardiology.

Supplementary material

Supplementary material is available at *European Heart Journal* online.

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