



Review

Young people with congenital heart disease — Transitioning to adult care

Karen Uzark^{a,*}, Jo Wray^b^a Department of Pediatrics, University of Michigan Mott Children's Hospital, Ann Arbor, MI, USA^b Division of Cardiorespiratory Medicine, Great Ormond Street Hospital, London, UK

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ABSTRACT

Congenital heart disease is the most common congenital anomaly and approximately 90% of those born with congenital heart disease today are likely to survive to adulthood. The majority require life-long specialist follow-up, requiring transition to adult-oriented services. The high frequency of patients lost to follow-up and with lapses in care is daunting and suggests that current transition preparation may be inadequate. In this review we define transition and the goals of transition and describe the concept of transition readiness. We identify barriers to effective transition, the key elements of preparation, and the importance of evaluating transition.

1. Introduction

The worldwide prevalence of congenital heart disease (CHD) is now estimated to be 1.35 million newborns with CHD every year [1]. With approximately 90% of children born with CHD expected to survive to adulthood, the number of adults with CHD is steadily increasing, representing an important global health issue [1,2]. While we celebrate improved survival through childhood and adolescence, the frequency of patients lost to follow-up and with lapses of medical care is daunting in adults with CHD, as high as 50% to 70%, and is associated with adverse outcomes including significant morbidity, potential mortality, and likely significantly impaired quality of life [3,4]. In survivors of tetralogy of Fallot repair, Wray and colleagues found that 24% of their patients were lost to follow-up and 48% of late deaths were in this group [5]. Disorders of psychosocial and cognitive development are key factors affecting the quality of life of individuals with CHD [6–8], and may be largely unrecognized in patients who are lost to follow-up.

Even among patients who eventually return to cardiac care, as reported by the Alliance for Adult Research in Congenital Cardiology (AARCC) with the Adult Congenital Heart Association (ACHA), 42% report a gap in care of > 3 years, 8% > 10 years [9]. The first lapse of care commonly occurred at age 19–20 years and, of great concern, the majority of subjects who reported gaps had moderate or severe complexity of CHD. In Canada, Reid and colleagues also found that one fifth of patients with complex CHD had not received any cardiology follow-up after their 18th birthday [10]. Furthermore, it is reported that the proportion of patients admitted via the Emergency Department nearly doubled surrounding the transition to adulthood [11].

Loss to follow-up and gaps in care represent a significant threat to

survival and functioning or quality of life in survivors with CHD. Given the importance of uninterrupted healthcare and the potential impact on outcomes, interventions to better prepare adolescents and emerging adults for successful transition to adulthood and to maximize lifelong physical and psychosocial outcomes in adults with CHD are imperative.

2. Transition Definition and Goals

Transition has been defined as the process by which adolescents and young adults with chronic childhood illnesses are prepared to take charge of their lives and their health in adulthood [12]. Transfer refers to the actual point in time at which responsibility for patient care is “handed off” to the adult provider [13]. As stated in the American Academy of Pediatrics Policy statement, the goal of transition in healthcare is “to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.” [14]. The aims of a transition program are to improve the patients' and their families' knowledge of the medical condition (and lifestyle implications); to prevent high-risk behaviors; to enhance communication skills and self-advocacy; to promote skills in decision making and self-management; to prevent patient loss to follow-up; to maintain medical insurance; to achieve educational and vocational goals; and to improve overall quality of life [13].

2.1. Timing of Transition

The transitional process should be individualized and is an ongoing process that should begin in early childhood and continue into

* Corresponding author at: University of Michigan Mott Children's Hospital, 1500 East Medical Center Drive, SPC 5202, Ann Arbor, MI 48109-5202, USA.
E-mail address: karenu@med.umich.edu (K. Uzark).

adulthood. The timing of transition and transfer should be guided by emotional maturity and developmental level or cognitive status, as opposed to chronological age [13]. Cultural and family dynamics are also important factors to consider that will influence the individual's transition readiness and achievement of self-care. Parental anxiety can lead to overprotection and may explain parents' reluctance at times to shift greater responsibility for management to their adolescent [15]. Guidelines recommend that patients transfer from pediatric to adult care between the ages of 18 and 21 years [13]. However, assessment of transition readiness is needed to ensure the optimal and individualized timing of transfer for each patient.

3. Transition Readiness

Transition readiness is a complex, multi-domain concept which encompasses the entire transition process [16]. Readiness for transition requires knowledge of the medical condition and treatment including lifestyle implications and health care needs. Other domains include self-management behaviors, and perceived self-efficacy. Self-management behaviors, the patient's autonomy regarding taking medications, asking questions, making appointments, decision-making, etc., are primarily related to a person's self-efficacy, a person's belief about his or her ability and capacity to accomplish a task or execute those behaviors, important to the development of resilience. Perceived self-efficacy supports one's willingness to accept responsibility for management of their health.

In a systematic review of transition readiness for adolescents with chronic illness, Stinson and colleagues acknowledge the key to a successful transfer is an adolescent's readiness to begin to transition [16]. Based on their review, they note the lack of a validated, patient-centered instrument to assess adolescents' acquisition of skills and knowledge remains a major limitation to a healthy transition process and transfer to adult care. In addition, they found the existing measures focus on readiness for transfer versus readiness for emerging adulthood [16].

Stewart and colleagues [17] evaluated transition readiness in young adolescents with CHD (ages 12 to 15 years) using the Transition Readiness Assessment Questionnaire (TRAQ), widely used and considered the best-validated generic transition-readiness tool evaluated in the USA, that measures transition readiness of youth with chronic conditions under two domains: (1) self-advocacy (e.g., communication and use of resources within the community and school), and (2) chronic disease self-management (e.g., scheduling medical appointments, asking questions of health care providers, filling prescriptions) [18,19]. Transition readiness was higher among patients who were older, more knowledgeable about their condition, had a history of primary cardiac repair, and had greater self-efficacy, and was lower for boys and patients on cardiac medications [17]. Transition readiness was unrelated to CHD diagnosis. Parental involvement was correlated with increased transition readiness and patient disease self-management skills. An important limitation, as the authors note, is that the TRAQ has not been validated for adolescents younger than 16 years of age [17]. In another study [20] using the TRAQ in 18–25 year olds with CHD, transition readiness did not differ as a function of disease category (moderate CHD versus complex CHD versus Heart Transplant) or where patients were being followed (pediatric vs. adult CHD clinic). The authors note that the similarity of scores among 18 to 25-year olds followed in a pediatric versus adult CHD clinic implies that the pediatric CHD providers in this study are not more likely to transfer patients who are more “ready” for adult care. Rather, there are likely system factors that determine in which clinic a patient is followed [20]. They further suggest that the TRAQ has limitations in the CHD population since ceiling effects were observed and a response of “not needed for my care” to 5 or more of the 29 TRAQ items was provided by 75% of participants [20].

Uzark and colleagues [21] evaluated transition readiness (knowledge deficits, perceived self-efficacy, self-management behaviors) in

patients 13–25 years of age with CHD or heart transplant, including the field-testing of a cardiac specific Transition Readiness Assessment measure administered with an e-tablet, web-based format. Transition knowledge deficits were common and associated with decreased self-efficacy and self-management skills in adolescents and young adults with heart disease. Perceived self-efficacy scores were higher in patients ≥ 18 years of age and were lower in patients with single ventricle than in patients with 2-ventricle heart defects [21]. The mean score for self-management behaviors was only 49.7 on a 100-point scale, higher in young adults, though only 54.2. As expected, higher perceived self-efficacy scores were associated with higher self-management scores. Greater transition knowledge and perceived self-efficacy were also associated with better psychosocial quality of life [21]. With respect to the Transition Readiness Assessment measure, preliminary data supported the instrument validity by confirming the expected relationship between knowledge, self-efficacy, and self-management scores and age [21]. Responsiveness was reflected in changes in scores over time with receipt of information [22].

3.1. Knowledge Gaps Identified

Overall, the most common perceived knowledge deficits identified by Uzark et al. [21] were related to health insurance (74%), pregnancy (70%), contraception (42%), how to contact your doctor (37%), and symptoms to call for (30%). Although the frequency of several specific knowledge deficits was significantly lower in young adults than in adolescents, the proportion of young adults (18–25 years) with these specific knowledge deficits still ranged from 23%–65%. Similar knowledge gaps in adults with CHD have been identified by others including reasons for follow-up and symptoms of deterioration of their heart disease [23]. Van Deyk et al. [24] found that adolescents with CHD had poor knowledge regarding their heart condition including the name of their heart defect, reasons for follow-up, the effects of competitive sports, symptoms that reflect deterioration of their heart disease, appropriate contraceptive methods, and the risks of pregnancy. Many young adults with CHD also have misconceptions about safe, desirable levels of physical activity, and have lower activity levels than recommended for their cardiac conditions [25,26]. After completion of a transition readiness assessment, Uzark et al. [22] reported that overall 66% of 13–25 year olds requested information from a checklist, 73% of patients ≥ 18 years of age. Interestingly, nearly 1 in 5 (18.3%) requested information regarding stress management. As reported by Clarizia and colleagues [27], children and adolescents more knowledgeable about their diagnosis demonstrate a better understanding about their transition to adult care (100% versus 7%, respectively) and are more likely to communicate directly with their providers than those who are less or not knowledgeable (88% versus 33%, respectively). Importantly, Ronning et al. [28] reported that patients identify lack of knowledge about their heart disease as a barrier to taking a more active role in decisions about their treatment and care.

3.2. Self-efficacy and Self-management

Self-efficacy or confidence in their ability to care for themselves is key to promoting self-management behaviors, crucial to successful transitioning. While self-management includes medical management such as scheduling appointments, asking questions of health care providers, and filling prescriptions, it also extends to other activities of daily living that may be affected by the presence of CHD. A study of adolescents with CHD showed that belief in self-efficacy was more important than severity of CHD in determining exercise and sports participation [29]. More recently, Banks and colleagues [30] also found that overall self-efficacy was associated with higher moderate to vigorous physical activity among all CHD groups.

While self-efficacy significantly contributes to improved self-care, low levels of self-care are common among adults with CHD as reported

by McCabe and colleagues [31]. As previously noted, Uzark et al. [22] also reported low scores for self-management in adolescents and young adults with CHD. In patients < 18 years of age, they observed that agreement between parent perceptions and adolescent self-report was fair to poor for perceived self-efficacy ($r = 0.35$) and for self-management ($r = 0.33$). Parents have an important role in promoting self-efficacy and self-management behaviors in individuals with CHD [17]. Ong et al. [32] found that perceived parental overprotection and heart defect complexity are associated with heart-focused anxiety in adults with CHD and suggest that parental overprotective behaviors may foster feelings of dependency and low self-efficacy. Parent-management may hinder patient self-management when it persists through adolescence and emerging adulthood and assessment of parental perceptions regarding transition should be included in evaluation of transition readiness.

4. Barriers to Effective Transition and Transfer

Beyond lack of readiness for transition to adulthood, it is evident that the point of transfer to adult care can be a time of increased risk for young people with CHD. Patients who are lost to follow-up or have extended lapses of care report being unaware of the importance or availability of adult specialist care or report that they thought that adult care was not needed [4,5]. A number of socioeconomic, clinical and patient-related factors have been associated with patients being lost to follow up or with lapses in care, including male gender, lower family income, greater geographical distance to adult center, feeling well, less complex CHD which did not require surgery, a history of missed appointments, specific beliefs, and living independently [10,33–35]. There are clearly therefore many barriers to the successful transfer of care, some of which are real while some are perceived. Drawing on both the cardiac and chronic illness literature, a framework for categorising barriers for the transfer of patients with CHD from pediatric to adult care has been proposed, in which barriers are organised into structural, institutional, social and neurocognitive domains [36], as summarised in Table 1 and discussed briefly below.

4.1. Structural Barriers

Much of the focus on structural barriers to successful transfer to adult care revolve around resources – and in particular decreased availability of insurance for adult care (particularly in the US where there is no universal health care system) [37,38], limited resources for providing adequate education and training to adult teams [39], and lack of reimbursement for time and coordination of care during transition for both pediatric and adult providers [40,41]. The need to transfer to a different institution or health care system has also been identified as a potential barrier, although it is also evident that intra-institutional transfer does not necessarily result in improved rates of successful transfer [37], with recommendations that efforts also need to be directed to retention of patients who are transferred within a single institution.

4.2. Institutional Barriers

At the institutional level, a lack of a structured transition program, including a timely transition plan and appropriate information, has been widely cited as a barrier to the successful transfer of care, both in CHD in particular [27,42] and chronic health conditions more widely [43,44]. Poor inter- and intra-agency coordination and communication and, specifically, a lack of a formal referral to the adult team [37,45] have also been identified. Provider-related barriers include patients' perceptions of a lack of health professional interest [5] and a lack of ACHD provider availability and training. At the patient level a greater geographical distance from their home to the adult centre has also been cited as a barrier for successful transfer [10].

Table 1

Barriers to successful transfer of young people with CHD from pediatric to adult services – perceptions of patients, families and health professionals.

Adapted from Everitt et al. [36].

Domain	Perceived barriers
Structural	<ul style="list-style-type: none"> – Insurance availability – Training and education for health professionals – Transfer to different institution/health care system – Lack of reimbursement for transition visits and care coordination
Institutional	<ul style="list-style-type: none"> – Lack of structured transition programme including timely transition plan – Lack of ACHD provider availability and training – Perceived lack of health professional interest – Lack of primary care physicians interested in caring for ACHD patients – Poor inter- and intra-agency coordination and communication – Lack of formal referral – Delays in appointments at adult centre – Lack of access to specialist allied health professionals – Cultural differences between pediatric (family centred, developmentally focused) and adult (patient centred, focused on independence and self-management) services
Social	<ul style="list-style-type: none"> – Provider-patient and provider-parent attachment – Patient knowledge and self-advocacy – Patient anxiety about inadequate care in adult services – Patient held negative beliefs – Patient vulnerability to risk taking behaviors – Parental involvement – Parental anxiety and knowledge – Geographical distance to centre
Neurocognitive	<ul style="list-style-type: none"> – Developmental delays – Impaired social, emotional and executive functioning – Mood disorders

4.3. Social Barriers

Much has been written about the 'attachment' of patients and parents to the pediatric team, resulting in their reluctance to move to adult services [42,46–48]. Similarly attachment to the patient by the pediatric provider or a lack of belief in the ability of the adult physicians to care adequately for their patient can also delay or hinder the transition process [49–52]. Concerns have been expressed about patients' knowledge about their condition, their awareness about the process of transition and what to expect in adult services and their self-advocacy and skills related to their ability to manage their condition [27,53,54]. The role of parents has also been identified as a barrier to transfer of care, specifically with respect to over-involvement, their own lack of knowledge and their increased levels of anxiety about their child's health and/or the move to adult services [55–59]. In a recent study of adolescents with a Fontan circulation and their parents, patients reported poor levels of knowledge about their condition, medications and treatment and parents reported high levels of anxiety about transferring to adult care [60]. Over-protective parenting can limit opportunities for the development of advocacy and learning in the patient, thus further fostering dependence and potentially delaying transfer [61].

4.4. Neurocognitive Barriers

Young people with CHD are at increased risk for developmental delay and cognitive impairment [62,63] and this can have a detrimental effect on their ability to acquire the necessary skills and knowledge to transition to adult care where the expectations and requirements are different to those in pediatric services [45,64]. Of particular concern is the role that poor social, emotional and executive functioning have in a patient's adherence to elements of their care and the increased risk of a poor transition as a result [35,65–67].

Barriers to successful transition have largely been identified via

questionnaires and surveys to patients, parents and providers of health care in pediatric and adult settings. As yet, there is no standardised instrument that could be used to quantify barriers but the development of such a measure would enable benchmarking in the future, with the aim of reducing barriers and enhancing facilitators of good transition.

5. Preparation for Transition

Patients widely report negative feelings about the idea of transition, including anxiety [68] and uncertainty about what to expect [69], and providing adequate preparation prior to the transfer to adult services is therefore critical [70], particularly in light of evidence of the impact of preparation on outcomes post-transfer [71]. There is general consensus that initial preparation for transition should start in early adolescence [72], and the importance of both a policy on timing and that the policy should be flexible have been highlighted in guidelines for managing transition for young people with CHD [13]. Furthermore, preparation for transition should also be synchronised with other life transitions [73,74]. A number of transition programs have introduced the concept of a ‘transition coordinator’, a health professional with clinical expertise who can assume responsibility for the whole process of transition and who can also champion transition and be a leader for change. Transition coordinators typically liaise with both pediatric and adult services as well as being an advocate for patients and families, and their presence has been identified as being helpful for all involved in transition [41,75]. For young people with CHD, a proportion of whom will have cognitive or psychosocial difficulties, preparation needs to be tailored to their individual developmental level and psychosocial needs. Two key aspects of a preparation programme are the provision of knowledge and skills training and one approach involves providing this within a resilience framework. Young people with a chronic illness acquire resilience when they are encouraged to positively appraise their competence and belief in their ability to cope with their health condition, using a strengths-based approach rather than one based on deficits, and a resilience framework enables both assets and resources to be focused on. Assets are positive factors which are intrinsic to the young person, such as self-efficacy, coping strategies and competency, whereas resources are external and include parental support and organisational structures.

5.1. Knowledge

Information which is both age-appropriate and developmentally appropriate and is relevant and salient for the young person with CHD is an integral component of all aspects of transitional care, but particularly at the stage of preparation for transfer. Understanding issues related to their specific cardiac condition in terms of their diagnosis, medical history and treatment are key elements [76]. One challenge for some young people with CHD is that they are sometimes not aware of what having CHD means for them and what it is that they need to take responsibility for because up to the point of preparing for transition it has been their parents who have carried the burden of knowledge and responsibility [77]. It has also been suggested that for a young person with CHD, an understanding of the normal heart and how their own heart differs from normal is helpful for comprehending the risks, complications and signs and symptoms of which they should be aware [13]. A knowledge of health behaviors and lifestyle issues, factors related to living as an adult with their condition and the role of health professionals involved or likely to be involved in their care should also form part of the training. A structured education program ensures that all topics are covered appropriately, over several sessions if necessary. Results of a recent study indicated that adolescents and young adults who did not participate in an educational program had gaps in their cardiac-related knowledge, particularly with regard to recommended follow-up and cardiovascular risk, with potentially serious implications for long-term outcomes [78].

Table 2

Knowledge – areas to be covered in an educational programme. Adapted and reproduced with permission from Wray J, Wright J. Transition to adult care. In: Kelly DA, ed. Diseases of the liver and biliary system in children. Wiley Blackwell 2017.

Condition and treatment, including effects on body, medical history, prognosis
– Diagnosis, previous surgery and treatments, co-morbidities and their significance, knowledge of the normal heart
– Medication regimen including names, doses, side effects, rationale for use, risks of non-adherence, important drug interactions
– Purposes of tests and procedures
– Relevant medical terminology
– Specific issues – e.g., immunizations, antibiotic prophylaxis
– Future treatments/surgery – possible and probable
Role of individual health-care providers, what they do, and how to access their services
– Differences between pediatric and adult care
– Meaning of transition
– Health insurance issues, prescription charges at transfer, other changes in the mechanisms for providing care
Healthy lifestyle in terms of nutrition, exercise, emotional wellbeing, general health, dental health
– Impact of drugs, alcohol, and smoking on condition and therapy
– Impact of condition and therapy on sexual and reproductive health
– Impact of condition and therapy on education/vocation/employment opportunities
– Advice on tattoos, body piercing
– Advice on travel
Confidentiality, consent, and rights
– Understanding of rights to confidentiality
– Consent process for medical procedures as an adult
– Social support groups and community organizations
– Reliable sources of information on condition, therapy, general health, vocation, etc. (and unreliable sources to avoid)

A further consideration is how the education is delivered and methods need to be developmentally appropriate, particularly when a young person has some degree of cognitive impairment. Tailoring an education program to the individual, in terms of what, when and how the information is provided will improve learning and retention of knowledge. Information needs to be accessible to young people, in a format that they want and available when they want it, and they also need to see it as relevant to their own health needs. Information websites, web-based learning and the use of social media are becoming increasingly popular, particularly as the majority of young people now have access to mobile technology [79]. Both adolescents and young adults with CHD also expressed an interest in using transition checklists to learn about managing their CHD, with a preference for these being internet based [79]. Table 2 outlines key areas which should be addressed in an educational program.

5.2. Skills

Providing appropriate skills training in self-advocacy alongside relevant knowledge acquisition is key to the development of resilience in young people. In Table 3 areas in which skills for transition need to be developed within a program of preparation are outlined.

5.3. Involvement of Parents/Carers in Preparation for Transition

Transfer to adult services can be an anxious time for parents, particularly as parents are likely to have had a long-standing relationship with the pediatric team since soon after their child's birth, building up trust in them over many years and as a result being reluctant to leave them. A recently published survey identified that less than half of adolescents with CHD in the US had parents who discussed their child's transition with providers, which may be a contributory factor to the

Table 3

Skills for transition.

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Health

- Feeling confident about seeing health professionals independently of parents
- Health information-seeking skills – ability to find reliable, accurate, relevant, and up-to-date information and developing the skills to distinguish from inaccurate information; using widely accessible resources appropriately (supported by professionals providing relevant resources)
- Accessing health care independently, including booking own appointments, contacting medical teams for advice (in both emergency and non-urgent situations), refilling prescriptions
- Awareness of own health – e.g. aware of signs and symptoms of endocarditis, arrhythmias, haemodynamic issues and appropriate actions
- Recognition of any specific mental health issues and appropriate actions
- Self-management of condition and specific tasks related to underlying condition
- Adherence to medical regimen, advice about health behaviors, clinic appointments
- Practical skills – e.g. INR testing
- Emergency strategies

Psychosocial

- Independent living skills – e.g., meal preparation, household chores, budget management, self-care, mobility (including independent travel away from home), driving, hobbies, and leisure activities
- Peer support, including independent social life
- Social competencies

Educational/vocational

- Communication skills
- Work experience
- Part-time job
- Disclosure to potential partners, employers

failure of some young people to transition successfully to adult care [80]. Parents have a vital role in enabling their child to develop skills related to independence and self-management and as such need to be meaningfully involved in the preparation, which should include helping the parent to 'let go', thereby enabling them to facilitate their child's progression towards autonomy and independence in adult services.

It is also important to recognise that parents are experiencing their own transition as their child moves towards adulthood but, unlike parents of healthy adolescents, parents of young people with CHD have to relinquish some of their parental authority in managing their child's health and empower their child to assume more responsibility for their own care. Parents' own coping can impact on their child's experience of transition and coping but meeting parents' specific information needs during the preparation for transfer can help reduce feelings of anxiety and uncertainty and help parents regain a sense of control [81] with a resulting positive impact on their child and their transition outcomes. Parents want to be informed about, and involved in, transition planning and preparation and they want information at an earlier stage. Finally, preparation should also involve preparing to end their relationships with the pediatric team as well as preparing to build new relationships in the adult service [82].

6. Evidence and Evaluation

Many transition programs for CHD have been developed and implemented in recent years but evidence regarding their effectiveness and impact is scant. This scenario is not restricted to CHD – in a recent systematic review [83] in which the effectiveness of transitional care interventions was evaluated, only four studies were identified, one of which involved patients with CHD [84]. All four studies were small, covering a limited range of interventions and with a maximum of 12 months follow-up, which might be too short a time for any changes to become apparent. Although there was some evidence of improvement in patients' knowledge in the study involving patients with CHD

and improvements in confidence and self-efficacy in other disease groups, the overall certainty of the evidence was low, limiting conclusions that can be drawn about the effectiveness of the interventions. Other reviews [85] have identified that methodological quality of reported studies is generally poor and the interventions frequently involve multiple components which makes it difficult to determine the effectiveness of individual elements. Furthermore, many of the interventions have been implemented with patients with diabetes and it is unclear how generalizable the findings are to the CHD population or how sustainable any observed improvements in outcomes are likely to be. Heery and colleagues conducted a systematic review of outcomes and experiences of transition specifically within the field of CHD, identifying thirteen papers for inclusion [86]. They also identified study quality to be weak or moderate and significant heterogeneity in terms of study design, sample criteria, variable definitions of lost to follow-up and lapse in care, varying time points at which experience data were collected and variability in data collection methods. They commented on the unsatisfactory justification for the use of operational definitions, lack of rigorous sampling, variable response rates, lack of use of validated instruments and single-center design. However, high rates of patients who are lost to follow-up or have long gaps in care between leaving the pediatric center and being seen in adult care were highlighted, together with the need for more education about their condition and improved preparation for transfer.

While it is clearly important to develop evidence-based transition programs, it is also imperative that monitoring and evaluation should be an integral element of any transitional care service [87]. However, identifying, agreeing and benchmarking appropriate standards and outcome measures has proved to be challenging. Despite this, there are a number of standards and outcomes that should be monitored, most of which are applicable to any young person transitioning from pediatric to adult health care, as shown in Table 4 [87]. The development of benchmarks for best practice in transition, such as those recently developed in the UK [88], now need to be complemented by the

Table 4

Potential standards and outcomes for monitoring and measuring transitional care in CHD. Adapted and reproduced with permission from Wray J, Wright J. Transition to adult care. In: Kelly DA, ed. Diseases of the liver and biliary system in children. Wiley Blackwell 2017.

Quality standards

- Measure services against quality criteria for young people accessing health care
- Measure standards against those reported in national transition documents
- Include opportunities for the patient to be seen without parents present, transition planning and summaries of psychosocial screening and transfer

Effectiveness and safety

- Outcomes of attendance at adult centre
- Attended first two appointments in adult service
- Engaged with adult services at key points (1,2 and 3 years) after transfer
- Adherence to treatment/medication protocols

Clinical outcomes

- Markers of heart condition
- Complications of heart condition/treatment
- Unplanned hospital admissions

Non-clinical outcomes

- Living independently
- Education/employment/vocation

Patient-reported outcomes

- Assessment of disease/condition/treatment knowledge
- Assessment of self-management and advocacy
- Assessment of quality of life and wellbeing

Patient-reported experience

- Patients' and their parents'/carers' satisfaction with the process of transition and transitional care

development of benchmarks for evaluation. Collecting key outcome data will not only enable programmes to continue to develop and evolve, it will also provide evidence to encourage the ongoing financing and championing of transition services for young people with CHD [89].

7. Conclusion

The majority of young people with CHD will now survive into adulthood, but may lack knowledge and skills related to the adult lifestyle implications of living with CHD. Furthermore, as most will require life-long follow-up, they will need to transition from a family-centered pediatric service to a patient-centered adult service. Despite a growth in transition services in CHD, loss to follow-up and lapses of care remain concerning, with potentially serious consequences for patients, their families and the wider health service. Evaluation of transition needs of patients, families, and providers and ongoing service development are crucial if services are to be effective in promoting long-term survival and optimal lifelong functioning and quality of life in adults with CHD. Future work should focus on identifying strategies to overcome barriers to successful transition of care in this population.

Conflict of Interest Statement

This paper (Young people with congenital heart disease – transitioning to adult care) is not under consideration for publication elsewhere. Both authors have read and approved the manuscript and have no financial interests or other potential conflicts of interest to disclose. Permission was granted.

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