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Adolescence to Adulthood: Safely Transitioning the Adolescent With Pulmonary Arterial Hypertension

[Michelle Ogawa](#)

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"//connect.facebook.net/en_US/all.js#xfbml=1"; fjs.parentNode.insertBefore(js, fjs);
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Adolescence can represent a challenging period of physical, cognitive, and psychological development. While adolescents struggle to develop self-identity, they must also deal with physiologic and sexual maturation, greater demands to become more independent, and increasing peer pressure to fit in. 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.¹ The health care system places an added burden on these chronically ill children when they reach adolescence, as they are often required to transition medical care from their established pediatric medical team to a new medical team in the adult setting. Therefore, it is vital that health care providers work with adolescent patients and their caregivers to promote psychological development and emotional well-being with supportive guidance and expectations through a formal transition process. This process should begin well before these

patients transfer to an adult practice. Addressing the unique needs of adolescents with PAH will enhance their ability to achieve these goals, leading to a successful transition from adolescence to adulthood.

The objective of this article is to identify the factors influencing the psychosocial development of adolescents and, ultimately, their readiness to transition to adult care. Current practices and perspectives regarding transition of care will also be presented to emphasize the need for further attention to this component of care. Finally, elements of care that should be included in transition programs for adolescents will be presented.

Studies on the psychological and social development of children with PAH have not yet been reported. Many of the supportive findings discussed in this article are focused on children with chronic conditions, such as cystic fibrosis (CF), diabetes mellitus, inflammatory bowel disease (IBD), and human immunodeficiency virus (HIV). Although there are disease-specific symptoms and therapies for each chronic condition, prior studies have shown insignificant psychosocial differences among children with different chronic conditions,^{2 3} supporting the relevance and use of these studies in this article.

Factors Affecting Psychosocial Development and Readiness for Transition

Disease diagnosis and severity, mental health, family dynamics, peer relationships, and the pediatric medical practice model represent significant factors that may affect the adolescent's psychological and social development, and, therefore, affect the patient's readiness for transition of care.

Timing of Diagnosis and Disease Severity

A patient diagnosed with PAH as a young child may be in a very different stage of development than a patient of comparable chronologic age that is diagnosed during adolescence. Children who have lived with their condition from a young age may be accustomed to their physical limitations and need for frequent medical interventions, including daily medication administration and hospitalizations. Adolescents who experience the onset of PAH later in life may struggle adjusting to the physical limitations associated with the disease and those limitations imposed or recommended by their health care provider.

Disease severity can also influence the adolescents' development and ability to manage their own medical care. Intravenous prostacyclin therapy may require greater dependence on an adult caregiver to manage proper mixing of the medication and dressing changes. For those children with comorbidities, the sheer number of medications may make for a complex and overwhelming daily regimen that relies on continued caregiver assistance and close oversight. This increased reliance on a caregiver may lead to potential stagnation or regression in developmental progress toward independence.

Patients with severe disease may need to miss school frequently for clinic visits or hospitalization, affecting their ability to complete schoolwork and maintain close peer relationships. Further studies, specifically among adolescents with PAH of varying disease severity with various treatment modalities, must be completed to better understand the effect their condition has on psychological development and quality of life.

Mental Health

Mental health, or emotional well-being, not only affects the adolescent's psychosocial

development, but it can also affect health outcomes. As children grow into adolescence, body image comes to the forefront with increasing concerns of how they are perceived by their peers. Adolescents with chronic conditions, both visible and nonvisible, have rated themselves to have higher body dissatisfaction^{4 5} and have engaged in more high-risk weight-loss practices than their healthy peers. For adolescents with PAH, appropriate diet and exercise recommendations should be reviewed regularly. Adolescents with PAH may find it difficult to adhere to recommendations for restrictive physical activities, such as avoidance of varsity sports and isometric exercises.

Depression has also been reported as more prevalent among adolescents with chronic illness than their healthy peers, with females more often depressed than males.⁶ Depression diagnosed in early adolescence among patients with type 1 diabetes mellitus was shown to persist through early adulthood.⁷ Among adults, depression has been associated with greater likelihood of noncompliance to medication treatment, potentially because of disbelief in treatment effectiveness, poor family and social network, and reduction in cognitive functioning, making it difficult to follow the treatment regimen.⁸ Caregivers should also be screened for signs of depression and provided with appropriate resources, as their beliefs and attitudes may influence treatment adherence for their child's medical care.⁹

Adolescents with chronic conditions have been shown to have significantly lower self-assessed scores of emotional well-being than their healthy counterparts.¹⁰ However, in this study, males with chronic conditions had significantly higher well-being scores than females with chronic conditions. More adolescents with chronic conditions perceived their family connectedness to be lower than adolescents without chronic conditions. However, higher scores for emotional well-being of adolescents with and without chronic conditions were significantly associated with a higher level of family connectedness. This finding demonstrates the sustaining influence of the family on adolescents, despite their greater focus on peer relationships.

The Family Unit

Family dynamics highly influence the psychosocial development of children with chronic disease. For most diagnosed in early childhood, the adult caregivers have been the primary caretakers, managing their children's medical care and making medical decisions. When these children become adolescents, the caregivers may find it difficult to transition the responsibility to them. For adolescents with PAH on intravenous prostanoid therapy, some anxious caregivers may shield their children from straying too far from home in case of an emergency, sheltering these adolescents from opportunities to spend time with their peers.

Parenting style has been associated with the adolescent's well-being in the family context of adolescents with diabetes.¹¹ Adolescents with maternal acceptance (eg, mother "enjoys doing things with you") had lower depressive symptoms and higher self-efficacy. Older adolescents who viewed their mothers as controlling (eg, "insists that you must do exactly as you are told") had higher levels of depressive symptoms and poorer self-efficacy. This association was not true for younger adolescents, demonstrating that older adolescents may find that this controlling parenting style clashes with their efforts as they are trying to gain autonomy and increased self-efficacy.

The balance of safely and slowly transitioning care to the adolescent can represent a difficult process that the health care team must address. Understanding the child's perception and experience of parenting is an important component of assessing well-being. Assessing the

caregivers' perception is also necessary to better understand the family dynamics and how these can influence the success or failure of transitioning care.

Peer Relationships

Peer relationships represent another vital and influential component of an adolescent's development and well-being. For adolescents with chronic disease, "fitting in" with their peers represents one of their most significant concerns.¹² For adolescents with multiple sclerosis (MS), negative peer reactions (eg, peers fearful of injections) were associated with the adolescents' experience of loss, rejection, and isolation.¹³ While adolescents who received positive reactions from their peers (showing interest in learning more about their disease and medications, and providing emotional support) were associated with having greater acceptance of their disease. Encouraging these adolescents to find positive peer relationships is vital to acceptance of their condition and will potentially lead to greater treatment adherence.

Pediatric Medical Practice Model

Family-centered care has been a standard of care recommended and instituted by the American Academy of Pediatrics (AAP) since 2003.¹⁴ Pediatric providers are encouraged to include the patient (when age-appropriate) and caregivers in medical decisions. Family-centered care is particularly essential for children with PAH on intravenous or subcutaneous prostacyclin therapy, as the health care team requires the commitment and involvement of the family to safely and effectively administer this medication.

Since the adult caregiver is legally responsible for the child until the age of 18 years, the caregiver is required to be involved in making all medical decisions in most cases. Thus, most interactions with the health care team involve both the patient and the caregiver.¹⁵ This necessary caregiver dependence limits the opportunity for adolescents to have individualized interaction without the caregiver and for autonomy in medical decision making.

Despite adequate preparation for transition of care, stark contrasts in the pediatric and adult practices and settings cannot be fully realized until experienced by the patient and family at the time of care transfer (**Table 1**). Recognizing these differences may help the health care team understand the patient and caregiver's perception and experience when the patient enters the adult practice.

Pediatric and adult providers must understand how the factors of disease timing and severity, mental health, family and peer relationships, and pediatric medical care can influence the psychosocial development of adolescent patients with PAH to better meet the needs of this patient population and to provide a successful and smooth transition into adult care.

Table 1. A Clash of Cultures: Pediatric Medicine vs Adult Medicine.

(Please note that these general comments may not be applicable to all practices.)

Pediatric Medicine

Adult Medicine

Family-centered care

Adult-oriented (autonomous) care

- Increased and often complete caregiver involvement in medical care (age-dependent)

- Patient is focus of all conversation; patient is expected to make all medical decisions

- Caregiver serves as the primary decision maker for ill child
- Child often not a part of decision-making process (age-dependent) Medical team primarily addresses caregiver. Child often hears information from parents (age-dependent)

- decisions with MD¹⁶
- Patient required to consent for communicate with extended family
- Assumed belief that patient understands condition and information presented by team

Pediatric health care team

(in addition to MD and RN)

- Child life specialist, social workers, child psychologist, hospital school teachers, medical play therapy
- Pediatric-friendly clinics and hospital rooms
- Access to peers in inpatient and outpatient settings
- Staff trained to address the unique needs of adolescent population

Adult health care team

(in addition to MD and RN)

- Medical professionals trained in adolescent needs, conditions, and treatment
- Adult-focused clinics and hospital rooms
- Focus on adult culture
- Decreased access to young people in outpatient settings

Shared information

- Adolescent patient not expected to make decisions regarding care without parental involvement
- Information communicated openly to all immediate family members
- Communication maintained between hospital and school settings
- Collaborative effort to communicate information related to disease and treatment options to patient and family¹⁷

Confidentiality

- Patient is decision maker
- Information regarding patient condition and treatment options are protected unless patient elects to share
- Education of disease process and treatment primarily provided to patient
- Patient information is not disclosed unless requested

Focus on disease and development¹⁸

- Multidisciplinary efforts to aid children in meeting developmental milestones

Focus on disease¹⁹

- Disease-specific focus of all information and treatment options
- Limited attention given to developmental needs

Transitioning Care

Current Practice

Despite the recognized need for a smooth transition of adolescent patients from the pediatric to adult practice, the medical community has not adequately met this need. For example, of 170 CF programs surveyed, only 28% of the pediatric CF programs report consistently offering visits focused on transition of care.²⁰ Fewer than 25% of these programs usually or always provide educational materials regarding transition. While 50% of CF programs consistently performed readiness assessments, only 18% of all programs had specifically designed transition programs to support the adolescent's development of readiness skills.

Similarly, only one-third of pediatric cardiology centers provide structured transition programs for their patients.²¹ The age of 18 years is often cited as the criterion for transitioning, with the majority of patients transitioning sometime between age 18-21 years.^{22 23 24} Surveyed adolescent patients and caregivers noted that at least one joint visit with the patient, caregiver, and pediatric and adult providers prior to transition of care was beneficial in providing them with greater confidence in the new provider, and greater satisfaction with subsequent medical care.²⁵

Patient Perspective

Understanding the patient's perspective and expectations throughout the transition process, whether formalized or not, can provide valuable information to improve current transition practices. Prior to actual transition of care, most adolescents report being indifferent or apathetic to the prospect of transitioning to an adult provider.²⁶ Although 74% of surveyed adolescents with sickle cell disease reported transition to adult care to be "extremely important," 79% of these adolescents reported having little or no prior thought about transition.²⁷

In terms of transition timing, 8 of 11 adolescent kidney transplant recipients reported that they did not feel involved in the decision of when they would be transitioned.²⁸ Although rare, a few adolescents have reported requesting transition before the required age criterion because they felt out of place in a pediatric setting and were treated more as a child rather than an adult.²⁹

When transition to the adult center was pending in the near future, the adolescents' greatest concern was their uncertainty of the adult clinic organization, and available support and resources once transitioned.³⁰ [fn]Moons P, Pinxten S, Dedroog D, et al. Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. J Adolesc Health. 2009;44:316-322.[fn] These concerns indicate a need for further education about this setting before transfer of care is completed. These patients also indicated that once in the adult center, they would expect the information to be primarily directed to them. However, they still wanted the provider to communicate the same information to their caregivers as well.[fn]Moons P, Pinxten S, Dedroog D, et al. Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. J Adolesc Health. 2009;44:316-322.[fn]

After completing the transition of care, patients who reported having their needs and expectations met during the transition process were more likely to be satisfied with the care they were currently receiving.³¹

Caregivers' Perspective

Unlike their children, caregivers tend to be more anxious and experience difficulties coping

with the transition of care.^{32 33} Caregivers of children with congenital heart disease have reported that they consider the pediatric specialist and cardiac surgeons to be the ones who saved their children's lives.[/fn]Moons P, Pinxten S, Dedroog D, et al. Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. *J Adolesc Health*. 2009;44:316-322.[/fn] These caregivers may be anxious to leave their long-term relationship with the pediatric provider and transition to a new provider.³⁴ They are also concerned that these new providers may not be adequately knowledgeable about their children's condition, may have higher expectations for the children to be independent, and may not involve the caregivers in the plan of care.³⁵

Adult Health Care Providers' Perspective

The perspective and experience of the adult health care team can provide invaluable insight into the effectiveness of current practices of transitioning adolescent patients into adult programs. For successful transition, these providers should engage in the transition process with the patient, caregiver, and pediatric team.

Active participation of adult providers throughout the transition process may increase their understanding of adolescent development, improving their confidence and ability to care for these patients. Of a large group of adult gastroenterologists surveyed, 89% felt that adolescent developmental issues were important.³⁶ However, only 46% felt competent addressing their developmental and mental health issues.

Internists were also surveyed and reported concerns of the adolescent patients' ability to make decisions independently and of caregivers relinquishing their involvement in their children's care after the transition was completed.³⁷ This latter concern should be contrasted with caregivers' concerns that the adult provider would not want them in the clinic room at the time of the first visit or involved in their children's care.³⁸ The internists also expressed concern about their inexperience addressing end-of-life issues with young adult patients, and potential end to the doctor-patient relationship at an early age.³⁹ The concerns of the health care provider, patient, and caregiver illustrate the need for a frank discussion with all 3 parties to delineate roles and appropriate expectations when the patient first enters the adult practice.

Much of the current literature on transition programs focuses on the lack of standardized practices, underscoring the need for more formal and standardized programs.^{40 41} Few studies have assessed the effectiveness of current transition programs on health outcomes. Further studies must be performed to examine the effectiveness of existing transition programs to determine which components of these programs promote safe and efficient transition of care.

Components of Transitional Care for Consideration

Finally, **Table 2** lists the components of care that should be included in a transition program. Since there continues to be very limited outcomes data demonstrating the effectiveness of instituted transition models, the recommendations listed in the table have not all been validated in formal studies. Therefore, the pediatric and adult health care teams should work collaboratively to formalize a transition program that best meets the patients' needs.

Table 2. Essential Components of a Transition Program.

Prior to initiating transition:

- Assess and evaluate adolescent patient's cognitive and psychosocial development
- Screen patient and caregiver for depression

Initiation of transition:

- Discuss concept of transition of care with patient (10-14 years of age) and caregiver
- Clearly define roles and role expectations for the patient, caregiver, and pediatric provider⁴²
Pinxten S, Dedroog D, et al. Expectations and experiences of adolescents with congenital heart disease being transferred from pediatric cardiology to an adult congenital heart disease program. *J Am Coll Cardiol* 2009;44:316-322.[/fn]
- Educate caregivers to guide through safe transition of care
- Create goals and timeline for transition with the patient and caregiver^{43 44}
- Provide educational materials, if available
- Interval assessment and review of age and developmentally appropriate expectations and goals

Goals and expectations for patient to meet before transition:

- Understanding of diagnosis and medical history⁴⁵
- Knowledge of medical therapies (medications—doses, frequency, and purpose)
- Additional medical knowledge:
 - Need for specific monitoring and anesthesia care, if applicable
 - Endocarditis prophylaxis, if applicable⁴⁶
 - 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, then complete under caregiver supervision, self-preparation)
 - Central venous catheter care
- Knowledge of purpose and adherence to diagnostic studies, including serum lab tests (eg, LFTs, BUN, creatinine)
- School/work plans—adaptation of school or work to disease and treatment
- Secure health insurance coverage as adult⁴⁷

Just prior to transition:

- Arrange joint visit including patient, caregiver, pediatric and adult care team¹⁶ in pediatric setting
- Review medical summary during joint visit^{48 49}

-
- Summary should include (but may not be reviewed during visit): psychosocial development, health, family involvement, treatment adherence, end-of-life issues
 - Provide formal written summary to patient and adult care team⁵⁰
 - Discuss timing for initial visit at adult practice and frequency of visits
 - Review need for further follow-up with other specialists, if applicable
 - Provide written material and verbal review of organizational order of adult setting^{51 52 53} [fn]
Dedroog D, et al. Expectations and experiences of adolescents with congenital heart disease transferred from pediatric cardiology to an adult congenital heart disease program. *J Adolesc Health*. 2009;44:316-322.[fn]
 - Tour the adult center
 - Identify adult care team members, provide contact information (designated point person)

After transition to adult program:

- Arrange overlap visit—pediatric provider attends initial clinic visit
- Redefine roles and role expectations for the patient, parent, and adult provider[fn]Moons P, D, et al. Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. *J Adolesc Health*. 2009;44:316-322.[fn]

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.

Key Words: adolescence, transition of care, psychosocial development, mental health, cystic fibrosis

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