

Transition From Pediatric to Adult Care for Young Adults With Chronic Respiratory Disease

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Advances in medicine and technology have led to improved survival rates of children with chronic respiratory disease such as cystic fibrosis, neuromuscular disease, and ventilator dependence. Survival into adulthood has created the need for adult specialists for conditions originating in childhood. Transition from pediatric to adult health care is a process that requires advanced planning and preparation and is not a one-time transfer event. Transition should be standard practice, but many children with special health care do not experience successful transition outcomes. Barriers to successful transition include lack of a standardized process, inadequate planning, and poor communication. Adverse outcomes have occurred in cases of abrupt or haphazard transfers. A successful transition process includes early introduction and ongoing discussion that engages the adolescent to plan and prepare for the eventual transfer of care. Care responsibilities should be gradually shifted from the parent to the adolescent in a manner appropriate for the adolescent's age and developmental status. Good communication and collaboration between pediatric and adult care teams is crucial to ensure a smooth transfer of care. Incorporating the 6 core elements of transition can be helpful in developing a successful transition program. This narrative review summarizes the literature for health care transition from pediatric to adult care including the rationale, barriers, factors associated with successful transition, and special considerations. The intent of this review is to increase clinician awareness of health care transitions and the components necessary for an effective transfer of young adults with chronic respiratory disease. Understanding the transition process is an important consideration for both pediatric and adult clinicians, including respiratory therapists. *Key words: transition; transfer of care; pediatrics; adult-oriented care; special health care needs; cystic fibrosis; neuromuscular disease; cerebral palsy; ventilator-dependent.* [Respir Care 0;0(0):1-●. © 0 Daedalus Enterprises]

Introduction

Advancements in medical care and technology have led to increased survival of children with special health care needs who, in the past, would not have lived into adulthood.

Children with special health care needs are defined as those who have an increased risk for chronic conditions and require health services beyond those normally required.¹⁻³ This includes children with cystic fibrosis, neuromuscular disease, congenital heart disease, cerebral palsy, and

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chronic ventilator dependence, and others who require the routine use of respiratory devices to maintain pulmonary stability. It has been estimated that > 9 million children are considered to have special health care needs, and roughly 500,000 turn 18 y old each year.¹

The improved survival of children with chronic illness has created the need for health care transition from pediatric to adult care for adolescents and young adults with special health care needs. Health care transition is defined as the purposeful and planned movement of young adults with chronic medical conditions from child-centered to adult-oriented health care systems.⁴ A consensus statement regarding health care transitions for young adults with special health care needs reported that the goal of transition is to maximize lifelong functioning and potential through appropriate and uninterrupted services while moving from adolescence to adulthood.⁵

Transition from pediatric to adult care was established as a priority for children with special health care needs by the Maternal and Child Health Bureau in the *Healthy People 2010* initiative.⁵⁻⁷ Despite decades of work in this area, there has been little progress.^{8,9} A national survey of children with special health care needs revealed that the majority had not met transition outcome measures related to planning, and essentially no improvement occurred from 2005 to 2010.^{1,9,10} A survey of in-patient general pediatric services in U.S. children's hospitals showed that only 38% of respondents reported having transition initiatives.¹¹ Additionally, in a study of 139 hospitalized adolescents and young adults 15–21 y old, < 40% reported having received some form of transition preparation.¹²

Transition involves both primary care and specialty services. Medically complex children often have multiple specialists involved in their care.¹³ While physicians maintain a critical role in the transition process, it is important that all clinicians, including those on both the transferring (pediatric) and receiving (adult) sides, are informed about what medical transition entails. Respiratory therapists routinely care for both adult and pediatric patients with chronic conditions such as cystic fibrosis, neuromuscular disease, cerebral palsy, and similar diagnoses originating in childhood. While many therapists are not likely to be actively involved in the transition process, a basic understanding of health care transitions can help ensure a smoother transfer for young adult patients who move from pediatric to adult care.

This review summarizes the literature regarding health care transition from pediatric to adult care, including the difference between transition and transfer of care, the rationale and barriers, disease-specific models, and special considerations. Factors associated with successful transition and the 6 core elements are also discussed. The intent of this review is to increase awareness of the necessary components for an effective transition process. This information is applicable to both pediatric and adult clinicians who care for children and young adults with chronic respiratory disease.

Transition versus Transfer

It is crucial to note that health care transition is a process and not a one-time transfer event.^{7,13-18} The process involves careful planning and coordination leading up to the actual transfer of care. Good communication is key to avoid some of the potential pitfalls associated with haphazard transitions. This includes communication among the provider, the adolescent, and family as well as between the pediatric and adult providers.^{5,7,19} Poorly coordinated transitions have been associated with young adults with chronic conditions being lost to follow-up.²⁰⁻²² Abrupt transfers may also lead to strained patient-provider relationships and mistrust.^{17,18} Lack of transition planning support is a challenge for both youth with special health care needs and those without, but children with special health care needs are at a higher risk for adverse outcomes from gaps in transition care.^{10,14,15,23} Failure to plan or inadequate transition planning may also result in young adults with chronic illness such as cerebral palsy or congenital heart disease to continue seeking care in pediatric facilities, which can have financial implications for these institutions.^{24,25}

Rationale for Transition

Transitions are a normal part of life. Graduation, entering the workforce, marriage, and starting families all represent different types of life transitions. Transition to adult health care is no exception and should be presented as a positive event as children with special health care needs who previously did not survive are now becoming young adults.¹⁴ Planning for health care transitions should be standard for all adolescents and young adults regardless of their health care needs.^{23,26} Pediatric providers are typically not prepared to assist with concerns considered to be adult in nature, such as employment and reproductive issues, which are better addressed by adult clinicians.^{7,16,27} Depending upon disease severity and complexity, children with special health care needs often rely heavily on their parents and caregivers to provide and assist with their medical care at home. Throughout the transition process, adolescents should be engaged to begin learning self-management and

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self-responsibility in preparation for eventually assuming their care or certain aspects of care when possible.^{7,16,28}

Condition-Specific Models of Transition

In 1970, the median age of survival for a child with cystic fibrosis was 16 y.¹⁷ With advances and improvements in medicine and technology, this median age has increased to > 40 y.²⁹ Increased survival has elicited the need for adult providers specializing in cystic fibrosis care. The first adult cystic fibrosis programs in the United States were accredited by the Cystic Fibrosis Foundation in 1993, and by 2008 the Foundation required the majority of young adult patients to transfer to adult providers by 21 y of age.³⁰ Transition programs are now considered standard for cystic fibrosis centers.

While cystic fibrosis programs have become a model of transition care for other diagnoses, transition programs for other conditions with pulmonary manifestations have not been as prevalent. A survey of pediatric pulmonology programs found that most did not utilize a standard transition process for ventilator-dependent patients, and many did not have a process in place.³¹ Unlike the consensus report for cystic fibrosis adult care,¹⁷ there are no published guidelines addressing transition of ventilator-dependent patients from pediatric to adult care.³² Although a consensus statement exists for transition of children with special health care needs,⁵ different chronic conditions bring unique disease-specific considerations that must be taken into account. For example, most young adults with cystic fibrosis will likely be able to assume responsibility for their care. However, that may not be the standard expectation for adolescents with cerebral palsy or other similar conditions depending on the severity of cognitive impairment.³³⁻³⁵ In these instances, the parents often become legal guardians and remain involved in the young adult's care for the duration of their lifetime.³³

Barriers to Transition

Many factors can influence the process of transition from pediatric care to adult health care. Differences between pediatric and adult care, education and training, changes in health insurance, degree of medical complexity, availability of services, and perceptions of the patient, family, and provider all have an impact on the course of transition. Other potential barriers to successful transfer include lack of transition planning, abrupt transfers, inadequate communication, and insufficient coordination of care.

There is some evidence to suggest that pediatric care and adult care embody 2 different medical subcultures.³⁶ Pediatric health care is typically family-centered, whereas adult care tends to be patient-centered.³⁰ Pediatric providers are accustomed to directing discussions to parents, while

adult providers communicate directly with the adult patient.¹⁴ These differences in the culture of care may present challenges for parents and caregivers of children with special health care needs if they have not been prepared for this change or if they have not involved the adolescent in decision-making or encouraged self-management. Patients and families often develop strong ties and long-standing relationships with the pediatric clinicians who have been involved in their care for many years and may be reluctant to transfer services.^{14,27,37}

Adult providers may be unfamiliar with many of the chronic conditions with a childhood onset and may not have received specialized training in providing care for young adults with these conditions.^{14,22,36} This has contributed to a lack of available adult providers and specialists who are experienced in caring for individuals with chronic illness originating in childhood.^{14,19,22} Studies evaluating resident and fellow physician training for transition care have indicated that very few received formal education and training for transition as part of the curriculum.^{38,39} It is unlikely that transition training is included in nursing or respiratory therapy programs, but it is an important consideration in caring for both adult and pediatric patients with chronic conditions with childhood origins.

Continuation of health insurance coverage has been an ongoing issue in health care transitions, but this has improved somewhat in the last decade. The Affordable Care Act and Medicaid expansion were both instrumental in ensuring better access to care and reducing gaps in coverage.⁴⁰ The provision of coverage through age 25 and the elimination of preexisting condition exclusions were key factors in improving care access. However, Medicaid coverage and benefits vary by state. Resources, services, and support accessible by children with special health care needs may not be offered to young adults and could have an impact on availability of durable medical equipment, medications, and home nursing services.³²

Clearly, the most evident barrier to successful health care transition is not having a process. Sudden and unexpected transfers of care have resulted in significant issues in young adults with chronic illness such as being lost to follow-up or forgoing care, poor adherence, and increased hospitalization.¹⁹⁻²² Some cases of abrupt transitions have been precipitated by crisis events such as pregnancy and nonadherence or meeting milestones such as high school graduation.^{15,41} There is a difference between eligibility for transition and readiness.¹⁹ Meeting age criteria for transition does not necessarily indicate readiness to transfer. Readiness requires advance planning and preparation. Preparation and planning are vital to ensure a smooth transfer from pediatric to adult care and to provide a positive experience for all involved, including providers and clinicians.

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Table 1. Health Care Transition Timeline

Event	Age				
	12	14	16	18	18–22
Introduction to transition policy	Begin transition planning	Prepare for adult care model and discuss transfer	Transition to adult care model	Transfer care	

Adapted from Got Transition (available at: <https://gottransition.org>).

Factors Associated With Successful Transition

While there are multiple attributable causes of failed transitions, components of care can be implemented to promote an organized and coordinated transition process. Recommendations vary for when to begin discussions regarding eventual transition to adult care and range from age 12 to 14 y.^{5,8,19,22,26,42} It is never too early to begin planning for the future. Introducing the idea of transition sooner rather than later allows time for acceptance and preparation. Some transition models for cystic fibrosis have suggested introducing the concept around the time of diagnosis to help set the expectation of surviving into adulthood and becoming independent.^{17,18,29} Table 1 includes recommendations for a transition timeline.

Providers and clinicians should engage adolescents in their care as developmentally appropriate.^{4,19,26} Adolescents with chronic respiratory disease should be knowledgeable about their condition and be involved in decisions that impact their care. Transition planning should be a shared responsibility of the care team, the patient, and parents. Care responsibilities can be gradually shifted to the adolescent as suitable for age and development.¹⁸ Initial tasks could involve identifying medications and treatments and can progress to understanding the purpose of each one.¹⁸ Adolescents who require aerosol or airway clearance therapies could learn to administer their own therapies if they are physically and intellectually able to do so. Eventually the adolescent might begin to address the care team directly with input from parents when needed.¹⁸ Self-management should be encouraged to foster eventual independence.⁷

Communication between the pediatric and adult care team is vital to the success of transition.^{5,19,41} Good communication facilitates collaboration and coordination of care. The pediatric provider should prepare and maintain a medical health summary that is portable, accessible, and involves the adolescent and family.^{5,19,28,41} This summary provides crucial information about the young adult patient to the adult providers and promotes collaboration between care teams.⁵

Utilization of a transition service coordinator or patient navigator can enhance the success of transition programs and facilitate a seamless transfer of care.^{17,43–45} The role of the coordinator is to ensure that the transition plan is

created and to assist with scheduling the initial adult out-patient clinic appointment.¹⁷ One pediatric institution has reported having a multi disciplinary consultation service to coordinate transition care for medically complex patients.⁴⁶ Having a dedicated individual or team assigned to assist with the transition process can help minimize gaps in service. Through personal experience in a pediatric out-patient pulmonary clinic, respiratory therapists have played key roles in the transition process for patients with cystic fibrosis, neuromuscular disease, chronic ventilator dependence, and other chronic respiratory conditions by coordinating care with adult pulmonary clinics.

Having a medical home has been associated with an increased probability that children with special health care needs receive transition planning and preparation.^{1,9,10} The concept of the medical home is to provide comprehensive primary care for those with special health care needs.¹³ This approach provides an ideal environment to deliver coordinated care that incorporates transition planning.

There are several key points regarding the transfer of care event to keep in mind, including interim care and transfer follow-up. The pediatric team should ensure there are enough prescriptions and supplies to last until the first adult appointment. If the young adult becomes acutely ill or experiences other issues after the last planned visit with the pediatric provider but before scheduled evaluation with the adult provider, the pediatric care team should be available to address those needs. Follow-up from the pediatric side with both the adult clinic and the young adult should also occur to ensure the appointment was attended and to assist the adult team with any questions they may have.

Special Considerations

Transfer of care should ideally occur between the ages of 18 and 21 y.²⁶ However, there are special circumstances that must be considered. Visits with the adult provider should not occur during times of acute illness; initial evaluations are best done during times of medical stability to begin establishing new relationships. Adolescents in end-stage disease or who are actively dying should not undergo the transition process and should remain with the pediatric team throughout those difficult situations.²⁹

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Table 2. Six Core Elements of Transition

Element	Description
Transition policy	Develop a policy with input from patients and families
	Ensure all staff are educated on policy and 6 core elements
	Introduce policy to patients and families beginning at age 12
Tracking and monitoring	Establish criteria and procedure for identifying adolescents ready to begin transition process
	Utilize a flow sheet or registry to track progress
Transition readiness	At age 14, begin performing regular transition readiness assessments
	Identify needs and discuss goals for self-care
Transition planning	Update readiness assessments, goals, and medical summary
	Prepare for adult-care approach beginning at age 18, including legal considerations for decision-making, privacy, and consent
	Discuss timing of transition
	Assist with identifying adult providers
Transfer of care	Plan transfer during a time of medical stability
	Transfer records to adult care team
	Communication between pediatric and adult providers
Transfer completion	Confirm that first appointment was attended
	Collaborative partnership between pediatric and adult care team

Adapted from Got Transition (available at: <https://gottransition.org>).

Adolescents with intellectual disabilities also represent unique considerations.^{30,33,34} While many young adults with chronic respiratory disease are able to live independently and manage their own care, there are a subset who will be unable to do so. In these situations, parents and caregivers remain involved to varying degrees in decision-making and providing care and are often appointed as legal guardians when necessary.³³ The traditional transition process may look differently under these circumstances.

Six Core Elements of Transition

In collaboration with the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health, the Got Transition Center for Health Care Transition Improvement was established (<https://gottransition.org>, Accessed June 11, 2020). Got Transition provides information and resources to help establish transition programs and processes, including the 6 core elements of transition: transition policy, tracking and monitoring, readiness assessment, transition planning, transfer of care, and transfer completion. These elements are not necessarily intended to be a model but rather to provide a customizable framework to

implement transition processes. Details regarding what each element entails can be found in Table 2.

Respiratory Therapists' Role

While many respiratory therapists may not be directly involved in the transition process for young adults with chronic respiratory disease, a basic understanding of the rationale and concepts can be valuable for all clinicians. The role of the respiratory therapist continues to evolve as opportunities expand to out-patient clinics and other settings beyond in-patient units. Some therapists with specific responsibilities in cystic fibrosis or home ventilator programs have had the unique experience of assisting with transition and transfer of care. It is possible that respiratory therapists are underutilized in this area, and increased involvement could have a positive impact on transition outcomes.

Through personal experience as a previous out-patient coordinator of a pediatric home ventilator program, I had the opportunity to be involved in developing a transition program and supporting patients and families throughout the process. It was a humbling experience at times, and much knowledge was gained. All therapists and clinicians who work with young adults with chronic respiratory disease in any capacity are encouraged to become familiar with the institutional transition policy and procedures and to seek resources to learn more about health care transitions. It could mean the difference between a smooth and seamless process or a bumpy and fragmented transfer event.

Summary

Health care transition from pediatric care to adult-oriented care is a major life event for young adults with special health care needs. Transition is a process and not a one-time transfer of care event. Advanced planning and preparation are vital to ensuring a successful transition to adult care. Collaboration and communication between pediatric and adult care teams are essential components to promote a structured and organized transfer of care. Knowledge and education regarding transition processes is an important consideration for both adult and pediatric clinicians.

Although transition is not an entirely new concept, research and related outcomes are still relatively young as some institutions are only beginning to introduce transition programs and incorporate new processes. There are many future research and quality-improvement opportunities, such as comparison of transition models, development of training programs for clinicians, and establishment of standard practice guidelines. Health care transitions for young adults with chronic respiratory disease may also

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represent new opportunities to increase the value of the respiratory therapist.

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