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Transition of Children with Neurological Disorders

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Abstract

Purpose of the Review The goal of the article is to describe a systematic approach through core principles and steps for the transition of the patient with a neurological disorder to the adult model of care, to provide steps and principles to help receiving providers successfully integrate the patient into their practice, and to discuss cultural, systemic, and discipline-based barriers to transition.

Recent Finding The literature has expanded rapidly. The recent publications help define the barriers to the process and are currently exploring the best methods to evaluate readiness, needs, barriers, and develop solutions for best practices. There is a consensus that there is a need for a systematic approach to transition and integration of the patient with a neurological disorder.

Summary The transition of the child and youth with special health care needs (CYSHCN) is complex with multiple barriers. An important concept is that these patients, their families, and medical care providers all benefit from a coordinated and collaborative methodology.

Keywords Transition · Tools · Barriers · Transfer · Models of care · Core elements

Introduction

Each year in the USA, more than 500,000 youth leave pediatric care and enter adult services, but only 40% of these individuals receive transition support that meets recommended criteria [1–3]. The primary goal of any patient's transition is to ensure that there is not an interruption in their healthcare delivery as they progress from the pediatric to the adult care system. Children and youth with special health care needs (CYSHCN) utilize health care more intensely than their peers: almost one half of all pediatric expenditures are for CYSHCN, primarily due to a higher utilization of inpatient care, and higher rates of readmission [4]. This article focuses on transitioning young adults living with neurologic conditions, a subset of the 18% of children and youth ages 12–18 who have special health care needs [4].

CYSHCN with neurological conditions pose particular challenges in transition. There is a wide spectrum of neurological disorders, including neuromuscular disorders with normal mentation; disorders in which cognitive or behavioral deficits are primary, such as intellectual disability or autism; and comorbidities from other disorders, such as epilepsy. Advances in medical care and therapeutics now allow patients with diseases that were once fatal in childhood to live into adulthood. The physicians who receive these patients in transfer may encounter diagnoses that are unfamiliar to them and that they have no experience in managing.

Without a structure to address transition, fragmentation and duplication of efforts are inevitable. A systematic approach helps to make sense of a complex process and to break the process down into achievable goals. But flexibility to address the specific requirements of a condition or the unique capabilities and limits of practice is necessary. General guidelines and tools may help to meet these needs and reduce the burden of transition for CYSCHN with neurological conditions and their health care providers.

GotTransition (http://www.gottransition.org) defines six Core Elements of Health Care Transition: Transition Policy, Tracking and Monitoring, Transition Readiness, Transition

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Planning, Transfer of Care, and Transition Completion. The Child Neurology Foundation convened a transition workgroup that created greater justification and further definition of the principles of transition for youth with neurological conditions [5••]. The CNF Transitions Project Advisory Committee formed in this effort also created a toolbox for providers and one for patients with neurological disorders (www.childneurologyfoundation.org/transition). These resources have primarily targeted pediatric providers, outlining a systematic approach for these providers to play in preparing their patient and families for transition. Adult providers also have roles to play in supporting transition and must be supported in preparing themselves and their practice to care for transitioning patients.

The websites gottransition.org and childneurologyfoundation.org offer extensive information and toolkits for clinicians. Importantly, these resources apply to both pediatric and adult health care providers. There are excellent and specific resources on the Gottransition.org to support the receiving adult providers as they integrate transitioning patients.

Steps to Transition

Transition is not transfer. Transition is an extended process that begins in early adolescence and provides a staged and gradual assessment of readiness, as well as tools and education to assure a successful move to adult care. Patients, families, and the treating pediatric health care providers frequently feel that the need to change healthcare models arises abruptly due to external factors.

Transition of CYSCHN

The steps to transition begin in early adolescence with the recognition that transfer will eventually occur. A smooth transfer or change of responsibility for health care from one physician to another represents the culmination of a successful transition. Systematic steps, as identified in Table 1, are required both before and following the transfer of care to accomplish this goal [6].

Table 1 Systematic steps are required both before and following the transfer of care to accomplish this goal

Core elements/steps in transition
1. Transition policy
2. Tracking and monitoring
3. Transition readiness
4. Transitioning to adult health care providers or integrating the young adult into adult health care
5. Transfer of care
6. Transfer completion

Tools are available to complement the goals in each of these defined steps (see Table 2). The Child Neurology Foundation accepted the challenge from the American College of Physicians (ACP) to modify the Got Transition website tools for use in patients with diverse and complex neurological disorders. The toolbox created by CNF focuses on these needs and is directly applicable to clinical practice.

Evaluation of instruments and tools is underway. Instruments to measure readiness for transition to adult health care, for example, are still in development. Currently, the most frequently used readiness measure is the TRAQ [7–11].

In pediatric care, establishing the anticipation that a transition will ultimately occur sets a framework in which the steps may seem more gradual. Changes in legal status, care providers, models of care, funding, care responsibilities, and social support for the patient and the family often make the milestones of a patient turning 18, and then 21, feel less like a celebration than like falling off a cliff. A systematic and logical transition eases these changes, although significant challenges remain. Patients and families are often reluctant to end their long-standing relationship with the pediatric provider. Identifying an accepting physician is often very difficult, and the time that complex care demands, as well as the financial obstacles this poses, are major barriers to a practicing physician who has heavy clinical demands.

Integration of the CYSHCN

When integrating a transitioning patient into an adult practice, elements similar to those advanced for pediatric practices are employed. Table 3 compares the steps and illustrates the similarities.

First, a policy that explains the adult clinic expectations and the philosophy concerning accepting and partnering with the patient should be developed and shared with new patients and, where appropriate, caregivers. This policy should include privacy and consent rules. Optimally the patient will have contact with the office and orientation before the visit. In busy practices, this is difficult.

Tracking and monitoring involve identifying the patients in this age group who are transferring from another provider and following their progress through the stages of transition. Transition Readiness includes a review of the patient's goals and capabilities and the legal aspects of healthcare transition, as well as their need for education about their disorder and its management [12]. This stage also involves orientation to the model of self-reliance that characterizes adult practice. An individual practice may identify providers interested in caring for young adults as well as those providers interested in the care of these patients with more complex care needs.

The final steps of transition and integration into adult practice involve communication with the patient's prior provider and consultation as needed. In addition to medical records and

Table 2 Transition steps and tool box

Transition steps	Available tools*
Transition policy (ages 12–14)	Letter/policy*
Transition tracking and monitoring (ages 14–18)	-Potential EMR templates -Flow sheets
Transition readiness assessment and plan of care (ages 14–18)	-Self-care assessment forms for parent and youth* -Patient's transition goals and priorities*
Transitioning to adult health care provider (ages 16–18)	-Medical summary and emergency plan* -Consents for release of information
Transfer of care (ages 18–21)	-Transition package: • Transfer checklist * • Transfer letter* • Plan of care* • Updated medical summary and emergency care plan* If needed: a. Legal documents (family) b. Medical fact sheet c. Additional provider records
*Tools available from: 1. gottransition.org 2. childneurologyfoundation.org (modified for patients with neurological disorders)	

Adapted from Gottransition.org and Childneurologyfoundation.org

any pertinent legal documents, a transition package should include documents that address the youth's goals, readiness, health priorities, and concerns. A medical summary and emergency plan is very helpful and should be updated regularly. The transfer of care occurs with the first visit and successful initiation of ongoing care.

Cultural Barriers to Transition

Some of the barriers to transition are culturally based. Interestingly, child neurology as a field is said to have "Pediatrics as its mother and Neurology as its father." The pediatric model is substantially different than the adult model: The broad family-centered approach typical of pediatrics stands in sharp contrast to the individual focus that characterizes classical adult care. Families often resist transition, because they have grown accustomed to a system that is very different than the one that they will be entering.

The pediatric approach to medical care delivery is comprehensive, both patient- and family-centered, and based on the medical home. The relationship is prolonged and developmentally based. This nurturing environment is supportive of both the patients and the families. The progression to the adult model of care with its inherent requirement of patient autonomy can be challenging, especially for patients with special needs. In the case of CYSHCN, impediments to delivering ongoing specialty medical care may arise as the patient approaches adulthood.

While patients with complex pediatric-specific disorders may continue specialty care for a longer period in the pediatric setting, other aspects of their care, such as general medical management, often need to be transitioned to adult medicine. Understandably, as patients age, they may develop conditions typically seen in adulthood (e.g., pulmonary or cardiac disorders), for which adult specialists are the most appropriate caregivers. Pediatric-based medical systems that require that patients of a certain age receive all care in adult facilities compel the transfer to adult care. Exceptions to these policies vary by the specific pediatric disorder and facility.

The autonomy of the patient and the patient's responsibility for their care is a major underpinning of the adult approach. Preparing patients for this disease-centered and individual-focused approach requires pediatric providers to support a gradual progression to self-care and anticipatory guidance [13]. Appropriately increasing self-responsibility is important to prepare the youth for the maximum level of independence and added responsibility. In comparison to the developmentally typical patient, the transition process is more complex in the patient with a significant disorder of development, intellect, behavior, or other chronic or degenerative disorder.

Table 3 Transition and integration steps: the six core elements

Transitioning from a pediatric care practice	Integrating into an adult care practice
1. Transition policy • Describes the practice's approach to transition	1. Young adult transition and care policy • Develop a policy outlining the practice's approach to accepting new young adults
2. Transition tracking and monitoring • Identify youth and incorporate into EMR if possible • Flow sheets are helpful to track the six core elements	2. Young adult tracking and monitoring • Establish criteria and process for identifying young patients • Flow sheets are helpful to track the six core elements
3. Transition readiness • Conduct readiness assessments beginning at 14 yr • Jointly develop goals with youth and caregivers	3. Transition readiness/orientation to adult practice • Identify adult providers in the group interested in caring for young adults or specific health care needs
4. Transitioning youth to adult health care providers • Develop medical summary and emergency care plan • Determine the need for legal referral for changes in decision making in patients with intellectual challenges • Obtain consent for release of information • Share resources- insurance, self-care, community services • Plan time for optimal transfer	4.Integrating young adults into adult health care • Communicate with the pediatric healthcare provider if necessary • Before visit ensure the receipt of the transfer packet • Provide linkages to resources such as insurance, self-care, and community support
5. Transfer of care • Confirm the date of the adult provider appointment • Complete the transfer package • Prepare letter to send with package • Reassure current providers will be available if questions arise from the new provider	5.Transfer of care and initial visit • Review the transfer packet and medical summary • Review if competency is an issue and the caregiver's rights • Review the young adult's health priorities • Update the medical summary
6. Transfer completion • Contact the youth or family/caregiver to confirm transfer • Confirm with the adult practice that all was in place	6.Transfer completion and ongoing care • Communicate with the pediatric based practice and consult if needed • Assist the young adult to connect with adult specialists • Continue ongoing care management

**Adapted from gottransition.org

Patient Barriers to Transition

A study of the transition and transfer of patients with congenital heart disease provided additional guidance regarding enablers and barriers to successful transition. As investigators focused on the significant numbers of patients lost to follow up, they identified important factors that influenced compliance. These factors included the patient's belief that specialized care as an adult is necessary, poorer health status, appointments independent of their parents, and referral by the pediatric practice to the specialized adult caregiver. The data also pointed out the concerning findings that youth with complex medical conditions expressed a lack of concern about transition and limited knowledge about their condition [14]. This study underscores the need for providers to educate youth about their disorders and the implications of noncompliance. The physician and family have the added responsibility of also taking additional responsibility until youth are developmentally ready to do so themselves.

While all individuals, including patients with chronic medical conditions, have a right to attain their maximum level of self-sufficiency, families and physicians frequently view patients with chronic or complex conditions as much more dependent than their peers. In studies of patients with chronic disorders, the adolescent patients themselves recognized and expressed a need for increased autonomy [15, 16]. The adolescents reported significant issues in being permitted to make their own medical decisions and being allowed to see the physician without their parents. Relinquishing the role as primary decision maker is often exceptionally difficult for the families. There is need on the "pediatric side" to maximize the patient's ability to make decisions.

Providers Barriers to Transition

Child neurologists and other pediatric healthcare providers define the identification of a receiving adult medical provider as a major obstacle to successful health care transition [17•]. There is a reluctance for the adult providers to accept CYSHCN. Compiling a list of accepting neurologists and other caregivers and then directly communicating with them allows for better collaboration for all involved. Providing this list to the family helps empower them in their decision-making. There is no question that the transition process for CYSHCN demands more time than for the average patient. The medical home, through primary care, is a major component of the process. A team approach with the engagement of the medical home and all subspecialty providers is certainly optimal in meeting all the demands of transition. There is support from both adult and pediatric providers for joint meetings with the patient, the presence of a transition coordinator and a written transfer plan [18,19••]. The primary medical home provider or one of the subspecialty providers can provide leadership of the team depending upon patient needs and provider capabilities. In truth, for CYSHCN where the main medical problem is neurological, this often falls to the child neurology team. An important message is that the value and need for the medical home do not conclude when transition and transfer are complete. The new primary care provider, whether an internist, family practice physician, or other, can benefit their patients by maintaining the medical home concept. The concept helps ensure compassionate collaborative care. Just as during pediatric care, the practice of medical specialist such as an adult neurologist may best fill the role. Here, the utilization of the child neurologist as a resource and available "consultant" for complex patients is valuable and offers support to the new medical provider.

A review of the obstacles to transition as defined by adult physicians helps identify the needed interventions and policy changes that can advance successful transition. Two of the most frequently identified barriers for adult neurologists are education and provider reimbursement. With pediatric patients now living into adulthood with complex disorders, including those previously thought to be fatal before the age of transition, there is a need for additional disease-specific and developmental education for adult caregivers. Additionally, the care of complex patients requires substantially increased time and resources. Therefore, funding to account for the higher care demands is necessary.

The reluctance of adult providers to care for CSHCN is not exclusive to subspecialists. A survey of adult-centered hospitalists regarding their perspective in caring for adults with chronic disorders that had a childhood onset revealed that 40% did not feel comfortable caring for these patients. The factors defined as obstacles/impediments included lack of training in adolescent development and the appropriate care of this complex group of disorders, along with deficient knowledge of the literature. The increased demands of care coordination with multiple specialties were also a deterrent [20]. In a review of adult neurologists' treatment comfort in caring for childhood-onset conditions, the highest reported confidence was in the care of youth with a headache and epilepsy. Neurologists' level of comfort dropped substantially in the care of patients with cerebral palsy, neuromuscular disorders, and most dramatically in patients with autism, cognitive/behavioral, chromosomal, or metabolic disorders. Fifty to 60% of respondents reported were not comfortable treating patients with these diagnoses [21•].

A less-discussed impediment to the acceptance of these patients is that the care requires redirecting decision-making from the patient to the family or caregivers. In CYSHCN who have significant impairment and limitations in their competency, the caregivers must be involved and appropriately informed to make medical decisions. Although this caregiver involvement is considered an added impediment to care for CYSHCN, there are direct parallels in geriatric care and individuals with dementia or any other disorder that affects a patient's ability to care for themselves. Here, the family is increasingly involved, and there is a gradual modification of the autonomy of the patient as the patient become less self-reliant. Care comes full circle.

Adult providers have stated in surveys that they feel ill-prepared to deal with developmental issues. A provider can relate by reflecting on how one talks and interact with their child or a niece, nephew, or grandchild. An adult can easily recognize the differences in literacy and knowledge and by doing so can "meet" the young child at the child's developmental level. In the same way, the recognition of limitations but also of capabilities allows a provider to relate to a developmentally disabled individual of any age. In this circumstance, a parent or caregiver is often necessary to provide care and support for the disabled patient. No one knows the patient better than the parent or caregiver. This "challenge" actually provides a wonderful opportunity to utilize caregivers as knowledgeable resources.

Importantly, while the transition process may seem like a new and additional burden on the receiving health care provider, in many ways, a transitioning patient is similar to a patient who presents for a second opinion evaluation. We are all very familiar with this practice and recognize the challenges. Whether one is the referring or receiving physician, it is best accomplished when the essential records and a medical summary are available.

Supporting Successful Transition

Education is not only needed for patients and families but also for providers in practice and currently in training. A survey assessed residents' preferences for curriculum regarding health care transitions for young adults and found their recommendation to be a curriculum that is continuous throughout training (80%) and includes clinical experiences (79%). Additionally, over half of those surveyed endorsed case discussions, lectures, and didactics. Interestingly, pediatric residents were statistically more likely than the internal medicine residents to perceive that there was value in seeing either older or younger patients than their program requires. Internal medicine residents prioritized as high need or of interest medical information on pediatric diseases that persist into adulthood and "caring for adult-aged patients reliant on caregivers" [22]. Practicing adult neurologists also endorsed the need for further training to provide appropriate care for YSHCN. Specific areas of need included education on child development and in disorders less prevalent in classic adult neurology practice.

The need for and complexity of transition must be conveyed and understood by third-party payers, including the government. There is a need to advocate for coding and payment for the services and the additional time necessary to appropriately educate and support the transition of a patient. There should be suitable payment for the accepting physician who will take the added responsibility of patients with special health care needs; there is no question that these patients require more time and support.

The value of transition—its benefit relative to cost—needs recognition on a national level [23]. Achieving this goal will require advocacy at all levels and can originate from disease-specific advocacy groups, medical societies, agencies, and individuals. Third-party payers, including the government, must understand that only with suitable payments will physicians and other healthcare providers be able to successfully provide the added care requirements of patients with special health care needs.

Conclusion

Over 90,000 youth with special health care needs leave pediatric care and entering adult services each year. This vulnerable population is particularly at risk for deterioration of their health during this period in their lives [24]. A staged transition process for children and youth with special health care needs (CYSHCN) is now recognized as a valuable practice to address the progression from pediatric to adult health care. There are common needs for all individuals with special health care needs, but those with neurological conditions pose particular challenges. The challenges are not only medical, reflecting the complexity of many of the diagnoses, but they are also further complicated by associated intellectual and behavioral issues.

Pediatric providers find the major obstacle to transitioning their patients to be the lack of accepting adult providers. On the other hand, the adult providers define the major obstacles to accepting CSYHCN education in the specific neurological disorders and the lack of knowledge of development. Adult neurologists, as well as adult hospitalists, are frequently not comfortable caring for these patients. This discomfort is especially true outside of the diagnoses of headache and epilepsy.

The concepts and associated tools discussed in this article support the primary goal of ensuring that there is not an interruption in healthcare delivery as the patient progresses from the pediatric to the adult care system. The six stages that begin in mid-adolescence build upon one another to systematically lead to a more seamless transfer between providers. This transfer is the culmination of a successful transition and leads to the provision of support, tools, and needed medical information for the accepting physicians and other healthcare providers. The accepting physician then becomes the home for medical care for these patients. An approach as described in the article supports a systematic integration of the patients and a lifetime of compassionate care.

Compliance with Ethical Standards

Conflict of Interest Ann H. Tilton reports personal fees from Ipsen Pharmaceuticals and Eisai, outside the submitted work.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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