JNP

Transitioning Youth With Attention Deficit Hyperactivity Disorder to Adult Health Care

Dianna D. Inman, DNP, CPNP-BC, Leslie K. Scott, PhD, PPCNP-BC, and Mollie E. Aleshire, DNP, FNP-BC

ABSTRACT

Attention deficit hyperactivity disorder (ADHD) is one of the most common childhood neurodevelopmental diseases and nearly two thirds of children with ADHD have symptoms that persist into adulthood. Approximately 750,000 children with special health care needs transition from pediatric to adult health care annually in the United States. For youth with ADHD, organized, coordinated, and systematic care transition from pediatric to adult health care providers is essential to prevent negative consequences related to unmanaged ADHD symptoms and to optimize health and promote maximum functioning. The Got Transition model's 6 core elements provide a guide to support successful transition for adolescents with ADHD.

Keywords: ADHD, adolescent, transition, transition care, young adult

© 2017 Elsevier Inc. All rights reserved.

INTRODUCTION

Attention deficit hyperactivity disorder (ADHD) is one of the most common neurodevelopmental diseases in childhood,[1] and > 60% of children with ADHD will have symptoms that persist into adulthood.[2] Each year in the United States approximately 750,000 children with long-term health care needs transition from pediatric health care to adult health care.[3] The health care transition is a process that requires an individualized, multifaceted, collaborative approach by the interprofessional health care team, adolescent, and family to ensure the adolescent has continuity of appropriate health care services as they move from the child-focused to the adult-focused health care system.[4-6] For youth with ADHD, an organized, coordinated, and systematic transition of care from pediatric health care providers to adult health care providers is essential to optimize health and promote maximum functioning.[4,5,7] Our purpose in this study was to describe the 6 core elements of Got Transition model and recommend strategies for nurse practitioners (NPs) to implement this approach for successful transition of adolescents with ADHD to adult health care services.[5]

BACKGROUND AND SIGNIFICANCE

ADHD

Eleven percent of US children 4-17 years old (6.4 million) have been diagnosed with ADHD. Rates of ADHD diagnosis differ by gender, with 13.2% of boys and 5.6% of girls having been diagnosed with ADHD during their lifetime.[8] Although the prevalence of children ever diagnosed with ADHD varies substantially by state, from a low of 5.6% in Nevada to a high of 18.7% in Kentucky, the overall percentage of US children with an ADHD diagnosis has steadily increased since 2003.[8,9]

ADHD is often considered a disease of childhood, yet more than half of individuals with ADHD as youth have symptoms that persist into adulthood, and these symptoms often cause functional impairment and emotional distress. It is estimated that 2.5%-5% of adults in the US have symptoms of ADHD and experience disability related to these symptoms.[10] Although individuals with ADHD can

Downloaded for Anonymous User (n/a) at University of Kentucky from ClinicalKey.com/nursing by Elsevier on April 07, 2021. For personal use only. No other uses without permission. Copyright ©2021. Elsevier Inc. All rights reserved.

be highly functional in adulthood, unmanaged symptoms associated with ADHD may have negative consequences. These symptoms, particularly inattentiveness, impulsivity, and hyperactivity, can interfere with an adult's personal, social, and economic quality of life, and are also associated with risk for persistent problems with relationships, employment, substance abuse, delinquency, and accidental injuries.[7,10,11]

Transition of Care

Transitioning youth with chronic conditions or disabilities to adult health care is not novel; however, the complexity of transition and the negative outcomes associated with poor transition of care are becoming more apparent.[6] Although the need for continued health care often exists, health care services and health care providers available during childhood and adolescence can abruptly become inaccessible when a young adult reaches a certain age (often at age 18 or 21) or a life-event occurs (eg, high school or college graduation, pregnancy, or employment).[7]

In 2011, the American Academy of Pediatrics (AAP) suggested that the primary goal of transition of care should be to "maximize life-long functioning and well-being for all youth, including those who have special health care needs."[4(p182)] Transition of care entails much more than referral to adult health care providers; appropriate transition allows young adults to assume adult roles and functioning and fosters autonomy and self-reliance.[4] Despite nearly a decade of research and recommendations related to transition of care for adolescents with chronic health needs, evidence-based guidelines are only recently becoming established,[4] and are often not implemented in practice for ADHD transition of care.[7]

Ineffective transition from pediatric to adult health care is often associated with poor health outcomes and loss to follow-up.[12] In Ogundele and Omenaka's study of transition of health care for adolescents with ADHD, only 15% of the adolescent participants successfully transitioned to adult services.[13] Early, evidence-based transition planning is essential to ensure continuity of care, promote treatment adherence, and aid youth with ADHD to acclimate to new life circumstances and avoid educational, social, and vocational problems; therefore, health care providers' duty is to assist adolescents with ADHD and their families throughout the transition process to adult-centered health care.[7]

TRANSITIONING CARE

Facilitators and Barriers to Transition of Care

Transition to adult-centered health care is not an event but rather a process that occurs over time and is a part of normal adolescent development.[6] The transition process should begin in adolescence and serve as a purposeful and planned movement from a child-centered to an adult-oriented health care system.[4] The AAP (2011) recommends that, by age 14, youth have an established transition plan of care that addresses medical, social, and psychiatric care.[4] Transition plans should be formulated collaboratively by the adolescent with ADHD, the adolescent's family, the pediatric health care providers, and the adult health care providers. Effective transition programs include developmentally appropriate care (suitable for both the youth's chronologic age and developmental stage), increasing levels of health care autonomy and responsibility for the adolescent, collaboration among health care providers, provision of community resources, a documented transition plan, and a designated health care team member who monitors transition.[4] Although employing an evidence-based transition of care approach is essential, transition plans must concurrently be patient-centered and individualized, because each transition is influenced by unique cultural, environmental, socioeconomic, medical, and other factors.[4-7]

Effective transition to adult-centered health care also requires awareness of and assessment for common provider, patient, and health care system barriers that may hinder transition of care for youth with a diagnosis of ADHD.[7,14,15] Some pediatric health care providers have reported a "fear of letting go" of adolescents with special health care needs.[14] In addition, there is often a paucity of adult health care providers with the needed knowledge and training to treat adult ADHD.[7,14,16] Adolescents and their caregivers may be afraid of "moving on" from their known pediatric health care team to the unknown adult health care system[7] and often face health literacy challenges. Impediments within the health care system that can negatively impact transition

Downloaded for Anonymous User (n/a) at University of Kentucky from ClinicalKey.com/nursing by Elsevier on April 07, 2021. For personal use only. No other uses without permission. Copyright ©2021. Elsevier Inc. All rights reserved.

include challenges related to access to care and health insurance coverage, inadequate meaningful use of technology, a lack of transition guidelines and readiness assessments, an unclear plan for time of transition, and stigmas associated with mental health disorders.[7,17] As pivotal members of the interprofessional health care team, NPs are well-prepared to lead and facilitate the transition of care process for youth with a diagnosis of ADHD.[6]

THE GOT TRANSITION MODEL

The Got Transition model is an evidence-based approach for implementation of recommendations for adolescent transition to adult health care established by the AAP, American Academy of Family Physicians, and American College of Physicians.[4,5] Got Transition has been studied in both primary care and specialty settings and has been found to be an effective guideline for the transition process.[5,18,19] Updated in 2014, the current model consists of 6 core elements that comprise the basic components of health care transition support in clinical settings. These components include establishing a transition policy, tracking and monitoring transition progress, assessing transition readiness, planning for transition to adult health care, transferring to adult health care, and completing transfer of care.[5] The Figure provides web resources for implementing the Got Transition model, including samples associated with each of the 6 core elements.

Core Element 1: Establish a Transition Policy

The first step in transitioning adolescents with ADHD to adult health care providers is to collaborate with youth and families to develop a transition policy outlining the practice's approach to transition and including details related to privacy and consent.[5] When developing a transition policy, circumstances that commonly affect youth with ADHD must be considered. For example, the age of termination of pediatric health care services often differs based on numerous factors, and adolescents who enter the workforce may transition care earlier than adolescents who enter college. Other factors to consider when establishing a transition policy include the possible ramifications of cultural preferences, out-of-state college attendance, relationship/marriage status, pregnancy, parenthood, and comorbidities.[5,6,20,21]

Once a transition policy has been developed, all health care providers must receive training about the policy and the distinct roles of the adolescent, family, and pediatric and adult health care teams in the transition process. A practice's transition policy should initially be shared with the adolescent with ADHD and their family at ages 12-14 years (assuming age-appropriate development), and the policy should be reviewed with the patient and family at least annually until full transition to adult health care.[5]

Core Element 2: Track and Monitor Transition

The second step toward effective and quality transition of youth with ADHD to the adult health care system is to establish a standardized transition tracking and monitoring system.[5] The AAP considers the use of electronic health records (EHRs) a means to improve the quality, efficiency, and safety of pediatric care,[22] and thus, the EHR should play an integral role in the transition to adult health care.[23] A transition tracking and monitoring system should include established criteria to identify youth who are transitioning or need to begin transitioning care as well as a process to track transition progress. Clinical decision support systems within the EHR can assist in the identification and tracking process by alerting clinicians when adolescents with ADHD meet certain criteria, indicating they may need to begin or progress in the process of transition of care.[24] Individual transition flow sheets then may be utilized to populate a registry to help monitor the transition process within the larger patient population.[4,5]

Core Element 3: Assess for Transition Readiness

Transition readiness assessment, the third transition step, should begin at 12-14 years of age and be scheduled at least annually with youth and families to identify and discuss individualized needs and goals for self-management of ADHD and transition to adult health care providers.[4,5,25] Readiness assessment topics should include the ADHD diagnosis, long-term health issues/needs, health and health care literacy, behavioral management, medication management, and daily activity management. Validated tools, such as the Transition Readiness Assessment[5] or the Transition Readiness Assessment Questionnaire,[26] should be incorporated into practice

Downloaded for Anonymous User (n/a) at University of Kentucky from ClinicalKey.com/nursing by Elsevier on April 07, 2021. For personal use only. No other uses without permission. Copyright ©2021. Elsevier Inc. All rights reserved.

Figure. Got Transition web resources (published with permission of Got Transition/Center for Health Care Transition Improvement).

Got Transition

- **Transitioning Youth To Adult Care Package**
  - http://gottransition.org/resourceGet.cfm?id=208

1. Transition Policy

- **Sample Transition Policy**
  - http://gottransition.org/resourceGet.cfm?id=221

2. Transition Tracking and Monitoring

- **Sample Individual Transition Flow Sheet**
  - http://gottransition.org/resourceGet.cfm?id=222
- **Sample Transition Registry**
  - http://gottransition.org/resourceGet.cfm?id=223

3. Transition Readiness

- **Sample Transition Readiness Assessment for Youth**
  - http://gottransition.org/resourceGet.cfm?id=224
- **Sample Transition Readiness Assessment for Parents/Caregivers**
  - http://gottransition.org/resourceGet.cfm?id=225

4. Transition Planning

- **Sample Plan of Care**
  - http://gottransition.org/resourceGet.cfm?id=226
- **Sample Medical Summary and Emergency Care Plan**
  - http://gottransition.org/resourceGet.cfm?id=227

5. Transfer of Care

- **Sample Transfer of Care Checklist**
  - http://gottransition.org/resourceGet.cfm?id=229
- **Sample Transfer of Care Letter**
  - http://gottransition.org/resourceGet.cfm?id=230

6. Transfer Completion

- **Sample Health Care Transition Feedback Survey for Youth**
  - http://gottransition.org/resourceGet.cfm?id=231\
- **Sample Health Care Transition Feedback Survey for Parents/Caregivers**
  - http://gottransition.org/resourceGet.cfm?id=232

to measure the readiness of the adolescent with ADHD to transition to adult care and to guide further evaluation and interventions by health care providers to support care transition.[4,5,25] Based on the overall transition readiness assessment, age, developmental level, and individual circumstances, other specific assessment tools should be used to assess specific areas that may impact transition readiness and preparation. Specific assessment tools that may be applicable include the ADHD Rating Scale IV, the Conners Adult ADHD Rating Scale, the Adult ADHD Self-Report Scale v 1.1 Symptom Checklist,

Downloaded for Anonymous User (n/a) at University of Kentucky from ClinicalKey.com/nursing by Elsevier on April 07, 2021. For personal use only. No other uses without permission. Copyright ©2021. Elsevier Inc. All rights reserved.

the Adult ADHD Quality of Life Scale, the Conners Parent/Teacher Rating Scale-Revised, the Vanderbilt ADHD Diagnostic Parent and Teacher Scales, the Health Utilities Index, the Short Assessment of Health Literacy, the Youth Quality of Life Instrument-Research Version, the Behavior Rating Inventory of Executive Functioning-Adult Version, the Weiss Functional Impairment Rating Scale-Self Report, the Academic Performance Rating Scale, and the Stanford Test of Academic Skills (task).[16] These tools provide the NP and interprofessional team with objective methods to track the progress the adolescent is making toward self-care management of ADHD and transition to adult health care services.

Core Element 4: Develop a Transition Plan

Transition plan development, the fourth step, is an ongoing process that requires regularly updating the plan of care, including readiness assessment findings, goals and prioritized actions, clinical information, and legal documents.[5] As a component of a patient-centered approach that promotes adolescent self-efficacy, motivational interviewing is an effective psychotherapeutic method that can be utilized throughout the transition planning process to facilitate the development of goals and prioritized actions jointly with the youth and the caregiver.[27]

The initial transition plan focus should be on patient and family education related to the diagnosis, treatment, management, and chronicity of ADHD. From 12 to 15 years of age, topics such as school, relationships, sexual activity, driving, and increasing autonomy should be assessed and discussed with the adolescent and family.[5,21] Directed agenda setting should utilize motivational interviewing topics such as disease management (eg, medication management, scheduling appointments), driving, sex, relationships, alcohol and other substances, athletics, and educational and/or career planning.[5,27]

At age 15-18 years, the youth, family, and health care provider should begin preparation for the adolescent becoming responsible for managing their own health and health care as well as readying for legal changes in decision-making, privacy, consent, self-advocacy, and access to information.[5,21] The plan of care should: reflect the adolescent's identified trajectory regarding vocational and educational choices[21]; consider optimal timing of transfer to adult care; and provide linkages to appropriate adult health care providers, insurance/financial resources, self-care information, and culturally appropriate community resources.[5]

Core Element 5: Transfer Care

The fifth step, actual transfer of care, is critical to ensure that the young adult continues to receive ongoing evaluation and management of ADHD. Essential to the effective transfer of care is confirmation of the scheduled adult health care provider appointment and collaboration with the youth and the adult health care provider to confirm the mutually developed transition plan and continuity of care. Written communication to the adult health care provider should have a transfer letter that includes: the effective date of transfer of care to the adult provider; the final transition readiness assessment; the current plan of care, including transition goals and pending actions; an up-to-date medical summary; and legal documents or additional provider records if indicated.[5]

Core Element 6: Complete Transfer

The final step in the transition-of-care process is completion of the transfer of the adolescent with ADHD from a pediatric to an adult health care provider. The young adult should be contacted within 3-6 months of care transfer to confirm that transfer of care to adult health care has occurred and to elicit feedback related to the transition experience. Ongoing communication and consultation with adult health care providers is often necessary to ensure continuity of care and to promote collaborative partnerships to prevent the loss of appropriate follow-up for young adults with ADHD.[5]

CONCLUSION AND RECOMMENDATIONS

ADHD commonly persists into adulthood; therefore, it is crucial that health care providers develop, utilize, and validate transition pathways to bridge the gap between child health care and adult health services for youth with ADHD. NPs can facilitate the effective transition of pediatric patients with ADHD to adult health care providers by applying the 6 core

Downloaded for Anonymous User (n/a) at University of Kentucky from ClinicalKey.com/nursing by Elsevier on April 07, 2021. For personal use only. No other uses without permission. Copyright ©2021. Elsevier Inc. All rights reserved.

elements of the Got Transition model,[5] a systematic, evidence-based approach for transitioning youth to adult health care services. Improved transitions of youth with ADHD from pediatric to adult health care services can improve quality of life and reduce ADHD-associated disability for young adults with ADHD.[6] JNP

References

1. US Centers for Disease Control and Prevention. Attention-deficit/hyperactivity disorder (ADHD). Facts about ADHD. 2016. http://www.cdc.gov/ncbddd/adhd/facts.html/. Accessed January 3, 2017.
2. Sibley MH, Swanson JM, Arnold LE, et al. Defining ADHD symptom persistence in adulthood: optimizing sensitivity and specificity. *J Child Psychol Psychiatry.* 2016. http://dx.doi.org/10.1111/jcpp.12620.
3. Davis AM, Brown RF, Taylor JL, Epstein RA, McPheeters ML. Transition care for children with special health care needs. *Pediatrics.* 2014;134(5):900-908. http://dx.doi.org/10.1542/peds.2014-1909.
4. Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics.* 2011;128(1):182-200. http://dx.doi.org/10.1542/peds.2011-0969.
5. Got Transition/Center for Health Care Transition Improvement. Six Core Elements of Health Care Transition 2.0: Transitioning youth to an adult health care provider. 2014. http://www.gottransition.org/resourceGet.cfm?id=208/. Accessed January 3, 2017.
6. Young S, Adamou M, Asherson P, et al. Recommendations for the transition of patients with ADHD from child to adult healthcare services: a consensus statement from the UK adult ADHD network. *BMC Psychiatry.* 2016;16(1):301. http://dx.doi.org/10.1186/s12888-016-1013-4.
7. Robb A, Findling RL. Challenges in the transition of care for adolescents with attention-deficit/hyperactivity disorder. *Postgrad Med.* 2013;125(4):131-140. http://dx.doi.org/10.3810/pgm.2013.07.2685.
8. US Centers for Disease Control and Prevention. Attention-deficit/hyperactivity disorder (ADHD) data & statistics. 2014; http://www.cdc.org/ncbddd/adhd/data.html/. Accessed January 3, 2017.
9. Visser SN, Danielson ML, Bitsko RH, et al. Trends in the parent-report of health care provider-diagnosed and medicated attention-deficit/hyperactivity disorder: United States, 2003-2011. *J Am Acad Child Adolesc Psychiatry.* 2014;53(1):34-46.e32. http://dx.doi.org/10.1016/j.jaac.2013.09.001.
10. Hansson Halleröd SL, Anckarsäter H, Råstam M, Hansson Scherman M. Experienced consequences of being diagnosed with adhd as an adult—a qualitative study. *BMC Psychiatry.* 2015;15:31. http://dx.doi.org/10.1186/s12888-015-0410-4.
11. Holbrook JR, Cuffe SP, Cai B, et al. Persistence of parent-reported adhd symptoms from childhood through adolescence in a community sample. *J Atten Disord.* 2016;20(1):11-20. http://dx.doi.org/10.1177/1087054714539997.
12. Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between paediatric and adult healthcare: a systematic review. *Arch Dis Child.* 2011;96(6):548-553. http://dx.doi.org/10.1136/adc.2010.202473.
13. Ogundele MO, Omenaka IL. An audit of transitional care for adolescents with ADHD in a North West England district. *Arch Dis Child.* 2012;97(Suppl 1). http://dx.doi.org/10.1136/archdischild-2012-301885.307.
14. O'Sullivan-Oliveira J, Fernandes SM, Borges LF, Fishman LN. Transition of pediatric patients to adult care: an analysis of provider perceptions across discipline and role. *Pediatr Nurs.* 2014;40(3):113-120, 142.
15. Reale L, Frassica S, Gollner A, Bonati M. Transition to adult mental health services for young people with attention deficit hyperactivity disorder in Italy: parents' and clinicians' experiences. *Postgrad Med.* 2015;127(7):671-676. http://dx.doi.org/10.1080/00325481.2015.1070658.
16. Turgay A, Goodman DW, Asherson P, et al. Lifespan persistence of ADHD: the life transition model and its application. *J Clin Psychiatry.* 2012;73(2):192-201. http://dx.doi.org/10.4088/JCP.10m06628.
17. Webb L, Shah PK, Harisiades JP, Boudos R, Agrawal R. Health care transition from pediatric care to adult care: opportunities and challenges under the Affordable Care Act. *J Pediatr Rehabil Med.* 2015;8(1):53-64. http://dx.doi.org/10.3233/prm-150318.
18. McManus M, White P, Barbour A, et al. Pediatric to adult transition: a quality improvement model for primary care. *J Adolesc Health.* 2015;56(1):73-78. http://dx.doi.org/10.1016/j.jadohealth.2014.08.006.
19. McManus M, White P, Pirtle R, Hancock C, Ablan M, Corona-Parra R. Incorporating the six core elements of health care transition into a Medicaid managed care plan: lessons learned from a pilot project. *J Pediatr Nurs.* 2015;30(5):700-713. http://dx.doi.org/10.1016/j.pedn.2015.05.029.
20. Singh SP, Tuomainen H. Transition from child to adult mental health services: needs, barriers, experiences and new models of care. *World Psychiatry.* 2015;14:358-361. http://dx.doi.org/10.1002/wps.20266.
21. Unwin BK, Goodie J, Reamy BV, Quinlan J. Care of the college student. *Am Fam Physician.* 2013;88:596-604.
22. Lehmann CU, O'Connor KG, Shorte VA, Johnson TD. Use of electronic health record systems by office-based pediatricians. *Pediatrics.* 2015;135:e7-e15. http://dx.doi.org/10.1542/peds.2014-1115.
23. Leu MG, O'Connor KG, Marshall R, Price DT, Klein JD. Pediatricians' use of health information technology: a national survey. *Pediatrics.* 2012;130(6):e1441-e1446. http://dx.doi.org/10.1542/peds.2012-0396.
24. Co JP, Johnson SA, Poon EG, et al. Electronic health record decision support and quality of care for children with ADHD. *Pediatrics.* 2010;126(2):239-246. http://dx.doi.org/10.1542/peds.2009-0710.
25. Hall CL, Newell K, Taylor J, Sayal K, Swift KD, Hollis C. 'Mind the gap'—mapping services for young people with adhd transitioning from child to adult mental health services. *BMC Psychiatry.* 2013;13:186. http://dx.doi.org/10.1186/1471-244x-13-186.
26. Wood DL, Sawicki GS, Miller MD, et al. The transition readiness assessment questionnaire (TRAQ): its factor structure, reliability, and validity. *Acad Pediatr.* 2014;14(4):415-422. http://dx.doi.org/10.1016/j.acap.2014.03.008.
27. Jackman K. Motivational interviewing with adolescents: an advanced practice nursing intervention for psychiatric settings. *J Child Adolesc Psychiatr Nurs.* 2012;25(1):4-8. http://dx.doi.org/10.1111/j.1744-6171.2011.00304.x.

All authors are affiliated with the School of Nursing at the University of Kentucky in Lexington. Dianna D. Inman, DNP, CPNP-BC, is an assistant professor. She can be reached at dianna.inman@uky.edu. Leslie K. Scott, PhD, PPCNP-BC, is an associate professor and pediatric track coordinator. Mollie E. Aleshire, DNP, FNP-BC, is an assistant professor.

The authors thank Beverly Hilton, medical librarian and liaison for the College of Nursing Medical Center Library at the University of Kentucky. In compliance with national ethical guidelines, the authors report no relationships with business or industry that would pose a conflict of interest.

1555-4155/17/$ see front matter

© 2017 Elsevier Inc. All rights reserved.

http://dx.doi.org/10.1016/j.nurpra.2017.01.013

Downloaded for Anonymous User (n/a) at University of Kentucky from ClinicalKey.com/nursing by Elsevier on April 07, 2021. For personal use only. No other uses without permission. Copyright ©2021. Elsevier Inc. All rights reserved.