The Medical Transition from Pediatric to Adult-Oriented Care

Considerations for Child and Adolescent Psychiatrists

Laura C. Hart, MD, MPH[a], Gary Maslow, MD, MPH[b,*]

KEYWORDS

• Transition from pediatric to adult-oriented care • Transitional care
• Adolescent health • Continuity of care

KEY POINTS

- The transition from pediatric to adult-oriented care is a process, rather than simply the hand-off from a pediatric to an adult-oriented provider, and should take place in stages over the adolescent years.
- Guidelines and tools have been developed to assist providers in addressing the transitional care needs of adolescents and young adults.
- Child and adolescent psychiatrists play a particularly important role for those adolescents and young adults with primarily mental health needs, mental illness with onset in the adolescent and young adult period, and adolescents and young adults with intellectual and developmental disabilities.

BACKGROUND

The need for transitional care, care provided as teens and young adults move from the pediatric to adult-oriented health system, is in some ways among the success stories of medicine. In the last 50 years, improvements in pediatric care have turned previously fatal childhood illnesses into chronic and often manageable ones. Survival rates for cancer have improved dramatically.[1,2] Many complex congenital heart defects can be repaired or palliated.[3] Cystic fibrosis can be managed with appropriate treatment.[4]

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[a] Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, 725 Martin Luther King Jr. Boulevard, Chapel Hill, NC, 27514, USA; [b] Psychiatry and Behavioral Sciences, Duke University School of Medicine, Durham, NC, USA
* Corresponding author. 2608 Erwin Road, Suite 300, Durham, NC 27705.
E-mail address: Gary.maslow@duke.edu

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Adults with these diseases were rare even 20 or 30 years ago, and now there are 400,000 adult-aged survivors of pediatric cancers,[1] over 1 million adults with a congenital heart disease,[5] and as many adults who had cystic fibrosis as children.[6] Adolescents and young adults cared for primarily by a child and adolescent psychiatrist are particularly vulnerable during this time. Before considering the details of transitional care more fully, it is useful to remember that transition is a process to help a teen or young adult with chronic illness move into a future that their predecessors with similar issues never had the opportunity to experience.

It cannot be emphasized enough that transition is a process, and not simply the moment that care is handed off from the pediatric to the adult provider.[7] That handoff is more appropriately termed the transfer of care and should be a step in the larger transition process, which ideally also includes education for youth about their illness, the opportunity to practice and develop self-management and self-advocacy skills, and a move toward greater independence before transfer, as well as time to get settled with the appropriate adult-oriented provider after transfer.[8]

At present, many teens and young adults experience poor health outcomes around the time of transition and transfer, such as loss of control of diabetes[9] and problems with organ rejection in transplant recipients.[10] Teen and young adults with mental health conditions face similar challenges during transition. One study found that only 28% of young adults with a *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition, diagnosis had received psychiatric care in the previous 3 months, whereas 50% of teens 12 to 17 years old had received care in the same timeframe.[11] In a prospective study in England, only 41 out of 154 young adults who were eligible for referral to adult mental health care were following long-term with adult-oriented mental health services.[12] In addition to less access to care, young adults also have higher rates of suicide than adolescents.[13]

BARRIERS

The barriers that are preventing more patients from getting effective transitional care have been well-documented. All of the parties involved in the transition process, including patients, parents, pediatric providers, and adult-oriented providers, have noted problems and concerns with the transition process. Patients find adult-oriented providers, clinics, and hospitals to be confusing to navigate and report feeling unsupported once they leave the pediatric setting.[14–16] Parents frequently report that providers address transition too late, leaving patients and families little time to consider all the needs of the transition process.[14,16–18] Pediatric providers cite a lack of time, training, and reimbursement for transition services as the major barriers of transitional care that they face.[19,20] Adult-oriented providers believe that they get little information from pediatric providers before seeing young adult patients and feel ill-equipped to provide care for young adults with pediatric-onset illnesses.[21,22] They also find that young adults lack the necessary knowledge and skills to manage their illness.[22]

The patient–doctor relationship presents another challenge in addressing transition effectively. Pediatric providers often become very close to the patients they care for and vice versa. Pediatric providers have often supported their patients and families through difficult medical and social problems. In some cases, a patient and her family may have been seeing the same doctor at regular intervals for the patient's entire life. When patients, parents, and pediatricians are faced with the difficult prospect of ending this years-long, strong, supportive relationship, all parties are understandably hesitant.[14,15,18] This hesitancy is probably part of the reason that only 40% of parents