Transition Planning for Chronic Illnesses in the Time of COVID-19

William R Hunt, MD1,2, Rachel W Linnemann, MD2,3, and Brandi Middour-Oxler, DNP2,3

Abstract
Transition from pediatric to adult care for those with chronic illnesses must have special considerations during the COVID-19 pandemic. The SARS-CoV-2 coronavirus has significantly disrupted social, economic, and health care practices globally. Young adults with special health care needs are at an increased risk for poor outcomes during this unprecedented time. We have found that heightened anxiety, health care service disruption, and other logistical complications surrounding the new virus may further confound health care transitions. Increased communication and collaboration with young adults is necessary to provide patient-centered care and ensure they successfully cross the transition chasm.

Keywords
COVID-19, telemedicine, transitions of care, cystic fibrosis, transition to adult care, young adult, chronic disease

Approximately 90% of children with special health care needs will live into adulthood and thus undergo transfer to adult medicine (1). Youth with special health care needs are at an increased risk for poor outcomes during their transition of care (2). As such, multiple professional societies have outlined the importance of a structured transition process with the intent of ensuring continuous care and a smooth transition for these patients and their caregivers (3).

The emergence of the novel SARS-CoV-2 coronavirus, and subsequent COVID-19 pandemic, has significantly disrupted social, economic, and health care practices across the world. Our cystic fibrosis practice has a well-established transition program managed by a dedicated transition program coordinator, yet COVID-19 has presented new and unique challenges. Heightened anxiety, health care service disruptions, and other logistical complications surrounding this new virus may additionally confound health care transitions (4,5). Flexibility and attention to additional health care variables must be considered in order to facilitate a successful transfer of care.

Establishing a well-developed transition policy and plan is an integral aspect of the transition process, regardless of the current COVID-19 pandemic (6). Gottransition.org has outlined 6 core elements to a successful transition: establishing a transition policy, formalized transition tracking and monitoring, assessing transition readiness, transition planning, the transfer of care, and then post-transfer follow-up. These elements should be molded into a program preferably with input from key stakeholders including pediatric and adult medicine providers as well as patients themselves (6).

Although having an established transition policy is important, it should not be so rigid that it is to the detriment of the patient. Age has historically been the impetus to initiate transfer to adult-centered care (7), but more evidence now supports use of objective measures of transition readiness as well as coproduction of care (8). Having open discussions with patients and their caregivers about transition timing allows patients to have input into the process, which will allow them a sense of control and may help alleviate certain fears.

Recent experiences in our center have highlighted the variability in transition timing desires among young adults as they now take into account COVID-19. For example, one individual undergoing transition had previously wanted to

1 Division of Pulmonary, Allergy, Critical Care and Sleep Medicine, Emory University, Atlanta, GA, USA
2 Children’s Healthcare of Atlanta and Emory University Cystic Fibrosis Center, Emory University, Atlanta, GA, USA
3 Division of Pulmonary, Allergy/Immunology, Cystic Fibrosis and Sleep, Department of Pediatrics, Emory University, Atlanta, GA, USA.

Corresponding Author:
Brandi Middour-Oxler, Children’s Healthcare of Atlanta and Emory University Cystic Fibrosis Center, Emory University, Atlanta, GA 30322, USA.
Email: bmiddou@emory.edu
meet the adult team in-person and was looking forward to a
shared transition capstone clinic. However, since the emer-
gence of COVID-19, the patient became apprehensive of
in-person visits and prefers to skip the transition clinic and
virtually follow-up with the adult team to minimize her num-
ber of office visits. Conversely, another individual had pre-
viously wanted to transition in the winter but is now
concerned that a second wave of COVID-19 may close
offices during that time. This patient now desires to transi-
tion before winter, as the in-person introduction to the adult
team is highly valued. Patients will differ in their personal
interpretation of medical and societal changes as a result of
COVID-19. Partnering with young adults individually to
discuss how COVID-19 affects their medical care and tran-
sition, with some degree of flexibility in the transition pro-
cess, empowers them while reinforcing the important task of
partnering in care.

Health care transitions can already be a time of heightened
anxiety for both patients and their caregivers as they navig-
gate away from the comfort of long-term relationships they
have developed with their pediatrician, to follow-up with an
initially unfamiliar provider (9). In the setting of COVID-19,
young adults may feel even greater anxiety (5). Patients,
particularly those with chronic illness, may dread transs-
fering to a setting that proportionally has a greater incidence of
severe COVID-19 infections compared to their pediatric
home (10). Offering screening tools such as the Generalized
Anxiety Disorder assessment and the Patient Health
Questionnaire-9 may help elucidate symptoms of worry,
anxiety, depression, and sleep disturbance that young adults
may not readily verbalize (5). An elevation in scores com-
pared to previous visits may indicate increased symptom
severity; however, the screening should be augmented with
relationship-centered communication as situational transi-
tion anxiety may not be captured by these tools. Pediatric
providers should elucidate concerns from their patients and
caregivers by creating a space in which it is acceptable to
acknowledge apprehensions. It is important to validate their
concerns and discuss them directly. It may be helpful to have
members from the adult medicine team discuss their
risk-reduction practices as well as clinical protocols with
patients and their families prior to transfer.

The transition chasm- that time in which a patient has had
their last clinical interaction with their pediatric provider, but
before they have officially established in-person clinical
relationships with their adult medicine team- may be pro-
longed due to complications of COVID-19. Reduced clinic
schedules, staff limitations due to furloughs or flexing, com-
plicated waiting processes due to social distancing, and loss
of patient resources may prolong this time. It is important
that patients have clear instructions and a concrete plan for
any unanticipated medical issues that arise as they cross the
transition chasm. Ensuring the young adult successfully
follows up in adult care is regarded as one of the most widely
agreed on indicators of successful transition (11). One assur-
ance to provide a lifeline to these patients through their
transition process is to establish a designated health care
team member to track their progress through the transition
journey as well as follow-up with them after their transfer.
Although having a dedicated transition coordinator is ideal,
team disturbances during COVID-19 may necessitate that
this responsibility of transition tracking and check-ins be
shared by several team members. As such, communication
between team members and the patient undergoing transition
is paramount.

During COVID-19, many practices have relied on tele-
health to provide patient care. This valuable platform can be
a lifeline to vulnerable patients during this pandemic. Impor-
tantly, patient satisfaction and perceptions of physician com-
passion are generally high with telehealth (12). Utilizing
telehealth may allow adult medicine providers to participate
in capstone transfer clinics (introducing themselves to the
transferring patient in the familiarity of the patient’s pedia-
tric clinic) more readily during COVID-19. Additionally,
transition coordinators, or designated transition trackers, can
more easily follow-up with patients after their transfer to
adult-centered care without further exposing them to unne-
cessary risk with in-person clinics.

The emergence of the COVID-19 pandemic has forced
many institutions to adjust to new norms and protocols.
Similarly, the transition journey to adult-centered care for
adolescents with chronic disease may be altered during this
unusual time. It is important for both pediatric and adult
providers to remain flexible in their transition planning and
support young adults during the transition to adult care. In
person transitions where adult medicine providers can meet
the patient and receive a real-time handoff from the pediatric
team are ideal but perhaps not realistic during COVID-19.
Telehealth platforms may help facilitate the transition pro-
cess and may remain useful even after the pandemic sub-
sides. During these uncertain times, it is more vital than ever
for pediatric providers to seek input from adolescents and
young adults regarding their feelings about transitioning.
Further, as the patient approaches the transfer event, it is
important to check in frequently as concerns may change
or intensify as the transfer of care nears.

Declaration of Conflicting Interests
The author(s) declared no potential conflicts of interest with respect
to the research, authorship, and/or publication of this article.

Funding
The author(s) received no financial support for the research, author-
ship, and/or publication of this article.

ORCID iD
Brandi Middour-Oxler, DNP  https://orcid.org/0000-0001-5343-
7386

References
1. Blum RW. Transition to adult health care: setting the stage.
J Adolesc Health. 1995;17:3-5.
2. Society for Adolescent H, Medicine. Transition to adulthood for youth with chronic conditions and special healthcare needs. J Adolesc Health. 2020;66:631-4.
3. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal M. A consensus statement on health care transitions for young adults with special health care needs. Pediatrics. 2002;110:1304-6.
4. Barach P, Fisher SD, Adams MJ, Burstain GR, Brophy PD, Kuo DZ, et al. Disruption of healthcare: will the COVID pandemic worsen non-COVID outcomes and disease outbreaks? Prog Pediatr Cardiol. 2020:101254.
5. Huang Y, Zhao N. Generalized anxiety disorder, depressive symptoms and sleep quality during COVID-19 outbreak in China: a web-based cross-sectional survey. Psychiatr Res. 2020;288:112954.
6. GotTransition. Six core elements of health care transition. 2020. https://www.gottransition.org/resources/index.cfm##six (accessed 13 June 2020).
7. McLaughlin SE, Diener-West M, Indurkhya A, Rubin H, Heckmann R, Boyle MP. Improving transition from pediatric to adult cystic fibrosis care: lessons from a national survey of current practices. Pediatrics. 2008;121:e1160-6.
8. Lapp V, Chase SK. How do youth with cystic fibrosis perceive their readiness to transition to adult healthcare compared to their caregivers’ views? J Pediatr Nurs. 2018;43:104-10.
9. Coyne I, Sheehan AM, Heery E, While AE. Improving transition to adult healthcare for young people with cystic fibrosis: a systematic review. J Child Health Care. 2017;21:312-30.
10. Coronavirus disease 2019 in children—United States. February 12–April 2, 2020. MMWR Morb Mortal Wkly Rep. 2020;69:422-6.
11. Suris JC, Akre C. Key elements for, and indicators of, a successful transition: an international Delphi study. J Adolesc Health. 2015;56:612-8.
12. Elliott T, Tong I, Sheridan A, Lown BA. Beyond convenience: patients’ perceptions of physician interactional skills and compassion via telemedicine. Mayo Clin Proc Innov Qual Outcomes. 2020;4:305-14.

Author Biographies

William R Hunt is an assistant professor at Emory University in the Department of Medicine. He is the director of the Emory Adult Cystic Fibrosis (CF) program and a transplant pulmonologist in the McKelvey Lung Transplant Center. His interests include transition care for young adults with CF, CF-related diabetes (CFRD), point-of-care ultrasonography, and lung transplantation.

Rachel W Linnemann serves as the director of the Children’s Healthcare of Atlanta and Emory University Cystic Fibrosis Care Center and the Co-Director of the Pediatric CF Program. She is a pediatric pulmonologist, and her academic interests include quality improvement, clinical trials, and interventions to improve the quality of life for people with CF.

Brandi Middour-Oxler is a doctorally prepared nurse practitioner and the cystic fibrosis transition program coordinator at the Children’s Healthcare of Atlanta and Emory University Cystic Fibrosis Care Center. Her interests include transition-related research, supporting young adults and their parents as they prepare for adult-centered care, and relationship-centered communication.