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

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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 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). Gottranstion.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

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meet the adult team in-person and was looking forward to a shared transition capstone clinic. However, since the emergence 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 number of office visits. Conversely, another individual had previously 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 transition 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 transition, with some degree of flexibility in the transition process, empowers them while reinforcing the important task of partnering in care.

Health care transitions can already be a time of heighted anxiety for both patients and their caregivers as they navigate 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 transferring 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 compared to previous visits may indicate increased symptom severity; however, the screening should be augmented with relationship-centered communication as situational transition 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 prolonged due to complications of COVID-19. Reduced clinic schedules, staff limitations due to furloughs or flexing, complicated 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 assurance 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 telehealth to provide patient care. This valuable platform can be a lifeline to vulnerable patients during this pandemic. Importantly, patient satisfaction and perceptions of physician compassion 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 pediatric 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 unnecessary 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 process and may remain useful even after the pandemic subsides. 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.

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