How can we measure or predict transition readiness?

By Emily M. Fredericks, PhD

The number of adolescents and young adults with chronic kidney disease or a renal transplant is making the transition from pediatric to adult health care is on the rise. However, the transition process often raises concerns among providers, parents, and patients. Providers may have a difficult time “letting go” of their patients, and may worry about the risk of medical complications following the transfer to adult-centered care. Parents and adolescents are often concerned about leaving their familiar pediatric providers, and worry about the care they will receive with new providers in an adult clinic. In addition, parents may express concern about whether their adolescent is able to manage their health independently, as may be expected in adult clinics. Thus, there is a need to develop strategies to assess a pediatric patient’s readiness to move to an adult-centered clinic (1–3).

What is “transition readiness”? Transition readiness is the ability of an adolescent and his/her family and medical providers to engage in the process of moving from pediatric to adult care. Yet, in order to predict readiness, it is necessary to define a successful transition. An important outcome of the transition process is the actual transfer to a new health care setting, provider, or both. However, the transition process does not end with the handoff in the adult clinic. Rather, the process of moving toward independent self-management will continue beyond the transfer of care. As we attempt to measure and predict transition readiness, it is necessary to consider how the transition process impacts patient satisfaction, quality of life, educational/vocational outcomes, as well as medical stability following the transfer to adult care.

How can I assess transition readiness in my clinic? Practitioners are encouraged to incorporate assessment of self-management skills, health-related knowledge, adherence, and psychological support into standard clinical care as we strive to promote optimal long-term outcomes for our pediatric patients. Ideally, the assessment of transition-related skills would be conducted using well-validated measures in the context of standard clinical care. While there is not an accepted “gold standard” transition tool, there is a growing literature supporting measures that assess areas of self-management and transition readiness (4–7). In addition, the American Society of Transplantation Pediatric Community of Practice Joint Transition Work Group has published a web-based transition resource that is publicly available (http://www.a-s-t.org/content/ast-pcop-web-resources-transition-adult-care) with resources that are not transplant-specific allowing for wider use.

How will I know when my pediatric patient is ready to transfer? In this issue, Miriam Kaufman, MD, FRCPC, describes the basics of transition preparation, which can assist pediatric providers in navigating this process early with patients and their families. There are potential barriers to transferring care, which may occur at the level of the patient, parent, family, and the pediatric/adult provider (3). When assessing a patient’s readiness to transfer care, it is important to address potential challenges, which may include medical instability, regimen nonadherence, poor psychosocial functioning, inadequate insurance coverage, and the lack of an identified adult provider.

It has been recommended that patients should not transfer from pediatric to adult health services unless they have the skills they need to function effectively in the adult health care system. Transfer of care should not be based solely on a pediatric patient’s chronological age. Rather, it is recommended that prior to transferring to adult-centered care, the adolescent should be able to describe their health condition, demonstrate responsibility for their health, and have the ability to manage their daily regimens (1–8). In adult settings, patients are typically expected to independently discuss medical care with the treatment team, schedule and attend appointments, refill prescriptions, and adhere to medications and treatment recommendations. This is often a shift in culture from a pediatric clinic, where parents may shoulder much of the responsibility for health management and communication with the health care team. Thus, before transferring a patient to our adult colleagues, it is recommended that pediatric providers foster the development of self-management skills in their adolescent patients by encouraging them to take an active role in their health.

Summary Before we can reliably predict transition readiness, further work is needed to define outcomes of a successful transition process. At this time, we know very little about how transition readiness skills predict long-term outcomes in the adult health care system. It is important to partner with adult providers to determine factors that are associated with competence and success in the adult health care system following the transfer from pediatrics. In the meantime, it is recommended that pediatric providers routinely assess adolescent and parent perceptions of transition, health-related knowledge, and self-management skills to evaluate readiness to move from pediatric- to adult-focused health care. The assessment of transition perceptions and self-management skills may identify patients and families who could benefit from more intensive support both before and after the transfer to adult care.

References