

7. TRANSITION OF CARE IN ADOLESCENTS AND YOUNG ADULTS

Principles

- Transitioning from pediatric to adult care is a challenging phase for patients with sickle cell disease, their caregivers and their health care providers.
- Effective transition from pediatric to adult medical care is a longitudinal process that relies on developmentally appropriate education and transfer of responsibility from the health care provider to the patient.
- Pediatric and adult sickle cell disease care providers should collaborate to develop an effective transition model for their patients and to monitor sickle cell disease-related outcomes after transfer to adult care.

Recommendations

Patient Education and Preparation

- Transition should not be left until an adolescent reaches 18 years of age, and should be started from a young age.
- There is no specific age to begin transitioning patients with SCD. Responsibility for medical care should be gradually shifted from the health provider to the caregiver(s), and finally to the AYA patient in a developmentally appropriate fashion.
- Pediatric health-care providers should provide patients and families with developmentally appropriate resources about SCD complications and management.
- Patients and caregivers should be evaluated for their transition readiness at various time points prior to being transferred to adult care.
- Pediatric sickle cell clinics should adopt specific education and assessment tools for transitioning SCD patients and their caregivers to adult care.

Planning and Implementation of the Transfer to Adult Care

- Pediatric and adult SCD care providers should communicate at least annually about patients between 17 and 18 years who are to be transferred within the calendar year.
- Prior to transfer to an adult facility, the pediatric health care providers should send a concise but complete summary to the receiving adult health care providers. At a minimum, this summary should include information about SCD-related complications, investigations and treatments. The content of this summary should be agreed upon by both the pediatric and adult health care providers to ensure effective communication.
- Adult health care providers should be educated about developmentally appropriate approaches for caring for newly transferred AYA patients.
- The transferred youth and their caregivers should have an opportunity to meet the adult health care team, and to visit their facility prior to their initial appointment.
- After transfer, the patient's first appointment at the adult facility should occur within the interval within which they would have normally been seen at their pediatric facility.
- Pediatric and adult SCD care providers should collaborate to identify quality indicators for monitoring SCD-related outcomes after transfer to adult care.

Background

With the evolution and improvement of comprehensive care for patients with sickle cell disease (SCD), there has been an increase in life expectancy, and an epidemiologic shift in the disease-related outcomes for this population.¹ In spite of better overall care for individuals with SCD, studies have shown that there is a sharp increase in disease-related mortality among young adults with SCD between 17 and 30 years of age, which is the time when most of these individuals would have been transferred to adult care.^{1,2}

Although adolescents and young adults (AYA) with SCD encounter developmental challenges similar to those of other youth with chronic health conditions, SCD poses unique barriers that must be considered during the transition process. Youth with SCD often come from different ethnocultural backgrounds from their health-care providers, which may influence their perceptions of their disease and health-care needs. Within certain cultural communities, there is also a social stigma that is often associated with SCD, which could make it difficult to provide support that is sensitive and relevant for a patient and their family.³ There have been recent studies to evaluate the role and effectiveness of culturally sensitive interventions for adolescents with SCD and their families.⁴ Furthermore, patients who have had prior neurological complications (e.g., silent or overt stroke) may have neurocognitive issues impacting on transition readiness.

Health-care transition is an important step in the lives of young people with pediatric-onset health conditions. Transfer to adult-centred care is an event, while transition is a process, one that involves preparing the young person and their family for this move, the transfer process, and negotiating with adult providers to accept these patients and provide developmentally appropriate care. Leaving the pediatric treatment centre and its medical team can be emotionally difficult for the patient, family and health care providers. Much of the early research in the field of transition was with young people with SCD,⁵ who have a condition that will not disappear or be cured, have significant levels of treatment, and who may experience racism within society and even in the health-care system. SCD is a lifelong chronic condition, and the nature of the transfer to adult care can therefore have a significant impact on the entire lifespan in people with SCD.⁶ Many organizations endorse transition planning in position statements, including the American Academy of Pediatrics and the Canadian Paediatric Society.^{7,8}

There are many ways to approach the issue of transition from pediatric to adult care. We will examine it from three viewpoints – preparing adolescents and their families; practicalities of the transfer process; and recommendations for the adult system and its approach to young adults.

Preparation for Transfer

Many position statements have argued that transition should start at the time of diagnosis. If one thinks of self-management, knowledge of condition and self-advocacy as needed skills for transition, then it is clear that skill building can start at almost any age. In addition to this, parents require varying amounts of time to accustom themselves to the reality of transition to adult care. Starting early may help many of them adapt to the idea that their child will be leaving a pediatric facility at some point, and also give them hope that their child will survive and be able to manage adult responsibilities. One tool that can be used for this is the “Sickle Cell Timeline” from the Hospital for Sick Children, which has suggestions for parents to promote developmentally appropriate autonomy in the areas of social, education, self-care, and medical care from a young age.⁹

There are a number of theoretical models that can be used to underpin this movement from dependency to responsibility. One that is very helpful is the Shared Management Model developed by Keikhefer and Trahms in Seattle.¹⁰ This model describes a gradual shift in responsibility for care from the health professional to the parent and then to the young person. For instance, in the case of patient “John” who has SCD, one can talk with families about “John’s Health” as a corporation that starts off with the doctor as the CEO and the parents as customers. Parents naturally move into the role of a manager, and this is often where things stay, with the young person as a customer of the corporation. With transition preparation, the youth moves up into a manager role and the parent moves up in the organization too. Eventually, “John” ends up as the CEO of “John’s Health,” and the parents and health professionals are consultants. With this model, the child sees the parents taking an active role rather than being a passive consumer of health care, which is important role modeling for their future.

Self-efficacy is a belief that one can competently cope with a challenging situation. It is affected by life experience, the nature of parenting received, cultural influences, and locus of control. The pediatric system has often been seen as a culprit, “babying” patients and creating dependency, which can decrease a young person’s ability to feel that they can cope with their condition and the adult health care system. Anything that we can do to help young people to increase their self-efficacy, by pointing out to them the times that they are effective in dealing with challenges (these don’t have to be medical challenges), helping them identify how they have surmounted obstacles, and providing them with tools to effectively deal with their issues will help them in their confidence in moving into the adult system. In addition, it has been shown that those adults with SCD who have higher self-efficacy have lower reported pain severity and physical or psychological symptoms.¹¹

Although young people need skills to navigate the adult world, these skills are less helpful if the youth does not have adequate information about SCD, about their own health history, and about the health-care system. Do not assume that children were listening (or able to understand) the explanations their parents have been given. There are many ways to impart this information, including small chunks of knowledge at medical appointments, education events, written materials, and electronic materials. Consider using youth-friendly materials such as comic books or videos of young adults sharing their knowledge and experience. A health passport is a useful pocket-sized tool to summarize important information related to the youth's SCD, which may serve as their personal resource about their condition.¹²

In addition to providing education and developmentally appropriate resources, it is important to evaluate the adolescent's and caregivers' readiness for transition through direct questioning and/or questionnaires. These readiness assessments will enable health-care providers and family members to attempt to bridge any knowledge gaps prior to transfer and, if this is not possible, to communicate these challenges to the adolescent's future health-care providers within the adult centre. There are validated generic and disease-specific tools that are available to assess transition readiness and self-efficacy, including the "Good 2 Go" readiness checklist, which is available through the Hospital for Sick Children.¹³ These tools should be used to evaluate patient and caregiver knowledge and self-efficacy at several time points prior to transfer to adult care.

Transfer to Adult Care

Leaving the pediatric system is a major event for families and young people. They have come to know (and hopefully like) many of their health professionals, know their way around the building, and have friends they see at appointments. They may have heard horror stories about the adult system, and parents are especially worried that they will be left out of the care of their offspring. The actual process of transfer can have a huge impact on transition, with the quality of information shared, the experience of the last visit, attention paid to non-medical transitions, and the alleviation of parental, patient, and team anxiety about the process all being crucial.

A number of models have been developed for transfer clinics. All of the models recognize the day as a rite of passage for the family. In and of itself, this helps families leave the pediatric system with a feeling that they are graduating rather than being kicked out. Almost all transfer clinics involve the youth meeting all or part of their new health-care team. This clinic could take place at either the pediatric or adult facility. When both exist in the same building, there could even be a ritual walk between the two clinics. These clinics can involve small groups for discussion of transfer challenges, meetings with the new providers, creation of a portable medical summary, presentation of a graduation certificate, and even a party. When planning for the ultimate transfer from pediatric care, it is important that the patient's medical and psychosocial supports are maintained as much as possible following their transfer to the adult facility. In cases where certain resources are unavailable at the adult centre, it will be necessary to refer the patient and their caregivers to community specialists and/or services who may be able to provide these supports.

Although a number of different clinic models exist, it is fundamentally important that there is regular and clear communication between the pediatric and adult health-care teams. This will facilitate a complete transfer of patient information, and allow for ongoing evaluation and improvement of the transition process.

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