

2. Transition from the Pediatric to Adult Care Setting

Principles

- To ensure transition and continuity of care for adolescent and young adults (AYA) and their families as they move from pediatric to adult care settings.
- To provide psychosocial support to AYA and their families as they face new and different challenges of adulthood.
- To ensure ongoing and optimal multi-disciplinary long-term care throughout adulthood.

Recommendation

- The transition from the pediatric to adult care setting is not a one-time event, but a process implemented over time to ensure adequate preparation of the patient, family, and care providers involved.
- Pediatric care providers should begin planning for transition when patients reach early adolescence a few years in advance of the transfer of care. The process should actively include parents/caregivers well as the patient.
- Transition planning should focus on educating the patients about the biological, medical, and psychosocial aspects of thalassemia, and equipping AYA patients with skills to manage their care responsibly and independently.
- During transition, pediatric and adult centres should collaborate to increase patient familiarity with members of the adult team and the adult system.
- After transition, AYA patients should be followed routinely to ensure they receive optimal care and that complications are identified and managed promptly.

Background

Thalassemia is a condition that requires continuous medical monitoring and treatment throughout the patient's lifetime. The risks, complications and treatment of thalassemia in infancy and childhood can differ than those in adults, therefore it is recommended that young adult patients transition to an adult care team that specializes in thalassemia care. This transition from the pediatric to adult care is a stressful time for AYA patients and their families and often occurs before the patient is emotionally and psychologically ready. During transition period patients are vulnerable both to emotional stress and lack of adherence.

Having a standardized process in place that begins in early adolescence can help to ensure the AYA patient and family are better equipped for transition. As the needs of each patient can be very different, this process should be individualized for more effective planning. The pediatric team initializes the transition process and the adult team should also be actively involved; collaboration and communication between the two teams is imperative. The ultimate goal of transitioning is to promote independence and self-efficacy of the youth, while simultaneously providing a continuous transfer of ongoing care from one team to the next.

Interventions

Preparing for Transition

- The transition from pediatric to adult care setting should be planned well in advance of the actual event. Preparation and discussion with the patient should begin in early adolescence.
- The transition process should actively include all members of the multidisciplinary pediatric team, the patient and the parents/primary caregivers.

- During transitioning, psychosocial support should be provided in both the pediatric and adult settings by means of a social worker, psychologist, nurse, and physician. Patients should be assessed for transition readiness by several tools available at the pediatric centre.
- If the pediatric site has standardized transition recommendations/policies in place, these should be used to guide the transition process. If available, involve the institution's transition team.

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Implementing the Transition Process

- Transitioning should focus on promoting patients' independence and self-management of their thalassemia. AYA patients should be trained to take charge of their own care and problem-solve health-related issues, including risks and complications, as independently as possible.
- Each patient is unique, and the transitioning process must be flexible to accommodate different developmental stages, readiness for responsibilities, and physical and mental disabilities. Expectations should be adjusted if necessary should challenges arise.
- Needs should be identified and appropriate supports established for patients who may not be able to achieve complete independence or self-management as a result of decreased mental or physical capacity.
- Care should be extended to AYA patients to assess the ability to navigate the healthcare system and disability services at colleges and universities.

Transfer of Care

- To ease the transition and reduce anxiety, efforts should be made to organize the transfer when the patient is well. Patients should not be transferred during an acute illness or period of major stress.
- If possible, the pediatric and adult thalassemia teams should schedule a joint clinic in which patients and their families can meet both teams together. This will allow the AYA patient and family to become familiar with members of the adult team assuming their care. Optimally, the transition clinic should occur in the familiar setting of the pediatric site where patients and families feel most comfortable. Subsequent overlapping visits with both pediatric and adult services should be considered if possible.
- Prior to the transfer of care, a member of the pediatric team should accompany the AYA patient and family to the new adult clinic so they may become familiar with the new site. At least one member of the adult team should assist in this process.
- The adult team should schedule their first appointment with the AYA patient prior to the transfer of care to avoid delays in care delivery. The medical care of the patient remains the responsibility of the pediatric team until the first appointment so as to ensure the patient has continuous medical coverage.
- Handover from the pediatric team should include: a written comprehensive summary covering the patient's medical history, current treatment, psychosocial concerns and any other relevant information; patient contact information; and all relevant test and imaging results.