

4. Psychological Aspects of Thalassemia Care

Principles

- To help patients and families manage the mental, social, and physical challenges of living with thalassemia during all stages of growth and development and throughout life span.
- To ensure health care providers consider patients' psychosocial functioning when providing care, especially when making treatment decisions.
- To foster healthy coping mechanisms, emotional well-being and effective self-management in patients.

Recommendation

- The multidisciplinary team at the specialist centre should include a social worker, psychologist and an access to psychiatrist referral with knowledge of the challenges faced by thalassemia patients during various stages of life.
- The psychosocial needs of thalassemia patients should be prioritized in ongoing planning for treatment.
- Support should also address age-specific challenges, transition periods, cultural influences and social and economic factors.

Background

Thalassemia is a life long condition requiring ongoing medical treatment and management of complications. This continuous medical management can place significant burdens on both the patient and family in all facets of life. Developmental stages and concerns, behavioural challenges, psychological functioning and social issues all play a role in the patient's treatment adherence, health status, and overall quality of life. In Canada, an increasing percentage of thalassemia patients are from families of recent immigrants, which poses the additional social, economic and cultural challenges. Greater support may be needed under these circumstances to ensure psychosocial well-being. Also, family dynamics must be assessed, especially in the pediatric setting, and the psychological needs of parents and siblings should also be considered during ongoing treatment planning and provision of patient care.

Interventions

Ensuring Adequate Services

- The psychologist and social worker should function as integrated members of the inter-disciplinary team and meet regularly with other professionals to discuss patients in an inter-disciplinary forum.
- Together with the health care team, the psychologist and social worker should regularly review patients, address issues and provide support. This is especially important during critical milestones such as initial diagnosis, commencement of treatment, puberty, transition to adult care, and major life events such as education, employment, marriage, pregnancy, and parenthood.
- Reviews should include all aspects of psychosocial development such as assessing: 1) patient relationships with family, peers, and significant others; 2) functioning at school, work and within the community, including neuropsychological assessments when necessary; 3) adolescent concerns of adjustment; 4) sexuality; 5) self-esteem, identity, autonomy, and coping-skills; 6) search for and adaptation to vocations.
- It is imperative there be good communication between the patient, family, and medical team throughout treatment. Communication should be in both written and verbal forms, as appropriate.

Delivery of Psychosocial Care

- All psychological and social support should be provided in a culturally sensitive manner.
- The health care team should discuss the practical and psychological challenges of transfusions and chelation with patients and families on a regular basis. These discussions should include the consequences of non-compliance with treatment.
- Psychological support should occur through different stages of patient's life. Support should be provided to patient and their caregivers at time of diagnosis, start of blood transfusion, initiation of chelation, school and education, through out development stages including puberty, transition time and major life events as an adult not restricted to employment, marriage and pregnancy.
- Psychological issues such as needle phobia or fear of blood should be treated at an early age to allow for a smoother shift of responsibilities during adolescence.
- The team should help facilitate building a sense of autonomy, self-reliance, and self-esteem in all patients. This should start early in the pediatric population to promote a smooth transition to adult services.
- The team should encourage shifting age-appropriate responsibilities from parent to child on a continuous basis, allowing the child to take control of disease management as appropriate.
- Resources and support should be provided to help patients develop positive coping skills toward their illness and to develop self-management skills, including healthy lifestyle behaviours. The medical team should provide additional support during times of complications, hardship, and major stressors.
- If serious psychological difficulty or psychiatric illness is suspected, patients should be referred to psychiatrists.