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Structure and Functions of Comprehensive Hemophilia Treatment Centres

Hemophilia is a complex disorder. The wide-ranging needs of people with hemophilia and their families are best met through the coordinated delivery of comprehensive care by a multidisciplinary team of healthcare professionals, in accordance with accepted protocols that are practical and national treatment guidelines, if available [1,2]. Comprehensive care promotes physical and psychosocial health and quality of life while decreasing morbidity and mortality [3,4].

Comprehensive hemophilia treatment centres (HTCs) should be established to ensure that people with hemophilia have access to the full range of services necessary to manage the condition. The keys to improving health and quality of life include prevention of bleeding, long-term management of joint and muscle damage, and management of complications from treatment including inhibitor development and tranfusion-transmitted infections. [5]

- The core multidisciplinary team should consist of:
  - a medical director, preferably a pediatric and/or adult hematologist, or a physician with interest and expertise in hemostasis;
  - a nurse;
  - a physiotherapist or other musculoskeletal expert (occupational therapist, physiatrist, orthopedist, rheumatologist) who can address prevention as well as treatment;
  - a laboratory specialist
  - a psychosocial expert (preferably a social worker, or a psychologist).
- The comprehensive care team may also include a chronic pain specialist, dentist, geneticist, hepatologist, infectious disease specialist, immunologist, gynecologist, vocational counselor etc., based on the needs of the patients and the clinical specialists available.
- All members of the core team should have expertise and experience in treating patients with bleeding disorders and be accessible to patients in a timely and convenient manner. Adequate emergency care should be available at all times.
- Ideally a coordinator (often the nurse) should staff the HTC full-time. Others team members will dedicate a percentage of their time to the HTC, based on the needs of the patient population. NOTE: Though ideal, the various health services provided or accessed by the comprehensive care team do not need to be at the same site, as long as communication among health professionals is frequent and adequate.
- The following support resources are also necessary:
  - Access to a coagulation laboratory capable of performing accurate and precise clotting factor assays and inhibitor testing.
  - Provision of appropriate clotting factor concentrates, either plasma-derived or recombinant, as well as other adjunct hemostatic agents such as desmopressin (DDAVP) and tranexamic acid where possible.
  - Where clotting factor concentrates are not available, access to safe blood components such as fresh frozen plasma (FFP) and cryoprecipitate.
  - Access to casting and/or splinting for immobilization and mobility/support aids, as needed.

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Functions of a Comprehensive Hemophilia Treatment Centre [2,5]

1. **To provide and coordinate inpatient (i.e. during hospital stays) and outpatient (clinic and other visits) care and services to patients and their families.**
   Patients should be seen by all core team members at least yearly (children every six months) for a complete hematologic, musculoskeletal, psychosocial assessment and to develop, audit, and refine an individual's comprehensive management plan. Referrals for other services can also be given during these visits.
2. **To initiate, provide training for, and supervise home therapy with clotting factor concentrates where available.**
3. **To educate** patients, family members, and other caregivers to ensure that the needs of the person with hemophilia are met.
4. **To collect data** on sites of bleeds, types and doses of treatment given, assessment of long-term outcomes (particularly with reference to musculoskeletal function), complications from treatment, and surgical procedures. This information is best recorded in a computerized registry and should be updated regularly by a designated person. Systematic data collection will facilitate the auditing of services provided by the HTC and support improvements to care delivery, help inform allocation of resources, and promote collaboration between centres in sharing and publishing data. Registries must be maintained in accordance with confidentiality laws and other national regulations.
5. **Where possible, to conduct basic and clinical research**. Since the number of patients in each centre may be limited, clinical research is best conducted in collaboration with other hemophilia centres.

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