Requirements for a reference thalassaemia centre
The structure/model for centres dealing with chronic/hereditary blood disorders

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Aims of Management

- Long Survival
- Good Quality of Life

Survival of patients

- Optimum treatment required for survival and quality of life.
- No treatment means early death
- Less treatment means poor quality of life and early death
Factors affecting survival

- The treatment protocol
- Adherence to it
- Family support
- Psychosocial support
- Quality of follow-up
- Early recognition and intervention of complications

Survival of thalassaemia patients in Cyprus by birth cohort
Ethical principles

- Quality of care is an ethical principle
- Equity of care is a universal principle
- Both quality and equity require planning at a central level

Quality of life

Depends on:
- Good clinical condition
- Psychosocial support
- Endocrinological monitoring of growth, puberty, hypogonadism, amenorrhoea, reproduction
- Complications e.g. diabetes, heart
- Bone pains
- Employment, marriage
Patient care

- Voluntary blood donation
- Safe blood
- Provision of essential drugs, chelating agents
- Free medical treatment
- Psychosocial support
- National registers

Patients must also cope with:

- The disease, its complications and chronicity
- Demanding treatment, especially chelation
- Family: supportive but may increase stress
- Caregivers (doctors/nurses) – overprotective, or figures of authority
- Society: peer relationships, stigmatisation, education, career, marriage
Comprehensive care

- Treating the whole person and the family, through continuous supervision of all the medical and psychosocial aspects...
- Every facet of the person – physical, emotional, psychological, educational, financial and vocational factors are addressed
- www.hemophilia.org

Comprehensive care?

- In a European survey (Enerca) – 20.5% of thalassaemia patients wait for more than 2 hours for the blood transfusion.
- 61.7% are transfused in the mornings – to suit the hospital without considering the educational (50% attend school or university) or employment (13% work full time) commitments of the patients
Patient needs – rarely satisfied

- 271 hours per month are spent on blood transfusions, chelation, other medical appointments, travel time, phoning’
  Compagno LM et al Ann NY Acad Sci, 2005

- Transfusion times to suite education and work
- Shortening waiting time
- Increasing communication time

Time

- Average time doctor spends with a patient in the US: 18.7 minutes
- Average time doctor spends with a patient in Germany: 15 minutes
- What about patients with chronic disorders?
The need for expert centres

- A centre where the quality of comprehensive, patient centred, care is assured
- The capacity to provide expert diagnosis or confirmation of diagnosis, including genetic tests and genetic counselling
- Laboratory as well as clinical capacity
- Training and education of stakeholders and service providers

Expert Centre
Adapted from the EU task Force Criteria

- A centre where the quality of comprehensive care is assured
- Where there is the capacity to provide expert diagnosis
- Well qualified staff with experience
- Supporting- self management
- Networking with secondary centres but also with other expert centres
Chronic Care Model

- Health care organisation
- Community resources
- Self management support
- Delivery system design
- Decision Support
- Clinical Information System

Wagner EH et al Health Aff 2001

Expert thalassaemia centre

The capacity to provide expert case management:

- Good practice guidelines and protocols
- Expert advice & information to patients
- Multidisciplinary team- coordinated
- Psychosocial support
- Staff/patient ratio
Patient-friendly services

- Staff willing to spend time and to listen
- Privacy and confidentiality
- Discuss sexuality, contraception, puberty, diet, risky behaviour, school problems, etc.
- Convenient appointment times – consider school and work
- Patients feel welcome and safe

Clinical information systems

- Using technology to organise data
- Monitoring patient health status
- Electronic patient records
- Identifying patient sub-groups for pro-active interventions
- Rights of patients to the contents of their records
- Electronic patient registries
- Networking between centres nationally and internationally
The EHR – a starting point

- Decision support
- Research
- National registries
- Networking

Decision support in thalassaemia centres

- Evidence-based guidelines (updated)
- National standards for optimal care
- Regular training of staff in using protocols
- Sharing information with patients
- Electronic infrastructure, telemedicine, videoconferencing between doctors, etc.
Delivery system design

- Coordinating the multidisciplinary team
- Defining roles in the team
- Regular follow up of patients
- Communicating with the patient at home
- Collaboration with primary care services and supporting local physicians

EurordisCare3 Survey

- 95% of patients consider that coordinating the sharing of medical information between health professionals in the specialised centre and the local health professionals is essential or useful
Self-management support

- Patient empowerment - improving autonomy
- Patient / caregiver partnership in setting goals, action plans, presenting solutions
- Patient information – person to person – to acquire skills and confidence in self-care
- Health workers' time
- Changing physicians’ attitudes: paternalistic to partnership

Community resources

- Supporting patients needs
- Educational needs of young patients
- Patient support groups and assistance from without the reference centre
- Links between the Centre and community agencies – social assistance
- Health education and information to the public
Additional standards

Links to primary/secondary services:

- Patients with poor access to the reference centre – distance, poverty
- Ethnic minorities/immigrant groups – scattered geographically
- Private/public sector relationship (does referral to the centre cancel the role of the private or primary care provider?)

Other duties of the thalassaemia service

- Epidemiological surveillance
- Collaboration/links with other national and international centres
- Close links with patient organisations
EurordisCare3 Survey

- 96% of patients agree that a specialised centre should involve patient organisations in order to benefit from their knowledge of the daily life and needs of patients

Expert centres

Sufficient activity and capacity to provide services, gain experience, and sustain quality:

What is the minimum throughput for each service?
Survival – treatment in specialised centres

Fig. 1. Kaplan-Meier overall survival curves of patients referred to specialized centers (IC) versus patients referred to nonspecialized centers (OC). Log-rank P-value = 0.0001; hazard ratio of IC versus IC adjusted for sex (Cox model): 18.1; 95% confidence interval = 4.7–69.0; P < 0.001.

Summary

Quality of care

Equity, Access, National plan

Multidisciplinary, centres of excellence

Decision support, IT support

Research Ethical/legal Community

Forni et al Am J Hematol 2009