

Requirements for a reference thalassaemia centre

Copying European Standards?

Thalassaemia International Federation
Dr Michael Angastiniotis
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- SUE 100
- SUE 100/101
- SUE 100/101/102
- SUE 100/101/102/103
- SUE 100/101/102/103/104



<http://www.drawing.com> to register the program
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Aims of Management

- Long Survival
- Good Quality of Life



Factors affecting survival

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

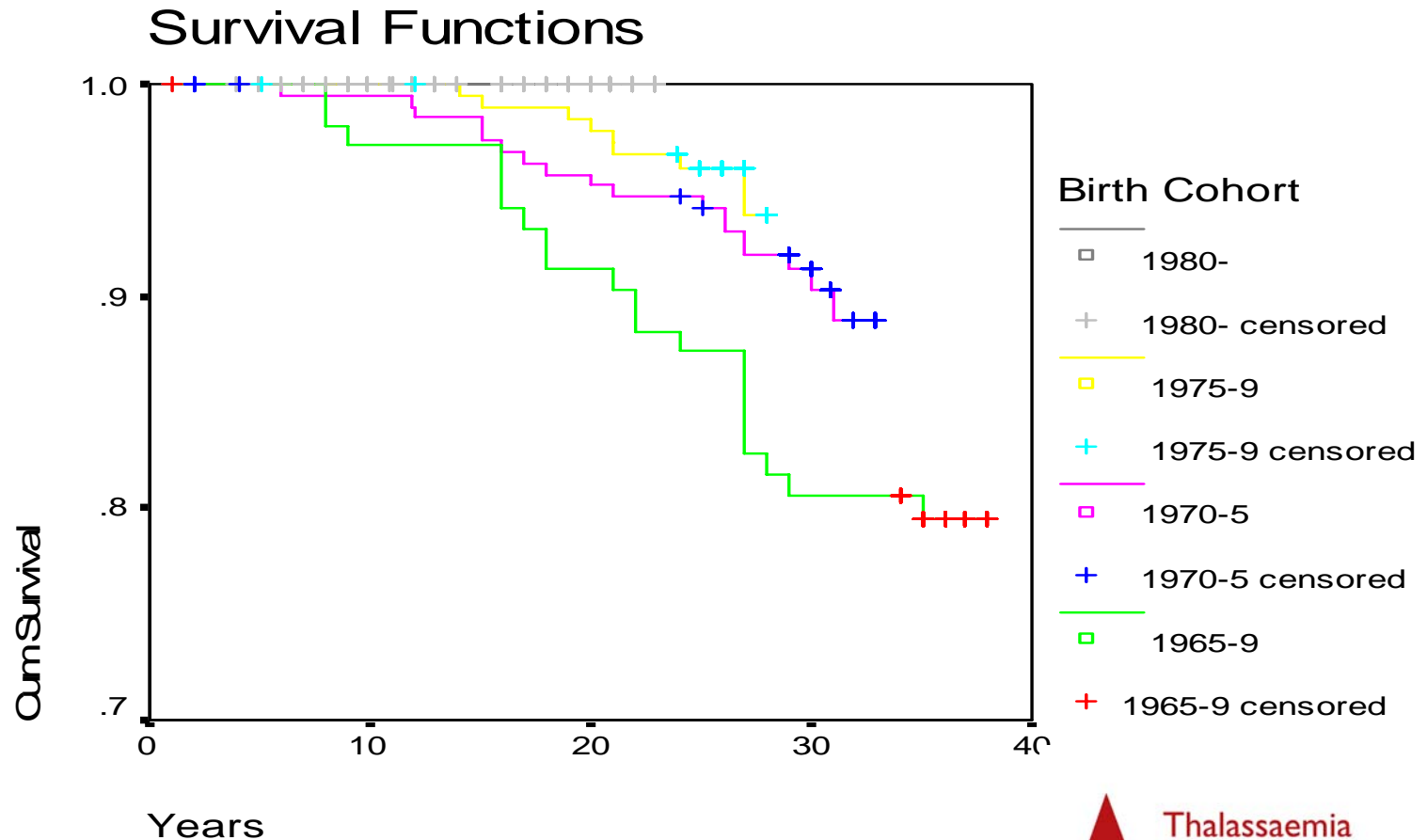


Survival of patients

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



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**



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**



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**
- **Expert Reference Centers. Quality of care.**
- **Psychosocial support**
- **National registers**



Quality of Care: 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?**



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**



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
- Access to the multidisciplinary team



Expert thalassaemia centre

The capacity to provide expert case management:

- Good practice guidelines and protocols
- Expert advice & information to patients
- Multidisciplinary team- coordinated with continuity of care
- Psychosocial support
- Staff/patient ratio



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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**



Decision support in thalassaemia centres

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



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



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

- **94% of patients consider that coordinating the sharing of medical information on the patient between all professionals who care for him/her in the specialised centre is essential (70%) or useful (24%)**



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**



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**



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EurordisCare3 Survey

- **Every year 28% of patients needed the assistance of a social worker**
- **18% difficult access**
- **9% very difficult**
- **4% impossible**



Additional considerations

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?)**
- **Transition from paediatric to adult services**



EurordisCare3 Survey

- **92% of patients consider that informing patients about their rights and guiding them toward social services, schools, leisure activities or vocational guidance is essential**



Other duties of the thalassaemia service

- **Epidemiological surveillance**
- **Collaboration/links with other national and international centres**
- **Close links with patient organisations**
- **Research**



Expert centres

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

What is the minimum throughput for each service?



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EurordisCare3 Survey

95% of patients consider that communicating with other specialised centres and professional networks to harmonise treatment and research at the national and the European level is essential (67%) or useful (28%)



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Expert centres

It is not the premises!

It is the quality of caring!

The time spent in listening!

The time spent in explaining!

Thank you!



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