HISTORY OF COMPREHENSIVE CARE

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- Eras of care
- Evolution of comprehensive care in countries
- Guidelines for comprehensive care – 2008
- What will the future bring?

ERAS OF CARE

1940s	Diagnosis, no replacement therapy or fresh blood, no surgery
1950s	Fresh blood, FFP, Dental work, acute haemorrhage, long hospital stays
1960s	Cryoppte, Factor concentrates, Joint correction, physio,
1970s	Home therapy, major surgery, inhibitors
1980s	HIV, Hepatitis, Joint replacement
1990s	Prophylaxis, Viral infections
2000s	Home delivery, Tolerisation, Hepatitis C
2010s	? Longer half-life factor, ?? Gene therapy

UNITED KINGDOM

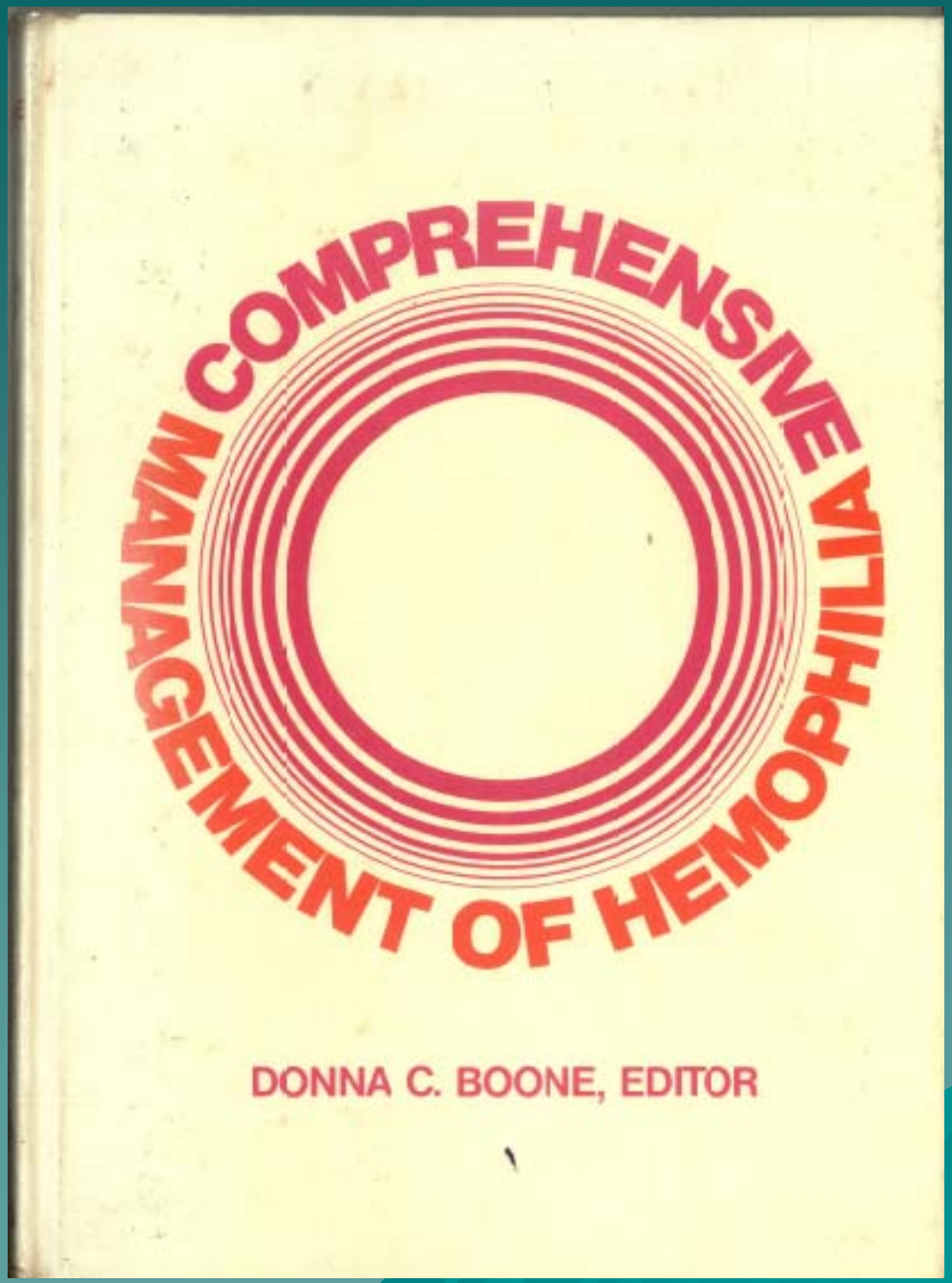
1950s	National approach to haemophilia care – Medical Research Council – 19 centres
1964	Ministry of Health
1968	Health memorandum – 36 centres – national meeting of doctors
1976	Revised criteria - 52 centres – with 7 designated Regional Haemophilia Centres
2001	Haemophilia Alliance – specifications – involving professional, hospital and community groups

'Thus over the past 50 years there has been national coordination of haemophilia care with arrangements having to change in response to advances in therapy as well as the way the government has overall managed the state national health service'

Ludlam C. Comprehensive care and delivery of care: the developed world in Textbook of Haemophilia ed Lee CA, Berntorp E, Hoots WK 2005 Blackwell, USA

Published 1976

Describing development and role of Los Angeles Hemophilia Rehabilitation Center



HEMOPHILIA REHABILITATION CENTER AT ORTHOPEDIC HOSPITAL, LOS ANGELES

- Beginnings in 1962
- Funded through grants from 1964-70 – then Regional Hemophilia Rehabilitation Center (for south-west)
- Multidisciplinary in scope
- Combined in one coordinated setting offering comprehensive medical, psychosocial and vocational-educational services
- Pediatrician, internist, hematologist, coag lab technician, orthopedist, nurses, physical therapist, pedoodontist, oral surgeon, psychiatric social worker, vocational rehabilitation counsellor

COMPREHENSIVE CARE USA – 1970s

- ‘Increasing number of haemophiliacs have become involved in self-therapy programs’
- ‘increases patient responsibility and decreases physician supervision’
- To detect and minimise problems as well as to maximize benefits and long term gains.. Developed a systematic multidisciplinary approach to each individual - comprehensive health care program’

Levine PH et al. Comprehensive Health care clinic for Hemophiliacs. Arch Intern Med. 1976,138,792-4

PROCESS

- Complete evaluation – 2-3 hours
- Reviewed - multidisciplinary
  - Blood tests, Factor levels, inhibitors
  - Nurse practitioner - BP, PR, weight, review venepuncture technique, preparation of concentrates, dosages, education
  - Doctor –history and physical examination –review with director
  - Orthopedic surgeon – joint range of motion and function
  - Oral surgeon
  - Psychologist or social worker
- Surgery

OUTCOMES OF COMPREHENSIVE CARE - USA

The minimum services provided by each center were:

- A coagulation laboratory of recognized high standards;
- A blood bank providing all of the blood components needed by hemophiliacs;
- A multidisciplinary hemophilia care team including a hematologist, an internist, a pediatrician, an orthopedic surgeon, a physical therapist, a dentist, a social worker, and a registered nurse;
- Formal linkages with mental health, genetic counseling, and rehabilitative services;
- A training course in self-therapy (home care) and updated hemophilia concepts for patients and family members;
- An outreach program to enable every hemophiliac within the area served to receive services of the program.

Smith P, Levine P. Benefts of comprehensive care of Hemophilia: five year study of outcomes. AJPH 1984. 74,6,616-8

TABLE 1—Outcome Data in 11 of 22 Federally Funded Comprehensive Hemophilia Diagnostic and Treatment Centers

Outcome Data	Year before Program	Fifth Year of Program
No. patients seen at primary centers	1783	3705
No. patients seen at affiliate centers	329	1037
No. patients receiving regular comprehensive care	1333	4682
No. patients on self-infusion ("home care")	514	2001
Average days/year lost from work or school	14.5	4.3
Average hospital admission/year	1.9	0.26
Average days/year spent as inpatient	9.4	1.8
Per cent patients with third party coverage	74	93
Out-of-pocket expense/patient/year	$ 850.*	$ 342.
Overall costs of care/patient/year	$15,800.*	$5,932.
Per cent unemployed adults**	36	12.8

*These figures represent retrospective estimates from small samples, in the case of most of the centers.

**See Results section of text.

Smith P, Levine P. Benefts of comprehensive care of Hemophilia: five year study of outcomes. AJPH 1984. 74,6,616-8

SYDNEY

- ‘The need to develop a broadly based service at Royal Prince Alfred Hospital became apparent about ten years ago when it was realised that haemophiliacs were using the hospital staff as their sole source of advice and guidance on every conceivable personal and social matter’
- ‘an extensive survey.. Uncovered much that was predictable – poor educational performance, inadequate vocational preparation and so on’
- Educate families and inform them of community sources… but having a constant source of support and guidance in the hospital clinic appeared to be the most helpful factor to patients and relatives’
- Change in key hospital and research staff not helpful. Burden of other duties
- ‘accordingly fulltime services of social worker and nurse made available to clinic’

Kerr CB. Comprehensive care for HaemophiliaJ. Roy. Coll. Phycns. Lond 1971 5,3,263-267

AUSTRALIA – RECENT HISTORY

- Individual states – dependent on personnel, state support
- 1999 Support from Medical Advisory Panel for designated Haemophilia Centres / data collection
- Variable approach
- Australian Haemophilia Centre Directors Organisation (AHCDO) – promote Haemophilia care – other professional organisations – Nursing, Physiotherapy, Social Work, HFA
- Australian Bleeding Disorders Registry (ABDR) – clinical and planning tool
- AHCDO using audit tool in paediatric centres (C Barnes) and adult centres (in progress – Dr J Lloyd)
- Develop gap analysis – present to DOHA

Comprehensive care centres

Colvin BT et al . European principles of Haemophilia care. Haemophilia 2008,14,361-374

- provide 24-h service with experienced staff;
- provide inhibitor care;
- have access to an immune tolerance service, with priority being given to newly developed inhibitors;
- provide people with haemophilia with safe and effective factor concentrate. People and especially children, should receive the product with the lowest possible risk of transmission of pathogens;
- provide 24-h, hospital based, experienced medical cover with one or more whole-time equivalent doctors;
- have designated nursing staff to co-ordinate treatment, treatment supplies, the home treatment programme and patient and family education;
- provide community liaison, including appropriate home and school visits;
- have a laboratory that provides 24-h assay cover and is able to measure the potency of inhibitors in a timely manner;
- have a laboratory that is subject to external quality assurance;
- have hospital-based nursing staff. Some centres may also find that hospital-based nurses offering community outreach are valuable;
- have available a dedicated physiotherapy service;
- have access to a social worker;
- have effective and dedicated data management;
- have access to rheumatology and/or orthopaedic services;
- have access to dental services;
- have access to obstetric and gynaecology services;
- have access to psychological support;
- if children are treated, have a paediatric Accident & Emergency department, paediatric day care, a paediatric ward and paediatric nurses;
- have access to a genetics laboratory;
- be able to manage the process of genetic counselling;
- have access to an antenatal diagnostic service;
- be able to care for patients with HIV and hepatitis C infection;
- be accessible for people with disabilities;
- follow-up patients regularly;
- provide home treatment for patients;
- be able to provide prophylaxis, especially for children and where otherwise indicated;
- keep reliable records;
- carry out clinical audit. Internal audit is essential; external audit is desirable;
- undertake medical education;
- participate in research;
- have broad experience in haemostasis and
- adhere to consensus guidelines in haemophilia, which should be available in each European country.

- Is comprehensive care required in 2010?
- If so what should it look like?
- How is it best organised?
- Involvement of GPs / community?

ISSUES

- Federal / State boundaries impacting funding and linking to cost of products
- Treatment products organised nationally
- Roles of Haemophilia Centres / staffing – thrombosis services
- Impact of prophylaxis on patient outcomes / health / Quality of life
- Aging population of persons with haemophilia
- Rural / regional care
- Inhibitor management
- Implementation of new therapies – coordination eg gene therapy, clinical trials
- Support for community organisations
- Gap analysis of Haemophilia Centres in Australia

PROGRESS IN THERAPY

- Acute management without replacement therapy
- Initial replacement with fresh blood, fresh frozen plasma
- Factor replacement with cryoppte and plasma derived conentrates allow active management of bleeding – joint, surgery dental work. Hospital based – intensive treatment of joint complications
- Home therapy / on demand – require education, venepunctue technique and regular supervision. Social/ emotional issues need to be addressed
- Recombinant products – less risk of viral infections
- Prophylaxis – prevent bleeds. Tolerisation
- Home delivery of product