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?
<table>
<thead>
<tr>
<th>Era</th>
<th>Medical Practices</th>
</tr>
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<tbody>
<tr>
<td>1940s</td>
<td>Diagnosis, no replacement therapy or fresh blood, no surgery</td>
</tr>
<tr>
<td>1950s</td>
<td>Fresh blood, FFP, Dental work, acute haemorrhage, long hospital stays</td>
</tr>
<tr>
<td>1960s</td>
<td>Cryoppte, Factor concentrates, Joint correction, physio,</td>
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<tr>
<td>1970s</td>
<td>Home therapy, major surgery, inhibitors</td>
</tr>
<tr>
<td>1980s</td>
<td>HIV, Hepatitis, Joint replacement</td>
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<tr>
<td>1990s</td>
<td>Prophylaxis, Viral infections</td>
</tr>
<tr>
<td>2000s</td>
<td>Home delivery, Tolerisation, Hepatitis C</td>
</tr>
<tr>
<td>2010s</td>
<td>? Longer half-life factor, ?? Gene therapy</td>
</tr>
</tbody>
</table>
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’

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, pedodontist, oral surgeon, psychiatric social worker, vocational rehabilitation counsellor
‘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’

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. Benefits 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

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

*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. Benefits of comprehensive care of Hemophilia: five year study of outcomes. AJPH 1984. 74,6,616-8
‘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’

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


- 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 cryopplasma derived concentrates allow active management of bleeding – joint, surgery dental work. Hospital based – intensive treatment of joint complications
- Home therapy / on demand – require education, venepuncture 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