NATIONAL HAEMOPHILIA CARE MEETING

Haemophilia Care – Goal settings and Prioritisation

Bengaluru, India
25th - 26th April, 2015

HEMOPHILIA FEDERATION INDIA
Healing Hemophiliacs in India Since 1983

Maulana Azad Medical College
New Delhi, India

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National Haemophilia Care Meeting 2015

National Haemophilia Care Meeting (NHCM) is a unique platform where different stakeholders in haemophilia care viz. state healthcare administrators, expert physicians involved in care of PWH and representatives of the national patient organization come together to discuss an area of health care that is unique in its requirements but through which many other patients can also benefit.

Though haemophilia is a rare disease and relatively expensive to treat, it should be recognized that very good treatment has been available for it for more than 3-4 decades. Not providing that to patients in India for so long has led to immense distress to these patients and their families. This needs to be addressed and this process has indeed begun and it gathering force with more than 15 states allocating funds from their budgets for the care and treatment of these patients. What is equally important to recognize that apart from this relatively rare bleeding condition, there are several more hereditary and many acquired bleeding conditions such as post-partum bleeds, snake-bites, sepsis related DIC, trauma and post-surgical bleeds in our hospitals which are inadequately managed causing avoidable morbidity and mortality because of the lack of knowledge as well as necessary facilities. Through the process of developing services for haemophilia, all these patients will also benefit. The first NHCM meeting held in 2013 was successful where participants from 15 states discussed about the plans made in different states and resources allocated by them for haemophilia care and learn from one another's experiences in the challenges faced and successes in their implementation.

The second NHCM meeting in April 2014 was conducted to discuss the burden of haemophilia in India, the barriers in providing adequate healthcare to people with haemophilia (PWH) and potential ways of overcoming them.

As more states continue to allocate resources for haemophilia care, it was considered necessary and important to continue this process. The third and the present NHCM was therefore conducted to discuss and agree the goals that we need to achieve in haemophilia care or at the least prioritise a few of these and try to achieve them in the near future. With participation from 14 states in this meeting, three topics were discussed as mentioned below.

Goals and Priorities in delivering Haemophilia Care Services

NHCM-2015 focused on three key topics namely
1. Principles of care – Setting the goals,
2. Creating Haemophilia Treatment Centres (HTC) – Providing specific clinical services,
3. Establish a state registry - Link ongoing haemophilia services to registry

1. Principles of care – Setting the goals

Using the published document of the 'European principles of care (POC)', the needs in India were discussed. It was recognized that the ultimate goals of good care are the same everywhere, even though it may take different paths and durations to get there in different parts of the world. Therefore these principles are essentially universal. The following were considered to be the core requirements that could be adapted to the Indian context

1. A coordinating group in each state with a 'nodal' officer & members from the some / all of the HTCs
2. Develop a common format for "State" Haemophilia Patient Registry

3. Establish Comprehensive Care Centres (CCCs) & Haemophilia Treatment Centres (HTCs) - Definitions in terms of services may be adapted as is practical at that time
4. Partnership with 'expert' institutions, patient organizations and industry in a PPP model for the delivery of haemophilia care
5. Provide safe and effective Clotting Factor Concentrates (CFC) at optimum levels – to minimize bleeding
6. Keep 'home treatment' as the ultimate goal with mechanisms to avoid misuse
7. Prophylactic CFC replacement starting with young children at the earliest possible.
8. Specialist services and Emergency Care for the management of serious complications
9. Make products available for treatment of bleeding in PWH with Inhibitors
10. Education & research – to improve haemophilia care with relevant local data

Since it may not be possible to initiate on all of these above mentioned requirements within available resources, the need to prioritise was felt with special emphasis on following goals.

1. Focus on detection & accurate diagnosis
2. Education & training of health care personnel
3. Graded development of infrastructure, services and therapies including prophylaxis depending on resources
4. Active patient participation and empowerment.
5. Access to clotting factor concentrates in quantities that will allow at least lower dose prophylaxis to be initiated.

2. Creating HTCs – Providing specific clinical services

Regarding discussion on establishing HTCs and clinical services that need to be provided for PWH, the following emerged as significant action points.

1. Identify institutions where HTCs / CCCs may be established – 'virtual' or physically defined
2. Designate and train a basic or comprehensive care team
3. Establish lab infrastructure and good diagnostic services
4. Provide basic / comprehensive clinical services particularly physical therapies
5. Establish system for outcome assessment
6. Have facilities for genetic counselling, carrier detection and prenatal diagnosis within each state
7. Participate in basic /advanced education and research

3. Establish a state registry - Link ongoing haemophilia services

With approximately 17,000 PWH registered with Haemophilia Federation, India (HFI) and with the changing profile of haemophilia care – from NGOs and private hospitals to the Government health care system, there was a strong need for establishing registry at the state level as this could serve to acquire, configure and disseminate information between various stakeholders' i.e. health care providers, state Governments and patients.

It was discussed that significant experience and expertise regarding registry has been built up within HFI with the registry that was initiated in the late 1990s. There is an electronic, interactive format in place in Karnataka which needs to be evaluated, assessed for its wider applicability & distribution to other states. Also issues related to source / responsibility for input of data, management, access and analysis need to be resolved and issues related to anonymity and confidentiality also have to be addressed. It would be best if this could be done within the Government system.

It also emerged during the discussion that having resolved such issues, a successful registry creation will aid the health care planners to understand the epidemiology of the disease, current morbidity and disease burden in India in several states, optimize resource allocation, prevent complications of the disease, track use of factors, quantity needed to treat, funding utilized and also the number of patients that are benefitted and the geographical region where these has been utilized.

Other issues

Several other related issues like procurement, distribution & inventory management of CFCs with special emphasis on the need to create a system for tracking was also discussed. It also emerged that resources were not a major constraint for supporting hemophilia care – National Health Mission (NHM) was found to be a major option in all states apart from other options that already existed in few states. The group also emphasized that training & creating awareness among Health Care Workers and PWH was equally important to help Governments implement their program as they were new every 2 – 3 years. It was also mentioned during the discussion that setting up services for haemophilia care will also help many patients with other bleeding disorders. In fact, there appeared to be an inverse correlation between Maternal Mortality Rate in different parts of India and the distribution of HTCs in the same regions.

Haemophilia Care in the States – Govt support

State Health care administrators from various states – Tamil Nadu, Maharashtra, West Bengal, Jammu & Kashmir, Haryana, Kerala shared respectively their State Government’s support, challenges they face and future opportunities for provision of Haemophilia care.

Funding for Haemophilia care – Options, Challenges & Solutions - Sharing ‘Success’ stories

Tamil Nadu

Funding options:

Haemophilia is included in Chief Minister Comprehensive Health Insurance Scheme. Patients whose annual income is less than72000INR are eligible for free treatment in all hospitals under this scheme.

Challenges:

1. Increasing number of patients is being registered in Medical college Hospitals.
2. All patients are provided free treatment lifelong in Govt Hospitals as a result drug requirement is on an increase.
3. Continuous procurement and supply of drugs on time.
4. Creation of laboratory services in all Govt. Medical college hospitals.
5. Continuous monitoring of drug position and transfer of medicine from one institution to another if needed
6. Training and sensitisation of Medical Officers and Paramedical staffs on regular basis on Haemophilia care.
7. Need for PWH to travel long distance frequently to get treatment since drugs are available only in Govt Medical college hospitals.

Possible Solutions:

1. More fund allotment.
2. PG course to be started, so that more number of experts available in Govt hospitals.
3. Drugs need to be available in Govt hospitals also where physician/paediatrician available, so that patient can avoid travelling long distance.
4. Day care centres to be started in all Govt Medical College Hospitals, so that patients need not stay in the hospitals.

Madhya Pradesh

Funding options:

1. Funds are being collected from different societies, individuals, businessmen, Corporate sectors, Prerna Sewa Society Bhopal, Saptak Fine Art Society etc.
2. Procurement of funds sanctioned by Chief Minister and Principal Health Secretary from NHM budget

Challenges:

1. Budgetary requirements not only for Free supply of Clotting factor concentrates but also for comprehensive care of patients viz. diagnosis, treatment, rehabilitation, and supportive care for patients by creating awareness through camps &mass Media, training of medical and paramedical personals and fostering research &development
2. Need for PWH to travel long distance frequently to get treatment since drugs are available only in Govt Medical college hospitals.
3. Need to involve faculties from all disciplines from government & private sectors
4. Need to involve other sectors especially media - both print & electronic

Possible solutions:

1. Free clotting factors were made available to all PWH in all District Head Quarters Govt. Hospitals;
2. Train a team of dedicated doctors, technicians, staff nurses and social workers and regular CMEs.
3. Regular source of funding needs to be identified and consistent funding needs to be made available throughout the year.
4. Develop State registry for hemophilia - future planning, need analysis, reliable data base on the demographic, clinical and interventional information of the PWH.
5. Establishment of HTC and coagulation lab at all district hospitals of MP with reference lab in GMC Bhopal , this will be helpful not only haemophilia but also to detect and manage other bleeding disorders which will also reduce MMR

West Bengal

Challenges:

1. Inadequate number of hemophilia treatment centres for diagnosis, management of hemophilia as a result leading to lack of diagnosis.
2. Non affordability of the cost of clotting factor treatment;
3. Early diagnosis, access to treatment, inhibitor assessment, management of inhibitor patients, Public unawareness still remain as potential issues and challenges in implementing effective hemophilia care.

Possible solutions:

1. Primary care is already available in all the Medical Colleges; to upgrade all the Medical Colleges to specialised Haemophilia Centre and upgrade its diagnostic facilities to include Coagulation assay, Correction study, Factor assay, Inhibitor assay.
2. Availability of clotting factors treatment free of cost to all PWH in the state.
3. To upgrade the diagnostic facilities available in Specialised Hemophilia Treatment centres to include mutation study and pre-natal diagnosis

Establishing services for haemophilia care - Challenges & solutions

Orissa

Challenges:

1. Procurement of free factor concentrates
2. Regulation in consumption of clotting factor therapies including consistent availability throughout the year,

3. Inadequate manpower and inadequate training to manage Haemophilia treatment centre
4. Lack of SOPs/Guidelines for PWH management in Indian scenario.

Solutions:

1. Procurement of clotting factors and availability to patients free of cost since April 2014
2. Inclusion of Factor VIII & IX in Essential Drug List, Govt. of Odisha
3. Establishment of Day Care Centres in Govt Medical Colleges and Centre of Excellence in SCBMCH. Expand these services to Dist. Headquarters Hospitals in future.
4. Inclusion of rFVIIa in Essential Drug List (Special Category) for inhibitor management
5. Establishment of genetic and pre-natal diagnosis in Govt. Medical College Hospitals.

Gujarat

Challenges

1. Lack of adequate infrastructure and skilled manpower
2. Lack of coordination between haemophilia society and various departments
3. Lack of adequate funding and availability of clotting factors.
4. Lack of components for delivering comprehensive care especially laboratory facilities, counselling, physiotherapy and availability of all specialists.

Solutions

1. Entered into a MOU with Corporate sector under Corporate Social Responsibility(CSR) for providing adequate funding and manpower
2. Identified and established a Hemophilia day care centre with delivery of comprehensive care services.
3. Identified other sources of funding apart from Govt. allocated budget for Hemophilia care for eg. NGOs and other industries - to donate for setting up HTC and day care centre
4. To bring about a co-ordinated effort amongst haemophiliacs, haemophilia society, NGO's and Hospital authorities.
5. To convert day care centre to Haemophilia 24 x 7 Treatment Centre soon and start Haemophilia Training Centre at the earliest
6. To encourage research work in the form of dissertations and some Post graduate students have already taken up their work in the field of Hemophilia.

Kerala

Challenges:

1. Lack of awareness regarding management of Hemophilia and lack of trained personnel and team work for the same
2. Difficulty in convincing the policy makers and lack of political and bureaucratic will – due to low health priority as less number of patients are affected in comparison to other diseases.
3. Budgetary constraints for procurement of clotting factor concentrates, and setting up components of comprehensive care centre
4. Lack of infrastructure in terms of Lab diagnosis and factor management

Solutions:

1. Enable patients to get coverage under RSBY, Karunya Benevolent Fund, Arogyakiranam and state pension scheme by processing their applications
2. Procurement of free generic drugs under EDL- CFCs were included in Essential Drug List in December 2014
3. Mobilization of funds through additional sources apart from Govt. funding like
    a. District Panchayat
    b. National Health Mission

    c. Karunya Benevolent fund - proceeds from Karunya Lottery channeled for patient care
    d. Private Public Partnership & NGOs (CSR, Voluntary consultancy services, Palliative care services) [Donations were received from Kelly Foundation, Thanal, Terumo Penpol , Cochin shipyard, Federal Bank, Maruti EECO, BPCL, SNEHAKKOODU, ASWASALAYAM, SAI SAMITHY – for employment, food, boarding and lodging].
4. Inter-sectoral co-ordination (NHM, SJ, Lottery, Labour - RSBY, Chis Plus&various schemes)
5. Involvement of elected representatives - Through patients mobilized representations from many panchayats, 34 MLAs and 4 MPs on their behalf for government support to hemophilia care.
6. Establish Zonal Hemophilia Treatment Centers with comprehensive care services that included Physiotherapy unit, lab services, training for doctors & paramedic staffs, camps & I.E.C activities.
7. Vocational training & rehabilitation center started and PWH were trained in 15 trades including soap making, mobile repairing, etc.

Way Forward

1. To start a database registry in association with all chapters of HFI in Kerala.
2. Submit proposal for aapproval of prophylactic therapy
3. Continuous capacity building including skill assessment
4. Establish Centre of Excellence and increase the number of centers
5. Extend the benefit to patients with other bleeding disorders

Maharashtra

Initial Challenges:

1. Lack of funding for Clotting factor treatment in Hemophilia as other epidemic diseases were given a priority.
2. Lack of trained manpower and infrastructure for delivering comprehensive care services

Solutions:

1. Inclusion of Hemophilia in Hematology Programme - under N.R.H.M., was approved, in Maharashtra state, in PIP 2012-13 and successfully implemented in 4 centers, namely District Hospital Thane, Nasik, Satara, & Amravati by starting Day care services that included comprehensive care delivery for Hemophilia, E tendering process, availability of IEC material etc.
2. Inclusion of Clotting factors in the Essential Medicine List that is NHM Free Drug Services.
3. Accessible treatment center, trained manpower with adequate infrastructure should be the aim for long term success; hence proposal for additional 4 centers were immediately accepted by the State Govt.
4. Diagnostic facilities should be improved for diagnosing new pts. & evaluating care

Prioritisation of goals in delivering Haemophilia care services

Goal Prioritisation at Treatment centre level

Though several goals were elaborated from a treatment centre perspective; following were the goals that need be prioritised as mentioned below.

1. Create distinct identity and space to provide care and cater to the needs of PWH that includes but is not limited to treatment services, physiotherapy, counselling services and educational awareness programs.

2. Establish diagnostic services that are easily available, accessible and free of cost to PWH –Offer basic lab services like PT/aPTT and correction studies to start with followed by factor assays and inhibitor screen as soon as possible after that.
3. Provide clotting factor concentrates and other adjunctive therapies to the PWH in an uninterrupted manner
4. Educational sessions and workshops to enable self-infusion of factor concentrates; this will enhance their confidence and serve as a stepping stone for home therapy in future.

Ongoing process and future goals after achieving the short term goals

1. Carrier detection & pre-natal diagnosis
2. Intersector coordination and collaboration
3. Fostering research –
    a. Measuring epidemiological and clinical burden PWH face in India
    b. Economic costs – direct and indirect
    c. Assessing outcome of care provided with appropriate tools

Goal Prioritisation at Patient Organisation level

Hemophilia Care Requirements.

Once priorities are met each element of hemophilia care may be revisited and upgraded

Good laboratory

1. Medical colleges
2. District Hospitals
3. Taluk Hospitals
4. 1 advanced lab in each state

Place for Treatment

1. Comprehensive Care Centers in Medical Colleges
2. HTC's in District Hospitals

Products for Treatment

1. Adequate and continued factor supply
2. Factor VIII & IX & 1 bypassing agent - Minimum 10-20000 IU/PWH /year
3. Virally safe product
4. Products for vWD treatment

Suitable manpower - Primary Requirement

1. Physicians/Pediatrician (trained in coagulation disorder) if hematologist not available
2. Haemophilia Nurse
3. Physical therapy team
4. Pathologist & technician – trained in the diagnosis of hemostasis disorders
5. Dentist

Add-on Requirement

1. Orthopaedician, General Surgeon &Gastroenterologist
2. Counsellor (Psycho-social)

Goal Prioritisation at State Govt level

Care to PWH was not a priority amongst other health care services in Kerala State Govt. as the estimated number of PWH in Kerala is approx.0.02% of entire Kerala population. However with adequate IEC activities and awareness raised by the media viz, print and electronic; Kerala State Govt. brought a significant change in including Clotting factor concentrates in Essential Drug List for which an estimated 6 crores INR has already been allocated. A Comprehensive Haemophilia Care Centre with state of the art facilities has started functioning at District Hospital, Aluva on 20.2.2014 jointly sponsored by N.R.H.M. and Ernakulum District Panchayat.

Among multiple factors that were discussed, following were emphasized to be prioritised from a State Govt. perspective

1. Start HTC and implement these at local level – for e.g. at Panchayat Raj / Municipality / Corporation by including such health related projects especially Haemophilia care. This also should include but not limited to drug procurement and staff recruitment.
2. Provide facility for factor replacement therapy and physiotherapy at District level to start with.
3. To bring inter-sectoral co-ordination and convergence among different stakeholders – viz. patients, patient organisations, treatment providers, State Govt, various funding agencies like NGOs, etc.
4. Enhance capacity building – by providing periodic training and a certificate course to all service providers who are involved in haemophilia care.
5. Build a strong program and robust action plan for IEC activities – to penetrate awareness regarding haemophilia into community by implementing it through ASHA workers/social workers/ self-help groups.
6. Vocational training for self-employment and productivity
7. Create a nodal referral centre for diagnosis, prompt treatment and referral services in complicated cases.
8. Appropriate budget to be factored in for initiating prophylaxis as standard of care in PWH
9. Create and maintain registry on PWH – to capture baseline demographics, treatment history and outcome data; this will help for better planning and resource optimisation - this may be integrated with the NCD programmes
10. Audit and accreditation process to be followed for quality check and quality services

Conclusion

Principles of care in Haemophilia management, ways and approach in establishing a Haemophilia Treatment Centre and the importance of creating a State Haemophilia registry (that can be integrated later into national registry) were discussed. Though many states had started making progress in improvement of Haemophilia care services, everyone agreed on the need of setting goals and more importantly prioritise among them to be achieved in short to medium term. Among those prioritised goals are not only to establish HTCs, allocate funding not only for procurement of clotting factor therapies as well as their regular supplies, distribution and appropriate utilization but also to run comprehensive care services. These should include diagnostic services, psycho-social counselling & support, physical therapies, training and capacity building and patient registry. With support, co-ordination and collaboration from multiple stake holders including patient organisations, treatment providers, State Governments, corporate entities, NGOs and National/State Health policy makers, we can create a unique cost effective care for people with haemophilia in India which could also become a model for care of other chronic disorders in India.

List of Participants

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