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WORLD STROKE DAY, 28th October 2021 National Consultation Report

Panel Discussion:

"Stroke Survivors and Civil Society engagement in strengthening National Stroke guidelines from patient's perspective"

Jointly organized by:

Stroke Support Alliance (initiative by DakshamA health) and Indian Stroke Association

Stroke Support Alliance

Indian Stroke Association

Dakshayani and Amaravati Health and Education
(DakshamA Health)

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EXECUTIVE SUMMARY

Stroke or a cerebrovascular accident is the fourth largest cause of death in India, and one of the greatest contributors to adult lifelong disability. This is silent-but-catastrophic disease that caused over 7.3 lakh deaths in 2019.The 'NPCDCS Guidelines for Prevention and Management of Stroke' were published in December 2019, and have since then undergone revision, but there is a lot to be done at both the national and the state level to make them implementable.

India is already the world capital of diabetes, a risk factor for stroke. CVDs including stroke have emerged as the second largest cause of death causing disruption to the lives of those affected as well as the family members. Stroke prevention and management requires a comprehensive approach, encompassing several aspects in the stroke patients' journey. Some critical measures include creating wider access to emergency care services, emergency care training of healthcare professionals, allocation of adequate finances for expanding access to the right medicines and care and creating large scale awareness at the population level. According to experts, delays in providing the right care, inability to recognise stroke and lack of triaging systems in hospitals remain some of the greatest challenges in saving a patient from stroke-induced fatality or disability in India. Other issues of concern are a) inability to identify the symptoms, b) delayed transportation of the patient to the place of care, c) untrained healthcare professionals, d) lack of access to CT scan and neurologists etc. Comprehensive guidelines for dealing with stroke across the entire spectrum of the patient journey, by blending learnings from successful models from within and outside the country and incorporating views from medical experts, patient groups and other key healthcare stakeholders in the public and private sector will lead to better implementation pathways and guidelines. For India to emerge as an economic power, the health inequities must be addressed urgently. Ayushman Bharat Yojana (PM-JAY), the Government of India scheme to provide free access to healthcare potentially to about 40% of the country's population, as well as of several innovative healthcare schemes introduced by the central and state governments within and outside National Health Mission are a step in the right direction. However, ABY misses Stroke and the entire neurological spectrum leaving patients below the poverty line without access to critical care.

This policy recommendation paper has been developed based on the deliberations from three multi-stakeholder roundtable discussions held in South (28th August), North (18th September) and West (18th July). ***The regional discussions were followed by a National Consultation held on October 28, 2021 and attended by 14 experts.*** The meeting was organized by DakshamA Health and Indian Stroke Association jointly and supported by Healthy India Alliance, PAIR- Patient Academy for Innovation and Research and Bombay Stroke Society. The paper reflects upon the urgent need for addressing Stroke as a health crisis and the possible tangible interventions suggested by the group of experts.

Stroke, as a medical condition is yet to gather required attention among key stakeholders, including the government and private healthcare partners, healthcare professionals and the public. NPCDCS, the National flagship program, was launched in 2010 and under this, the government has established 298 NCD cells to provide services for early diagnosis and treatment for non-communicable diseases. It was indeed an excellent start towards addressing the rising incidence of NCDs and the interventions have been commendable. But, as we continue to witness a rise, especially in stroke and its associated conditions, it is apparent that there are gaps in the system which need to be identified and addressed with a more focused approach.

KEY TAKEAWAYS:

INFRASTRUCTURE AND HUMAN RESOURCES

Only one-fourth of stroke patients arrive at a medical care center within six hours of experiencing the symptoms of stroke. Distance from the hospital, contact with a local doctor, and low threat perceptions of symptoms etc. were cited as independent factors for delay in arrival

A) Low doctor-population ratio— General shortage of doctors in India and the lack of trained medical professionals in emergency care contributes to poor stroke management. India's doctor-population ratio (1:1495) is less than WHO recommended 1:1000 even after the big rise in medical education capacity in the recent years. As per the National Health Profile 2018, the situation is worse in states like Uttar Pradesh, Bihar and the whole of the northeast region

B) Inadequate infrastructure and untrained medical professionals in hospitals are the other two critical triggers for stroke-related mortality and morbidity burden. Many Indian hospitals lack the necessary infrastructure required to treat stroke patients efficiently. Lack of training in stroke care also leads to medical practitioners and paramedics misidentifying the symptoms.

C) Non- availability of neurologists & physicians round the clock for the stroke care. India has only about 2,500 neurologists for a population of 1.3 billion, and approximately 1800 neurosurgeons (including about 25 women) for 1.27 billion people. Of the 330 approved medical colleges, only 59 have neurosurgical departments recognized for a MCh Neurosurgery training program. Of these about 500 neurologists are in major cities and metros

D) Lifesaving interventions like thrombolytics is only used in a few private institutes due to their high cost and people paying out of pocket. District hospitals often lack the ability to thrombolyse due to non-availability of drugs at the time of intervention and lack of physician skills.

E) Green Corridors and emergency transport

Well-managed ambulance services systems with trained people capable of recognizing and providing emergency support to stroke victims

RESEARCH AND INNOVATION

A. Patient registries and data

We need to find a way to establish a national registry of stroke for research and epidemiological analysis. Currently three registries are in force, however data collection is still an issue and the largest registry has only about 37000 cases

B. Research gaps and challenges

We need to more research and stroke experimental setups to understand clinically relevant stroke models including both radiological and neurological outcomes, long-term follow-up studies on treatment, large-scale preclinical stroke trials, along with the inclusion of stroke comorbidities in pre-clinical research. Research and evidence on post-stroke rehabilitation effects on the survivors must be collected widely that will give an opportunity to discover new rehabilitation therapies.

C. Role of telemedicine and Digitalization

- Telestroke is one of the most efficient ways to reach remote locations where a stroke patient can be thrombolyzed within golden hours of time. We need a comprehensive strategy that can be applied in these remote locations. This type of model can help to improve the current dismal rate of thrombolysis (currently less than 1%), as well as lower the rate of disability in stroke patients. Tele-rehabilitation and tele-prevention are all significant steps forward to be considered.
- In India, a patient-centered, geography-focused, and low-cost top-down supported technology approach is required. Establishing partnerships with IITs and collaborating with them to develop low-cost devices for stroke patients in India could a viable approach.

CARE CONTINUUM PATHWAYS AND PATIENT INVOLVEMENT

A. Primary level of healthcare:

- Currently, under the NPCDC program, 298 NCD clinics have been set up at district and community health centre levels across the country for early detection, referral, and management of all common NCDs, including stroke. Early diagnosis of hypertension, diabetes, and other risk factors has been made possible in clinics. Early diagnosis of stroke symptoms, as recommended by the BEFAST protocol, can help to avoid stroke-related impairment. Stroke can be prevented if a mechanism is established for the detection and identification of early signs and symptoms of stroke under the NCD clinics. Primary care physicians and community healthcare workers should be strengthened, and more stroke stabilization centres should be established at the grassroots level.

- Training frontline healthcare workers physicians, and community healthcare workers in stroke management through the development of a stroke care modules.
- Establishment of community-based palliative care centres that provide post-stroke patients with home rehabilitation services must be taken into consideration.
- Non-identification of symptoms is the main cause for delay in hospitalization. Raising mass awareness about the symptoms of stroke and B.E.F.A.S.T protocol in rural areas is very critical and patient groups can play a key role in supporting such awareness initiatives.
- Strong referral mechanisms can help in early intervention of stroke preventing disability and deaths.
- Behavior change communication: Disseminating information on stroke risk factors along with the prevention and management of post-stroke related complications at community level. This can help prevention of reoccurrence and other complications.

B. Secondary level of healthcare:

Establishing small stroke units at the district hospitals with CT scan and Tele Radiology services along with the availability of life-saving drugs may minimise the long-term effects of a stroke and even prevent death.

C. Tertiary level of healthcare:

Emergency department: Emergency department staff should be educated to diagnose and treat all types of strokes. The ED should maintain clear channels of communication with EMS and the acute stroke team. Continuous training and monitoring of the personnel should be provided for stroke diagnosis and management.

Stroke unit: A hospital unit with highly trained clinicians and a multidisciplinary approach to treating and caring for stroke patients should be established. They should be able to admit patients who are in a state of instability, monitor vitals, diagnose the etiology of stroke, and discharge patients with rehabilitation and secondary prevention counselling. They should adopt telemedicine to improve treatment access in rural and isolated places.

INCLUSION OF STROKE UNDER HEALTHCARE INSURANCE:

Most stroke survivors continue to live with disability, and the costs of ongoing rehabilitation and long-term care are paid out of pockets by family members, putting their families in financial hardship. Because a stroke is a life-threatening neurological event that necessitates treatment/thrombolysis in the hospital, it should be recognized as a separate Neurology package under Ayushman Bharat-PMJAY. This will only assure that the beneficiaries have access to therapy for one of India's main causes of mortality. Along with this stroke rehabilitation should also be included as part of the package.

REHABILITATION AND PALLIATIVE CARE

- Rehabilitation services are available in India, however they are mostly in private hospitals in

tier 1 and tier 2 cities.

- The primary reason for people discontinuing their rehabilitation is the lack of affordability of rehabilitation services. The lack of information and knowledge about the significance of post-stroke therapy, and the inability to travel long distances for rehabilitation, are the main hurdles to accessing rehabilitation services. The importance of post-stroke rehabilitation should be emphasized through community-wide awareness programs, and cost-effective advanced rehabilitation treatments should be made available at all levels of healthcare.
- There is an urgent need to establish a skilled stroke rehabilitation workforce, which can be accomplished by providing them with stroke rehabilitation training. There should be an accreditation and certification program to differentiate the generalized therapists from the stroke and neurology specialization therapists. Stroke survivors and families need to educated on the need to go for specialized services.
- Rehabilitation is limited to physiotherapists in India. To give a holistic approach to rehabilitation, we need to bring together speech therapists, occupational therapists, and physiatrists under one umbrella.

PATIENT PERSPECTIVES POST STROKE

A. Mental Health:

Mental health issues are often neglected post-stroke. The effects of a stroke on the brain might affect one's personality, mood, and emotions. All this means there is a strong link between stroke, depression, and anxiety. This can also impact on their recovery and sometimes they are unable to focus on rehabilitation due to mental stress. Therefore, Psychological therapy and management of mental health difficulties must be broadly implemented. As a result, post-stroke mental health disorders must be managed as part of the rehabilitation along with counselling sessions for patients and their families.

B. Caregiver burden:

Caregivers are the backend support for the stroke survivor and play crucial role in their recovery process. Due to this, sometimes they are forced to leave their jobs to take care of the survivor. In some of the family stroke survivors are the only earning members, this adds to the financial burden and make it difficult for them to manage their daily living. Therefore, caregivers require appropriate support to physically and mentally cope with these abrupt shifts in responsibilities and family dynamics, but such services are either unavailable or insufficient.

C. Impact on employment post stroke:

People having difficulties at work, or possibly being at risk of losing their employment, because of stroke-related disability. Unemployment is linked to physical and emotional health issues following a stroke.

D. Financial cover for stroke:

Except for immediate hospitalization and critical treatment, most insurance policies do not

cover stroke. Under critical care insurance, additional riders are available to cover specific components of operation and medication. Apart from this, nursing and physiotherapy are not included under the insurance. For a limited time, rehabilitation is covered but speech therapy, neuropsychotherapy, cognitive therapy, robotics, and other similar services are not covered.

E. Incorporating and involving patient champions and patient advocates from the pool of patients in the policy formulation of stroke is recommended to provide a holistic view and bring the lived experience to the policy dialogue.

F. Stroke support groups: Peer support based on shared experience may be beneficial in reducing feelings of isolation and anxiety, as well as offering information about community outreach programs. Patients and their families should be referred to support groups by hospitals and clinicians and we must educate patients about the notion and its significance of joining patient groups

CONCLUSION

Stroke is a medical emergency and time sensitive. The time taken from "door to needle" can affect the clinical and rehabilitation outcomes significantly. With the revised National Stroke guidelines and steps taken to address this critical condition by MOH, many patients will benefit and recover better. However, there are still many areas that need urgent address, especially financial risk protection, referral systems, robust formularies with no stockouts, transport mechanisms and patient and stakeholder education. The national consultation was a step to identify and work on some of these areas. Several stakeholders will need to come together and work collaboratively to make the journey to recovery for stroke patients easier. With every stakeholder, the patient and caregivers have an important role in bringing their perspectives and lived experience to shape the policy and guidelines. The document could serve as a conversation starter to bring the patient voice closer to the table and help normalize patient engagement in stroke guidelines. Besides MOH, several other ministries also need to be involved, if QOL of a survivor has to be improved.

We are grateful to the patients, cares, families and stakeholders who have participated in this consultation and enriched it with their insights

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Speakers- National Consultation

Dr. Jeyaraj Pandian, President, Indian Stroke Association, Chair, Principal (Dean) and Professor of Neurology Christian Medical College	**Dr. Pradeep Joshi, Technical officer, NCDs, WHO India**
Dr. Sanjiv Kumar, Chairperson, Advisory Committee, Indian Alliance of Patients Group and Former Executive Director, National Health Systems Resource Centre, MOHFW, Gov. of India	**Dr. Padma Srivastava, Professor, Head, Department of Neurology, Chief, Neurosciences Center, AIIMS, New Delhi, Hon Professor, UCLAN, UK, Past President of Indian Stroke Association**
Dr. Shirish Hastak, Regional Director Neurology/ Stroke and Neuro Critical Care, Global Hospitals, Past President Indian Stroke Association 2010-11	**Dr. Bipin Gopal, State Nodal Officer (NCD,NTCP) GoK**
Dr. S Sunder, Consultant Physiatrist and Founder Managing Trustee, Freedom trust, Chennai	**Dr. Arvind Sharma, Head - Dept of Neurology Sr. Consultant Neurologist, Stroke Specialist & Neurosonologist at Zydus Hospitals, Ahmedabad, Secretary, Indian Stroke Association**

Dr. Dharam Pandey, Head Of Department - Department of Physiotherapy & Rehabilitation Sciences at MANIPAL HOSPITALS	**Dr. Sunil Narayan, Professor (Senior Scale), Department of Neurology, Jawaharlal Institute of Postgraduate Medical Education and Research**
Dr. Shriram Varadharajan, consultant Neuroimaging and Stroke Interventions, KMCH, Coimbatore, India	**Dr. Madhuri behari, Consultant Neurologist, Fortis Flt. Lt. Rajan Dhall Hospital, Vasant Kunj**
Mr. Jitendra Varshney, IBM Consultant, Stroke survivor	**Mr. Sameer Bhide, writer, consultant, Author of a book One fine day, stroke survivor**
Tamanna Sachdeva- Project Officer, Policy and Advocacy, DakshamA Health	**Dr Ratna Devi, CEO, DakshamA Health**
Ankit Dabra, Project Officer, Policy, Advocacy and Capacity Building, PAIR Academy	**Avinash Deo, Learning Management Systems, Pair Academy**

Speakers – West consultation

S. No	Name	Organization
1	**Dr. Shirish Hastak**	Consultant Neurologist, Global Hospitals
2	**Dr. Uma Sunder**	Professor, Department of Neurology Services, Internal Medicine, Lokmanya Tilak Municipal Medical College & Lokmanya Tilak Municipal General Hospital, Sion Hospital
3	**Dr. Pawan Ojha**	Fortis Hiranandani hospital vashi as a senior neurologist.
4	**Dr. Rahul Chakor**	Prof. & H.O.D. Neurology T. N. Medical College & B. Y. L. Nair Ch Hospital
5	**Dr. Abhishek Srivastava**	Director, centre for physical medicine and rehabilitation consultant
6	**Dr Dinesh Kabra**	Department of Neurology, CIIMS Hospital
7	**Dear Dr. J S Kathpal**	Consultant neurologist, Choithram Hospital and Research Centre
8	**Dr. Sudhir V. Shah**	Consultant Neurologist, Director of Neurosciences : Sterling Hospital, Professor and Head department of Neurology; at KM school of PG medicine and research, Sheth V. S. General Hospital, Ahmedabad
9	**Dr. Ratna**	Dakshayani and Amaravati Health and Education(DakshmA)
10	**Ms. Tamanna Sachdeva**	Dakshayani and Amaravati Health and Education(DakshmA)

Speakers -South consultation

S. No	Name	Organization
1	**Dr. Sunil K Narayan**	Professor (Senior Scale), Department of Neurology at

		Jawaharlal Institute of Postgraduate Medical Education and Research and Convenor, Stroke Subsection Indian Academy of Neurology.
2	**Dr. P.N Sylaja**	Professor and Head of Neurology, In-Charge, Comprehensive Stroke Care Program, Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST), Past President, Indian Stroke Association.
3	**Dr Sanjith Aaron**	Professor of Neurology Christian Medical College Hospital Vellore, India
4	**Dr. Sapna**	Professor of Neurology, Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST
5	**Dr. H.V Srinivas**	Neurologist in Bangalore and currently practices at Sagar Hospitals
6	**Dr. Dr. V. Natarajan**	Consultant neurologist, BSS Hospital, Chennai.
7	**Dr. Subhash Kaul**	Sr. Consultant Neurologist, KIMS Hospital
8	**Dr. Kiran Patil**	Consultant Neurologist
9	**Dr. Ratna**	Dakshayani and Amaravati Health and Education(DakshmA)
10	**Ms. Tamanna Sachdeva**	Dakshayani and Amaravati Health and Education(DakshmA)

Speakers-North consultation

S. No	Name	Organization
1	**Dr Jeyaraj Durai Pandian**	President, Indian Stroke Association, Chair, Principal (Dean) and Professor of Neurology Christian Medical College
2	**Dr VY Vishnu**	Assistant Prof. of Neurology, AIIMS, New Delhi
3	**Dr Dheeraj Khurana**	Prof of Neurology, PGIMER, Chandigarh
4	**Dr Sudhir Sharma**	Associate Professor, IGMC, Shimla
5	**Dr Ivy Sebastian**	Consultant, St Stephens Hospital, New Delhi
6	**Dr Vinita Daniel**	Associate Professor, SGPGI, Lucknow
7	**Dr. Anupama Shah**	Associate Professor, Jammu Medical College, Jammu
8	**Dr. Ratna**	Dakshayani and Amaravati Health and Education (DakshamA)
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