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THERE IS LIFE AFTER A STROKE, WITH PROPER REHABILITATIVE THERAPY

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Strokes need specialist intervention after the attack and during rehabilitation. | Photo Credit: iStockphoto

In April 2021, in the midst of the pandemic, Diya, a 20-year-old BDS student was rushed to the emergency stroke unit of Sri Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST). She was in a coma following a major stroke. She had severe brain swelling and needed emergency surgery. As she was rolled into the theatre, no one would have believed that two years later, she would live to tell her tale.

On World Stroke Day, Diya, now in her third year BDS, stood before a packed audience at SCTIMST and spoke about her long and often frustrating journey of recovery, the depths of depression and despair that she often sunk into and how her loved ones never let her give up on herself. “Diya suffered a rare complication following the COVID vaccination: venous thrombosis. This resulted in a major stroke. Post-surgery, she had weakness in her limbs, her speech was affected and it took a year of rehabilitation for her to recover. She was young, highly motivated but most importantly, her family was with her every step of the way, which made a full recovery possible,” said Sylaja P.N., Professor and Head of Neurology, who heads the Comprehensive Stroke Care Centre at SCTIMST.

In sharp contrast, far away in a small shack behind a row of small two-room houses off the coast of Poovar, lies 42-year-old Francis. He was on a fishing boat at sea, along with his brothers and friends, when he suffered a major stroke. By the time he was brought ashore and taken to the hospital, much time had elapsed. He was treated in the Government Medical College for over a month and discharged, because, “there was nothing more to be done”.

Paralysed on one side of the body, his speech incoherent, Francis is now confined to his bed. He spends his days alone because his wife has to go fish vending to feed their family of five. Apart from the palliative care volunteers who make a weekly visit to change the urine catheter, he has no contact with the outside world. The once robust fisherman is now a bag of bones, with atrophied muscles. Tears trickle down the corner of his eye when the palliative nurse holds his hand and asks him, “*Sukhamano?*” (Are you good?)

“There is life after a stroke. ”Dr. Sylaja P.N., Professor and Head of Neurology

“There is life after a stroke. With proper rehabilitative therapy, family support, motivation and mental health support, most stroke survivors can make a good recovery and lead near-normal lives. They can at least be made independent so that they do not become a burden on their families. Some very motivated patients like Diya make a complete recovery. But each person’s life and socio-economic background is different. It is sad but the after-stroke life of 50-60% of stroke survivors in the country resonates with that of Francis,” Dr. Sylaja said.

At least two-thirds of stroke survivors experience motor, sensory, visual, swallowing, language, cognitive, and psychological impairments that can limit daily activities and restrict participation in family, work, and social life.

According to literature, the proportion of people with a disability five years after a stroke ranges from 25% among those who had minor strokes to about 50% among those who had moderate strokes and 80% among those who had severe strokes. Ten years after a stroke, roughly half of survivors continue to remain disabled..

A stroke is a life-changing event and while there has been a lot of attention on medical technologies like thrombolysis and thrombectomy to deal with the acute management of stroke, secondary prevention strategies and neuro-rehabilitation services for stroke survivors continue to be neglected, consigning these persons to a lifetime of disability.

The extent of functional recovery after a stroke is variable and depends on several factors, including health and socioeconomic status before the stroke, age, the severity of the stroke, its location and size, comorbidities, and the quality and quantity of rehabilitation received after the event.

The road to recovery from a stroke is a long and lonely process. Interdisciplinary stroke care (involving physiotherapists, speech therapists, psychologists, and occupational therapists) can dramatically improve the outcome of stroke patients and provide them good quality of life. Community-based support groups are crucial to handhold the stroke survivor and the family through the long recovery process.

However, there is a huge unmet need for rehabilitation facilities for stroke survivors across the country where most patients are discharged without a proper rehabilitation plan. Awareness about the importance of continuous and consistent post-stroke rehabilitation is poor among the general public and the services are also mostly available only to those with some capacity to pay.

The recent report of the World Stroke Organisation-Lancet Neurology Commission, “Pragmatic solutions to reduce the global burden of stroke”, highlights that for each of the four pillars of the stroke quadrangle — surveillance, prevention, acute care, and rehabilitation. Specific interventions are required so that the global burden of stroke can be brought down, particularly in low and middle-income nations.

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Implementing primary and secondary stroke prevention strategies and evidence-based acute care and rehabilitation services are the need of the hour to bring down the stroke burden. However, low awareness of stroke and its evidence-based management among communities, health-care professionals, and policy makers is just the beginning of the problem.

Poor awareness of stroke amongst the public and delays in taking the patient to an appropriate hospital (with the means to perform thrombolysis) is often compounded by a lack of a proper public emergency response system, infrastructural deficiencies in government hospitals, lack of expertise in hospitals to triage and manage those with stroke efficiently and quickly, shortage of neurologists and radiologists in the system to administer thrombolysis to eligible stroke patients and above all, the absence of standard care pathways and protocols.

If, till recently, the focus of all emergency stroke-related interventions was clot-busting therapy or thrombolysis, only a fraction of patients who reach hospitals within the critical window period of 4-6 hours were eligible for this therapy. Strokes due to large vessel occlusion or blockages in the brain constitute up to 30% of all acute ischaemic strokes. These strokes in large vessels are responsible for a significant proportion of permanent stroke-related disability.

Neurologists have now shifted the focus to Mechanical Thrombectomy (MT) for treatment of strokes in large vessels. Thrombectomy involves a catheter placed in the femoral artery, which is navigated up the aorta and into the cerebral arteries to retrieve the clot.

The procedure is deemed safer, effective and capable of removing clots up to 90%, as long as the patients (select patients as per guidelines) are treated rapidly within 24 hours. Thrombectomy can reduce the rate of neurological disability significantly by 40-60%.

Thrombectomy however requires a cath lab and hospitals which are equipped
to perform thrombolysis can refer the patient to a thrombectomy centre for comprehensive stroke care once the emergency has been dealt with.

India has 566 stroke centres (primary and comprehensive together), of which only 360 have thrombectomy facilities, most of which are in the private sector. Even after massive public awareness programmes, less than 50% of the patients recognise stroke signals. The thrombolysis rate in India is abysmally poor at less than 5% and even in the U.S., this is still less than 25%. There are also issues of some atypical presentations of stroke which physicians at the primary care fail to recognise, leading to delayed referrals

“Maintaining a patient in a stroke unit where there are mandatory ICU protocols for prevention of complications of stroke like aspiration pneumonia and a team of neurologists, radiologists, interventional radiologists and nurses trained in stroke management for continuous evaluation gives the best outcome for patients. However, there are less than 300 such stroke units across the country and most are in the private sector, unaffordable to most patients. Unless more stroke units with endovascular thrombectomy facilities are established in government hospitals, especially the government medical colleges, we cannot hope to reduce the mortality and morbidity burden of stroke,” points out Dr. Shylaja.

Kerala, which has one of the highest prevalence of hypertension (44%) in the country, is also one State which has tried to de-centralise stroke care since 2018, with commendable results. The State is the only one in the country which has stroke units (thrombolysis facility with a neurologist) in 10 of its 14 districts

SCTIMST was a technical consultant to the State Government for the training of primary care physicians in all aspects of acute stroke management and to establish stroke-care pathways with an added accent on good stroke rehabilitation, which involves getting trained community-level health workers to visit stroke survivors at home to aid with rehabilitation. The district stroke units have so far managed to perform over 256 thrombolysis successfully and residual paralysis was reported only in 4% of cases, said Bipin Gopal, State nodal officer for NCD programmes. Two thrombolytic drugs — TPA and Tenecteplase — are supplied to the stroke units by the

government at no cost to the patients.

However, the system has not been able to expand the number of these facilities or upgrade any of the centres to a thrombectomy centre because of the shortage of funds and trained medical professionals to run these centres. The health system has only 15 neurologists. General transfers in the health services with no attention to the clinical requirements in each institution means that the neurologists as well as the casualty medical officers trained to recognise strokes are constantly moved around.

One out of four strokes in the country are said to be recurrent strokes and secondary stroke prevention strategies, which stress adherence to medication and adequate risk factor control, are important in preventing stroke recurrence. However, both adherence to medication and risk factor control are sub-optimal in low- and middle-income countries.

A community-based study conducted by SCTIMST with the Department of Health in Kollam district in Kerala to determine the efficacy of post-stroke care in the community showed an overall medication adherence of just 43.8% among stroke survivors. Of the 896 stroke survivors in the community, only 35% had checked their BP and blood sugar in the previous six months. Even after education by trained healthcare workers, only 20% more did their blood investigations.

“People did not seem to think that having medication on long term was necessary or that it was important. Some believed that their kidneys would bear the side effects of medication in the long term. Some just forgot to take their meds. None who had been prescribed diabetes and hypertension medication had any idea about their blood sugar or blood pressure targets. They blindly took the drugs with no monitoring in between. This is the reality of primary as well as secondary prevention efforts in the community. But we cannot give up on these education and interventions at the community-level,” a senior Health official said.

“Secondary prevention of stroke and stroke rehabilitation needs more focus in the current scenario. We need more rehabilitation centres with interdisciplinary teams and community support groups to encourage stroke survivors to become independent and productive members of their households once again. We need governments to invest more in stroke prevention and rehabilitation,” Dr. Sylaja said.

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