



# Current Gaps in Patient Education – A review of unmet needs in neurological disease conditions in India

Special focus on Epilepsy and Stroke conditions

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**Abstract:** There have been many broken attempts across segments of healthcare sectors be it the government of India, hospitals, healthcare institutes, or industry dealing in drugs and devices to bring patient awareness about their health and how can they live a quality life (QoL).

However, the focus on patient education has not been at the forefront of the healthcare industry as such in India. There is a tremendous need for the right patient education, especially in Neurological disorders. There is a need to acknowledge the magnitude of the burden, and global efforts to label neurological disorders a "global epidemic" have resulted in increased disability and mortality., emphasizing the public health approach and integration of neurology care with general health care.

The gross mismatch between the need and the available trained personnel and infrastructure are posing challenges to health in India, where there has been an increase in neurological disorders and an epidemiological transition. Planners and policymakers for providing neurological care to the community. With close collaboration with tertiary institutions, non-governmental organizations, and the private sector, alternative methods of optimally utilizing district, community health, satellite clinic, and rural health care models may make it easier to reach the goal of providing neurology care to the "unreached."

The disability-adjusted life years (DALYs) are creating a huge economic burden on society at large. The neurological disease burden has increased over the last few decades owing to stroke incidence rise in India. There were 6.5 million stroke cases in India as reported in 2016. Hence, it becomes critical to address the issue of patient education for the larger good. Patient education can prove pivotal in helping the patient to live a QoL and reduce DALYs when it is given in the right manner to a patient and the caregiver.

**Key Words:** Epidemic, Disease Burden, Patient education, stroke, neurological disorders, caregiver

**Acronyms:** DALYs – Disability Adjusted Life Years, QoL – Quality of Life, PwE – Person with Epilepsy

## Introduction

Patient education is the need of the hour in all diseases. As we know that chronic disease conditions are taking a toll on humankind in recent times as we can see the prevalence of chronic conditions has risen humongous.

Patient education is the process by which doctors and other healthcare workers impart information to patients and their caregivers about health, diseases, and their prevention and management. This also includes the transfer of information about his or her health status and needs. Patient education aims to involve the patient and his or her family actively in healthcare-related decisions, and also, promote a healthier lifestyle. (3)

The key benefits of patient education are as follows:

- A better understanding of disease or disability, investigations, and treatment
- Improved understanding of ways to manage multiple aspects of a medical condition, therefore, the better-informed choice about therapy
- Increased compliance with medication and other instructions from doctors, since patients understand the need for the same.
- Better patient outcomes since patients are active partners in their health
- The process of informed consent is easier and patients are more satisfied with their treatment plans and outcomes.
- Increased patient satisfaction, less confusion and repeat visits/ phone calls for clarifications.
- Risk management by managing patient expectations. This also translates into a lower risk of malpractice litigation and violence against the doctor.
- In chronic diseases, where outcomes depend on long-term medication adherence despite side effects, patient information is especially important.

Patients are searching for a reliable and valid wellspring of data that they can admittance to scatter their questions and fears. (1,2)

Patient Education is a sophisticated subject for the national government, local authorities, health authorities, and educational agencies. Patient education plays a very important role in maintaining QoL, inclusive, and fair social, psychological, and physical environment. It is calling for the best practices, using an empowering, multi-dimensional, multi-professional approach that relates to all settings, organizations, and parts and levels of society, including schools, colleges, universities, health services, the community, and the workplace to create a common platform where from the patient of varied chronic conditions can access the disease education to reduce the DALYs.

Along with instructing society, patient education is a fundamental necessity and the finest approach method to make people competent to think about their disease condition and accept the journey that they are going through. Being the main concern of society and government impedes, it becomes indispensable during academic activities also, to edify the students on how to take care of themselves as well as their families and society.

Making a healthy milieu in society along with keeping aware people of various factors of health is, of course, a good decision of the government would be if they appoint experts in almost the entire region to make an aware society of disease conditions which can eventually help societies at large to decrease the overall burden on the society.

The right patient education provided by health care professionals like nurses, physiotherapists, clinicians, and industry professionals can be crucial in reducing disease burden. The key is highlighting the need for patient education and making it a requirement for clinicians, hospitals, and institutes to provide the right education to every chronically ill patient who seeks treatment. In order to assist the patient in leading a high-quality life, the caregiver should assume responsibility for the patient as well as for the healthcare department, mandatory steps, nutrition, fitness, growth, social health, etc.

Epilepsy is the most common disease in neurology, making it the most common condition seen by neurologists in India. There are significantly fewer cases than people with this condition. In rural regions, individuals resort to witchcraft than visiting a clinician due to the conviction that epilepsy isn't a sickness however an otherworldly revile on the individual experiencing it.

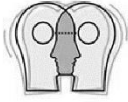
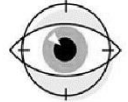




Epilepsy affects approximately 50 million people worldwide [5] and more than 10 million in India [6]. Patients and caregivers can benefit from epilepsy-related education in order to improve treatment outcomes for PwE [7]. In most low and center pay nations like India with outrageous deficiencies of prepared faculty for treating PwE [8], patient training is frequently ignored.

There must be models for patient education that save time and money. The SARS-CoV-2 pandemic and an expectation of additional such occasions in the future have likewise brought to the front a requirement for however much persistent consideration as could be expected, including patient training, to likewise be made accessible basically.

Likewise, epilepsy, the burden of stroke is expanding in India; Stroke is currently the fifth most common cause of disability and the fourth most common cause of death. According to previous research, the annual incidence of stroke in India ranges from 105 to 152/100,000 people.

However, there is a lack of uniform methods and insufficient data in published studies. (16)

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	<b>B</b>	Balance – Sudden difficulty with balance
	<b>E</b>	Eyes – Sudden problems with vision in one or both eyes
	<b>F</b>	Face – Face or smile droops on one side
	<b>A</b>	Arms – Sudden weakness in arm or leg
	<b>S</b>	Speech – Unable to repeat a simple sentence, or slurred words
	<b>T</b>	Time – If you observe any of these symptoms, go to hospital

There are two types of stroke, ischemic and hemorrhagic. Ischemic strokes account for approximately 85% of strokes and are usually caused by a blood clot within a blood vessel in the brain.

Hemorrhagic events account for 15% of strokes and are caused by a leaking or ruptured blood vessel in the brain.

You could also have a transient ischemic attack (TIA), where symptoms resolve within 24 hours. Most strokes are caused by risk factors such as atrial fibrillation, hypertension, high cholesterol to name a few.

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## Epilepsy patient care handout. (12)

## DO:

- Keep your cool and stay with the person.
- If you can, Time the seizure (if someone is nearby ask them to help)
- If they have food, fluid or vomit in their mouth roll them on to their side immediately
- Protect them from injury by moving any hard objects away from the area
- Protect them by placing something soft under their head and loosen any tight clothing
- Gently roll the person onto their side as soon as possible and tilt their chin upwards to assist with breathing and to protect their airway
- Stay with the person until the seizure ends naturally, and calmly talk to the person until they regain consciousness (usually a few minutes)
- Reassure the person and let them know you will stay with them until they recover or until a paramedic arrives if an ambulance has been called
- Keep onlookers away, as waking up to a crowd can be embarrassing or confusing for the person.

## DO NOT:

- Restrain the person's movements, or move them, during the seizure (unless they are in danger)
  - Put anything in the person's mouth
- Give the person water, food or pills unless they are fully alert.

Table 1. Knowledge Scores of Persons with Epilepsy and caregivers. (9) India's progress in neuroepidemiology over the past four decades has been documented, with historical milestones highlighted.

Knowledge scores	People with Epilepsy		Independent t-test (p-value)	Caregivers		Independent t-test (p-value)
	Control group (n = 33)	Intervention group (n = 32)		Control group (n = 33)	Intervention group (n = 32)	
Pre-test	9.42 ± 3.99	8.96 ± 4.35	0.696	8.78 ± 4.59	9.68 ± 3.61	0.384
Post-test	16.06 ± 2.81	18.03 ± 2.45	0.003*	16.27 ± 2.40	17.81 ± 2.07	0.007*
Paired t-test (p-value)	<0.001*	<0.001*		<0.001*	<0.001*	

Independent t-test and paired t-test; \*p-value < 0.05.

A rough estimate of over 30 million people with neurological disorders (excluding neuroinfections and traumatic injuries) can be derived from the range of prevalence rates of the spectrum of neurological disorders from various regions of the country, which ranged from 967 to 4,070 with a mean of 2394 per 100,000 people. Through population-based surveys, the prevalence and incidence rates of common disorders like epilepsy, stroke, Parkinson's disease, and tremors vary a lot from region to region in the country.

Table 2. Burden of neurological disorders, in disability-adjusted life years (DALYs) in the World

Year	2005			2030		
Population	6441919466			7917115397		
Total DALYs	1469 610 066			1526745574		
Disorder	DALYs	%	Per 100000 population	DALYs	%	Per 100000 population
Epilepsy	7307975	0.50	113.44	7441536	0.49	93.99
Alzheimer and other dementias	11077525	0.75	171.96	18394267	1.20	232.34
Parkinson's disease	1616523	0.11	25.09	2015065	0.13	25.45
Multiple sclerosis	1509696	0.10	23.44	1648303	0.11	20.82
Migraine	7659687	0.52	118.90	7596089	0.50	95.95
Cerebrovascular disease	50784770	3.46	788.35	60864051	3.99	768.77
Poliomyelitis	115167	0.01	1.79	13261	0.00	0.17
Tetanus	6422611	0.44	99.70	3173636	0.21	40.09
Meningitis	5336882	0.36	82.85	2038968	0.13	25.75
Japanese encephalitis	561038	0.04	8.71	149931	0.01	1.89
Total for all neurological disorders	92391874	6.29	1434.23	103335108	6.77	1305.21

For robust national data on neurological disorders, a standardized screening questionnaire and uniform case determination and diagnosis methodology are essential. Higher paces of commonness of neurological problems in provincial regions, 6-8 million individuals with epilepsy, and high case casualty paces of stroke (27-42%) call for critical techniques to lay out outreach nervous system science administrations to take care of remote and rustic regions, foster Public Epilepsy Control Program and lay out stroke units at various degrees of medical services pyramid.

According to the disability-adjusted life years (DALYs) for common neurological disorders (epilepsy, dementia, Parkinson's disease, multiple sclerosis, cerebrovascular disease, poliomyelitis, tetanus, meningitis, and Japanese encephalitis), neurological disorders accounted for 4.2% of the global burden of disease in 1996 (10) and significantly increased to 6.29 percent in 2005. (11)

Further rise in burden is expected and by 2030 it is estimated to be 6.77% (Table 2)

## Need of the hour:

It is extremely challenging to reach out to various social strata in India with the kind of patient education materials that can assist patients in general in leading high-quality lives due to the country's vast cultural, religious, and religious diversity. because the prevalence of chronic diseases is rising on an annual basis and places a tremendous social and economic strain on our society.

As a result, it is necessary to close these care gaps for patients. The fundamental methodology of fostering a hearty framework which will help patients of various illness conditions to address the DALYs. Additionally, these patients can improve their quality of life and manage their chronic conditions by adhering to their physician-prescribed treatments and changing their lifestyles.

The main problem is neurological disorders; India has about 2500 qualified neurologists who can treat these conditions, or one neurologist for every 10 million people. (13) The difficulty clinicians have in spending the required amount of time with each patient they see in a day of practice is the gap in the patient-clinician interaction.

The initial interaction with a few prominent neurologists suggests that the patient needs to be educated about their disease.

The medical system should take responsibility for patient education with a focus on 5 main points:

### **1. Take advantage of educational technology:**

Technology has made patient education materials more accessible. Educational resources can be customized and printed out for patients with the touch of a button. Make sure the patient's individualized needs are addressed. Don't simply hand the patient a stack of papers to read, review them with patients to ensure they understand the instructions and answer questions that arise. Some resources are available in several languages.

### **2. Determine the patient's learning style**

Similar information may be provided by a range of techniques. Providing education using different modalities reinforces teaching. Patients have different learning styles so ask if your patient learns best by watching a DVD or by reading. A hands-on approach where the patient gets to perform a procedure with your guidance is often the best method.

### **3. Stimulate the patient's interest**

Patients must understand why this is important. Establish rapport, ask and answer questions, and consider specific patient concerns. Some patients may want detailed information about every aspect of their health condition while others may want just the facts, and do better with a simple checklist.

### **4. Consider the patient's limitations and strengths**

Does the patient have physical, mental, or emotional impairments that impact the ability to learn? Some patients may need large print materials and if the patient is hearing impaired, use visual materials and hands-on methods instead of simply providing verbal instruction. Always have patients explain what you taught them. Often people will nod "yes" or say that they comprehend what is taught even if they have not heard or understood. Consider factors such as fatigue and the shock of learning a critical diagnosis when educating patients.

### **5. Include family members in health care management**

Involving family members in patient teaching improves the chances that your instructions will be followed. In many cases, you will be providing most of the instruction to family members. Families play a critical role in health care management.

Teaching patients and their families can be one of the most challenging, yet also rewarding elements of providing nursing care. First-rate instruction improves patient outcomes dramatically. (14)

## **Conclusion:**

To improve clinical outcomes, clinicians must spend more time with each patient. The clinician's interaction with the patient must be enthusiastic, motivated, and responsive to the individual patient's needs. For individual members of our society to realize the benefits of clinician health education, there is a need for a robust, hearty engagement between patients and clinicians.

Patient education will help patients and caregivers to manage chronic conditions more accurately and more disease education and awareness will reduce the disease burden on society. Government and health policy should support the right patient education among society at different levels not confined to clinics or hospitals, however, should be imparted through schools, institutes, and rehabilitation institutes as well.

It is fundamental to the patient-clinician relationship that each partner understands and accepts the degree of autonomy the patient desires in the decision-making process. (15)

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