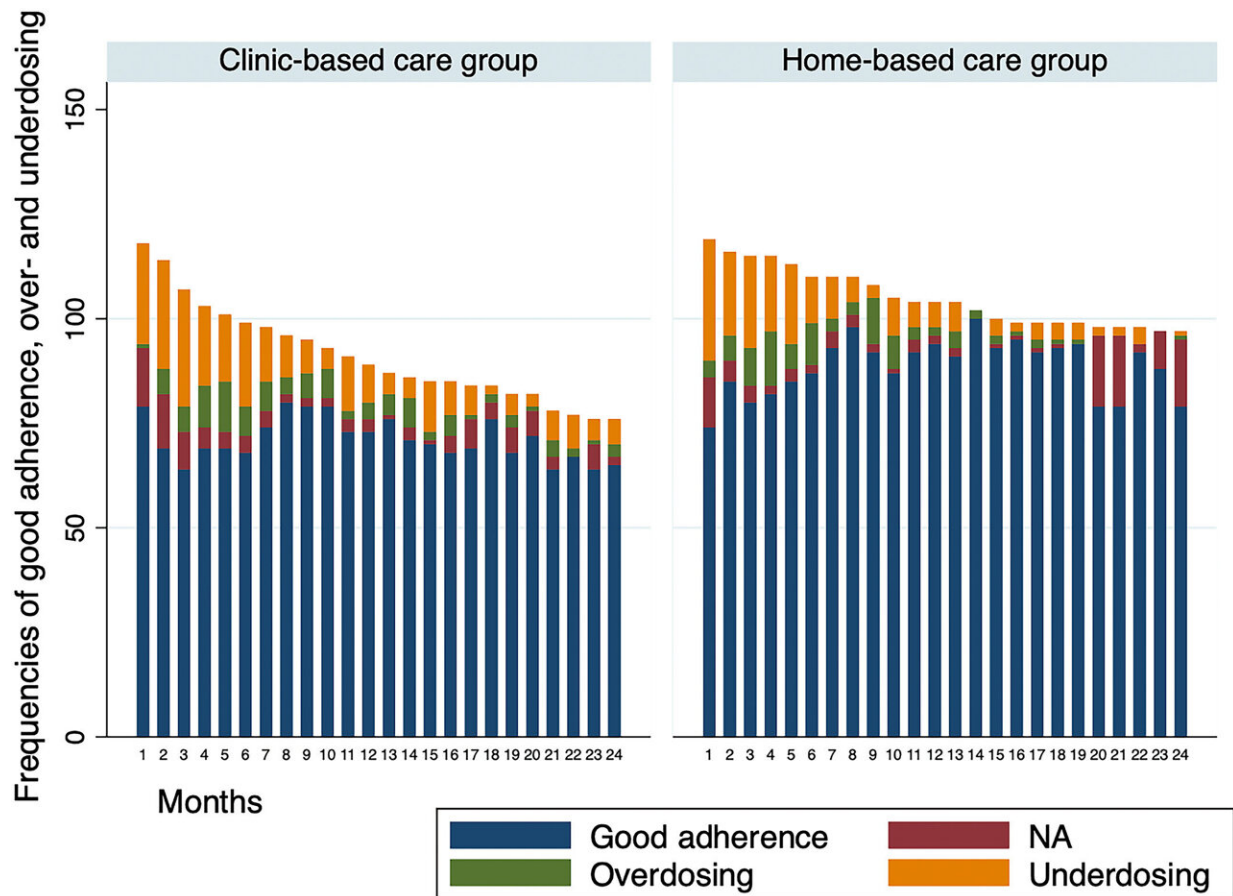


Bringing epilepsy care closer to home may improve outcomes

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Monthly medication adherence measured by pill counts in the two arms. Credit: *Epilepsia Open* (2022). DOI: 10.1002/epi4.12659

Access to care affects people with epilepsy worldwide. Bringing care

closer to home can help—but what about bringing care inside the home?

The primary treatment gap consists of people who have epilepsy and are not receiving treatment. There's another group of people: those who are diagnosed but stop taking their medication, creating a secondary epilepsy treatment gap. There are many reasons for this treatment gap, including adverse effects of anti-seizure medications (ASMs), cost of medications, access to medications, and a lack of understanding among people with epilepsy about how the medications work and the importance of taking them as prescribed.

Bringing care closer to people's homes can reduce the secondary treatment gap. In countries with low numbers of neurologists, the World Health Organization encourages the delivery of epilepsy care by primary health care providers. For people in rural or [remote areas](#), this closes the distance between home and clinic, increasing the chances of treatment adherence.

Home delivery of epilepsy care is another opportunity to reduce the secondary treatment gap. Care is given by trained workers on a regular basis, who also provide medications. This model of care ensures medication delivery to the person with epilepsy and provides opportunities for adherence monitoring and counseling on self-management. These aspects could improve adherence and lead to better seizure control.

To evaluate this idea, a recent randomized trial compared home-based epilepsy care to clinic-based care over a two-year period in Ludhiana, India. Twenty-four geographic clusters, each composed of 10 people with epilepsy, were randomized to either home-based care or clinic-based care.

Researchers completed a door-to-door survey in several areas of the city,

identifying people with epilepsy. Those identified were invited for a neurological evaluation, including EEG and MRI, to confirm an epilepsy diagnosis. They were then invited to take part in the study, which is now published in the journal *Epilepsia Open*.

Clinic-based care

People attended clinic at the government district hospital once a month, where they were seen by a neurologist. They received routine advice and information and were provided with ASMs at no cost.

"There is actually no neurologist in the district hospital in Ludhiana," said Gagandeep Singh, the study's principal investigator, a neurologist and professor in north India. "In fact, in most cities in India, the district hospital does not have a neurologist. But our Health Minister said that for this study, we could have a neurologist go to the hospital once a week to see patients with epilepsy."

Home-based care

People received monthly visits from community [health workers](#) or nurses, who provided ASMs at no cost. The health workers also counseled people about stigma management, epilepsy self-management, first aid, and the importance of medication adherence.

The community health workers in Ludhiana are ASHA workers, the backbone of India's community health program. They focus mostly on [reproductive health](#) and immunizations; study researchers trained them to dispense ASMs to people with epilepsy and to provide guidance around adherence and self-management.

Home-based care associated with better adherence

and fewer seizures

After two years, "There were much less people in the home care arm that dropped out," said Dr. Singh. "Their adherence was significantly better, and their seizure control was also significantly better."

By the end of the trial, 37% of people in clinic-based care had left the study, compared with 19% in home-based care. Reasons for dropping out were varied.

Home care recipients were 1.8 times as likely to be adherent to their ASMs, compared with people in clinic-based care.

"People who have to come and collect their medicines, even if they're free of cost, they will still not come," said Dr. Singh. "Coming to the clinic might cost a little bit [for transportation], but more often what it does is people lose one day of wages. And that's a lot for them."

However, when medications are provided at home, "adherence is better, compliance is better—it's much simpler for them to take the medicines," he said.

People in the home-care arm could still visit the clinic on the advice of a health care provider, and those in the clinic-care arm could make visits outside the regular schedule. Hospitalization rates were about the same in both groups.

Learning from hypertension research

India's public health system was created to manage infectious disease rather than chronic disease, said Dr. Meenakshi Sharma, author of the study and a scientist and program officer with the Indian Council of

Medical Research. She said that studies on treating hypertension also have highlighted the effectiveness of more localized treatment. Studies found that control rates for more localized care averaged 60% to 65%, whereas control rates at district hospitals were around 35%.

"We have to provide ways by which drugs can be provided nearer to the home of the patient," she said. For hypertension control initiatives, researchers calculated the amounts of medication that were needed, and stuck to two or three types of anti-hypertensives. "The procurement of the drugs became easier, and we could supply primary health centers and health and wellness centers," she said. Patients also were given 30-day supplies rather than 7-day supplies, to reduce the need for visits.

For epilepsy care, "We have to make sure that the drugs are available at our primary health care center level," she said. A system of care, adapted from hypertension initiatives, might look something like this:

- People suspected of having epilepsy are transferred to the district hospital level for diagnosis and treatment initiation.
- Once stable, they are shifted back to the primary health care level, where they are managed and medication is dispensed.

Adherence was measured with pill counts; people whose counts were off by more than two pills were considered non-adherent."

This is what has been done in previous [epilepsy] studies," said Dr. Singh. "In conditions like hypertension, the bar for adherence is something like 80%. But epilepsy is a condition that if people miss even a single pill, they are at risk. That is why we used this stringent criterion."

Improving care through education

"Treatment really needs to come closer to home," said Dr. Singh. "And primary care education with regard to epilepsy is extremely important." He noted that to meet the goals of the Intersectoral Global Action Plan (IGAP), many low-resource areas will need to ensure that primary care personnel are educated about epilepsy.

Educating people with epilepsy about their condition also is crucial in initiatives to shrink the treatment gap, said Dr. Singh. "Most people in resource-limited communities think of medicine or health care as something that is basically meant for acute conditions, or conditions which are extremely serious," he said. "In the case of someone with epilepsy, the person has acute seizures or status epilepticus, will go to the hospital, get treatment, come back home, take treatment for some time and then stop taking treatment. Then after a few weeks or months or years, again they have seizures and again they have problems."

In Dr. Singh's study, more than 90% of participants had less than a high-school education. "I think health literacy about epilepsy treatment has a lot to do with basic levels of education," he said.

Dr. Sharma agreed. "Once we have set up a facility as a health center, we face the challenge that the patient either doesn't come to the hospital to take the necessary treatment or get the diagnosis, or he doesn't adhere to the treatment."

People with epilepsy also tend to visit traditional healers as well, she said. "We need to have social scientists with us, understanding what is happening in the community and how to change health-seeking behaviors. That's a big challenge, not only for epilepsy but for all non-communicable diseases."

How can these results apply to other areas of the

world?

Even within India, there are different geographical and sociocultural environments, said Dr. Singh. "One has to find out the best way of addressing the treatment gap, decreasing burden, decreasing morbidity and mortality. We need to look at it from a wider angle, which probably includes more specialist involvement, primary care education, community awareness—there are so many things that need to be built up into a comprehensive model of care for epilepsy."

Dr. Sharma agreed. "One model is not going to fit in every place. And for areas where we have specialists, we have to think in a hub-and-spoke kind of model. For areas where there is no nearby medical college or district hospital, we have to look at different kinds of challenges and build a model accordingly."

She said the home-care study has expanded understanding of how the health care system works from the patient's point of view. Community messages—[epilepsy](#) is treatable, adherence is crucial—must be initiated and repeated to eventually improve people's understanding and willingness to enter and remain in the health care system.

"I'm very sure we will be able to come up with two or three different models which are going to cater to the regional variations in our country," she said. "But this is going to be a long journey."

More information: Gagandeep Singh et al, A cluster-randomized trial comparing home-based primary health care and usual clinic care for epilepsy in a resource-limited country, *Epilepsia Open* (2022). [DOI: 10.1002/epi4.12659](https://doi.org/10.1002/epi4.12659)

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