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# Case-control and qualitative study of attrition in a community epilepsy programme in rural India

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Dropout from epilepsy programmes is a serious problem in developing countries and has not been systematically studied before. We set up a community-based programme for children with epilepsy in rural India. The aim of this study was to assess reasons for dropout.

We assessed medical and sociodemographic variables for their effect on dropout at 12 months using an unmatched case-control design on 32 cases and 62 controls. We also interviewed the parents of 32 children who dropped out of treatment, using a topic schedule.

Two-thirds of the dropouts occurred within the first 6 months of treatment. Severely impaired children were more likely to drop out (odds ratio 4.60, 95% CI: 1.0–21.0) and families who had tried AEDs before were less likely to do so (odds ratio 0.12, 95% CI: 0.015–0.88). Denial of diagnosis, access problems and symptom resolution were the other main reasons underlying attrition.

Active ascertainment methods should be reconsidered in community programmes. Very poor families without a male head or with long journey times are at high risk of dropout. People with severe impairments need appropriate integrated rehabilitation.

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*Key words:* epilepsy; dropout; india; community; children; ascertainment.

## INTRODUCTION

Epilepsy is a major unrecognized source of chronic morbidity in developing countries, especially for children. The prognosis of epilepsy is variable, at one extreme syndromes may remit with or without treatment, at the other patients may be severely impaired by co-existing mental retardation, motor problems or psychiatric complications<sup>1</sup>. Over 90% of people with epilepsy are untreated at any given time, a measure known as the treatment gap<sup>2</sup>. However, it seems that even where treatment facilities exist, many people drop out of follow-up. Dropout is thus an important component of the treatment gap and merits special study.

Many developing countries lack an integrated system of primary and specialist care available to all at no cost. In India, people with epilepsy mostly live in rural areas away from hospitals and health centres. They often consult traditional healers, private practitioners (qualified and unqualified) and may depend for pri-

mary care on the services of a non-governmental organization (NGO). As in many other countries, there is social and legal prejudice about epilepsy, which sometimes prevents patients or their families from seeking help.

In India, attrition from epilepsy programmes has been very high. In both rural and urban programmes, some attached to tertiary centres, 22–61% of patients did not return after the first visit, and only 11–39% were still attending after 1 year, despite many having frequent seizures<sup>3–6</sup>. The reasons for attrition have not been systematically studied, although opinions have been offered that drug side-effects, lack of drug efficacy, the failure to achieve a quick cure, the difficulties of communicating the need for long-term treatment, and ‘ignorance and lack of sophistication’ are to blame<sup>2,4,7,8</sup>. No doubt access and erratic drug supply are other explanations<sup>4,9,10</sup>. Experience from TB and leprosy programmes shows that patients tend to drop out when their symptoms improve<sup>3,11,12</sup>.

We established a community-based service for children with epilepsy in rural West Bengal, India. Children had been identified by screening the community using key informant and house to house survey methods<sup>13</sup>, and enrolled in a clinical trial of first-line antiepileptic drugs<sup>14</sup>. Children were followed up in a monthly clinic and visited at home by disability workers. Despite close monitoring, 34% of subjects dropped out of follow-up, a proportion similar to other research settings, such as in Kenya (27%) and Ecuador (28%)<sup>15,16</sup>. We wanted to systematically examine the reasons behind families' decisions to drop out of the treatment programme, specifically to identify sociodemographic and medical predictive factors, and also gain a qualitative understanding of how decisions concerning attendance were made.

## MATERIALS AND METHODS

The study took place in 24 Parganas(S), a rural district of West Bengal, India. This is an area not far south of Calcutta, with mainly agriculture and local trades. The 94 subjects in the study were aged between 2 and 18 years, with an equal number of boys and girls, 32 children had dropped out at 1 year, and 62 had remained in follow-up. Twenty-five percent had partial seizures, 39% secondary generalized and 36% primary generalized seizures, with a median of 50 lifetime seizures, 25% had a cerebral impairment, and 62% had tried antiepileptic drugs before. The median family size was six, 74% of households were nuclear, 45% of mothers were illiterate, and the median income was Rs. 1000 (about \$30).

Field workers visited all defaulting families to enquire about their reasons for non-attendance. If they indicated to the field worker that they did not intend to return to the clinic, we then counted them as dropouts after their next non-attendance. We recorded in-depth interviews with these families at home between late 1995 and 1996. The interviews were semi-structured using a topic schedule to explore three main areas: what the opinion of the parents was regarding epilepsy as a problem; whether they believed that allopathy (Western medicine) was efficacious; and the perceived balance of benefit and inconvenience of the intervention. The interviews were translated and transcribed later the same day.

Sociodemographic and medical risk factors were also assessed for ability to predict dropout. Cases were subjects who had dropped out, with unmatched controls being the 62 subjects remaining in follow-up. Age was measured to the nearest year, cerebral impairments as the presence of cerebral palsy or severe mental retardation or focal neurological deficit; seizure type as per operational definitions as partial,

primary or secondary generalized<sup>17</sup>; number of lifetime seizures grouped as less than 10, 10–100, more than 100; treatments were phenobarbitone or phenytoin; family characteristics were size and type; maternal education measured as ability to read, write, tell the time, graded as illiterate or barely literate, literate and intermediate; income as reported average monthly income in rupees, social support defined as the satisfaction with total sources of social support, measured by the Dunst Family Support scale<sup>18</sup>. Risk factors (age, sex, the presence of cerebral impairments, seizure type, number and duration of seizures, antiepileptic drug, prior treatment, family characteristics, maternal education, income and social support) were entered into a multiple logistic regression model in Stata 5.0 for Macintosh and results reported as odds ratios with 95% confidence intervals<sup>19</sup>.

## RESULTS

There were 10 dropouts in the first quarter (of which five were in the first month), 13 in the second, four in the third, five in the fourth. Age, sex, seizure type, number and duration of seizures, treatment group, family characteristics, maternal education, income and social support did not predict dropout in multivariate analysis. Children with symptomatic epilepsy (with cerebral palsy, severe mental retardation or focal neurological deficit) were less likely to remain in follow-up (odds ratio 0.12, 95% CI: 0.015–0.88), and children who had received antiepileptic drugs before were more likely to remain in follow-up (odds ratio 4.60, 95% CI: 1.0–21.0).

Sixty-two percent of families defaulted at one time or other. Default occurred because of seasonal income, intercurrent illness in family members, domestic (especially women's) commitments, religious festivals, local cultural customs and beliefs, and unpassable roads during the rainy season. The reasons for complete dropout, as obtained from interview, were different, and are summarized in Table 1. These were mainly denial of diagnosis, symptom resolution, access, opportunism, and perceived lack of benefit from intervention.

Six families found the diagnosis of epilepsy unacceptable, five of these children had not previously been diagnosed. All had been identified by the survey. Three of these children had complex partial seizures manifesting as odd behaviour and these families preferred alternative labels of 'mental illness' or 'a bit thick' for their children's conditions, one family had in fact taken their child to see a 'mental doctor'. Two other families were unconvinced of the diagnosis, one because attacks had been seen only at school not at home,

Table 1: Main reasons for dropping out of treatment, India 1996.

Main reason	First quarter	Second quarter	Third quarter	Fourth quarter	Total
Diagnosis unacceptable	4	1		1	6
Access	1	5			6
Symptom resolution		2	1	2	5
Financial opportunism	3	1	1		5
Continuing seizures		1		2	3
Alternative treatments	1	1			2
'Not worth' treatment		2			2
Side-effects			1		1
Unknown	1				1
Death			1		1
Total	10	13	4	5	32

the other whose father believed she was still having febrile convulsions (rather than afebrile seizures) at the age of 10. The sixth child was a teenager who lacked emotional support from his family and therefore denied the persistence of attacks.

Five children dropped out when their symptoms resolved: three had other life events which overshadowed clinic appointments: the mother of one older body died; an older girl got married; and another teenage girl got a job in the city. All had become seizure free on medication.

Four children from the farthest village dropped out because they could not afford to come any more. They were also amongst the poorest families, earning Rs 500, half of the median income in the study. Another poor family, without a male head, sent their child away to work as a servant in another household which was not informed of her diagnosis.

Mother: 'I can't go alone, so her father goes. If I could go I would. But he can't go, he's ill and he can't go in time either...and we can't get the money together. Nowadays she fits two or three times a night.'

Father: 'Why don't you give us a job? At your office, some small job? As a sweeper. Then we'll eat. You're doctors, you give help, why don't you make our lives a little easier?'

[parents of girl with epilepsy]

Three children with continuing seizures dropped out. One child's epilepsy syndrome was re-diagnosed as complex absences, rather than complex partial seizures, and therefore was referred elsewhere for sodium valproate. The other child was severely disabled after untreated meningitis, with hemiplegia and

few self help skills. His mother had difficulty giving him tablets, which he tended to spit out. Monotherapy and dual therapy had not effected seizure control. The third family had a girl with severe mental retardation which they had trouble accepting, and did not give the medication.

The parents of three children had given false addresses to avail themselves of our low-cost services and could not be found by field workers. Two families had registered their children's names at our clinic believing it would lead to child sponsorship and dropped out when it did not.

One family was reluctant from the outset to use allopathy and reverted to homeopathy after some months, having never taken the prescribed allopathic treatment. Another mother had been treating her child at the Christian Mission Clinic. She felt she was getting a better service there since the drugs 'from Mother Theresa' were expensive and there was a long waiting list to see the doctor.

She had an allopathic tablet once but it made her sweat and the homeopath said how can you expect anything from us if you've given her allopathy? We didn't give her any vitamins after she had typhoid, that's why she has it (epilepsy) the homeopath said. We thought we would give homeopathy one more try before the last resort (allopathy).

Poverty forces hard decisions. Two families with children with mental retardation and epilepsy simply did not see an advantage in treating seizures which they felt were relatively inconsequential to the child's full problem. The older boy, in his late teens, also had severe behaviour problems, and died shortly after the end of the study.

We can't tell if the medicine is doing him any good. Perhaps he's OK without tablets, then he'll have a really bad five days. We didn't get any benefit from anything. Since he's not getting any better, his future is in God's hands. If he lives, he lives...

[father of child with intractable epilepsy]

Only one person dropped out because of side-effects: a young woman with infrequent complex partial epilepsy, very occasionally generalized, became drowsy after starting medication, threw the tablets away, deciding that the medicine was worse than the illness.

## DISCUSSION

Families that had tried AEDs before were more likely to stay in follow-up. These families had both accepted the diagnosis of epilepsy before entering the study, and had belief in the effectiveness of medical (allopathic/Western) treatment. In contrast, a number of families were dissatisfied with the new label of epilepsy which our survey had given their children, and they dropped out early on. Others had a better experience with other sources of treatment (mission hospital, homeopathy). This raises the question of whether a population survey is an appropriate or ethically justified procedure for ascertainment of a stigmatizing disorder. Our experience suggests that it may cause unnecessary distress.

Cerebral impairment strongly predicted dropout. Children with central deficits have a poorer prognosis for seizure control and treating seizures has a more limited impact on quality of life than in a person with a 'pure' seizure disorder. These families believed it worthless to treat epilepsy if it did not ameliorate associated neurological problems, or they had witnessed no improvement in seizures on treatment. Since a quarter of the children had a serious central deficit and therefore had greater rehabilitation needs than others, there is a strong argument for an intervention to include broad-based intervention that addresses the developmental and disability needs of the child and family. Conversely, some of those with good prognosis entered remission, dropped out and returned to normal lives in work and family life. This should be judged as a successful outcome of intervention.

Access and financial opportunism, both associated with poverty, were related to dropout. Nobody found the clinic fees excessive, rather it was the social and financial costs associated with taking a day off normal activities and travelling to the clinic. The families with access difficulties were the most disadvantaged, three

lacked a male head and another had a male head unable to work because of chronic illness. Many came from the farthest village 30 km away, too poor to take a bus, sometimes taking 3 hours to travel each way by cart and foot. We tried to offset defaulting by being flexible about clinic appointments, and in emergencies had delivered medicines to the home. Financial gain was the probable motivation for a handful of families and this has to be understood in a context where donor organizations may influence the community by introducing their own development schemes.

We did not find that maternal illiteracy, lack of drug efficacy, or side-effects were significant causes of dropout. This study has demonstrated diverse reasons for attrition in a rural community setting. A combination of clinic-based and home-based medical and rehabilitation input is needed to maintain good quality and continuity of care. In future, we would reconsider the use of active ascertainment methods, and at the outset identify families at high risk for dropout—long journey times, very poor, and lacking a working male head of household. Certain authors have suggested deposit schemes to counteract dropout but we see no place for this in a context where capital is scarce and families may already have sizeable debts to landlords and moneylenders<sup>20</sup>. Lastly, this study demonstrates the need for epilepsy management to be set not only within the context of rehabilitation and integration, but also integrated into the wider programmes aimed at the alleviation of poverty.

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