Mortality implications and factors associated with non-engagement in a public epilepsy care initiative in a transient population.

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ABSTRACT

Background: Community-based, public care programs are a requisite to close the epilepsy treatment gap in disadvantaged communities in low and middle-income countries. Potential beneficiaries may, however choose not to engage in these programs. *Aims*: To describe factors associated with, and mortality consequences of non-acceptance of a public epilepsy care initiative. *Methods*: In this cross-sectional study, we contacted 207 (36%) people out of 575 who screened positive for epilepsy during a population-based survey of 59,509 people. They were invited for neurological evaluation and care provision (including antiseizure medications) but chose not to engage. Structured questionnaires and qualitative interviews were conducted to determine reason for their non-engagement. Factors associated with non-engagement were evaluated by univariate and multivariate analysis. We conducted verbal autopsies for those who had died. *Results*: Ten (5%) of the 207 individuals died since the initial screening, six, due to epilepsy-related causes. Of those who could be contacted (n=48), 40 (19%) were confirmed to have epilepsy. Non-engaging individuals were likely to be older (OR: 1.02; 95%CI, 1.01, 1.11), locals (OR: 4.32; 95% CI, 1.55, 12.03), and earn less than US$ 78/month (OR: 3.6; 95%CI, 1.62, 8.06). Reasons for not engaging included a belief that epilepsy is inconsequential, loss of daily wages owing to health care facility visit and physical infirmity. *Conclusions*: Non-acceptance of a community-based public epilepsy care initiative is associated with high premature mortality, mostly attributed to epilepsy related causes. Older age, ethnic status and economic deprivation are factors associated with non-acceptance, though the underlying reasons may be varied.

Key Words: Premature mortality; Risk factors; Verbal autopsy; Low and middle-income countries

Introduction

An enduring propensity to seizures is a characteristic feature of epilepsy[1]. Seizures in most people with epilepsy, however, remit with simple, low-cost treatment regimens[2–4]. Over three-quarters of these people live in low and middle income countries (LMICs) and up to three-quarters of whom are unable to access treatment on account of socio-cultural, economic, political and health systems' issues[5 6 7 8 9]. This treatment gap is compounded by resource constraints, mainly encompassing the lack of specialists, diagnostic facilities, medicine supplies and healthcare inequity in a mostly pay "out of pocket at delivery" environment[10 7,11]. Surveys have showed a dismal picture in terms of availability and affordability of even low-cost traditional anti-seizure medications (ASMs)[12].

Public financing of comprehensive epilepsy treatment in resource-limited settings averts substantial disease burden in a cost-effective manner in simulated models[13]. Realistically, however, community-based interventions with free-of-charge ASMs have been rarely implemented[3,4,14,15]. These community projects have been challenged by uncertain and incomplete turn-outs as well as modest attrition rate[14]. Directing attention to people with epilepsy who choose not to engage in such programs may provide indications for scaling up epilepsy coverage. Besides, an assessment of the influence of peoples' attitudes towards, and behaviours regarding, epilepsy and its treatment on the choice/s to access (or not) care is desirable[16].

We implemented a programme to provide care in the community for people with epilepsy[17]. Some chose not to engage in the program. We subsequently reached out to these people to ascertain their current condition and to determine if they had epilepsy and, in which case, factors associated with, and reasons for non-engagement. Here, we describe our approach to reach the people who chose not to participate.

Methods

Study settings

The methodology for the community-based intervention in Ludhiana, an industrial city in Northern India has been previously reported[17]. Briefly, potential participants were identified during a door-to-door, community screening survey using a previously translated and validated questionnaire by field health workers[18,19]. People who screened positive were invited for neurological evaluation at a teaching hospital in the district. The evaluations inclusive of EEG recording, MRI brain scanning and treatment planning were provided free-of-charge and transport costs, reimbursed. Once a diagnosis of epilepsy was confirmed, the participants entered a cluster-randomized trial, which encompassed cost-free ASM provision, epilepsy self-management and stigma abrogation and monitoring (for seizure control and ASM adherence) either at home by field health workers or at clinic as usual. A proportion of those who screened positive for epilepsy in the initial survey chose either not to present for neurological examination and participate in the trial. Soon after the evaluation phase finished, we undertook a cross-sectional study with limited evaluations using mixed methods of those who chose not to engage in the care initiative.

Participants

Non-engaging individuals were those who failed to visit hospital clinic despite three telephonic reminders and an additional home visit by study team field-workers during the initial screening and evaluation exercise[17].

Field visits and assessments

We revisited the homes of non-engaging people approximately 12 months after screening. Subsequently, telephonic contact was attempted with those who were either untraceable and whose houses were found locked during the revisits. If telephonic contact was established, their houses were visited again. During the home visits, the study team explained the purpose

of their visit and nature of the investigation and obtained written informed consent.

We first conducted unstructured, tape-recorded interviews to capture free views of the people with presumed epilepsy. In these interviews, reasons for not engaging were probed. Perceptions about epilepsy and the need for treatment and knowledge about treatment options were explored. The offer of care was renewed. Next, the team administered a structured questionnaire, prepared from items provided by two senior investigators (GS, RKB) and resolved and finalized after consensus. Items in the questionnaire were read out and responses recorded. Neurological evaluations to determine diagnoses were performed in the home environment. No investigations were performed but past medical records when available, were perused and findings recorded. Lastly, we visited the homes of those who had died since the initial screening. During these visits, a neurologist (GS), experienced in verbal autopsy protocols, used the WHO verbal autopsy tool to ascertain the cause/s of death in those who died[20,21]. A family member or someone in the household, who was aware of circumstances surrounding the death provided the information.

During home visits, we collected demographic information including age, sex, religion, educational and income. We used these data to estimate socio-economic status according to the Revised Kuppuswamy scale[22]. This scale is a composite scale derived from educational achievement, employment and family income that correlates with the presence of several health conditions and has been widely used in India for over three decades. We extracted demographic data of those who could not be contacted from forms used during the initial screening campaign. Details about epilepsy, health seeking behaviours and reasons for previous non-attendance were also recorded. The basic version of the latest International League Against Epilepsy seizures and epilepsies classifications were used[23,24]. Two clinicians coded potential cause/s according to ICD-10 in those who had died.

<u>Qualitative assessments</u>

The tape-recorded versions of the unstructured interviews were transcribed to Punjabi language and these were reviewed by two co-authors experienced in qualitative interview analysis (AC, RKB) [25]. They assembled the transcripts in to a thematic framework and then, indexed and sorted themes and subthemes. These were then independently interpreted and discussed to achieve consensus and presented at meetings of the study team.

Statistical analyses

Purposely, two groups were constituted: (i) those who attended neurological evaluation and enrolled and (ii) those who did not attend despite reminders. Data normality was assessed using the Shapiro-Wilk test. The association of non-engagement with various explanatory variables including age, sex, education, income, socio-economic status, ethnic origin (native Punjabi Vs. interstate migrant) and prior use of antiseizure medications were first explored in univariate analyses. Categorical variables were compared using the Chi Square test and continuous variables, by the Wilcoxon rank sum test. Those variables for which, $P<0.2$ were entered in to a logistic conditional regression model. Odds ratios with their 95% Confidence Intervals were estimated to identify variables associated with non-engagement (at $P<0.05$). For this model, socio-economic status was treated as a binary variable with higher class as the reference category. Stata version 15.0 (StataCorp TX, USA) was used for analysis.

Ethical and funding considerations

The study was approved by the Ethics Committee of Dayanand Medical College & Hospital (vide IEC no. 2017-281). The community trial was registered with the Clinical Trial Registry of India (Re.: 2017/09/015380). Data will be available at Dryad to interested researchers upon reasonable request.

Results

Circumstantial outcomes

Of 59,509 people surveyed, 575 (0.96%) screened positive for epilepsy and were invited for further neurological evaluation. Two hundred-and-seven (36.0%) of them declined the invitation and 368 (64%) accepted (Fig. 1). A year later, to assess reasons for decline in the 207 people who did not engage, we found 39 (19% of the non-attendees) locked households and 44 (21%) house relocations. Another 46 (22%) were unwilling to be interviewed and 20 (10%) were missing or unaccounted for. Ten (5%) individuals had died since the initial screening (Fig. 1). The remainder 48 (23%) were evaluated for epilepsy. Epilepsy was confirmed in 40 (19%) and refuted in eight (4%). Eventually, 38 (18%) of those considered to have epilepsy were interviewed. Two refused to participate in the interview (Fig. 2).

Mortality

The unadjusted marginal probability of death in those who chose not to engage in the care initiative (n=207) was 0.057. This was elevated in comparison to the enrolled group (n=240), which experienced only 2 deaths (suicide: 1; dengue-related: 1) in the same period of time, giving a crude odds ratio of 5.8 (95% Confidence Intervals, 1.26 to 26.76) (P=0.024). *Post hoc*, the achieved power with an α of 0.05 and confidence limits of 95% was estimated to be 1.00. Verbal autopsies (n=10) suggested six deaths directly related to epilepsy (Table 1), including status epilepticus (n=5) and possible SUDEP (n=1). Two were attributed to the underlying condition that led to epilepsy.

Factors associated with non-engagement

Non-engaging people were likely to be older [Mean ± SD age: 26±16 years Vs. 33±20 years (in participating individuals); p=0.019], locals (as opposed to immigrants) [n=33 (87%) Vs. n=92 (62%) in the participating subgroup; p=0.002], and have a family income less than US$ 78/month [n=18 (47%) Vs. n=58 (24%) among participants; p=0.003] (Table 2). In the multivariate analysis, age (OR: 1.03 ; 95%CI, 1.01, 1.11),

ethnic status (OR: 4.32; 95%CI, 1.55, 12.03), lower income (OR: 3.62; 95%CI, 1.62, 8.06) and socio-economic status (OR: 3.91; 95%CI, 1.64, 9.31 for lower socio-economic status) were associated with non-engagement. Thirty of the non-engaging individuals were on ASMs and 11 had a seizure in the preceding month. Reasons for non-engagement included indirect costs associated with neurological evaluations (n=11; 29%), inability to travel on account of disability (n=9; 24%) and being on prior satisfactory treatment (n=20; 53%) (Fig. 2). Several provided more than one reason for non-engagement. *Post hoc*, we compared age and gender distribution of those non-engaging who could be contacted with those who could not be contacted and these were found to be similar (P=0.103 for age; P=0.819 for gender distribution).

Qualitative assessments

Major themes emerging from the qualitative analysis included being on prior treatment with good seizure control, a day's income loss for hospital visit, incapacity to attend hospital due to frailty and consequently need of an escort. Other reasons were distinct as verbatim quotes below suggest:

(Mother of a child with epilepsy) "*My husband did not allow us to come over. He said this is a medical college project and in these teaching medical colleges, patients are handled by amateurs. Students might give wrong medicines and these might produce side-effects…….*"

(An immigrant labourer) "*I took medicines for several years but my seizures were not controlled. The medicines led to only dizziness but no fever. I feel that somebody back in my hometown has performed a kind of black magic. I fall to the ground with teeth clenched and become stiff.*"

(Father of child with epilepsy) "*We go out of town to get his medicines. I am not sure if it is a doctor or just a pharmacist but he is seizure-free. I do not want to get in to the hassle of filling up so many forms.*" He, however agreed to respond to the

questionnaire.

(Grandmother of child with presumed seizures) "*She just perhaps fainted a couple of times. I do not think that she needs any treatment.*"

Discussion

The findings of this study underscore the implications of non-engagement in a public care program in many ways. Individuals who chose not to engage were nearly six-times more likely to die in contrast to those who enrolled. This alarming finding, though unexpected, confirms the premature mortality burden associated with epilepsy in LMICs[26]. Sixty percent of the deaths were related to epilepsy. Population-based studies of mortality from the LMICs are few but it can be inferred from a meta-analysis of these studies, that the proportionate mortality due to status epilepticus (5-57%) and SUDEP (1-20%) is high[21]. In comparison, studies from HICs have shown that the risk of dying due to status epilepticus and SUDEP are as low as 0.2/1000 and <1.5/1000 people respectively[27]. Our findings emphasize the public health implications of premature mortality patterns associated with epilepsy in disadvantaged communities[28]. A considerable number of premature deaths can be prevented by implementing an affordable and high-quality public care provision program for epilepsy in LMICs. Our findings also explicate the excellent performance of verbal autopsies in assigning causes of death directly attributed to epilepsy (Table 1) that despite the susceptibility to misclassification bias[20].

The challenges encountered in carrying out a public care initiative for epilepsy are emphasized in this report. Our community-based reassessment confirmed the transient nature of the population with frequent migration in and out of and within the study area. Despite this, non-engagement was associated with being local in the multivariate analysis

(Table 2). This could be related to different treatment-seeking attitudes of locals and migrants. Other factors associated with non-engagement included older age and lower socio-economic status (Table 2). Our structured and qualitative assessments identified various reasons for non-engagement; many people offered more than one reason (Fig. 2).

There are several limitations to our study. These include its cross-sectional design, large number of unaccounted respondents, the lag between death and verbal autopsy and the diagnostic uncertainty in those who died[29]. We were unable to establish contact with a large number of people who did not engage as they were mainly impoverished interstate migrants, thus, predisposed to emigration and relocation. Epilepsy in transient populations has been previously addressed[30]. The challenges presented to implementing a care program including barriers to care provision by emigration in resource-constrained settings, however, have not been previously emphasized. Nation-wide linking within health databases could be a solution but seems unrealistic because of resource constraints and large populations.

Conclusions

Our study underscores the high mortality associated with epilepsy in disadvantaged communities. Besides, our findings provide insights to the demand-side, individual-level beliefs and behaviours of people with epilepsy. Implementing an epilepsy-care initiative in communities with limited resources may encounter such issues. Stigma and misbeliefs about epilepsy causes are rife as shown in the unstructured assessments. Marginal expectations and perceptions about epilepsy treatment still exist as some people resign to the futility of medications to control seizures, whilst others believe that the odd seizures are too trivial to be treated. Clearly, community awareness campaigns need to address these misperceptions. Lastly, cutting across the demand-side barriers by devising innovative user-friendly approaches will be critical to the success of public epilepsy care programs.

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Authors' statement: We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Conflict of Interest

The authors declare no conflict of interest in relation to this work.

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Table 1: Reasons of death in those who died.

S No.	Gender	Age at death (years)	Cause of Death* (Immediate / Underlying causes)	VA code	ICD 10 code	Time between death and VA (days)#	Treatment
1.	Female	37	Encephalopathy / HIV/AIDS related	VAS-01.03	B24	301	On ASMs - records not available
2.	Male	20	Probable SUDEP / Epilepsy	VAS-08.01	G40.909	315	Nil
3.	Male	43	Status epilepticus / Epilepsy	VAS-08.01	G40.901	272	Nil
4.	Female	12	Status epilepticus / Epilepsy	VAS-08.01	G40.901	55	On ASM; had many seizures/month; died in hospital
5.	Male	37	Aspiration pneumonia / Brain Tumor	VAS-02.99	C71.9	201	(Levetiracetam 500 mg bid; rare seizures
6.	Female	60	Status epilepticus / Epilepsy	VAS-08.01	G40.901	230	On ASMs but records not available 2-3 seizures/month
7.	Female	10	Status epilepticus / Epilepsy	VAS-08.01	G40.901	256	On ASMs; details not available; poor adherence due to poverty
8.	Male	7/12	Status epilepticus / Epilepsy	VAS-08.01	G40.901	193	On ASM; records not available
9.	Male	45	Encephalopathy / Lung cancer	VAS-02.03	C39	238	Nil
10	Male	60	Unclear / Stroke	VAS-08.01	I63.9	238	On ASMs: records not available

*The recorded immediate and underlying causes of death could not be obtained as medical records and death certificates destroyed during funeral in all cases.

#The large and variable time-gap between death and verbal autopsy reflects the unexpected occurrence of the deaths and cross-sectional design of the study.

Table 2. Comparison of socio-demographic characteristics of trial-enrolled and non-engaging respondents.

Characteristics	Participants (n=240)	Non-engaging respondents (n=38)	Univariate comparison		Multivariate analysis	
			Chi-square	Statistical significance	OR [95% Conf. Interval]	Statistical significance
Age (Mean ± SD) (years)	26±16	33±20		0.019	1.03 (1-1.1)	0.026
Gender: Female	80 (33%)	15 (39%)	0.550	0.458	1.2 (0.49-2.9)	0.685
Ethnic origin: Punjabi	148 (62%)	33 (87%)	9.153	0.002	3.85(1.35-10.9)	0.011
Education: Illiterate	106 (44%)	17 (45%)	0.004	0.984	1.21 (0.49-2.95)	0.676
Occupation (Self): Unemployed	153 (64%)	28 (74%)	1.425	0.233	1.75 (0.6-4.8)	0.278
Family Income / Month: Less than US$ 77.6/month	58 (24%)	18 (47%)	8.890	0.003	4.2 (1.8-9.8)	0.001
Socioeconomic Class*	197 (82%)	24 (63%)	7.209	0.007	4.17 (1.7-10.2)	0.002
Marital Status: Single/Divorce	153 (64%)	22 (58%)	0.482	0.487	1.59 (0.5-4.6)	0.392
Prior use of anti-seizure medications	156 (65%)	28 (74%)	2.300	0.129	2.58 (0.97-6.82)	0.057

*Based on Revised Kuppuswamy Scale (Ref. 11)

438 LEGENDS TO FIGURES
439
440 Fig. 1. Flow chart depicting the circumstantial outcome of screened-positive subject during
441 and after the door-to-door population survey (Ref. 10).
442
443 Fig. 2. Diagrammatic representation of reasons (elicited during the structured interviews)
444 attached with non-participation in the epilepsy care initiative.
445

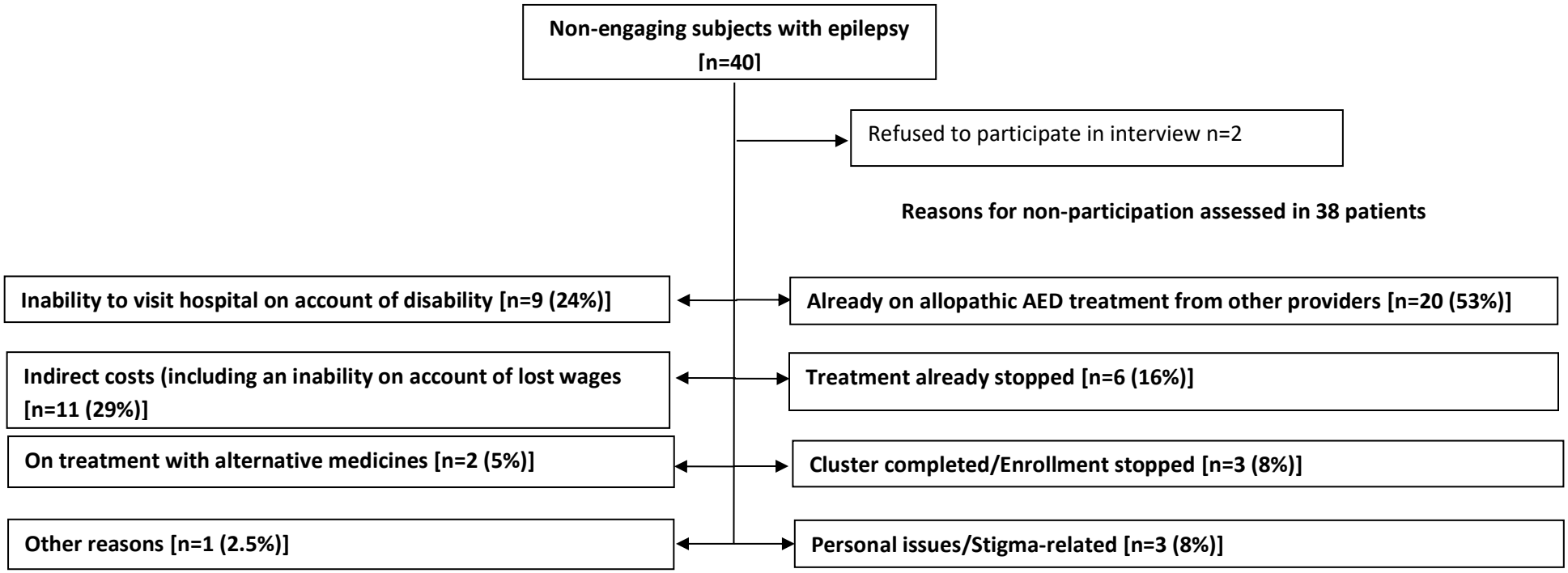
Non-engaging subjects with epilepsy [n=40]
Refused to participate in interview n=2
Reasons for non-participation assessed in 38 patients
Inability to visit hospital on account of disability [n=9 (24%)]
Already on allopathic AED treatment from other providers [n=20 (53%)]
Indirect costs (including an inability on account of lost wages [n=11 (29%)]
Treatment already stopped [n=6 (16%)]
On treatment with alternative medicines [n=2 (5%)]
Cluster completed/Enrollment stopped [n=3 (8%)]
Other reasons [n=1 (2.5%)]
Personal issues/Stigma-related [n=3 (8%)]

Fig 2

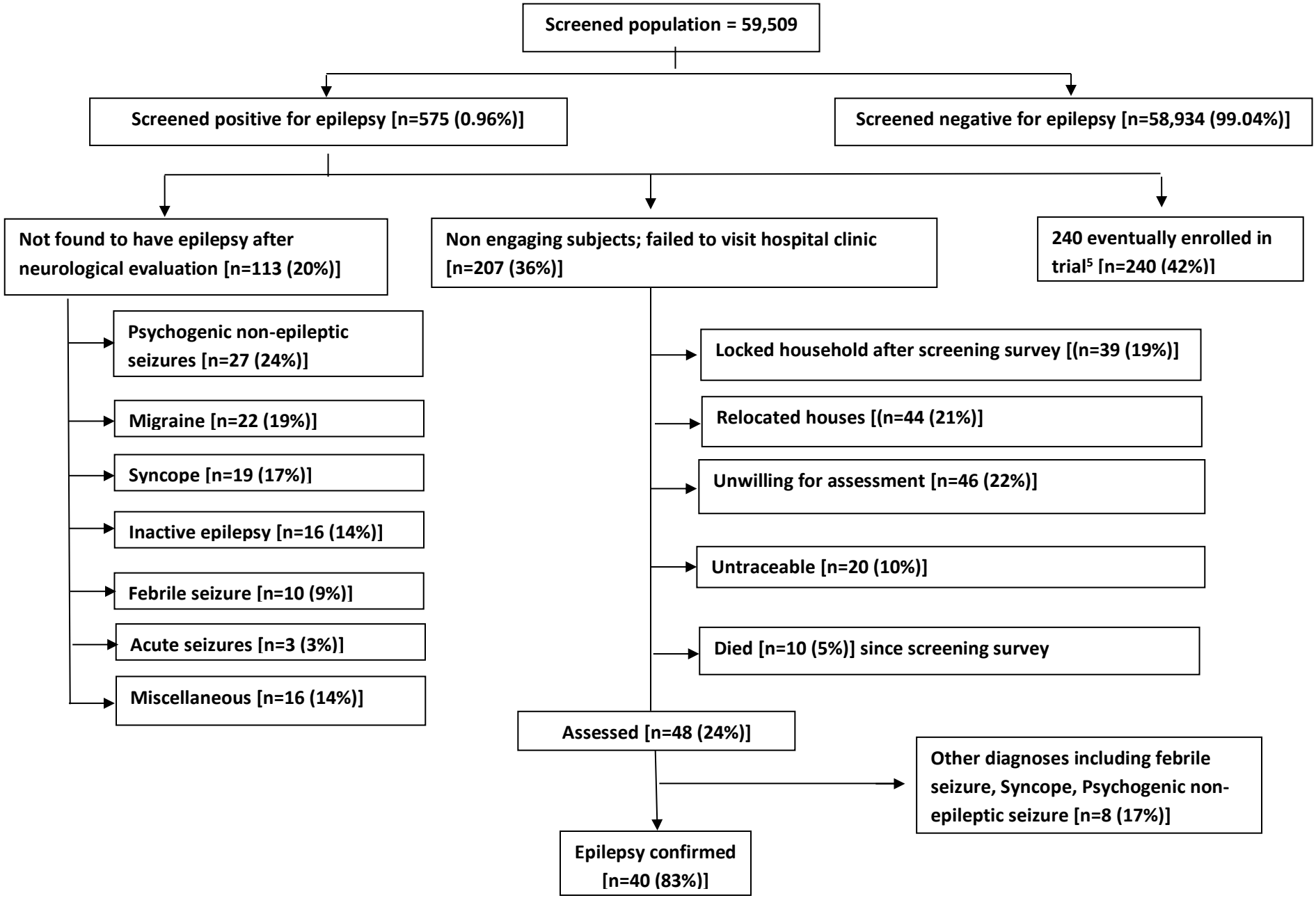
Screened population = 59,509
Screened positive for epilepsy [n=575 (0.96%)]
Screened negative for epilepsy [n=58,934 (99.04%)]
Not found to have epilepsy after neurological evaluation [n=113 (20%)]
Non engaging subjects; failed to visit hospital clinic [n=207 (36%)]
240 eventually enrolled in trial[5] [n=240 (42%)]
Psychogenic non-epileptic seizures [n=27 (24%)]
Migraine [n=22 (19%)]
Syncope [n=19 (17%)]
Inactive epilepsy [n=16 (14%)]
Febrile seizure [n=10 (9%)]
Acute seizures [n=3 (3%)]
Miscellaneous [n=16 (14%)]
Locked household after screening survey [(n=39 (19%)]
Relocated houses [(n=44 (21%)]
Unwilling for assessment [n=46 (22%)]
Untraceable [n=20 (10%)]
Died [n=10 (5%)] since screening survey
Assessed [n=48 (24%)]
Other diagnoses including febrile seizure, Syncope, Psychogenic non-epileptic seizure [n=8 (17%)]
Epilepsy confirmed [n=40 (83%)]

Fig 1