

# Empowerment of Local Primary Health Care to Bridge the Childhood Epilepsy Treatment Gap in an Outreach Financially-Constrained District in Pakistan

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## Abstract

**Introduction:** There is huge childhood epilepsy treatment gap (CETG) in developing countries because of nonadherence to antiepileptic drugs (AEDs), and this can adversely affect the course of childhood epilepsy (CE). There is a dearth of data in such countries on the effectiveness-assessment of community interventions regarding treatment improvement for the children with epilepsy (CWE).

**Study type:** Case control interventional study.

**Objectives:** This study was designed to determine the effectiveness of interventions through free community childhood epilepsy center by combining outreach monthly free pediatric neurology camps and telepaedsneurology aiming at bridging the huge treatment among CWE.



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**Methods:** After integration and implementing childhood epilepsy (CE) into primary care for last two years, in a case control interventional study, 240 CWE (160 being treated and followed in the free community childhood epilepsy center and 80 as control, not being treated at this center). The age ranged from 4 months to 18 years, in whom treatment initiated with antiepileptic drugs (AEDs) for the past 3 months prior to the data collection date were evaluated. Data was collected by a questionnaire divided into three parts 1) demographical information about patients, 2) information about childhood epilepsy treatment and AED (s) medication adherence profile using the Morisky Medication Adherence Scale-8 (MMAS-8) and 3) data on intervention-effectiveness of the community childhood epilepsy center (CCEC) on bridging the treatment gap in comparison with cohort not being intervened by this center. Ethical approval was obtained from the institutional ethics committee.

**Results:** Male to female ratio was 1.26:1. After two years of intervention by top-down-bottom-up-childhood-epilepsy-program-center (TDBUCEPC), childhood epilepsy treatment gap (CETG) dropped to 20% (was 90% in 2014), however the treatment gap was 82.5% among the cohort not being intervened at this center. Adherence to antiepileptic drugs by self-report was 85% (was 42% in 2014 without community intervention) among the children being treated, provided free AEDs with consultations and followed at the epilepsy center, whereas, currently adherence was 37.5% among the children not being intervened at this center.

**Conclusion:** Integration and implementation of CE into primary health care in outreach financially-constrained districts in Pakistan is one of the best strategies to bridge the huge TGCE, by empowering the local communities to provide free treatment for CWE.

## Introduction

Acknowledging epilepsy as a neglected condition by the World Health Organization (WHO) in 2004 has led to increased emphasis on the development of adequate treatment strategies in low- and middle-income countries [1,2]. Despite these efforts, most children with epilepsy (CWE) still lack appropriate treatment in these countries. The epilepsy-treatment gap is defined as the proportion of people with epilepsy who require but do not receive treatment; it has been proposed as a useful parameter to compare access to and quality of care for epilepsy across populations [3,4]. The most contributing factors to the childhood epilepsy treatment gap (CETG) are the following:

inadequate skilled healthcare manpower,

- high treatment costs,
- limited or no antiepileptic drug access, and
- unfavorable cultural beliefs [5].

Cost-effective epilepsy treatments are available, and an accurate diagnosis can be made without technological equipment. Nonetheless, a vast majority of individuals with epilepsy in many resource-poor regions do not receive treatment [6-8]. There is substantial heterogeneity across and within countries, with treatment gaps higher in rural than urban areas [9]. Similarly in 2014, we documented treatment gap of childhood epilepsy (TGCE) of 92% and nonadherence to AED (s) 58.3% in Bhakhar city, an outreach financially constrained district in Pakistan [10,11]. There is already robust evidence for a range of cost-effective interventions, but little evidence on how these may be delivered in diverse low-resource settings [12]. Despite the existence of evidence-based interventions for epilepsy in primary care there is limited data on how to successfully translate this knowledge into sustainable practice [13]. On the basis of these findings, we proposed top-down-bottom-up-childhood-epilepsy-program (TDBUCEP), a package of care by integrating childhood epilepsy into primary care to empower the local community health facility by monthly childhood neurology camps in Bhakhar city and telepediatric neurology consultations. This combination of interventional packages aimed at improving the recognition and management of childhood epilepsy (CE) to achieve optimal outcomes. This study was undertaken for impact evaluation of

TDBUCEP in bridging the CETG in an outreach financially-constrained district.

## Methods

### Study design

A community-based case control interventional study was conducted in free clinical pediatric neurology camps at two community centers in different parts of Bhakhar city on 7th and 8th December 2018.

**Conduct of study:** Before conducting the study a thorough advertisement about these free camps for children with neurological disorders was done for 2 weeks through local newspapers, pamphlets, posters, banners at every possible place and visiting most of the private hospitals in and around the city. Special help was sought from mosque imams and school teachers for announcing the camps and encouraging the community to visit these camps. At the meeting the aim of the study was presented, and communal consent sought. They were assured that the information collected would be treated confidentially and that it would be used only for the purpose of study.

**Participants and procedures:** The study was done in Bhakhar city arranged by the clinical and field staff of top-down-bottom-up-childhood-epilepsy-program-center (TDBUCEC) in two public community centers, to avoid the bias of better treatment at the Centre. For the clinical effectiveness this study was conducted by cross-sectional snap survey of free camps for childhood epilepsy and other paediatric neurological disorders under the supervision of visiting paediatric neurologists (visiting program supervising team) in Bhakhar city. The final diagnosis of childhood epilepsy, treatment gap and AED (s) nonadherence was ascertained by one of the three visiting pediatric neurologists supervising their own teams, if doubt consensus was made between the three pediatric neurologists. One whole day was spent at each community center.

Participants were recruited from the two free pediatric neurology camps in Bhakhar city. Children were eligible to participate if they: (1) received an epilepsy diagnosis and were prescribed an AED, (2) had no comorbid medical conditions requiring a daily medication, (3) had no significant developmental disorders

reported by their caregiver, and (4) the family was fluent in Suraikee (local language). Children aged 4 months to 18 years of age, diagnosed with epilepsy and treatment initiated with at least 1 AED for the past 3 months. Data collection was done using a questionnaire which was divided into three parts; 1) demographical information about patients and their caregivers along with clinical details of epilepsy; 2) gathered information about AED (s) medication adherence profile with the help of the Morisky Medication Adherence Scale-8 (MMAS-8) [14], modified for treatment of childhood epilepsy; and 3) evaluation of interventional effectiveness of TDBUCEPC bridging the childhood epilepsy treatment gap (CETG) and AED (s)-adherence improvement by integrating childhood epilepsy into primary health care. Data were collected by interviewing participants and reviewing patient charts using structured and pretested questionnaire by trained data collectors. AED (s) nonadherence was measured by an eight-item modified Morisky Medication Adherence Scale. A modified MMAS-8 item was developed from the original MMAS-8 by Morisky et al. was translated into English and Suraikee (local language). The first seven items are dichotomous response categories with yes or no and the last item is five-point Likert scale response [14].

**Ethical Issues**

Ethical approval for the study was obtained from the Ethical Committee of the Brain Associates, Lahore. Verbal consent was obtained from the household heads and adolescent patients and from parents or close family relatives of children. Parents or close family members acted as proxy for children and persons who were unable to understand respond to the questions during all the phases of the survey. The Rukhsana Shafqat Memorial Primary Health Care Center does not have ethical committees and has no concern except conducting the free camp and providing support. Participants were assured that if they want to refuse to participate, their care or dignity would not be compromised in anyway, since there was no relationship between participation and health or treatment outcome. Confidentiality was maintained by anonymous questionnaire and informed consent was obtained from each participant.

**Results**

**Patient characteristics associated with childhood epilepsy treatment gap**

The study enrolled 240 children and of these 95 (39.6%) CWE were ≤ 5 years of age. Among the 240 children and adolescents with epilepsy who were interviewed, 160 (66.6%) reported seeking treatment from TDBUCEPC and 80 (33.4%) were diagnosed commenced on AED (s) from different other sources

including faith healers, physicians and government health facilities. The average survey duration for each patient was 15 to 20 minutes, and this analysis was of TGCE, adherence/non-adherence to AEDs and factors associated with promoting drug adherence. The age range of the patients was 4 months to 18 years (mean: 10+3.4 years). There was a male preponderance (134, 58%) with a male: female ratio of 1.26:1. Of the total 240 patients, 98 (41%) had CETG, whereas 142 (59%) were being treated according to the guidelines of ILAE. Among the 160 CWE commenced AED (s) and being followed at TDBUCEPC center, 128 (80%) were compliant with treatment according to ILAE guidelines for treatment of childhood epilepsy (CE). In comparison, among the cohort of 80 CWE not being intervened by TDBUCEPC, 66 (82.5%) had CETG and 14 (17.5%) were compliant with appropriate treatment. Additional patient demographic information is presented in Table 1.

Of the total 240 CWE, 166 (69%) were adherent and 74 (31%), were non-adherent to the prescribed AED (s) for different reasons. Among the 160 CWE commenced AED (s) and being followed at TDBUCEPC, 136 (85%) were adherent, while 24 (15%) were nonadherent to the prescribed drugs. While among the 80 CWE not intervened by the center, 50 (62.5%) were nonadherent and only 30 (27.5%) were adherent to the prescribed AED (s) (Table 11).

**Factors associated with adherence/nonadherence to AEDs**

Factors that were found to be significantly associated with medication adherence in the univariate analysis are costs of AED (s), no response to AEDs, counseling by local faith healers, side-effects of AEDs, Poor/no counseling by the treating physician (s) and non- availability of AED (s). Among the 50 CWE not being treated and followed at TDBUCEPC, 28 (56%) reported the cost of their treatment causing nonadherence, whereas on 2 (08.30%) being followed at TDBUCEPC reported this cause of their nonadherence. Uncontrolled seizures were reported associated with 33.3% of the patients being followed at the center as compared with 12% nonadherent patients among not being followed at the center. Misleading and false counseling of local faith healers was significantly associated with nonadherence, more prevalence among the CWE being followed at free childhood epilepsy center (25%), as compared with the cohort not being intervened by TDBUCEPC (12%). Additional significant factors Associated with AEDs-adherence/nonadherence are shown in Table 3. No significant differences were found in the prevalence of CETG and AED (s) nonadherence/adherence among CWE without community intervention in 2014 and in 2018 (Tables 4 and 5).

Epileptic Patients following at top-down-bottom-up center (n=160, 100%)					Epileptic patients not following at top-down-bottom-up center (n=80, 100%)			
Age group	Male	Female	Total (%)	TG (%)	TG (%)	Total (%)	Female	Male
2 months-2 years	18	15	33 (20.65%)	8/35=23%	15/16=94%	16 (20%)	6	10
>2 years-5 years	22	10	32 (20%)	6/26=23%	16/18=89%	18 (22.5%)	8	10
>5 years-10 years	34	24	58 (36.25%)	10/61=16.4%	22/26=85%	26 (32.5%)	12	14

>10 years-15 years	10	15	25 (15.6%)	4/25=16%	10/14=71%	14 (17.5%)	4	10
>15 years-18 years	4	8	12 (7.5%)	4/13=15%	3/6=50%	06 (7.5%)	4	2
Total:								
160 (100%)	88 (55%)	72 (45%)	160 (100%)	32/160=20%	66/80=82.5%	80 (100%)	34 (42.5%)	46 (57.5%)

**Table 1:** Distribution of epileptic children with treatment gap (TG) in 2018 by age group and gender in Bhakhar District-Pakistan (n=240).

Epileptic patients following at top-down-bottom-up center (n=160, 100%)					Epileptic patients not following at top-down-bottom-up center (N=80, 100%)			
Age	Male	Female	Total (%)	Nonad (%)	Nonad. (%)	Total (%)	Female	Male
4 months-2 years	18	15	33 (20.65%)	06 (3.50%)	10 (12.5%).	16 (20%)	6	10
>2 years-5 years	22	10	32 (20%)	04 (2.50%)	12 (15%).	18 (22.5%)	8	10
>5 years-10 years	34	24	58 (36.25%)	08 (5%)	16 (20%).	26 (32.5%)	12	14
>10 years-15 years	10	15	25 (15.6%)	04 (2.50%)	10 (12.5%).	14 (17.5%)	4	10
>15 years-18 years	4	8	12 (7.5%)	02 (2.50%)	02 (2.5%).	06 (7.5%)	4	2
Total:								
160 (100%)	88 (55%)	72 (45%)	160 (100%)	24 (15%)	50 (62.5%).	80 (100%)	34 (42.5%)	46 (57.5%)

**Table 2:** Distribution of epileptic children with nonadherence to AEDs by age and gender in Bhakhar-Pakistan in 2018 (N=240).

Patients non-adherent to AED (s) following at top-down-bottom-up center (n=24, 100%)				Patients non-adherent to AED (s) not following at top-down-bottom-up center (n=50, 100%)		
No	Reasons for non-adherence to AED (s)	No	Percentage	Percentage		No
1	Cost of AED (s)	2	8.3	56		28
2	No response to AED (s)	8	33.3	12		6
3	Counselling by local faith healers	6	25	12		6
4	Side –effects of AEDs	4	16.8			2
5	Poor/no counselling by the treating physician (s)	2	8.3	10		5
6	Non-availability of AED (s)	2	8.3	10		3
Total		24	100	100		50

**Table 3:** Reasons for nonadherence to AEDS (s) among children in 2018 with epilepsy in Bhakhar-Pakistan (N=74).

Epileptic children with treatment gap in 2014 (n=130, 100%)				Epileptic children with treatment gap in 2018 (n=80, 100%)		
Age group	Male	Female	TG (%)	TG (%)	Female	Male
4 Mon-2 years	20	10	29/30 (98)	15/16 (94)	6	10
>2 years-5 years	8	12	19/20 (94)	16/18 (89)	8	10
>5 years-10 years	25	20	41/45 (92)	22/26 (85)	12	14

>10 years-15 yrs	12	16	25/28 (88)	10/14 (71)	4	10
>15 years-18 years	5	2	06/07 (86)	03/06 (50)	4	2
Total 130 (100%)	70 (54%)	60 (46%)	120/130 (92)	66/80 (82.5)	34 (42.5%)	46 (57.5%)

**Table 4:** Comparison of treatment gap (TG) among children with epilepsy in 2014 and 2018 in Bhakhar District-Pakistan (N=210).

AEDs non-adherence among children with epilepsy in 2014 (n=120)				AEDs non-adherence among children with epilepsy in 2018 (n=80).		
Age group	Male	Female	Nonadherence	Nonadherence (%)	Female	Male
4 Mon-2 years	16	10	14/26 (58.3%)	10/16 (62.5%)	6	10
>2 yrs-5 years	18	12	18/30 (60%)	12/18 (66.6%)	8	10
>5 years-10 years	20	18	22/38 (58%)	16/26 (61.5%)	12	14
>10 years-15 years	12	10	22/14 (63.3%)	10/14 (71.4%)	4	10
>15 years-18 years	2	2	02/02 (50%)	02/06 (33.3%)	4	2
Total 120 (100%)	68 (56.6%)	52 (43.4%)	70/120 (58.3%)	50/80 (62.5%)	34 (42.5%)	46 (57.5%)

**Table 5:** Comparison of antiepileptic drugs (AEDs) non-adherence among children with epilepsy in 2014 and 2018 in Bhakhar District-Pakistan (N=200).

## Discussion

Several studies have reported that over 90% of people with epilepsy (PWE) in developing countries do not receive appropriate treatment for their condition, a phenomenon known as the treatment gap (TG) [15]. In agreement in 2014, we documented childhood epilepsy treatment gap (CETG) of 92% in Bhakhar City [5], an outreach financially-constrained district in Pakistan and planned multimodal interventional plan to narrow this huge CETG through TDBUCEP by integration of CE into primary care and empowering it by monthly travelling from Lahore for free treating and teaching paediatric neurology camps and provision of telepediatricneurology consultation/advice on Skype/mobile phones. At the time of the study, no public or private health facilities were available for children with epilepsy in Bhakhar city. We could not find any such interventional program in developing countries for bridging the CETG in world literature but are plenty for adults with epilepsy [16-19].

The lack of regional information on this important condition is noted by Preux and Druet [20]. Even when epilepsy is recognised and treatment sought, the 'treatment gap is exacerbated by the scarcity of trained health personnel, the cost and difficulty of access to technical investigation and poorly sustained drug treatment [21]. There are many studies assessing the strategies to bridge adult treatment gap, but we could not find specific strategy to narrow the CETG, especially in noncosmopolitan territories in developing countries [22-24]. Socioeconomic status might expose people to specific vulnerabilities and health-damaging factors, which can be evaluated using a model of inequality [25]. Our strategy of bridging the CETG is combination outreach clinics and telemedicine, considering its appropriateness and cost effectiveness for the outreach poor communities in developing countries like Pakistan. We documented that 41.25% of our total study population was  $\leq 5$  years of age with slight male preponderance, in contrast to the findings of Prathyusha et al. who reported that that in their cohort 71% of the children were  $\leq 5$  years of age and 73.24% were males [26].

Efforts are ongoing to improve the quality of childhood epilepsy care through the development and implementation of different strategies and physician's performance measures and other performance metrics. Active efforts should be focused on ensuring that community health programs providing health services for underserved populations are connected to epilepsy specialists. A potential strategy to reduce this treatment gap is the detection, monitoring, and treatment of epilepsy with community-based -rehabilitation-center (CBRC), in which outreach-community clinics play an important role in this strategy [27]. The use of local resources potentially results in high cost-effectiveness, particularly in resource-poor settings [28], and this can adopted for outreach financially-constrained districts in Pakistan. We integrated and implemented CE into private charity primary health care in Bhakhar city. In addition to our monthly free paediatric neurology camps, we provide teleepitroencephalography interpretation advice and teleconsultations on Skype/mobile phone. These implementations of new diagnostic tools that do not rely on conventional healthcare systems, such as wireless electroencephalography recordings [29], or the use of teleconsultations [30] are important future opportunities and their role in health has been already established.

Internationally, a variety of approaches are being tried including mobile clinics and training of district medical officers in India, training of village doctors in rural areas of China, and improving the epilepsy expertise of community health workers in Kenya [31,32]. Our multimodal interventional strategy of education, detection and treatment of Childhood Epilepsy by TDBUCEP Bhakhar district reduced CETG Of 90% in 2015, to 20% in 2018. Even among the cohort of CE with no local intervention, CETG is 82.5%, indicating the immense usefulness of this territory-wise interventional strategy. This suggests that healthcare workers with basic training of childhood epilepsy treatment could effectively treat CWE at a community-based CE services integrated into primary care. The combined cost-effectiveness and close

collaboration with the local community allows overcoming the barriers of bridging the huge treatment gap in outreach poor communities. The most important one such barrier is due to nonadherence to AED (s) due to diverse reasons, but other causes like non-availability of specialist care for epilepsy at the local community level in addition patient's/ parent's intentional or nonintentional ignoring the treatment are important. We documented similar findings in our study, as nonadherence to AED (s) was the predominant cause of huge treatment gap among our control cohort. Our study provides important information on the main causes of non-adherence to antiepileptic drugs in poor communities. First, we find that adherence to treatment is not influenced by gender, age and duration of treatment. This is consistent with the results from the previous studies, which did not find any demographic differences between AED-adherent and AED nonadherent patients [33-35]. The rate of nonadherence is estimated to be between 30-80% of patients, depending on the patient population being analysed [36]. In agreement, in a community-based snap-short survey among children visiting free pediatric neurology camps in Bkhakhar city, we documented AED (s) non-adherence among 58% of the children being treated as epilepsy in 2015, but without any local community childhood epilepsy services [6]. ++Most (80%) of the parents of these CWE were getting/trying to get treatment for children from Lahore having too much travelling cost and consultation fees of the epilepsy specialist over there. Maintaining adherence over a long period is essential, but can be challenging for many patients in resource poor communities especially in outreach financially-constrained communities like Bhakhar District, as many patients become non-adherent, which can range from the patient not taking medication exactly as prescribed to completely discontinuing all medications [37,38]. The nonadherence to AED (s) can be due to patient-related factors and socioeconomic conditions, however socioeconomic status is a stronger predictor of adherence, with lower socioeconomic status associated with higher nonadherence [4]. For this reason the childhood epilepsy treatment in developing countries remains far from satisfactory, mainly because of: the general lack of medical personnel, non-availability of medications; Nonadherence to AEDs; and lack of information and/or education on epilepsy for both patients and medical staff [39,40].

Most of the barriers can be very effectively taken care-off by providing childhood epilepsy services in the particular local community. We did this by integration and implementation of childhood epilepsy services into primary health care: Rukhsana Shafqat Memorial Primary Health care Center. After two years of this incorporation, we evaluated its impact upon AED (s) adherence among CWE diagnosed and being followed in this free CE center in comparison with CWE not being followed at the center and affording treatment from their/parent's pocket. Targeted management programs and communication strategies are necessary to improve adherence to AED treatments in patients with epilepsy and avoid the clinical consequences of poor adherence. Because nonadherence is a dynamic process [41,42]. Evidence-based adherence intervention needs to be targeted to those at highest risk: children with epilepsy in financially – constrained communities [43]. At TDBUCEC, like others [44], the initial assessment, diagnosis and prescription could take place during focused visits by trained staff, including community pediatricians and nurses. Tackling them all in an integrated primary care programme has formed a systematic approach with an increased chance of effectiveness and sustainability. By our multimodal interventional strategy, adherence to AED (s) improved to 85% and nonadherence was only 15% in December

2018. This task-sharing strategy has improved the accessibility of childhood epilepsy care for services users and caregivers and has been perceived as having a positive impact on improving adherence to AEDs among CWE, evidenced by data collected in snap short interventional study in two community centers in Bhakhar city. So, the findings from our study suggest that proximity of this new service in the outreach city has decreased the cost of transportation for the majority of service users thus improving access to services and has improved AEDs adherence among CWE.

Bhakhar Childhood Epilepsy Centre receives no government funding and is largely funded from private sources, mainly philanthropic donations. Similarly Tang et al., documented that with the community involvement, the number of patients with epilepsy who missed AEDs decreased to 45.0% from 64.3% [41]. Whereas, other previous randomized intervention trials demonstrated that there was no consensus about enhancing compliance through various measures [42,43]. In comparison, our multimodal package of intervention techniques, including education, reminders, provision of free AEDs and CE consultations proved to be effective in enhancing AED adherence. Similar to other studies, patients may have overestimated their adherence in their self-reported data in our cohort being managed at TDBUCEPC Bhakhar [44].

One of the strongest barriers to AEDs adherence in the outreach and financially-constrained communities is the cost of treatment (cost of AEDs and consultation fees for the specialist). In agreement we found that our current second cohort of CWE who were not being followed at TDBUCEC and were affording all the expenses associated with epilepsy treatment from their own pocket still had AEDs nonadherence 62.5%, which was documented 58% in the same settings in 2015 by self-reported adherence among CWE (statistically not significant): children with epilepsy whose parents/carers were buying AEDs were about 5 times more likely as to be nonadherent as compared with those who were getting their AEDs free of charge from TDBUCEC Bhakhar. Among the 50% nonadherent CWE in this cohort, 28 (56%) were so due to purely/predominantly financial reasons. This is similar to what has been reported by Faris et al. and Snodgrass et al. respectively [45,46]. The cost of drugs limits caregivers from purchasing them in case they are not available free or at a very low cost. Similarly Nazziwa et al. reported that the commonest reason given for missing drugs was lack of drugs due to their high cost as reported by 36 (48.7%) of study participants comprising of children and adolescents [47]. None of the carers/ patients reported intentional nonadherence: this may be due self-reporting-bias. Similar findings have been reported from various parts of world with limited resources, allocated for epilepsy care [48]. Interestingly other studies in world literature suggest that adults and children in resource-limited settings maintain or achieve better rates of adherence compared to those in resource-rich settings, without any explanation for this. [49-51].

Low treatment adherence is strongly associated with uncontrolled seizures among epilepsy patients [52]. A study that compared two epilepsy patient groups (non-adherent patients, n=298; adherent patients, n=110) also found non-adherence to be associated with reduced seizure control [53]. Although it is widely accepted that nonadherence leads to poor seizure control, our findings also suggest that uncontrolled seizures may, paradoxically, contribute to nonadherence. As 10 (31.5%) of nonadherent patient in our study group discontinued the drugs because there was inadequate seizure control, even in 12% of the cohort not being followed at

the community center uncontrolled seizures were the predominant cause of nonadherence to AEDs.

Jones et al. [54] documented that a strong correlation existed between poor seizure control and non-adherence with 63% of those with poorly-controlled epilepsy being non-adherent compared to 38% of the well-controlled group. Other important barriers for adherence to AEDs are counseling by local faith healers, Side –effects of AEDs, poor/no counseling by the treating physician (s) and non- availability of AED (s). Also, our study investigated the impact of the patient-physician relationship and found that doctors counseling was poor in 10% of the both cohorts of current study, indicating importance of good counseling by the treating physicians. Similar results have been reported in other studies [55]. We documented when most of the barriers are removed, misguidance by local health healers was predominant cause of nonadherence among 8 (25%) of the CWE being followed in the CE center as compared to 6 (12%) of the cohort not being followed at the center. Holy persons like wali, fagir or sheikh, all are muslims' clerics, have the privilege of exercising power through the Baraka (blessing) or intercession (shifaa) acquired from their ancestors and the blessed knowledge they have learned. These holy persons use their blessing of God to heal through prayer, charms, summons and amulets [56]. This resulted in nonadherence in about one-fourth of our cohort being treated at TDBUCEC and about half of this percentage were among the study not being followed at our center. This is similar to the world wide believes that supernatural and spirits influence human being and affect their wellbeing and health especially in epilepsy [57-59]. Though the no of nonadherent CWE cohort being followed at the center was small, about 19 % of these were prescribed AED (s) not available at the center pharmacy, where as this finding was prevalent among 10% of the cohort not following at our center, so both these cohorts were nonadherent to their prescribed medication. It appears that successful interactions with medical personnel can increase adherence. Gopinath et al. [60], investigated the patient perspective of the doctor–patient relationship and found that both the number of visits and effective communication between the two promoted AED (s) adherence. Similar to this, we found that in 12.5% of the patients being followed at the center and 10% not following at the center, poor or no counseling by the treating physician was a contributing factor. To overcome strong barriers to bridge CETG, the childhood epilepsy care should be multidisciplinary and long term, linking primary and secondary care, and empowering patients towards improved management of their condition. Such programmes have been successful in improving the diagnosis and management of adults with epilepsy in communities in India, Zimbabwe and Ethiopia [61-63].

Strengths of our study are that it evaluates longitudinal intervention-effectiveness in community and compares results with the similar cohort but without any community helping intervention (case control). Like others, our study has some limitations. First, we did not address the role played by education programs, which could positively influence adherence to treatments for instance, by facilitating the management of adverse reactions. Nor did we assess the risk of associated pathologies, which may influence adherence by suggesting that AED is futile [61]. There are also limitations inherent in collecting self-reported data. Adherence was measured using patient report, and patients may have overestimated their adherence. Future research is warranted to augment patient-reported data on non-adherence with one of the well-known measures.

Epilepsy care should be multidisciplinary and long term, linking primary and secondary care, and empowering patients towards improved management of their condition. Such programmes have been successful in improving the diagnosis and management of adults with epilepsy in communities in India, Zimbabwe and Ethiopia [62-64]. Projects in Africa have shown that intervention models are effective if there are adequate resources and commitment. Any intervention should, however, be fully integrated into the context of primary health care delivery. Personnel should be trained and committed to epilepsy treatment to the same extent as required for any other illness or health problem. Local communities should be brought into the planning and implementation process so that long term sustainability is further fostered. Sustainability may also be improved through the use of support groups [65]. It underscores the need for renewed promotion of community awareness and cultural reorientation on views on epilepsy, developing health and related systems to be more sensitive to epilepsy management, and improving the standard of living in outreach noncosmopolitan settings of LMICs.

### Conclusion

We have concluded that in addition to understanding local cultures, communities must be brought into the planning and implementation processes of any intervention to bridge the CETG. This study highlights the presence of a widened CETG in an outreach financially constrained district in Pakistan, characterized by strong cultural perspective on childhood epilepsy, a weak health system with regards to epilepsy treatment and a low socio-economic status. The TDBUCEP is an effective strategy in bridging the epilepsy treatment gap in such districts and implementing the modified WHO mhGAP for children. Poor healthcare infrastructure and high levels of poverty and social stigma hamper conventional interventions. Developing and upgrading human resources is a primary challenge in scaling up. In extending childhood epilepsy care to all outreach district of Pakistan, continuous training and retraining on CE, is essential to maintaining the quality of epilepsy care at a constant level. The combined cost-effectiveness and close collaboration with the local community allows TDBUCEP to overcome these barriers. Our lessons learned in Bhakhar District may also be applicable to surrounding districts where the epilepsy treatment gap is equally high. However, what gets measured gets done" summarizes the importance of monitoring and evaluation for the planning and implementation of the programme and should be done periodically.

### Competing Interests

None of the authors has any conflict of interest in relation to this work to disclose. Ethical publication 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.

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## Disclaimers

The content of this article is solely the responsibility of the authors and does not necessarily reflect the official views of the Rukhsana Shafqat Memorial Primary Care Center. The donors of TDBUCEPC had no role in the design and conduct of the study; the collection, management, analysis, and interpretation of the data; or the preparation, review, or approval of the manuscript.

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