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## Integration of integrative brain disorders in primary health care in hard-to-reach financially deprived district in South Punjab-Pakistan: Developing pro-poor approaches

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### Abstract

**Background:** There is a huge treatment gap for neurological, neuropsychiatry, neurodevelopmental and neurodisability disorders' (altogether called brain disorders-BDs) care in low-Middle Income Countries (LMICs) like Pakistan. The provision of cost-effective and efficient measures to combat these disabling problems has become exigent for low-income countries. This makes a call for using the existing primary health care (PHC) structure to address the needs of the vast majority of the population, especially in hard-to-reach locations.

**Aim:** The aim of this paper was strengthening and extending the existing systems of urban charity primary care to deliver free multidisciplinary and interdisciplinary health services for BDs in a hard-to-reach district along with addressing demand-side and supply-side barriers and enablers concurrently.

**Methods:** In 2009, we started monthly brain health outreach program (BHOP) for geographic accessibility, availability, affordability and acceptability of paediatric brain health services in District Bhakkar, a hard-to-reach district in South Punjab- Pakistan. Since then we have been continuing monthly camps in different locations of Bhakkar city and its four Tehsils. We did collaboration with existing free urban primary health care in 2019, adjacent to DHQ Hospital Bhakkar where different neurology subspecialty camps are done on different designated week days for each subspecialty in every month in addition to our rotatory camps in different locations of district Bhakkar. Two newly joined consultant paediatric neurologists were asked to review about diagnostic gap (DG), treatment gap (TG), antiepileptic drug adherence gap (Ad. G) being blind of the purpose of this analysis.

**Results:** To date there is no health facility for brain disorders in the whole district. Over the passage of time, we built simple core team then multidisciplinary teams of paediatric neurologists, adult neurologists, adult's psychiatrists, neurodisability consultants, behavioral and occupational therapist offering different neurology subspecialty services. All employees working in this center are local; we have trained them; they are acting as key informants and are very useful for removing stigma of brain disorders especially among females. More than 3000 epileptic patients are registered in this free community centre. Impact evaluation upon the management of childhood epilepsy showed that younger the age, worst was the management status: DG decreased from 77.7% to 3.2%, TG decreased from 89.2% to 4.2%, Ad. G decreased from 66.1% to 13.2%.

**Recommendations:** A collaborative network between stakeholders in the public and private sector, as well as non-governmental organizations with the help of relative visiting brain subspecialists from tertiary care facilities are required that promotes and provides brain health care in hard-to-reach districts.

**Conclusion:** Integrating brain health into primary care services is a critical, affordable, and cost-effective approach to delivering services for people living in financially deprived hard to reach locations, but requires contribution of brain subspecialists from the tertiary care facilities.

**Keywords:** Brain disorders, hard to reach locations, integration, primary health care, demand side, supply side, brain health outreach program

### Introduction

Globally, neurological, neuropsychiatric and neurodisability disorders (altogether called brain disorders) are estimated to have increased at a rate of 37.6% over the past 20 years due to several factors, including poor health services in hard to reach and financially constrained

Districts <sup>[1]</sup>. The prevalence of chronic non-infectious neurological disorders ranges from 4% to 5% in lower income countries (such as Pakistan) as compared to 10% to 11% in high income countries <sup>[2]</sup>. Difficulties involved in delivering health care to communities residing in financially constrained far-flung areas have been well documented <sup>[3]</sup>. Specialist medical practitioners have conducted clinics in primary care and rural hospital settings, private/public for a variety of reasons in many different countries <sup>[4]</sup>. Following various international calls for action from global leaders, civil society and Member States, in February 2009 the WHO launched a program to increase access to health workers in remote and rural areas through improved retention <sup>[5]</sup>. Health outreach programs (HOP) describes medical outreach programs as initiatives that aim to “play a critical role in improving and extending the reach of healthcare through clinical activities far flung areas <sup>[6]</sup>. Such clinics (health outreach programs- HOPs) have been regarded as an important policy option for increasing the accessibility and effectiveness of specialist services and their integration with local primary care services in public, private or charity sectors. The primary purpose of community health outreach programs is to offer services for the community and educate the health care providers on what resources are available to help them take control of their health.

Health professionals practicing in well-served areas in secondary-level or tertiary-level facilities can support their colleagues working on the front line, but also serve the population directly. Physical outreach strategies can include remote day consultations, rotation in health structures, and mobile clinics. All categories of health workers including paediatric brain health specialists are involved in outreach activities. Various service models are used around the globe to increase access to local specialists, including outreach or visiting consultant models, where specialists travel away from their main practice to provide regular services in hard-to-reach and financially constrained locations <sup>[7, 8]</sup>. Most developing countries lack specialists, especially paediatric brain specialists. This is particularly the case in remote or rural areas, where front-line health centers are very often staffed only with newly medical graduates or paramedical staff. Outreach strategies can provide specialist visits to underserved populations. In some cases, specialists go to remote facilities for short periods of time but on a regular basis. With virtual strategies, specialists are consulted in a more rapid and interactive way and their advice increase the capacity of front-line health workers. Furthermore, the continuous availability of qualified health workers, such as provided by the telemedicine model, can enhance the referral system. Quick and direct connection to a qualified health worker will allow the patient's referral needs to be better identified <sup>[9, 10]</sup>.

This paper defines outreach as any health service that mobilizes health workers to serve the population or other health workers away from their typical work and living locations. Permanently recruited health workers from the same community can provide outreach services in remote areas on a defined timetable. Outreach services might be volunteer, paid, or required for public officials. For everyone to benefit from improved services, expansion should start with the poor and their health needs. Outreach involves all health providers, especially children and adolescent brain health specialists.

## **Our Paediatric Brain Health Care Outreach Program is for Hard-to-Reach District**

The corresponding author and his chief neurotechnologist started HOP in 2010 for paediatric neurology disorders in Bhakkar district, which is far-flung with poor road communications and is agricultural financially constrained district in South Punjab-Pakistan. They started this HOP without anybody's help or financial support from pharmaceuticals; Top-Down-Bottom-Up (consultants will travel to the community and would train and strengthen the local available health care facilities/care providers), under the auspices of the Brain Associates, 218 D, Model Town Lahore. Later on, other paediatric neurologist colleagues joined; group of six paediatric neurologists is proving the free services district since then. Through these camps and surveys (HOP) of paediatric brain disorders in 2014, they documented childhood epilepsy treatment gap (CETG) of 90% and 54% of the children with active epilepsy were nonadherent to the prescribed prophylactic anti-seizure drugs: major etiologies for these were poverty and non-availability of medical trained professionals <sup>[11, 12]</sup>. In low-income countries (LIC) like Pakistan, health care and related expenditures feature prominently as causes of impoverishment. Krishna from India identified the cost of treatment for illness to be the cause of 85% of all cases of impoverishment <sup>[13]</sup>. Heltberg and Lund found that the costs associated with illness among the poor in Pakistan resulted in reduced food consumption, withdrawal of children from school, sale of major assets, putting children to paid work and even bonded labor, while only 12% were able to recover from the associated economic shock <sup>[14]</sup>. In agreement we found that the average cost for one paediatric neurologist consultation from Multan or Lahore costs the residents of Bhakkar PRS 16000, excluding the consultant's fees, costly drugs and investigations <sup>[15]</sup>. Whereas this can be managed at the cost of PRS 100-200 locally in Bhakkar city in an hour or so.

## **Program activities and objectives**

There are two types of physical strategies: mobile strategies and facility-based models for far-flung financially constrained areas, but we have combined both of these. Provision of services for paediatric brain disorders in conjunction with established primary care services builds on existing human and financial resources to promote practical clinical and social outcomes for these disorders <sup>[16]</sup>. Limited yet significant evidence from developing countries that have established such programs indicates that a feasible and cost-effective means to meet this goal may be to provide diagnosis and, in many cases, treatment for brain disorders at the first point of entry into medical care, in conjunction with secondary, tertiary or brain health specialists' support <sup>[17]</sup>.

Bottom-up approaches to community engagement, generated by and through the community, are generally more effective than top-down approaches where modes of engagement are mandated by external funding initiatives <sup>[18]</sup>. After decade's experience, we realized if both Top-Down and Bottom-UP strategies are combined in community health care facility surveying major percentage of the outreach communities, especially if weakly supported with telemedicine, would be of extremely beneficial for such financially deprived neglected communities. We could not find such supportive facility in Bhakkar city. Though we

were having free monthly camps for treatment, awareness about paediatric neurology and guiding the health providers about the proper management of childhood brain disorders, impulsivity about seeing the specialists as and when required was compelling the parents to seek consultation for their children from Lahore or Multan costing PRS 16000 for single consultation. These expenses are for transportation, boarding and lodging only, even from the public teaching hospitals.

The poor overall performance of the publicly financed PHC system had prompted Mr. Shafqat Mahmood (famous philanthropist of Bhakkar city) and his family to establish and run Rukhsana Shafqat Urban Primary Health (RPHC) center as a charity. We contacted him; he was very happy to maintain this facility and employing a general physician, other medical and paramedical staff according to our requirements along with arrangements for telemedicine support for the patients being treated in this center. In 2018, we collaborated with RSPHC designed to invigorate the lives of children and adolescents and alter the negative attitudes for chronic non-communicable neurological disorders among this financially deprived paediatric population. The focus of the project is brain fitness and provision of free paediatric brain health services at doorsteps of the communities. With the passage of time this center has been developed into a paediatric and adult brain health medical center having different brain subspecialists travelling from three cosmopolitan cities (Lahore, Multan and Faisalabad-Table 1). Our multidisciplinary team of paediatric brain health subspecialists along contacted Mr. Shafqat Mahmood and signed collaboration with him with the following two objectives:

**Objective 1:** To strengthen the capacity of charity urban primary health care

**Objective2:** Establishment of free community center for paediatric brain health care.

**Objective 1: To strengthen the capacity of charity primary health care**

Strengthening primary health care has been shown to improve population health outcomes and reduce all-cause mortality and is a cost-effective strategy for achieving universal health coverage (UHC) [19]. Community and civil society engagements are fundamental components of any strategy to achieve all health goals and targets of the health sustainable developmental goals (SDGs). Our program is to strengthen the capacity of RSPHC center through a layered support system involving volunteer/paid community members and paid staff working at this center. Majority of the health workers of this center had little or no prior experience in providing health services for brain disorders, but have been trained in health provision for children with brain disorders. Since the collaboration with RSPHC, paediatric neuropsychiatrists, consultant neurorehabilitation and childhood behavior therapy consultants travel monthly from three cosmopolitan cities (Lahore, Multan and Faisalabad) 5-7 hours journey by car, on their own without any monetary benefit. Two Clinical psychologists and two doctors of physical medicine residents of Bhakkar city are employed and are working with these visiting consultants. Every consultant has his/her camp on the monthly basis for continuity, sustainability and continuous more awakening

about brain disorders in out-reach communities in this financially constrained district. In addition to their clinical duties, all visiting have regular program of teaching medical and paramedical staff working in RSPHC and support/point out barriers /enablers of supply and demand sides of brain health care provision of their respective subspecialty. The involvement of empowered people and communities as co-developers of services improves cultural sensitivity and increases patient satisfaction, ultimately increasing use and improving health outcomes. In agreement with other studies, this person-centered nature of effective primary care aligns with the central role of people in PHC and supports the use of patient-centered measures in its evaluation [20]. Bottom-up approaches to community engagement, generated by and through the community, are generally more effective than top-down approaches where modes of engagement are mandated by external funding initiatives [21].

**Objective2: Establishment of free community center for paediatric brain health care**

PHC is a cost-effective way of delivering services, so focusing on it is the best-value way for countries to move towards universal access [22]. Pakistan is a very vast country with some of the most developed beautiful cities interlinked with well-maintained motorways, like Lahore and Islamabad, but other district like Bhakkar are far-flung hard-to-reach and financially deprived with very poor health care provision. Travelling from Lahore to Bhakkar: Total Driving Distance Travelled is 436 Km; Driving Time. 6 hrs. 12 Minutes; Flight Distance. 311 Km; Flight Time; 53 Minutes. Solutions exist to improve the equity of access to care, but it is clear that situations are more difficult in some places than others and that poverty remains a major factor in limiting progress. Access to health care has four dimensions: availability, geographic accessibility, affordability and acceptability [23]. Barriers to accessing health services can stem from the demand side and/or the supply side [24]. Demand-side determinants are factors influencing the ability to use health services at individual, household or community level, while supply-side determinants are aspects inherent to the health system that hinder service uptake by individuals, households or the community. The need to differentiate demand-side from supply-side barriers is related to the formulation of appropriate interventions [23, 24]. However, the access barriers may not always be mutually exclusive and may interact and influence each other [25].

Among the many strategies of provision of health facilities for community's residents of far-flung financially constrained areas, the two types of physical strategies are: 1) mobile strategies and 2) facility-based models and both can be combined as we have done. The stakeholders vary and strategies also differ according to the country its health needs and priorities and the level of health service supply in the area. We use the definition of access to health services as used by Peters *et al.*, which implies 'the timely use of service according to need [26]. In 2010 we started a health outreach program (HOP) by monthly camps for paediatric brain health care, as we could not find any public or private health facility providing health care for brain disorders for paediatric and/or adult population. The objectives were: 1) to create awareness about paediatric neurology disorders (PNDs); 2) treating PNDs in the community at door steps of the patients: 3) referral of PNDs only to the public teaching



hospitals as and when required with guidance. The barriers for brain health care provision (BHCP) are assessed along the four dimensions of access (each of them having supply-side and demand-side aspects). However, quality of care is an integral component of each of the four dimensions. Service location and household location are important barriers and are demand-side barriers and on supply-side barriers. These factors are outside the control of the public as users of health services (demand side). We had our monthly camps in different locations, tried remove these barriers, but the impulsivity of seeing the specialists as and when required compelled the people travel to Lahore or Multan costing that PRS- 16000 for single neurology consultation, excluding wasted earning time, costly medicines and investigation even from a free public teaching hospital. Initially communities had shown lack of trust in our services and the intermediaries who were linking the population with our team of paediatric neurologist proving free paediatric neurology consultations at door steps of these neglected communities, with the impression that we were there to siphon the patients to our private clinics, making people reluctant to use the respective services [27]. Involving almost all the stakeholders, after few years community's response was amazing starting from 20- 30 patients in a camp increased to on the average 180 -220 patients in every camp, which were carried out in all areas of the district irrespective of distance and roads to the area.

#### **Paediatric Brain Health Services Access Enablers**

Our interventions aimed at facilitating access to health services implementation at district level addressing demand and supply side simultaneously, as this is known to constitute the most appropriate geographical situation for strengthened PHC [28]. These interventions can be implemented at district level by group of specialist, health sector alone or in collaboration with other government departments and nongovernment or civil-society organizations through the public and/or private sector, as we collaborated with RSPHC center. We have involved the community participation into interventions addressing access barriers as it 'reduces the power gaps between the population and health systems [29].

Though in the world literature more focus is on financial demand-side interventions, the highest number of interventions appears to be non-financial and supply-side based. Demand side means the direct channeling of resources to a population group to obtain health services. [30] Our objectives of facilitating the demand side approach are: (1) targeting service delivery; (2) improving provider behavior; (3) promoting competition and consequently improving quality of care; and (4) improving care-seeking by targeted groups. Supply-side financing is considered a means for strengthening health service delivery based on the amount of financial input [31]. We briefly describe our interventions to enable access on demand-side or supply-side, and as non-monetary or monetary initiatives.

#### **Demand-side, non-monetary interventions**

Visiting consultant, employed community workers of RSPHC center and all community stakeholders provide counseling about brain health services, including their availability, intention and associated costs (free services), address barriers related to Lack of Information on Health Care Service/Providers (availability) and Health Awareness

(acceptability). Community leaders' participation is a cross-cutting intervention that addresses the four access dimensions: 1) reduces transport costs; 2) improves information about services as well as health aspects; 3) donates cash within the community when needed; and address household expectations and community cultural preferences. With empowerment strongly embedded in its features, community participation overcomes community and cultural preferences and stigma (acceptability), and enables greater availability of visiting brain subspecialists (availability). A range of preventive and curative interventions can be implemented by professional health workers (employed in RSPHC center), through so-called community-based interventions, which tackle issues related to service location, transport-associated costs and means (geographical accessibility), free integrative brain health care, (affordability) and treatment availability [32]. As these medical and paramedical professional health workers are recruited from within the community, many acceptability barriers are reduced for health interventions they promote about the whole range of services being provided by RSPHC center. As these workers belong to the far-flung areas and are employed in their own community on competitive salaries, after training and experience they don't leave the center. They also act as key informants and

#### **Supply-side, non-monetary interventions**

We are Providing an essential most cost-effective health facilities predominantly used by the all communities of this outreach district, as there are no paediatric adult neurology services in public or private sector. The intervention deals with location of the service (geographic accessibility), ensures availability of free drugs for the deserving and other consumables and offers health services tailored to needs of the communities offered by the top-notch experts of brain health (Availability), involves free service provision (affordability), and mostly conforms with households' expectations as services are provided at sites most used by them (Acceptability). As there is no alternate, affording people also avail this facility and intern they are motivated and help in sustainability of the project. We are providing integrated outreach services for tackling the issue of the location of the health care provision and transport costs for the household (geographic accessibility) and this has increased availability. The integrative care of brain disorders for paediatric and adult population is very cost effective. The management committee which comprises of the local resident in conjunction with visiting consultants regulates the issues of service provision and cost. Emergency transport with an associated communications with the accepting authorizes on the proper referral form from RSPHC center is very helpful and encouraging for patient requiring local secondary or tertiary care help from cosmopolitan cities.

This center has been converted into established better-staffed peripheral health unit, which addresses the geographic accessibility and availability dimensions by bringing services closer to the intended target. A medical officer has been employed 6 days a week, from, 9 AM to 4PM, who has been trained to deal with basic paediatric neurology disorders and communicate with the respective consultant as and when required. Provision of culturally sensitive health care is improved through specific courses and by employing members of the same ethnic communities

as those whose concerns are to be addressed (acceptability)<sup>[33]</sup>. Improved management, generating financial resources according to local needs (availability); and to enable accountability whereby providers are more responsive to preferences and expectations of the local population (acceptability)<sup>[39]</sup>. Improved management, including supervision by financing community leaders and confidential feedback mechanisms (Performa 1), potentially holds the greatest promise as it is effectively addressing all four dimensions related to access barriers and tackle each associated aspect, as long as sufficient resources are available (finance committee assures for that). Also, management committee comprehensively deals with issues related to human resources (visiting consultant and local employees), finances, service organization and health delivery.

### Supply-side, financial interventions

Performance-based financing is a strategy that potentially addresses all dimensions of access barriers but particularly affects quality of care through better-motivated health care providers. All employees are paid competitive salaries according to the locality, neither are allowed to do practice or work elsewhere, nor do they wish to do so. High-quality health services involve the right care, at the right time, responding to the service users' needs and preferences, while minimizing harm and resource waste<sup>[34, 35]</sup>. Needs-based financing is allocated based on a formula reflecting populations' health needs, incorporating the proxies of size, age and sex of the populations and degree of poverty addressing the dimensions of availability of services, affordability by reducing costs of services and geographic accessibility by reducing the distance to providers (volunteer consultants travelling and establishment of health facility in the community)<sup>[37]</sup>. The principal (Mr. Shafqat Mahmood and his family) provides major financial support for the overall expenditures of this health facility. The application of user fees for government/private service provision is a contentious issue. The removal of user fees or the granting of exemptions improves affordability, but only if it is accompanied by other measures; improved drug supply and management supervision. We have observed the same, as indicated Pariyo *et al.*, removal of user fees increases utilization of curative public health services but distance from the facilities remains a considerable access barrier for the poor<sup>[36]</sup>. In agreement with Ensor and Cooper, we have observed that there are number of identified access barriers but the literature on interventions to address these is disproportionately small<sup>[38]</sup>. Conversely, the framework of useful interventions can be used to assess the appropriateness of existing interventions where the barriers to access are known. Community participation, community-based interventions, health equity funds, provision of required essential services, improved management and pay-for-performance appear to address all four dimensions access barriers. However, these interventions do not necessarily affect all the aspects of the barriers to access within each dimension and often vary according to the comprehensiveness of services delivered. Although the above interventions are presented separately for the sake of developing the analytical framework, in reality most are used in combination, and their success may depend in fact on their particular configuration and joint implementation<sup>[39]</sup>. We agree with O'Donnell and De

Brouwere *et al.*<sup>[38]</sup>, demand-side and supply-side barriers must be addressed concurrently to have the biggest effect<sup>[40]</sup>. However, we emphasize that the quality of care has to be developed before any other intervention can be successfully implemented<sup>[41]</sup>.

The myriad of existing, non-mutually exclusive barriers that concurrently impede access to health services render a single intervention less effective than combining several of them. The selection of interventions for effectively reducing barriers to access will thus depend on the dimensions and aspects of the barriers to be tackled, geographical context, human and financial resources available. Further studies are needed to assess the contextual factors that influence the effectiveness and efficiency of interventions designed to address access barriers, and to identify what combination of interventions may produce the optimum result. While we focus on interventions with potential positive effects on overcoming access barriers in the short or medium term, ongoing efforts should be directed to address issues that require considerable long time to tackle, including a steady supply of consumables, funds are provided, monitoring and supervision are regularly conducted. This often require the presence of qualified personnel who tend to reside in urban and more affluent areas while the poor, who live predominantly in rural areas, mostly consult private (un-certified) drug shops and other unqualified private providers.

While we focused here on the district as the geographical unit for implementation of interventions, while others can focus on the process of scaling up interventions to wider geographic areas or narrow areas. The framework has been developed for application in the hard-to-reach financially deprived district in South Punjab, although apart from socio-economic and cultural aspects, barriers and interventions remain conceptually similar to a considerable extent. In areas, where context-specific cultural aspects have a substantial influence on access to health care, the framework requires adjustment prior to application so that these cultural factors are fully captured. We did not select interventions according to their strength of evidence base, and many of the advanced interventions have not been subjected to rigorous evaluations. The analytical framework can be used as a template to identify interventions, or a combination thereof, that can tackle specific access barriers, or to analyze why interventions do not achieve the desired result of increasing access or you can tweak according to your objects.

### Impact Evaluation of Brain Health Project upon Childhood Epilepsy

Bhakkar Top-Down-Bottom-Up childhood epilepsy initiative has demonstrated a model that is cost and clinical effective in reducing the childhood epilepsy treatment gap (CETG)<sup>[15]</sup>. This epilepsy Initiative was launched in 2012 in a phased approach and collaboration was made with RSPHC in October, 2919. The project has been successful in ensuring the adequate and sustainable availability of medicines, of anti-seizure medications via the management committee procurement system. The Program also includes strengthening of local brain health services being provided in RSPHC to increase sustainable access to anti-seizure medications (AEDs), reinforcing referral systems, ensuring better monitoring of childhood epilepsy, provision of free antiepileptic drugs (AEDS) for the deserving patients and

raising awareness to support people living with epilepsy and their families. For impact evaluation of this program upon childhood epilepsy, a study was conducted in RSPHC by the two newly joined paediatric neurologist, blind to the purpose of results, on 16 October, 20 November and 19 December, 2022. All CWE being followed at RSPHC for  $\geq 3$  months were assessed for diagnostic gap (DG), treatment gap (TD) and nonadherence (Ad.G) in these three paediatric

neurology camps at RSPHC. This comparative study (intervention vs. control CWE in 2015) was assessed for effectiveness of the Top-Down-Bottom-Up program strategies for these three initial benchmarks improvements. Marked improvement has been documented in all three baseline benchmarks, more marked for the younger age groups, Table-1.

**Table 1:** Impact evaluation of paediatric brain health outreach program upon childhood epilepsy 2022 vs. 2015

Treatment pattern of Childhood Epilepsy 2022 (n=280).						Treatment pattern of Childhood Epilepsy 2015(n=130).			
No	Age Gr	Gender	DG	TG	Nonadh.	Nonadh.	TG	DG	Gender
1	$\geq 2$ Mon to 2 yrs	Male. 35	0/67= 0%	0/67= 0%	06/67= 9%	20/30= 66.6%	29/30= 98%	27/30= 90%	Male. 20
		Females.32 (67- 24%)							Females.10 (30 -%)
2	>2Yrs to 5Yrs	Male. 34	0/60= 0%	0/60= 0%	7/60= 11.6%	14/20= 70%	19/20= 94%	16/20= 80%	Male. 8
		Female. 26 (60-21.4%)							Female. 12 (20-%)
3	>5Yrs to 10Yrs	Male. 48	4/78= 5%	4/78= 5%	10/78= 12.8%	28/45= 62%	41/45= 92%	38/45= 84.4%	Male.25
		Females30 (78- 27.8%)							Female. 20 (45-%)
4	>10Yrs to 18Yrs	Male. 40	5/75= 6.6%	8/75= 10.6%	14/75= 18.6%	24/35= 68.6	27/35= 77%	20/35= 57%	Male. 17
		Female. 35 (75-26.8%)							Female. 18 (35-%)
Total	$\geq 2$ Mon to 18 Yrs	Males.157 Females.123 280-100%	9/280 =3.2%	12/280 =4.2%	37/280 =13.2%	86/130= 66.1%	116/130=89.2%	101/130=77.7%	Males=70 Fe. 60 130

Age. Gr = Age Group, DG= Diagnostic Gap, TG= Treatment Gap, Nonadh= Nonadherence

Unfortunately, in far flung financially deprived areas in poor developing Asian countries generally there is lack sufficient neurologic expertise and/or advocacy for the development and implementation of epilepsy-care guidelines. The diagnosis of epileptic seizures and epilepsy and ascertainment of the cause are difficult tasks, especially in low-income countries where socioeconomic and cultural constraints are obstacles to the recognition and acceptance of the disease [42].

Effective guidelines require local adaptation, implementation, impact assessment, and program revision. In agreement in 2015 we document improper (under/over)diagnosis of epilepsy, highest (90%) among  $\geq 2$  months- 2 years and relatively lower for elder ages: (57%) among  $\geq 10$  to 18 years of age, Table 1. Similarly the diagnosis of epilepsy is often difficult and has been estimated that 20–30% of patients referred for management of refractory seizures do not have epilepsy [43-45].

The treatment gap (TG), defined as the proportion of people with epilepsy (PWEs) who are not appropriately treated [46], is  $>80\%$  in many countries. In Asian countries, the TG ranges from 30 to 98% and is higher in rural areas than in urban areas [47, 48].

Likewise in 2015 we found very high CETG in Bhakkar city [11], with highest in the youngest age group and relatively lower in older age groups. By our multipronged strategy for treatment of CWE (monthly camps of paediatric neurologists and establishing free paediatric neurology center supported with telemedicine in RSPHC-Bhakkar) the treatment gap was significantly reduced. At baseline, the treatment gaps were 98% and 94% among the age groups of  $\geq 2$  Mon - 2 yrs and  $>2$  yrs to 5yrs, respectively. This huge CETG was completely taken care of, but after only more than decade's efforts and hard work of the whole local and visiting teams. For the older age groups ( $>5$ yrs to 10 yrs and

$>10$  yrs to 18 yrs) the base line treatment gaps were lowered from 92% and 77% to 5% and 10.6% respectively. The primary endpoint was the difference of the CETG before and after the intervention at RSPHC. Similar to our findings, in LMIC there are significant disparities in the care available for children with epilepsy (CWE). Most neurologists work in the urban private sector, where the level of care is similar to that found in developed countries. However, in the poorer urban (like Bhakkar) and rural areas this level of care is rarely available [49].

Antiepileptic drug (AED) therapy has been demonstrated to be effective in 70% of the patients in achieving seizure control [50]. However, adherence to treatment remains a primary determinant in effective seizure control. Rate of adherence can be described as the percentage of the prescribed doses of the medication actually taken by the patient over a specified time period [51].

Accordingly in 2015 we found very high percentages of the CWE were nonadherent to the prescribed antiepileptic drugs (AEDs), varying from 62% to 70% in different age groups, Table- 1. The childhood epilepsy is a chronic condition that can be treated by cost-effective first-line antiepileptic drugs (AEDs) [52] but several studies, like ours, have documented low availability and low affordability of AEDs in many LMICs both in the public and private sectors [53-55]

Rates of adherence to antiepileptic drugs are variable in different studies ranging between 20-80%. In children however, these rates are even lower estimated between 25 - 75% [56, 57].

Provision of free AEDs for CWE from RSPHC decreased the nonadherence to AEDs. Nonadherence improved from 66.6% to 9%, and from 70% to 11.6 in age groups of  $\geq 2$  Mon - 2 yrs. and  $>2$  yrs. to 5yrs, respectively. However, nonadherence improved from 62% to 12.8%, and from 68.6% to 18.6% respectively among the age groups of  $>5$ yrs



to 10 yrs. and >10yrs. to 18 yrs. Adherence is influenced by several factors that include socioeconomic factors, the health care system, the characteristics of the disease, the treatment the patient receives, and patient-related factors<sup>[58]</sup>. Supplying free antiepileptic drugs to poor children in far-flung- areas and regular provision of information about expected treatment response to children with epilepsy and their caretakers may help improve adherence. The treatment gap for epilepsy is high in deprived areas, but this could be reduced with low-cost interventions. Treatment cost and unavailability of drugs represent important barriers in treating people with epilepsy especially in financially deprived rural setting. Acceptance of epilepsy treatment may be markedly improved by integrating it into existing primary health care services. In agreement we propose multipronged packages of care based on the availability of resources. Ideally, the delivery of these packages should be integrated into existing primary health care with the help of NGOs and other nonmedical staff involved in community-based and mental health care.

### Future Aspirations

1. To create appropriate and cost-effective diagnostic and treatment plan including laboratory, neurophysiology and imaging studies of paediatric neurology patients admitted to the inpatient service for short stay 4-24 hours.
2. To carry out the management of paediatric neurological emergencies around the clock with one paediatric neurologist on video call.
3. Provision of neuroimaging studies for paediatric neurology patients.

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