

Epilepsy treatment gap and stigma reduction in Pakistan: A tested public awareness model

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ABSTRACT

High epilepsy treatment gap (ETG) and stigma remain a major issue globally. Addressing the basic problems is necessary, for advances in management to be effective. According to the 1987 population-based study, prevalence of active epilepsy in Pakistan is 0.98% with 98.1% ETG in rural and 72.5% in urban population and the presence of stigma. These dismal figures were a stimulus for our reported activities. Recognizing the problems faced by 2.2 million people with epilepsy (PWE) in the country, a group of volunteers mostly from the medical community has attempted to address these issues with an ongoing sustained awareness program over the last 18 years, working within the constraints of prevailing healthcare system, with gratifying results. In 2001, under a nongovernmental organization (NGO), the Comprehensive Epilepsy Control Programme of Pakistan (CECP) was launched to address the various paucities in knowledge, attitude, and practice about epilepsy; especially ETG and stigma. The CECP has two primary components: Epilepsy Support Pakistan (CECP-ESP) for awareness and mass education and National Epilepsy Centre (CECP-NEC) for holistic management of PWE, professional education, and research. Both work in tandem, and there is an overlap of their activities. This article only evaluates the outcome of sustained awareness activities of the CECP-ESP, through direct and indirect measures after 5 years of its initiation. A significant reduction in ETG and stigma exclusively through public awareness has been possible. This model can be easily replicated by any country, with involvement of the local population.

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1. Introduction

Epilepsy is the commonest neurological disorder; 50–60 million people are estimated to be affected worldwide. About 80% of people with epilepsy (PWE) reside in developing countries (World Bank categories, low and lower-middle income (LLMIC)), more than 85% receive no or inadequate treatment and carry more than 90% of the financial burden of epilepsy [1–5]. Estimated prevalence of active epilepsy in developing countries ranges from 0.5 to 1.0% [1], with a higher prevalence in their rural areas [2,3,6,7]. The prevalence is 2–3 times more in LLMIC than in upper middle income (UMIC) and high income countries (HIC) [2,3,7,8].

Treatment gap is defined as the difference between the number of people requiring treatment and the number that is actually receiving it, expressed as a percentage [2–6,9,10]. Epilepsy treatment gap (ETG) is high in LLMIC varying from 22% to 100% and less than 10% in UMIC and HIC [1–14]. High ETG in LLMIC is due to constraints at social, cultural, financial, and governmental levels and includes poverty, illiteracy, lack of awareness about the disorder, deeply rooted erroneous cultural beliefs and perceptions, wrong treatment-seeking behavior, lack of governmental prioritization, inadequate national health budget, poor

health infrastructure, inadequate skilled manpower, difficult accessibility to distant healthcare facilities, and poor supply, quality, or availability of antiepileptic drugs (AEDs) [1–10,15–17]. A wide-ranging variation in ETG within a LLMIC has also been reported. Negative attitudes are reported to be more in higher educated population than in lesser educated ones. Similarly, more stigma appears in the urban than in the rural population [15,18]. Low ETG in diverse select populations of a LLMIC has also been reported [2,7,14,18].

Stigma in epilepsy plays a huge role in the well-being of PWE as it causes more sufferings than the physical affliction. Discrimination against PWE is global. Social prejudice, marginalization, condemnation, exclusion, underrating, and denial of education, work, and marriage are some of the several problems associated with it [2,12,15,19–21]. They are treated as lepers and even buried separately [12]. Perceived stigma is probably more than the enacted societal stigma. People with epilepsy deny acknowledging their problem out of fear and embarrassment thus, hindering efforts to battle epilepsy [19,20]. Stigma for epilepsy is reported to be more than for acquired immunodeficiency syndrome (AIDS) [22,23]. It is difficult to quantify stigmatization because of numerous variations in culture, which explains availability of only a few quantitative studies on stigma [24].

The results of our 1985–87 population-based epilepsy epidemiologic and Knowledge, Attitude, and Practice (KAP) study [6,15,16] were the

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main impetus for our undertakings. Prevalence of active epilepsy was 0.98% with 98.1% ETG in rural and 72.5% in urban population with the presence of considerable stigma [6,15]. Recognizing the problems faced by 2.2 million PWE in the country, a group of volunteers, mostly from the medical community, along with some concerned citizens have attempted to address these issues, working within constraints of prevailing healthcare system. In 2001, a nongovernmental organization (NGO) launched the Comprehensive Epilepsy Control Programme of Pakistan (CECP) to address the various lacks in epilepsy-related social and medical issues. The CECP has two primary components: Epilepsy Support Pakistan (CECP-ESP) for public awareness and National Epilepsy Centre (CECP-NEC) for holistic management of PWE. Both work in tandem, and there is an overlay of their activities. This paper evaluates the outcome of the CECP-ESP's sustained awareness activities only.

2. Methods

The core group planned and executed the entire project with the help of medical and nonmedical volunteers. The methodology is broadly divided in four phases (Appendix A). For improved effectiveness, provision to modify, stop, and replace activities was kept. This study was approved by the Institutional Review Board of Jinnah Postgraduate Medical Centre, Karachi.

2.1. Phase 1 – dissemination of information on epilepsy

Multipronged activities, running concurrently, to create basic public awareness about epilepsy were planned in two phases: sensitization of the population with a simple bulleted message followed by detailed information about epilepsy using various media. Famous PWE from the community were identified and invited to be part of the campaign as motivational figures.

2.2. Phase 2 – Structured District Module

Week-long activities were planned and sequentially replicated in districts of the country. Nonmedical volunteers on location executed and monitored six days intensive public awareness through various modes in the entire district (average population: 1.5 million). Free epilepsy camp was conducted on day 07 (a Sunday) by CECP volunteer neurologists from Karachi. By design, AEDs were not distributed. Clinic of the CECP-trained district physician(s), preferably holding a diploma in clinical neurology, was given the status of a satellite epilepsy clinic for future consultations, in coordination with CECP neurologists. Epilepsy update workshops for local primary care physicians were conducted after every camp to further enhance human resource in the district.

2.3. Phase 3 – building of a tertiary care epilepsy center

Parallel to the awareness campaign, a tertiary care epilepsy center (CECP-NEC) was built by the NGO in the country's oldest public sector teaching hospital in Karachi. The CECP-NEC will provide integrated epilepsy services under one roof.

2.4. Phase 4 – countrywide awareness to change the nation's mindset and reduce stigma

Nationwide reduction in ETG and stigma is only possible through continuous awareness and education of the general population in epilepsy at national level. An attempt to change the nation's mindset towards epilepsy is ongoing through regular paid telecast of a short comprehensive television documentary for expansive geographical reach without requiring human resource.

2.5. Assessment of outcome measures

Evaluation of this extensive project was integral to decide its perpetuation or termination depending on its success or failure. In the absence of definite tools, two methods for assessment were planned: direct method at the end of 5 years of sustained awareness activities and indirect for annual assessment.

2.5.1. Direct method

Evaluation of the impact of epilepsy awareness activity especially on treatment gap was done through a repeat population-based study in 2006, as part of the Total Neurologic Survey of Pakistan using 1985–87 epilepsy protocol, a gold measure for comparative assessment of pre- and postintervention scientific studies.

2.5.2. Indirect method

Indirect assessment is done through annual AED sales data, obtained from a well-known undisputed source (personal communication). All other variables have remained constant. This method is not acceptable to conventional researchers; however, it helps CECP estimate annual escalation, diminution, or stagnation effect of ongoing awareness activities.

3. Results

Since 1987, unaccounted random epilepsy awareness and education activities for public and medics through various media were arranged all over Pakistan on a personal or institutional level. Following the CECP-ESP launch in 2001, numerous epilepsy awareness activities were undertaken simultaneously with much overlap, and these activities continue to date.

3.1. Phase 1

Awareness activities were initiated with public sensitization through a short, bulleted message. "Epilepsy is a treatable medical disorder. It is not caused by evil spirits, djinns, witchcraft or any other such causes. For diagnosis and treatment contact your doctor" was coined to be used for all awareness activities. Tens of thousands of Epilepsy Awareness Stickers in an eye-catching red and white color scheme were pasted on nationwide fleet of ambulances, intercity passenger buses, intercity cargo trucks, oil tankers, and other long-distance moving vehicles. With a display life of 6 months, the message reached far off corners of the country. Additional activities such as graffiti, billboards, roadside banners, distribution of flyers, and slogan-engraved ballpoint pens were undertaken in most parts of the country.

In the subsequent phase, detailed information about epilepsy was done repeatedly through various activities in print and on electronic media. Results of these activities cannot be quantified. It is guesstimated to have been read, heard, or seen by millions.

School Awareness Workshops for teachers and senior students were conducted in 18 large schools in Karachi; 800 teachers and 1825 students were addressed. Students' interaction was rewarding but had limited reach and was not cost and time effective. Hence, it was replaced with nationwide affixation of 45,130 illustrated Epilepsy Awareness Posters in schools and public places. These posters were especially valuable in the no-go areas of the country with poor law and order situation. State employed 800 lady health visitors, already doing house-to-house visits in their local neighborhood for common medical conditions, were inducted in epilepsy awareness training and motivated to identify PWE and encourage them to seek proper treatment.

In 2003, Abdul Sattar Edhi, Pakistan's most revered saintly social worker, in league of Mother Teresa but with much more extensive and diversified social work, came out-of-shadow because of the CECP-ESP campaign and became its most motivational ambassador.

3.2. Phase 2

The 7-day Structured District Module was applied in 69 of a total 141 districts in Pakistan in a period of 5 years where 12,741 suspects of epilepsy were evaluated; 7962 with epilepsy were given medical treatment advice and counseled, ensuring follow-up by the local physician trained in epilepsy. It is estimated that the 6-day intensive awareness activity covering every corner of the district created epilepsy awareness among millions of residents in 69 districts. Epilepsy Update Workshops for primary care physician were also held, training 2100 physicians. Additionally, 1000 final year medical college students were also addressed. This very successful activity had to be abandoned because of security reasons in the country.

3.3. Phase 3

Building of the CEC-NEC, a dedicated tertiary epilepsy care facility within the premises of Jinnah Postgraduate Medical Centre, a tertiary care public-sector teaching hospital in Karachi was undertaken. The building was constructed, furnished, and equipped through voluntary donations. This NGO-owned and run epilepsy icon is operational since April 2007. It is the hub for integrated epilepsy-related activities in the country, providing holistic management to PWE especially the poor, along with awareness, educational, and research activities. It houses the secretariats of Epilepsy Associations of Pakistan (International League Against Epilepsy's (ILAE) Pakistan Chapter) and Epilepsy Support Pakistan (International Bureau of Epilepsy's (IBE) full Pakistan Chapter). Although epilepsy management is not the purview of this article, brief mention would add to its value as it is the hub of awareness, too. The CEC-NEC to date has 9400 + documented PWE from all over Pakistan who are assessed, followed up, and provided all required AEDs at a token cost of ~10% of actuals. Interictal Electroencephalographys (EEG) with video recordings are performed at token cost; 17,000 + EEGs have been performed and digitally archived to date.

3.4. Phase 4

In tandem with the ongoing efforts, electronic media was used to reduce stigma, which is the most difficult and neglected component in awareness campaigns. A short comprehensive television documentary was produced, with Mr. Edhi, a PWE himself, being the motivational presenter. It covers all medical and social aspects of epilepsy. This has proven to be the best value-for-money activity conveying a comprehensive awareness message to almost every household in Pakistan as well as in its neighboring countries where these television channels are also viewed. Dissemination of our message was possible at global level through expatriate viewers of these channels in foreign lands. The duration, by design, was kept minimal to maintain viewers' limited attention span. Versions of the documentary in various languages have been produced and include national language Urdu, English, and three main regional languages. Each telecast cycle consists of twice a day telecast for 3 months, in a near-prime time viewer slot. Twelve telecast cycles have been completed to date. From the data provided by marketing departments of two television channels, it is estimated that through 2160 telecasts, 132 million people in Pakistan have viewed this documentary (personal communication), which is nearly half the population of Pakistan. The likelihood of repeat viewership is possible, which would only reinforce the message. Besides this, the social media is being used for added awareness activities.

3.5. Assessment of impact of the CEC-ESP awareness campaign

3.5.1. Direct assessment

After 5 years of sustained awareness activities (2001–2006), repeat population-based survey in the urban areas showed a decrease in ETG from 72.5% (1985–87) to 25% (2006).

3.5.2. Indirect assessment

Antiepileptic drug sales data from 1998 to 2018 have been analyzed. The retail cost of AEDs has remained unchanged throughout this period. As gabapentin and pregabalin are used mostly for neuropathic pain in Pakistan, its data were not considered. Indirect measure shows a 15.6% compound annual growth rate in AED sales along with a significant growth in manufacturing of various AEDs (Fig. 1).

The CEC-ESP's efforts have not only proven to have reduced the ETG significantly, but has also shown a satisfactory impact on stigma reduction. Quantification was not done because of lack of a standardized epilepsy stigma scale. Also, the extent of concealed perceived stigma cannot be quantified even if available. However, it can convincingly be stated that stigma reduction in Pakistan is highly palpable with a significant increase in the number of people uninhibitedly talking about epilepsy and seeking treatment, substantiated by increasing AED sales.

4. Discussion

Prevalence of active epilepsy is reported to be more in socially deprived and less affluent classes and is twice or thrice the quantum in LLMIC than in UMIC and HIC [2,3,8]. In LLMIC, active epilepsy is two times more in the rural as compared with the urban population [2,6,7,25].

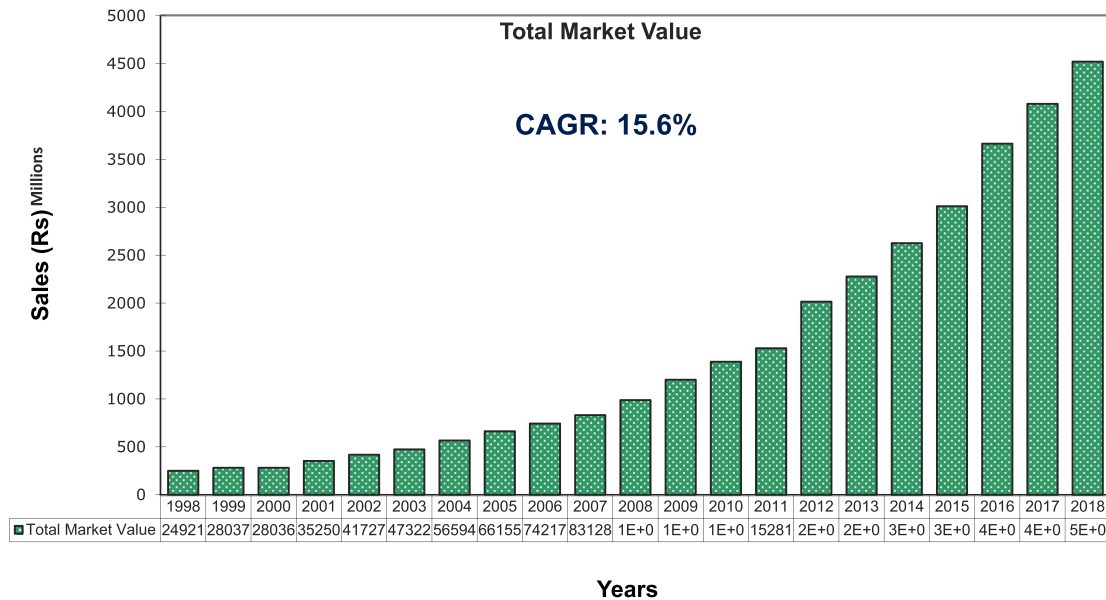
Epilepsy-related issues including treatment status and stigma in Pakistan is prototypical of a LLMIC. As in most LLMICs, lack of governmental priority for epilepsy, insufficient national health budget, and no public health insurance with private health insurance being uncommon and denied to PWE; hence, epilepsy treatment in Pakistan is an out-of-pocket expense [1,17,26,27]. Civil society organizations in the country are not motivated to work for epilepsy, and charitable donations towards epilepsy care are negligible as compared with public charities received for other health conditions, which is also reported in HIC [21]. Poor awareness and treatment facilities for preventable causes of epilepsy like brain infections, decent obstetrics, head injuries, and stroke add to the burden [5]. Epilepsy stigma remains a major global issue to date [22,23] and is a significant hurdle in treatment in Pakistan.

Without understanding and addressing the baseline problems, no advancements in management can effectively decrease ETG. In 1997, realizing the gravity of the situation ILAE/IBE/World Health Organization (WHO) Global Campaign Against Epilepsy (GCAE) was launched to improve acceptability, provide adequate epilepsy treatment services, close the ETG, and reduce social and physical burden of epilepsy. Prototype demonstration projects (DP) were initially initiated in four countries: China, Brazil, Zimbabwe, and Senegal, and then extended to more regions, of which some are ongoing. Outcome assessments have been documented, but all have not been able to evaluate ETG quantitatively [27–36]. China is probably the only country who has been able to maintain the continuity of DP, having integrated it in their national healthcare policy and extended them to other provinces [37,38]. Funding and availability of AEDs by the government and other organizations has helped China in sustaining and replicating the project in other parts of the country as envisaged by GCAE [33].

In 2009, GCAE established Global Outreach to provide global attention to self-initiated epilepsy-related awareness initiatives that vary from evaluation of baseline epilepsy status, awareness and education of a target population, pre- and post-AED intervention studies for ETG assessment, some larger scale well-planned studies that could not go beyond pilot projects or recommendations and some innovative projects for awareness and epilepsy care have been undertaken in LLMIC. Majority had limited reach, were time-locked, or unsustainable probably because of financial and human constraints [30–32,34,35,39–47]. All initiatives are appreciated by the authors. The Connectors Project in United States is proof that even today, areas in HIC with inadequate epilepsy care exist and need attention [48].

Epilepsy awareness campaign in Pakistan was started in 1987. Dis-mal ETG and KAP status recorded in the 1985–87 population-based study was an impetus for a formal campaign, initiated a decade prior

INDIRECT MEASURE OF SUCCESS – GROWTH IN AED SALES (Pregabalin & Gabapentin excluded)*



Total Anti-Epileptic Market Value & Growth 1998-2018 Local currency (PKR)

* Data based on MAT-Q4 data

ims

Fig. 1. This graphical representation using annual AED sales figures is the indirect outcome measure of the CECP-ESP awareness activities. Taking 1998 as baseline until the end of 2018, the compound average growth rate (CAGR) is 15.6%, with other variables remaining unchanged. Gabapentin and pregabalin figures have been omitted as they are mainly used for neuropathic pain. Source: IMS Health Pakistan (Private) Limited.

to GCAE. Before initiation of an intensive sustained awareness, it was necessary to rectify the poor human resource, required to address the needs of made-aware community. Development of human resource trained in neurology took nearly a decade. In the meantime, epilepsy teaching workshops for primary care physicians and awareness activities on personal and institutional levels were done. By 2001, there were a decent number of physicians with varied levels of neurology training. A team of volunteer specialists with the support of some concerned citizens officially launched the CECP, which has an integrated approach towards epilepsy service delivery as recommended by WHO [49]. While the CECP-ESP activities are ongoing since 2001, the CECP-NEC became operational in 2007 and both work in tandem, within constraints of the prevailing healthcare system.

The importance of sustained dissemination of epilepsy awareness is stressed, as a single interaction with the masses is insufficient and ineffectual in addressing KAP, stigma, or drug compliance [50–53]. An extensive literature search then showed no guidelines or references to address ETG and stigma. Methods of assessing its outcome on a national level, exclusively through sustained awareness, were also unavailable. The CECP-ESP devised its own strategies, based on results of the 1985–87 study, cultural and societal perceptions about epilepsy, educational status of the local population, personal experiences, available financial and human resources, and some undertakings reported in literature. The evolution of this modular approach project was stepwise, starting from a small designated area in the port city of Karachi and then extending to the entire city with a population of about 22 million. Karachi is the economic hub, where menfolk from all parts of the country converge for financial opportunities. They have also proven to be effective carriers of

the awareness message to their remote ethnic communities. Subsequently, awareness activities were extended to districts, provinces, and finally, the entire country. This unique methodology includes built-in checks and balances to review and modify implementations based on success or failure. The CECP has not only been able to produce a workable model to decrease ETG and stigma purely through public awareness without any drug intervention, but has also analyzed the outcome by direct and indirect methods.

The CECP-ESP activities are distinct from other reported projects in a number of ways: (i) target is entire population of Pakistan, (ii) designed to be a sustained ongoing public-targeted project and not time-locked; ongoing since last 18 years, (iii) ground realities were established prior, (iv) a volunteer-run NGO project, supported by public donations only; no technical support or financial grants from the government or funding organizations applied or received, (v) has an indigenously evolved methodology, within the constraints of existing health delivery system, (vi) awareness is the exclusive mode of intervention, (vii) AEDs intervention excluded by design, (viii) includes all seizure types, (ix) no age limit, (x) diagnostic ascertainment done only by neurologists, (xi) for sustainability and integrated epilepsy services the iconic tertiary care CECP-NEC has been built, (xii) reduction of stigma by changing the common man's mindset through public awareness, (xiii) motivational national celebrities with epilepsy joined the campaign, and (xiv) has provision to modify, stop, and replace activities.

In 2012, the Institute of Medicine published detailed recommendations for epilepsy public education and awareness, most having been undertaken by the CECP-ESP and reaching the crescendo of changing the nation's mindset through 'paid telecast' of epilepsy awareness

documentary on commercial television channels. Two studies are reported to have used public awareness as the only interventional tool. Epilepsy Foundation, USA has undertaken a large multidimensional collaborative public education and awareness drive. The published report of its activities over one and a half decades provides a detailed account of all undertakings but without determining its impact on ETG and stigma [54]. The Bolivian study was limited to a select rural population, time-locked with no specialist onboard. Statistical analysis of KAP & stigma, with reevaluation, was done within a short period. This financially assisted study did not evaluate ETG [55].

Prevalence of epilepsy stigma is not trivial and cannot be easily quantified [19,24]. Stigma remains an important feature in the history of epilepsy [21]. Stigmatization still exists in developed countries though on a lower scale [19,27,56–59]. Sociocultural factors like education, gender, religion, and urban/rural setting can affect the extent of stigma and be variable within the same country [58,60]. Although some studies have looked into perceived stigma, concealment of information, fearing breach of confidentiality and its societal repercussions is high, with relatives being the biggest stigmatizers [61].

Quantitative evaluation of epilepsy stigma in select population is reported [24,62–64]. A number of Stigma Scales like the Brazil [55,60,65,66], Jacoby [13,58,59], Kilifi [67,68], and other epilepsy stigma scales [15,16,18,20,69–73] have been used. For comparative studies, no uniform, cross-culturally valid epilepsy stigma scale is available because of wide differences in societal and cultural beliefs; hence, the CECP-ESP did not use any formal stigma assessment tool. However, it can definitely vow for a palpable decrease in stigma by way of an increase in positive treatment-seeking behavior and free usage of the culturally taboo word ‘mirgi’ (epilepsy), indicating increased awareness and social acceptance. Also, the staggering increase in annual AEDs sales each year (Fig. 1), with all variables including cost of medicine remaining constant, is proof enough of acceptance of epilepsy as a treatable medical disorder.

Sustainability for long-lasting efficacy, and medico-ethical reasons is important in any type of interventional projects [28]. Local community involvement and ownership is very important for their success [1,7,10,28,31,32,40,41,55,73]. Government and other funding organizations tend to add restrictions, limiting flexibility in changing predesigned protocols, and are usually time-locked. Withdrawal of medicines at the end of AED-interventional projects in LLMIC usually results in compromised or no treatment with high chances of withdrawal seizures and status epilepticus. Ethically, a backup plan for such projects should always be made. The CECP-ESP can claim its success because it was designed to be a sustained, nonrestrictive, nongovernmental, NGO-based project with donations solicited for all activities. Philanthropists, general public, and some commercial organizations as part of their corporate social responsibility have contributed. Voluntary generation of funds from the local community is preferred in Pakistan as governmental pledges hardly see the light of the day or get sidelined, as epilepsy is still not the priority.

An analysis of attributable factors suggests that awareness and proper counseling can increase treatment-seeking behavior by 11%, presence of a near home treatment facility by 12%, and free AED provision by 40% [3,4]. Our study disproves these figures as we have achieved a significant change in treatment-seeking behavior with reduction in ETG only by sustained mass awareness on a national level.

Results of these sustained ongoing activities by both direct and indirect methods are unequivocal evidence of our success. About half the population of Pakistan has been educated about epilepsy through public awareness per se. An extensive literature search fails to show any such ETG reduction campaign making our effort distinctive. This model can be replicated in other developing countries where sequential application of the four phases can be tailored according to available resources (financial and human) in the country as they dictate how much one can achieve. Completion of each phase can be tested with an impact factor.

4.1. Limitations

Logistic and management issues of repeat population survey were the same as that in the previous study, with political turmoil, riots, and lawlessness at its zenith during this study period. The public was not cooperative in receiving our volunteers, being skeptic and apprehensive to divulge details about their family members. Situation in the rural areas was far worse and could not be accessed. However, we plan to reevaluate the rural population in the near future.

4.2. Strengths & weaknesses

Our greatest strength has been the dedicated efforts of our volunteers and constant financial support by our gracious donors. Time limitations of our human resource to support the ongoing campaign have become the main weakness. Pakistan is a country known for public charities where people not only donate as a religious obligation but philanthropy is a strongly ingrained culture of the country. Significant contributions towards public health sector alleviate some despondency of the poor citizens. However, the ratio of donation towards epilepsy is much less as compared with other health issues.

5. Conclusion

Pakistan's efforts are probably unique. Under the banner of the CECP-ESP, focused and sustained epilepsy awareness program is ongoing since 18 years through different indigenously developed projects; old ones in tandem with the new ones; dropping off those lacking further viability. We have so far been able to reach half the population, and it is important for this campaign to continue for at least another 5 years or may be more to achieve our goal of changing the mindset of the entire nation. We hope that our efforts will encourage other LLMIC to attempt to reduce ETG and stigma in line of this tested modular approach, where each phase can be planned and executed within the available resources and its impact assessed.

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Declaration of competing interest

None of the authors have any conflict of interest to disclose.

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Appendix A. A model to reduce epilepsy treatment gap and stigma through public awareness

A.1. Phase 1 – dissemination of information on epilepsy

A. Public sensitization through a short, bulleted message

- Effective slogan coined to be used for all awareness activities.
- Epilepsy Awareness Stickers on nationwide fleet of ambulances, intercity buses, intercity cargo trucks, oil tankers, and other vehicles.
- Graffiti, billboards, roadside banners.
- Distribution of awareness pamphlets at epilepsy awareness programs, market place, public transports, waiting areas of intercity bus terminals, railway stations, busy traffic signals, banks, supermarkets, outside mosques, and waiting areas of PCP clinics.
- Distribution of slogan-engraved souvenirs in various awareness programs.
- Cyclic radio transmission of awareness message several times a day on designated days.
- Awareness ticker on cable television during prime time.
- Rickshaw awareness campaign; placement of awareness banners on this most used public transportation mode. Epilepsy awareness rickshaw train in which 10 rickshaws completely redesigned for epilepsy awareness purposes, ply on roads in a trail and stationing for some time at public places on route to distribute awareness material.
- Setting up of epilepsy awareness booths on weekends at busy large malls that are frequented by families. Awareness done through fun and games.
- Epilepsy awareness booths at health expos.
- Epilepsy awareness walks.
- Epilepsy awareness kite-flying festivals (kites with printed awareness slogan)
- Art Competition for school children with the topic epilepsy.
- Awareness through short live-enacted drama.
- Bringing local famous PWE out of shadows and help boost our campaign.

B. Spreading of detailed information on epilepsy

- Through print and electronic media; newspapers, magazines, and national and private television channels.
- School Awareness Workshops for teachers and senior students.
- Awareness workshops at colleges and medical and nonmedical universities.
- Especially designed illustrated Epilepsy Awareness Posters with display life of more than 6 months in schools and public places nationwide.
- Awareness workshops for state employed Lady Health Visitors
- Specialists' talks on morning shows of Pakistan Television's news and global channels, with live interactive sessions with the viewers. These programs are widely watched by nonworking household members.
- Specialists Meet the Press sessions.

A.2. Phase 2 – Structured District Module

- Week-long epilepsy awareness activities.
- Sequential replication in each district of the country.
- Nonmedical volunteers on location execute and monitor six days intensive public awareness activities through various modes in the entire district like banners, announcements from mosques, epilepsy awareness documentary telecast by local cable operators, graffiti, and flyer distribution. Most important mode being loudspeaker-mounted vehicles (usually two rickshaws) decorated with awareness banners playing the prerecorded short epilepsy awareness messages, plying through every nook and corner of the district, halting at crowded public places.

- Free epilepsy camp on day 07 (a Sunday) by volunteer CECP neurologists.
- No AED distribution.
- Epilepsy update workshop for local primary care physicians.

A.3. Phase 3 – building of a tertiary care epilepsy center in Pakistan – an 'icon' of epilepsy

- Building of a facility designated for integrated epilepsy-related activities under one roof. Hub of national epilepsy-related awareness events, provision of holistic management, epilepsy educational, and research activities.
- Secretariat of Epilepsy Association of Pakistan (ILAE Chapter) and Epilepsy Support Pakistan (IBE full chapter)

A.4. Phase 4 – countrywide awareness to change the nation's 'mindset' and reduce stigma

- Regular 'paid' telecast of a short comprehensive television documentary.
- Awareness activities through social media.

A.5. Assessment of outcome measures

Direct method: Repeat population-based study using the previously used protocol.

Indirect method: Total-country AED sale figures to assess the effectiveness of the awareness activities through change in AED sales over the years.

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