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Experience of implementing integrated services for children with Epilepsy in primary health care and primary health nurse role in an outreach financially - constrained district in Pakistan

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Introduction: Of the 35 million people with epilepsy who live in developing countries, around 85% receive no treatment at all. Cost-effective, sustainable epilepsy care services, delivering uninterrupted Antiepileptic Drugs (AEDs) through established primary health care facilities, are needed to decrease these treatment gaps.

Objectives: The aim of this study was efficacy assessment of integration of childhood epilepsy in primary health with help of primary health nurse and local paediatrician to narrow the treatment gap among Children With Epilepsy (CWE) in an outreach financially-constrained district in Pakistan.

Methods: The data about Childhood Epilepsy Treatment Gap (CETG) and impact of integration of childhood epilepsy in primary health care in improving it was collected in free paediatric neurology camps on 7th and 8th December 2018. We evaluated 240 CWE (160 fully supported and 80 as control), in whom treatment was initiated with AEDs at least 3 months prior the study date. 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: Age ranged from 04 months - 18 years with male to female ratio of 1.26:1. AED(s) adherence by self-report was 85% (was 42% in 2014 without community intervention) among the supported CWE and was 40% among the control: without any gender preference in either group. After two years

of intervention by Top-Down-Bottom-up-Childhood-Epilepsy-Program-Center (TDBUCEPC), CETG dropped to 20% (was ≥90% in 2014 without local community support), however still it was 82.5% without any support. Nonaffordability treatment cost was the most important cause of non-adherence to AEDs among CWE; however other less important caused were lack of trained personals, parent's negligence and misbelieve. The most effective cause of adherence promotion and bridging the wide treatment gap was integration of childhood epilepsy services in free local primary health care.

Conclusion: Our experiences showed that strengthening of the local primary health care service along with training or primary nurse and local pediatrician is an efficient approach in bridging the huge treatment gap among CWE in financially poor settings. This experience may be of value for other resource-poor settings.

Biography

Muhammad Akbar Malik was born in a very small village, on the eastern brim of River Chinab, just 5 Km from Maralah Barrage, without any barrier between the purest natural water the river and his village. After initial education in Open Air High School Kulluwal, got his Medical Education from Lahore, was trained in Lahore. He got highest qualification in the field of pediatrics. He went to Ireland and passed his MRCPi in the field of paediatric. Then he moved to UK and was trained in Pediatric Neurology and pediatric neurophysiology. He established the first teaching pediatric neurology and neurophysiology department in Children's Hospital Lahore. He is currently working as the Chairperson charity program Top-Down-Bottom-Up-Childhood-Epilepsy-Program with aspiration to bridge the treatment gap of childhood epilepsy in outreach and financially constrained communities in Pakistan, in addition to his voluntary services of visiting consultant paediatric neurologist in Shaukat Khanum Memorial Cancer Hospital and Research Centre Lahore. His interest in Neurology began medical school. Neurology cases were like solving a puzzle when he was trying to localize the lesion. Later on, he learned that Neurology and sorting out this in financially constrained settings.

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