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Epilepsy stigma in children in low-income and middle-income countries

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Epilepsy is common in children in low-income and middle-income countries (LMICs), with estimates ranging from 21 to 41 in 1000 older children (aged 6–9 years). There are few prevalence studies of epilepsy in young children (younger than 6 years) in LMICs because acute symptomatic seizures are common during this period and can be confused with epilepsy. Risk factors for epilepsy include intracranial infections and birth complications. Epilepsy is associated with mental health and neuro-developmental problems in children.¹ The epilepsy treatment gap is largest in children. Management of seizures is dependent upon parents, who might not access medical treatment because of stigma, costs, and misperceptions of the seizures as being benign.

Stigma is characterised by three constructs: dimension (negative stereotypes or attitudes and discrimination or devaluation), context of experienced stigma (self, institution, and in the community), and target of stigma (child, family, or care services; figure).² Stigma starts with labelling trait differences; stereotyping the label, lowering of self-esteem, and feelings of inadequacy culminate in social withdrawal and covertness. The stigma associated with epilepsy takes three forms: internalised attitudes of the person (ie, felt stigma), actions of others (ie, enacted stigma), and consequences of association with those who are stigmatised (ie, courtesy or secondary stigma). Stigma is engendered by the perceived lack of control when having a seizure, with the child and epilepsy considered as a single entity. Stigma can defy human cognition and class—some health-care workers in Africa reported that they would not employ or marry a person with epilepsy.³ Stigma represents a hidden burden of epilepsy that is omitted from disability-adjusted life-year measures.

The stigma of epilepsy in LMICs can be illustrated by labelled stereotypes (children with epilepsy are considered to be mentally retarded or infectious), and by devaluation

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or discrimination of these children as being different from their peers. The most common context of stigma is the general public as stigmatisers, although older children can self-stigmatise. Additionally, insufficient epilepsy services and experts are a form of institutional stigma that leads to neglect of the needs of children with epilepsy. Caregivers of children with epilepsy are targets of stigma when they take children for treatment in known epilepsy centres or are blamed for their child's epilepsy. Institutions of care can be targets for stigma, through experiences of stigma by health-care workers and by being under-resourced.

Some experiences of stigma in children with epilepsy are similar to adults (eg, socioeconomic exclusion, isolation, and underutilisation of care), but there are salient differences.

Parents report perceived stigma because they are blamed for their child's situation. These parental experiences of stigma cause strained family interactions and difficulties communicating about their child's health to wider society.⁴ Parents and relatives unknowingly inculcate stigma into children with epilepsy, through their reinforcement of stereotypes and attitudes. Children with epilepsy rely on parents for treatment decisions and are likely to be more stigmatised because of their perceived powerlessness. Self-stigma occurs less in young children, becoming apparent with age and development through learned behaviours from society and family.

Assessment of stigma should be comprehensive and robust, with both quantitative (tools that elicits beliefs, attitudes, and perceptions) and qualitative (informant interviews) approaches. These tools should be contextually and culturally appropriate and can be developed locally (eg, the Epilepsy Stigma Scale in Kenya⁵), or adapted from international tools (eg, Rosenberg's 10-point self-esteem scale and the Epilepsy Stigma Scale in India).⁶ Quality of life and psychological stress scales should be part of the planned battery of assessments.

Stigma can be affected by factors in three social systems: microsystems (eg, biosocioculture), mesosystems (eg, institutions), and macrosystems (eg, environment). Stigma in children is increased in the presence of medical comorbidities and long durations of anti-seizure medication.⁷ Stigma is common in generalised seizures because they are dramatic and in complications of epilepsy (eg, gingival hypertrophy following phenytoin use or intellectual disability).⁸ Stigma scores are highest in the poorest people, in children with unemployed parents, and in urban areas. Stigma scores might be higher in older children, who have more awareness of stigma. Other context-specific devalued statuses might add complexities to epilepsy stigma in children (eg, race and gender issues in India or HIV-orphanage residence and poor economic status in Africa).⁹

Stigma affects the quality of life of children with epilepsy, but few studies formally assess this interaction. A child with epilepsy might be refused admission to school, with Guinean children citing embarrassment due to seizures as reason for non-school attendance.¹⁰ However, school attendance can also be affected by other epilepsy-related factors (eg, intellectual disability). Stigma exacerbates psychiatric comorbidities in children with epilepsy, and in a survey of parents of children with epilepsy in India psychological stress due to fear of shame and rejection was cited if they divulged their child's diagnosis.⁴

Epilepsy stigma might deter parents from seeking care for their children for fear of being discriminated against by the community. Stigma is associated with poor self-efficacy management in children with epilepsy by their parents and can persist even after seizures are controlled by anti-seizure medication.

Interventions for epilepsy stigma should be multi-component, cost-effective, scalable, and directed towards tackling forces that engender and sustain stigma (self, the public, and institutions) and to those stigmatised (child and family or caregivers). Most intervention studies in LMICs are fraught with bias, and criteria for evaluation of efficacy should be robustly defined. Peer support groups have reduced internalised stigma in adolescents, and traditional health practitioners offer psychosocial support to victims of stigma in LMICs. Epilepsy stigma should be addressed by joint efforts of epilepsy stakeholders, such as National Epilepsy Coordinating Committees, whose role includes awareness creation, advocacy for policy change and practice, and promotion of responsible journalism.

References

1. Kind CJ, Newton CRJC, Kariuki SM. Prevalence, risk factors, and neurobehavioral comorbidities of epilepsy in Kenyan children. *Epilepsia Open*. 2017; 2: 388–99. [PubMed: 29588970]
2. Mukolo A, Heflinger CA, Wallston KA. The stigma of childhood mental disorders: a conceptual framework. *J Am Acad Child Adolesc Psychiatry*. 2010; 49: 92–103. [PubMed: 20215931]
3. Ali MA, Nwakuba OP, Abdu WI, et al. Awareness, attitude, and understanding toward epilepsy among workers in a state specialist hospital in Maiduguri, northeastern Nigeria. *Ann Afr Med*. 2020; 19: 237–45. [PubMed: 33243946]
4. Rani A, Thomas PT. Stress and perceived stigma among parents of children with epilepsy. *Neurol Sci*. 2019; 40: 1363–70. [PubMed: 30903416]
5. Mbuba CK, Abubakar A, Odermatt P, Newton CR, Carter JA. Development and validation of the Kilifi Stigma Scale for Epilepsy in Kenya. *Epilepsy Behav*. 2012; 24: 81–85. [PubMed: 22481043]
6. Hassan, H, Thomas, TP. A study on psychosocial correlates among adolescents with epilepsy. National Institute of Mental Health and Neurosciences; Bangalore: 2019.
7. Kirabira J, Nakawuki M, Fallen R, Zari Rukundo G. Perceived stigma and associated factors among children and adolescents with epilepsy in South Western Uganda: a cross sectional study. *Seizure*. 2018; 57: 50–55. [PubMed: 29567525]
8. Carter JA, Mung'ala-Odera V, Neville BGR, et al. Persistent neurocognitive impairments associated with severe falciparum malaria in Kenyan children. *J Neurol Neurosurg Psychiatry*. 2005; 76: 476–81. [PubMed: 15774431]
9. Cluver L, Orkin M. Cumulative risk and AIDS-orphanhood: interactions of stigma, bullying and poverty on child mental health in South Africa. *Soc Sci Med*. 2009; 69: 1186–93. [PubMed: 19713022]
10. Fitts W, Rahamatou NT, Abass CF, et al. School status and its associations among children with epilepsy in the Republic of Guinea. *Epilepsy Behav*. 2019; 97: 275–81. [PubMed: 31260925]

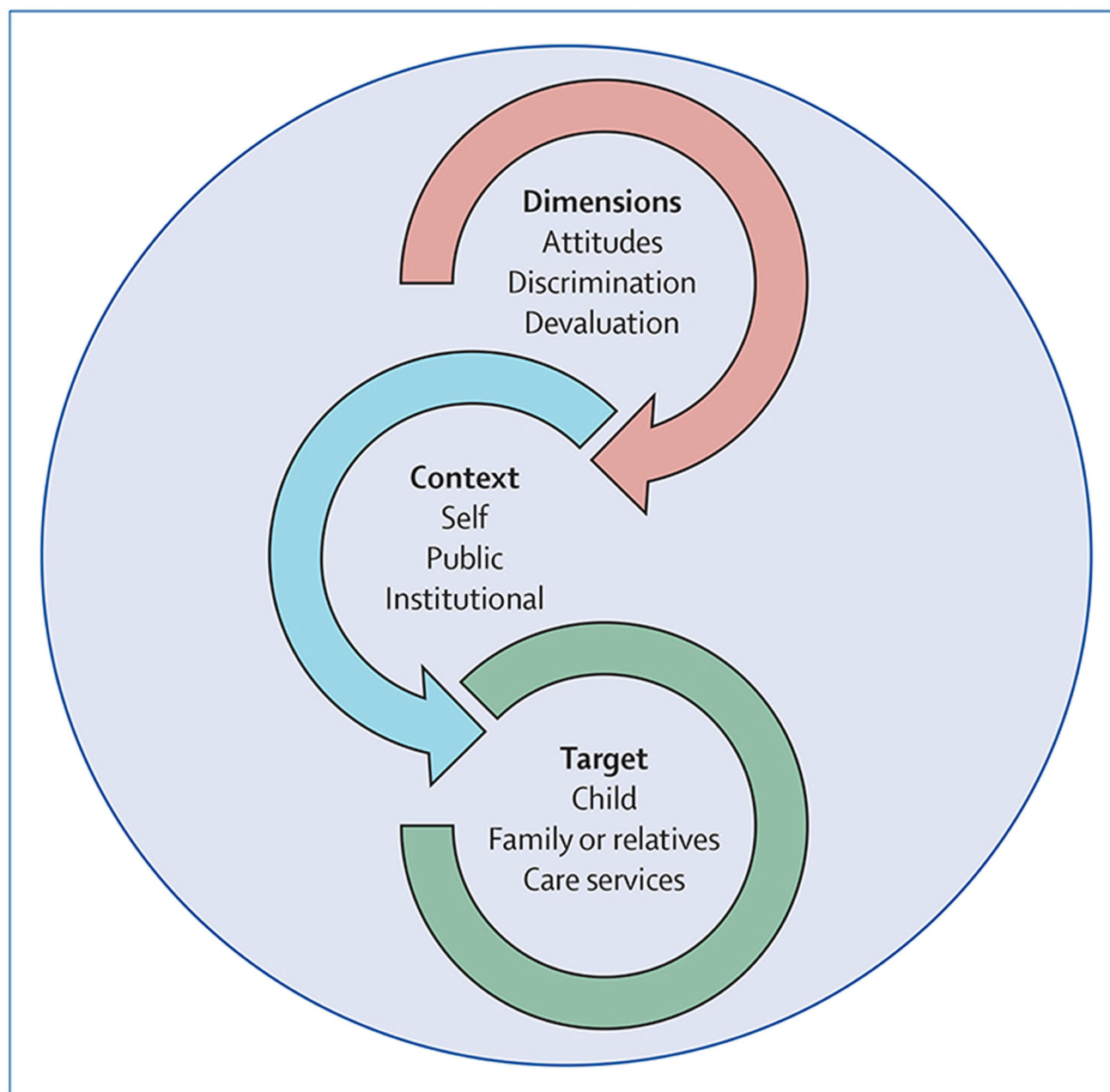


Figure. The three constructs of stigma