



Peer support groups as an intervention to decrease epilepsy-associated stigma

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ABSTRACT

Eighty percent of people with epilepsy (PWE) reside in low-income countries where stigma contributes substantially to social and medical morbidity. Peer support groups (PSGs) are thought to be beneficial for people with stigmatized conditions, but little data exist regarding PSG effectiveness. We facilitated monthly PSG meetings for men, women, and youth from three Zambian clinics for one year. Pre- and post-intervention assessments measured internalized stigma, psychiatric morbidity, medication adherence, socioeconomic status, and community disclosure. Of 103 participants (39 men, 30 women, and 34 youth), 80 PWE (78%) attended ≥ 6 meetings. There were no significant demographic differences between PWE who attended ≥ 6 meetings and those who attended < 6 meetings. Among youth attending ≥ 6 meetings, internalized stigma decreased ($p < 0.02$). Among adults, there was a non-significant stigma decrease. No differences were detected in medication use, medication adherence, or psychiatric morbidity. Peer support groups effectively reduce stigma for youth and may offer a low-cost approach to addressing epilepsy-associated stigma in resource-poor settings.

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1. Introduction

The World Health Organization's Global Campaign Against Epilepsy (GCAE) is dedicated to reducing the burden of epilepsy worldwide [1]. With a treatment gap of greater than 75% in many low-income countries, resources committed to improving the lives of people living with epilepsy (PWE) are primarily directed towards expanding access to antiepileptic drugs (AEDs) [2]. However, as the GCAE has noted, the psychosocial burden of epilepsy must also be addressed as it is an integral part of well-being for PWE and is inextricably linked to the medical burden of the disease.

Stigma continues to contribute significantly to the psychosocial burden of epilepsy in both developed and developing countries [3].

Stigma can be divided into three subtypes based on mechanism of action: internalized stigma, which refers to beliefs and fears within PWE; interpersonal stigma, which refers to discrimination from others directed at PWE; and institutional stigma, which refers to society's position on epilepsy as reflected by its traditions and laws [4]. Internalized stigma is also referred to as 'felt stigma' and may be influenced by shame associated with epilepsy as well as fear of encountering stigma from others [5,6]. These theories suggest, and research has shown, that stigma permeates all aspects of life for PWE, including employment [7–9], housing quality [8,9], psychological well-being [10–15], and AED adherence [16,17].

The most commonly used measure for felt stigma is a three-item scale originally employed for stroke but adapted and validated for epilepsy by Jacoby et al. for use in Europe [5,18]. This measure has reported significant variation in epilepsy-associated stigma across the globe, although it is unclear how much of this variation can be attributed to true geographic differences in felt stigma and how much is due to cross-cultural variability in the performance of the three-item scale [10,19,20].

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Despite considerable research characterizing epilepsy-related stigma, comparatively few studies examine the effectiveness of interventions designed to reduce stigma or the forces that influence stigma [21]. Gutteling et al. noted that educational programs significantly improve public attitudes towards PWE, but it is unclear if these improvements result in decreased interpersonal stigma [22]. Snead et al. found that a six-week psycho-educational group intervention did not significantly improve health-related quality of life for youth with epilepsy, which can be influenced by felt stigma [23]; however, little additional information exists regarding interventions aimed at decreasing felt stigma.

Personal empowerment has long been considered the opposite of felt stigma [24–26]. Personal empowerment is a multi-dimensional concept that includes having access to information, feeling part of a group, increasing one's positive self-image, and overcoming stigma [27]. Peer-delivered interventions, which are commonly employed in mental health, are based on the belief that individuals who have endured and overcome illness-associated adversity can support, encourage, and advise others facing similar situations. When used in the context of infectious diseases, peer-delivered interventions increase disease-related knowledge, decrease social isolation, and improve medication compliance [28–30]. Peer support groups (PSGs), in which individuals regularly meet to help each other address common problems or shared concerns, enhance individual social support and have been correlated with improved quality of life [26,31]. If PSGs decrease felt stigma, they might offer a low-cost intervention for highly stigmatized populations like PWE in resource-poor settings such as Zambia.

To better understand the utility of PSGs for PWE residing in a region where epilepsy is highly stigmatized [8,20], we undertook a year-long PSG intervention for groups of men, women, and youth aimed at determining the effect of PSGs on felt stigma, medication adherence, and psychiatric morbidity.

2. Methods

2.1. Participants

Men, women, and youth were selected for participation from health clinics associated with three sites in Zambia: two urban (University Teaching Hospital and Chainama Hills Hospital in Lusaka) and one rural (Chikankata Hospital in Mazabuka). Eligibility criteria included medical record documentation (either inpatient or outpatient) confirming a diagnosis of epilepsy in the six months prior to the first PSG meeting and the ability to participate in group conversations in the local regional language (Nyanja, Bemba, or Tonga). Recruitment differed between rural and urban sites. At the rural site, an existing patient registry of PWE was stratified by village, to avoid inclusion of patients who knew one another, and used to randomly select eligible patients for PSG participation. At the urban sites, where patient registries are unavailable, a study staff assessed the eligibility of patients obtaining routine epilepsy care services at clinics associated with the study site and approached eligible patients for study inclusion. Eligible patients were invited to participate in the PSG series conducted nearest their residence. At all sites, verbal and written invitations for participation, along with the study consent form, were privately delivered to potential participants. The consent form was read and discussed orally and, for those providing prior verbal consent, written consent was obtained in the participant's preferred language in the first PSG meeting. Signed consent forms could be marked with the participant's name, an "X" or a thumbprint, based on the participant's preference. In addition to written assent from participating youth, verbal consent and written consent were sought from their parents. Prior to initiation, this study was approved by the University of Zambia's Research Ethics Committee and Michigan State University's

Biomedical Institutional Review Board and was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki.

2.2. Intervention procedures

Peer support group facilitators included a psychiatric clinical officer, a ward auxiliary member with ten years of experience as a clinical staff member and as a research assistant for patients with epilepsy, and an administrator with ten years of experience managing an epilepsy clinic and supporting clinical research in epilepsy. Prior to study initiation, PSG facilitators and clinical officers associated with the study participated in a week-long intensive training program. Training topics included principles of facilitating PSGs and understanding disease-related stigma using examples from an HIV stigma toolkit [32]. Training also included sessions on research ethics and patient confidentiality as well as administration of the study evaluation instruments. Direct English to local language translations of the study instruments were avoided due to the immense variations in the local language dialects. Instead, significant time was dedicated to ensure that the staff administering the instruments mastered the nuances of each item in English so that they could be translated into the dialect of each study participant. This approach also assured that those administering the evaluation could provide appropriate clarification of each question as needed. All study staff members were local Zambians fluent in English and familiar with the languages and culture specific to their study site.

Between October 2009 and December 2010, separate PSGs for men, women, and youth with epilepsy were conducted at each study site. Each PSG met once a month for 2 h with content determined by meeting participants. The trained facilitators encouraged participants to share life experiences and, ultimately, to exchange problem-solving advice and discuss coping techniques related to epilepsy and epilepsy-associated social and medical challenges. In addition, either a physician or a clinical officer trained in epilepsy care was present at each PSG meeting to answer any medical questions that arose. At the start of each PSG meeting, discussion topics were selected by attendees, and an attendee was elected to serve as the chairperson for that meeting. Minutes were taken independently at each meeting by two study staff members, compared for accuracy, and later translated into English for review by the investigators.

Peer support group meeting venues and times were scheduled around participants' availability; refreshments were provided at each meeting. All participants were refunded 20,000 kwacha (~4 USD) to cover round trip transportation costs for each PSG meeting they attended. Transport refunds were also provided for an accompanying family member of youth, if necessary. No other payments or incentives were provided.

2.3. Pre- and post-intervention assessments

Within a week of the first group meeting, study facilitators interviewed all consenting participants for baseline assessments. Participants who attended six or more meetings were re-interviewed within one week of the final PSG meeting to assess the impact of the intervention. The survey instrument was designed for administration via structured interview and included items regarding demographic information, economic status, seizure characteristics and frequency, felt stigma, community disclosure of epilepsy, antiepileptic drug use and adherence, psychiatric morbidity, and personal safety. Household wealth was assessed using a measurement previously developed for this population which enumerates and values common household items [8,33,34]. A composite score for housing quality was created using a ranked score for three household features (materials for walls, roof, and floor, range 0 to 15) [8,33]. Household food security was determined by comparing access to food at the time of interview (after the harvest) and access to food during the dry season (generally

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