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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 exists 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, 34 youth), 80 PWE (78%) attended 6 meetings. There were no significant demographic differences between PWE that attended 6 vs. <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, adherence, or psychiatric morbidity. PSGs 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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Keywords

Africa; rural; urban; men; women; youth; psychiatric morbidity; medication use; community disclosure; medication adherence

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 wellbeing [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].

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 increase 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.

Methods

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 records 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, 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 located nearest to their residence. At all sites, verbal and written invitations for participation were privately delivered to potential participants, along with the study consent form. 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 at the first PSG. 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 and written consent was 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.

Intervention procedures

PSG facilitators included: a psychiatric clinical officer, a ward auxiliary with ten years of experience as clinic staff and as a research assistant with epilepsy patients, 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 are 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 two hours 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 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, discussion topics were selected by attendees and an attendee was elected to serve as 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.

PSG 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 they attended. Transport refunds were also provided for an accompanying family member of youth, if necessary. No other payments or incentives were provided.

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 during the dry season (generally February through April) [20, 33, 34]. Those who ate fewer meals in the dry season than at the time of interview were deemed food insecure. To assess stigma, the three-item stigma assessment, which has been used in this setting previously, was employed [5, 8, 34, 35]. Interviewers were also asked to report if adult participants exhibited any visible stigmata consistent with epilepsy as this has been correlated with stigma in this population [20]. Physical stigmata of epilepsy in this setting include burn scars that result from seizures while cooking over an open flame as well as facial scarring associated with seizure-related injury [36].

AED adherence was assessed using questions regarding when the individual last took the medication and how many doses he/she missed in the last month. These questions have been used to assess antiretroviral adherence and correlate well with pharmacy records in this setting [34]. Individuals were considered to be adherent if they had taken their AED in the previous 24 hours and had not missed any doses in the previous month. The Shona Symptom Questionnaire (SSQ) was used to assess psychiatric morbidity [37]. The SSQ is a 14-item instrument designed to detect the presence of culturally relevant manifestations of common mental disorders. Prior validation of this instrument indicated that individuals with scores greater than five warrant further psychological assessment [38]. This instrument was developed and validated in neighboring Zimbabwe and has been successfully used in Zambia in other populations [34]. Questions regarding household cooking, lighting, and water source were included to assess the participants' risk of burns and drowning. Among

adults, personal safety was also assessed by inquiring about instances of physical abuse and, for women, rape and transactional sex [8].

Statistical analysis

Responses to interview questions were recorded on paper copies of the survey instrument. Completed surveys were entered into Microsoft Excel and verified for accuracy before importing into SAS 9.3 for analysis. (SAS Institute Inc, Cary NC) Surveys were securely stored in the on-site project offices after data-entry.

For participants attending at least six peer support meetings, outcomes were assessed for normality and two-tailed comparisons were made between baseline and intervention assessments using, as appropriate, paired t-tests, the non-parametric equivalent (Signed Rank test), or McNemar's χ^2 test. A p-value of <0.05 was considered statistically significant. A *post hoc* analysis was also completed to assess baseline predictors of PSG attendance.

Results

Baseline participant characteristics

One hundred and three PWE participated in a PSG – 69 adults (44% female) and 34 youth (44% female). The demographic, economic, and clinical characteristics of participants are outlined in Table 1 and suggest this study population is similar to participants of previous observational studies of PWE in Zambia [8]. Seven youth participants (21%) were not enrolled in school despite being of eligible age. A fourth of men and a third of women were deemed food insecure. Eight men (21%) and 14 women (47%) had physical stigmata associated with epilepsy. Although 97 participants (94%) were taking an AED at the time of enrollment, seizure control was often poor with over a quarter of participants having experienced a seizure in the previous week. Forced disclosure of epilepsy status was common among adult participants; 63% of women and 49% of men had their epilepsy status disclosed against their wishes to their community. The baseline burden of psychiatric morbidity was also high – nearly half of participants warranted additional psychological assessment and support based on the recommended >5 score cutoff[37]. Felt stigma scores ranged from 0 to 3, with over half of participants reporting some level of felt stigma at baseline.

Effect of PSG Intervention

Eighty PWE (53 adults, 27 youth; 78% of original sample) attended six or more PSG meetings. Fifty-two adults and 27 youth were re-interviewed at the conclusion of the intervention. One female adult participant relocated during the study and could not be reached for re-interview after attending seven PSG meetings. As shown in Table 2, there were no significant differences between participants who attended six or more PSG meetings and those that attended fewer than six PSG meetings. Although there was a borderline association between increased baseline stigma and poorer PSG attendance among youth ($p=0.056$).

Among youth, PSG participation significantly decreased felt stigma (mean 1.58 vs. 1.04; $p=0.02$). There was a non-significant decrease in felt stigma for adults (mean 1.26 vs. 1.06; $p=0.20$). A *post hoc* power analysis indicated that with 51 adult participants, we had 80% power to detect a change in felt stigma of 0.43 ($\sigma=1.096$). As shown in Table 3, PSG attendance had no effect on psychiatric morbidity, AED use, or medication adherence. A decrease in school enrollment was observed for youth participants; however, further inquiry attributed this difference was due to the age-appropriate completion of secondary school.

Discussion

The WHO's GCAE acknowledges the need to address the psychosocial aspects of epilepsy, such as felt stigma, that significantly impact the lives of PWE. PSGs encouraged personal empowerment among PWE by providing participants with social support and offering coping strategies, possible solutions for common problems faced by PWE in this setting, and further knowledge about epilepsy both from other PWE and from medical professionals. The presence of medical staff at each PSG may have dispelled misconceptions about epilepsy, such as contagion beliefs, that have been shown to be related to increased felt stigma in this setting [20].

This study found that PSGs with content driven by participants and facilitation by local personnel with minimal training are an effective intervention to address stigma among youth in this resource-poor setting. Since youth with higher baseline stigma may be less inclined/able to attend PSG sessions, future studies should further examine predictors of PSG attendance among highly stigmatized youth in order to improve PSG attendance and evaluate the relative impact of PSGs on individuals carrying a greater baseline stigma burden.

Among adults, no improvements in stigma or other parameters were evident after 12 months of PSG participation. Despite this, multiple adult participants expressed an interest in continuing to meet regularly without formal support via transport refunds or refreshments. At least one men's group has continued to meet.

It is important to note that although financial supports for transportation costs were provided, participation rates were well below 100%. Reasons given for meeting absences reflect the challenges of being a PWE in Zambia, and included feeling too unwell to travel after having had a seizure and experiencing side effects associated with AED use. Nevertheless, PSGs were shown to effectively decrease felt stigma among youth.

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Highlights

- Internalized stigma is a significant problem for people with epilepsy
- Monthly Peer Support Groups for one year decreased stigma for youth with epilepsy
- A non-significant decrease in stigma among adults with epilepsy was also found
- Peer Support Groups may be a low cost way to address stigma in low-income settings

Table 1

Participant Baseline Demographic, Economic, and Clinical Characteristics

	Men (n=39)	Women (n=30)	Youth (n=34)
Age, years			
Mean (SD)	32.2 (8.7)	30.4 (9.7)	15.2 (1.9)
Rural location, yes	14 (36%)	12 (40%)	11 (32%)
Marital status			
Never married	20 (51%)	9 (30%)	
Currently married (monogamous)	13 (33%)	11 (37%)	
Currently married (polygamous)	3 (8%)	0 (0%)	
Previously married *	2 (5%)	8 (27%)	
Remarried	1 (3%)	2 (7%)	
Educational status (adults: years in school; youth: currently in school, yes)	Mean 8.2 (SD 3.7)	Mean 6.1 (SD 3.3)	27 (80%)
Employment status, yes	23 (59%)	5 (17%)	-
Spouse employment status, yes (if applicable)	3 (18%)	11 (85%)	-
Median housing quality score (IQR)	11.0 (6.0–12.0)	12.0 (3.0–13.0)	13.0 (6.0–13.0)
Median household wealth in Kwacha	K1,220,000	K295,000	K902,500
Median in USD (IQR)	\$358 (52–676)	\$86 (9–256)	\$264 (123–795)
Food Insecure, yes	10 (26%)	10 (33%)	-
Physical stigmata of epilepsy present †	8 (21%)	14 (47%)	-
Median age of epilepsy onset, years (IQR)	16.5 (8–28)	14.0 (10.5–20)	-
Most recent seizure			
1 week ago	10 (28%)	8 (27%)	9 (27%)
>1 week ago to 1 month ago	12 (33%)	5 (17%)	7 (21%)
>1 month ago to 1 year ago	8 (22%)	9 (31%)	7 (21%)
>1 year ago	6 (17%)	7 (24%)	11 (33%)
Presently taking an antiepileptic drug (AED), yes	37 (97%)	28 (93%)	32 (94%)
Adherent to AED, yes	20 (51%)	18 (60%)	21 (60%)
Disclosure status (Do people in your community know you have epilepsy?)			
Yes, because I told them	8 (20%)	5 (17%)	-
Yes, because others told them or they saw me have a seizure	19 (49%)	19 (63%)	
No	11 (28%)	6 (20%)	
Missing	1 (3%)	0 (0%)	
Shona Symptom Questionnaire			
Mean (SD)	5.0 (3.1)	5.6 (2.6)	5.58 (3.4)

	Men (n=39)	Women (n=30)	Youth (n=34)
Median (IQR)	4.0 (3.0–8.0)	6.0 (3.0–8.0)	5.0 (3.0–8.0)
Requiring psychiatric support [‡]	18 (46%)	20 (67%)	15 (43%)
Felt stigma “Because of my epilepsy...”			
I feel some people are uncomfortable with me, yes	17 (47%)	14 (45%)	23 (67%)
I feel some people treat me like an inferior person, yes	17 (45%)	13 (43%)	18 (53%)
I feel some people would prefer to avoid me, yes	16 (42%)	9 (30%)	20 (59%)
Mean Felt Stigma Score (SD)	1.3 (1.3)	1.2 (1.2)	1.79 (1.2)
Personal Safety			
Well, stream or river used as household water source ^{††}	7 (18%)	5 (17%)	4 (12%)
Kerosene/gas, candles or fire used for household lighting ^{‡‡}	22 (56%)	19 (63%)	15 (43%)
Wood, charcoal or kerosene stove used for cooking ^{‡‡}	23 (59%)	20 (67%)	14 (40%)
Familial physical abuse, yes	6 (15%)	12 (40%)	-
Rape, yes (women only)	-	4 (13%)	-
Transactional sex, yes (women only)	-	3 (10%)	-

* Divorced, widowed, or separated and not remarried

[†] Interviewer assessed

[‡] Scores > 5 using the Shona Symptom Questionnaire

^{††} Proxy measure for increased risk of drowning

^{‡‡} Proxy measure for increased risk of burns

Table 2

Participant Characteristics Associated with PSG Attendance

	<6 meetings	6 meetings	p-value
ADULTS	(n=16)	(n=53)	
Gender, Female	6 (40%)	24 (44%)	1.00
Mean educational attainment, years (SD)	6.7 (3.6)	7.4 (3.7)	0.52
Currently employed	5 (33%)	23 (43%)	0.57
Mean wealth, kwacha (SD)	K1,683,333 (2,306,105)	K1,812,407 (3,989,752)	0.87
Familial physical abuse, yes	3 (20%)	15 (28%)	0.74
Disclosure status (Do people in your community know you have epilepsy?)			
Yes, because I told them	3 (20%)	10 (19%)	0.11
Yes, because others told them or they saw me have a seizure	6 (43%)	32 (59%)	
No	6 (43%)	11 (20%)	
Mean number of children at home, women only (SD)	2.67 (1.4)	2.75 (1.9)	0.92
Physical stigmata, yes	2 (13%)	20 (37%)	0.12
Baseline Shona Symptom Questionnaire Score, mean (SD)	5.5 (2.7)	5.2 (2.9)	0.74
Baseline felt stigma score, mean (SD)	1.1 (1.3)	1.3 (1.3)	0.54
YOUTH	(n=7)	(n=27)	
Gender, female	3 (33%)	12 (46%)	0.70
Currently in school, yes	6 (85%)	21 (78%)	1.00
Mean wealth, kwacha (SD)	K2,332,857 (2,759,491)	K2,011,852 (3,157,030)	0.80
Mean Baseline Shona Symptom Questionnaire Score	5.0 (2.7)	5.8 (3.6)	0.59
Baseline felt stigma score, mean (SD)	2.5 (0.8)	1.6 (1.2)	0.056

Table 3

Effect of PSG Intervention

	Pre-intervention	Post-intervention	p-value
Adults (n=53)			
Felt stigma score, mean (SD)	1.26 (1.24)	1.06 (1.05)	0.20
Shona Symptom Questionnaire, mean (SD)	5.2 (2.9)	5.7 (3.0)	0.12
Requiring psychiatric support *	26 (48%)	24 (44%)	0.81
Currently taking an AED, yes	52 (96%)	50 (98%)	1.00
Drug adherence, yes	31 (58%)	25 (46%)	0.26
Disclosure status (Do people in your community know you have epilepsy?)			
Yes †	43 (80%)	45 (83%)	0.69
No	11 (20%)	9 (17%)	
Youth (n=27)			
Felt stigma score, mean (SD)	1.58 (1.2)	1.04 (1.3)	0.02
Shona Symptom Questionnaire, mean (SD)	5.7 (3.6)	5.0 (3.1)	0.49
Requiring psychiatric support *	13 (48%)	11 (41%)	0.73
Currently taking an AED, yes	24 (92%)	24 (92%)	-
Drug adherence, yes	15 (58%)	13 (50%)	0.75

* Scores > 5 using the Shona Symptom Questionnaire

† Includes forced and voluntary disclosure