

## Stigma and psychiatric morbidity among mothers of children with epilepsy in Zambia

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**Background:** Epilepsy-associated stigma contributes substantially to the social, medical, and economic burden of disease for people with epilepsy (PWE), but little is known about its impact on caregivers of PWE.

**Methods:** To better understand stigma experienced by caregivers of PWE, factors that influence caregiver stigma, and the effect of stigma on a caregiver's psychologic well being, we interviewed 100 caregivers of children with epilepsy in Zambia. Questions assessed maternal knowledge, attitudes, and practices related to epilepsy, maternal stigma, mother's proxy report of child stigma, and maternal psychiatric morbidity.

**Results:** Of 100 mothers, 39 (39%) indicated that their child was stigmatized because of his or her epilepsy. Maternal proxy report of child stigma was highly correlated with maternal stigma (OR: 5.4,  $p=0.04$ ), seizure frequency ( $p=0.03$ ) and seizure severity ( $p=0.01$ ). One in five of 100 mothers (20%) reported feeling stigmatized because of their child's epilepsy. Higher maternal stigma was associated with lower familial and community support (ORs: 65.2 and 34.7, respectively; both  $p<0.0001$ ) as well as higher psychiatric morbidity (OR: 1.2;  $p=0.002$ ). Formal education and epilepsy knowledge were associated with decreased maternal stigma (ORs: 0.8 and 0.7, respectively; both  $p<0.001$ ).

**Conclusions:** One in five mothers of PWE feel stigmatized because of their child's epilepsy. As maternal stigma is associated with psychiatric morbidity, educating caregivers about epilepsy and screening for anxiety and depression are warranted.

**Keywords:** Affiliate stigma, Africa, Caregiver, Depression, Education, Felt stigma

### Introduction

Epilepsy, a condition characterized by sudden, recurrent seizures, affects an estimated 70 million people worldwide.<sup>1</sup> Eighty percent of people with epilepsy (PWE) live in developing countries like Zambia, where treatment is largely unavailable and, as a result, seizure control is often poor.<sup>2</sup> Epilepsy-associated stigma continues to contribute substantially to the social and economic burden of disease for PWE.<sup>3</sup> However, the extent and impact of epilepsy-associated stigma on family members and caregivers of PWE remains largely unexplored.

Multiple definitions have been used to describe stigma; however, it is generally agreed that the process of stigmatization

involves 'labeling, stereotyping, separation, status loss, and discrimination'.<sup>4</sup> When examining stigma from the perspective of PWE, stigma can be divided into two types. Interpersonal or 'enacted' stigma describes stigmatizing behaviors or attitudes which, if acted upon, would lead to discrimination directed at PWE by individuals not affected by epilepsy. Internalized or 'felt' stigma describes self-stigmatization by PWE.<sup>5</sup> This self-stigmatization results from the internalization of enacted stigma and the individual shame associated with a diagnosis of epilepsy.<sup>6</sup> Epilepsy-associated stigma, although perhaps less apparent, also impacts the family members and caregivers of PWE. 'Courtesy stigma' describes the extension of enacted stigma to those in close proximity to PWE,<sup>7</sup> whereas 'affiliate

stigma' refers to a caregiver's self-stigmatization in response to the individual's beliefs about epilepsy and subjective experiences with encountered or perceived courtesy stigma.<sup>8</sup>

Investigations into epilepsy-associated stigma have been primarily limited to the stigma experienced by PWE. Shibre et al. asked relatives of PWE in Ethiopia about their experiences with stigma; however, as relatives' responses were combined with those from PWE for analysis, it is challenging to characterize their experiences with stigma.<sup>9</sup> Other publications that have queried caregivers regarding stigma have done so to obtain a proxy for PWE's felt stigma.<sup>10-12</sup> It has been suggested that proxy report of felt stigma may not be accurate, as felt stigma relies heavily on perceptions of and interpretations of enacted stigma;<sup>13</sup> however, this has not been formally assessed to date. Among caregivers of children with epilepsy, maternal proxy report of increased child-felt stigma has been associated with increased seizure frequency<sup>11</sup> and decreased maternal confidence in seizure control.<sup>10</sup>

The relationship between stigma, caregiver characteristics, and caregiver mental health is complex and poorly understood. Work by Mak and Kwok with caregivers of children with intellectual disability suggests that the relationship between courtesy stigma and affiliate stigma is partially mediated by a caregiver's perceived ability to control and perceived responsibility for the child's condition.<sup>8</sup> Among these caregivers, affiliate stigma has been repeatedly associated with increased anxiety and depression.<sup>14,15</sup> Although it is well known that caregivers of children with epilepsy often experience increased stress and frustration,<sup>16</sup> chronic sorrow,<sup>17</sup> and depression,<sup>10,18-20</sup> the prevalence and role of affiliate stigma in the development of these psychiatric morbidities is not known. However, addressing the influence of affiliate stigma is essential for the well being of the caregiver and also because the caregiver's psychiatric morbidity adversely affects the quality of life of children with epilepsy.<sup>21</sup>

To better understand stigma experienced by caregivers of PWE, factors that influence caregiver stigma, and the effect of stigma on caregivers' psychiatric morbidity, we conducted interviews with the primary caregivers of children with epilepsy in Zambia. In this setting, the primary caregiver for a young child is typically the child's mother. A secondary aim of these interviews was to investigate the characteristics that influence proxy reports of child felt stigma.

## Materials and methods

### Study population

The study population consisted of a convenience sample of mothers obtaining non-urgent epilepsy care for their child at four Lusaka-area clinics. The study sample was restricted to mothers because early pilot work established that neither other female relatives nor fathers accompanying children to visits were comfortable responding to interview questions. These sites are secondary level clinics, staffed primarily by medical officers and psychiatric clinical officers, and were selected for study because they have established days for epilepsy clinics. Potential study participants were restricted to mothers over the age of 18 years who were the primary caregivers for a child with epilepsy under the age of 8 years. Mothers of children attending the

clinic for the first time were not eligible for study inclusion, to ensure that that the child had an established diagnosis of epilepsy.

C. Sakubita-Simasiku, a graduate student in sociology and primary school teacher who is also the mother of a child with epilepsy, conducted all the interviews. Eligible mothers were approached while they were waiting for their child to be seen by healthcare providers at the study sites. At these clinics, appointment days are scheduled but not times. Therefore, patients typically have a lengthy wait before seeing a provider. The consent forms were read aloud and privately discussed with mothers before obtaining written consent in the participant's preferred language (English, Nyanja or Bemba). Before the study was started, approval was gained from the University of Zambia's Humanities and Social Sciences Research Ethics Committee.

### Instruments

The survey instrument was designed to be administered via semi-structured interview and included questions on the following: maternal knowledge, attitudes, and practices related to epilepsy; maternal stigma; child felt stigma obtained via maternal proxy; and maternal psychiatric morbidity. Maternal knowledge, attitudes, and practices (KAP) related to epilepsy were assessed using seven questions adapted from an Epilepsy Knowledge, Attitudes, and Practices instrument developed and validated in Zambia.<sup>22,23</sup> Using the six items related to maternal knowledge of epilepsy, a knowledge score was calculated for each mother (range 0-6). A permissive score for child activities was also calculated, using six items describing activities that the child might participate in (range 0-6). To assess the mother's perception of the child's stigma and maternal stigma, the three-item stigma scale was employed.<sup>24</sup> This instrument creates a ranked score for stigma severity and has been used in this setting previously.<sup>25</sup> Maternal psychiatric morbidity was assessed using the Shona Symptom Questionnaire (SSQ), which is a 14-item screening instrument that queries culturally relevant symptoms of psychological disorders.<sup>26</sup> This instrument has been used successfully with other populations in Zambia and was not modified for this study.<sup>27,28</sup> Individuals who score greater than five on the SSQ are considered to warrant further psychological assessment.<sup>29</sup>

Additional survey questions included: maternal and child demographics; maternal economic status; child developmental and nutritional status; and child seizure characteristics. Economic status was assessed using a measurement that enumerates and values common household items.<sup>25</sup> Child developmental disability was assessed using the 'The Ten Questions' screen, which has been validated to detect moderate to severe cognitive, motor, vision and hearing disabilities in children as young as 2 years using a caregiver report.<sup>30</sup> This screen has been previously used successfully in Lusaka.<sup>31</sup> A composite score for developmental disability was created by summing the disability present for each child (range 0-8) and dichotomized to reflect severity of disability. Nutritional status was obtained by comparing child height and weight measurements to WHO child growth charts. All questions were directed at the mother; none was put directly to the child with epilepsy.

## Statistical analysis

Responses to interview questions were recorded on paper copies of the survey instrument before entry into Microsoft Excel. Entered data were then verified for accuracy before importing into SAS 9.3 (SAS Institute, Cary, NC, USA) for analysis. Outcomes were assessed for normality and two-tailed comparisons were made using logistic regression. Multiple logistic regression was not performed, as confounding variables pertinent to the relationships examined have not been established. A p-value of <0.05 was considered statistically significant.

## Results

Between February and September 2010, 100 mothers of children with epilepsy were interviewed. Three interviews were excluded from analysis because the children were attending the clinic for the first time and they did not have an established diagnosis of epilepsy.

Maternal and child demographics, child clinical characteristics, and maternal KAP are outlined in Tables 1–3. The average age of mothers was 32.4 years (SD 6.4). Fifty-seven percent (55/97) of the children with epilepsy were male (average age 5.6 years; SD 2.1). The mean disability score for the children was 2.4 (SD 1.0); 98% of mothers (95/97) reported that their child exhibited some sort of developmental disability. Only 23/37 of children old enough to attend school (62%) were enrolled. Epilepsy-related illness was most commonly cited reason for not enrolling the child in school (10/14 children, 71%). Although most mothers believed that their child's medication was extremely or somewhat effective, recurrent seizures were common. Sixty-six percent of children (63/97) had seizures at least once a month. Despite this, 46% (45/97) of mothers thought that it was not difficult to care for their child. Interestingly, 77% of mothers (75/97) had also used traditional medicine to treat their child's seizures.

Maternal education and knowledge regarding epilepsy were high (9.7 years, SD 2.3 and 3.8 SD 1.3, respectively), yet 25% of mothers (24/97) did not know what causes epilepsy. Six individuals (6/97, 6%) correctly identified the causes of epilepsy, but explained that their response was in accordance with what health professionals had told them and not what they believed. Forty-six percent of mothers (44/97) indicated that epilepsy was the result of witchcraft. When caring for their child during a seizure, 59% (56/97) knew to place their child on his or her side. However, 21% (20/97) inappropriately held him or her down and 20% (19/97) place something in their child's mouth.

Thirty-eight percent of mothers (37/97) indicated that they thought that their child was stigmatized by others because of his or her epilepsy. Community and familial rejection of the mother and child with epilepsy was common. Twenty-one percent of mothers (20/97) felt that their child had been rejected by the community. Twenty percent of mothers (19/97) reported feeling stigmatized because of their child's epilepsy. As shown in Table 4, three-item stigma scores ranged from 0 to 3, with 14% of mothers (14/97) endorsing the highest level of stigma. In addition, mothers reported substantial psychiatric morbidity (mean 4.2; SD 2.1). Forty percent of mothers (39/97) scored greater than five on the SSG, suggesting a need for additional psychiatric assessment and support.

**Table 1.** Demographics of 97 mothers and their children with epilepsy attending four Lusaka-area clinics in Zambia

Maternal demographics	
Age (years), mean (SD)	32.4 (6.4)
Marital status	
Married	77 (80)
Divorced/separated	3 (3)
Widowed	8 (8)
Single	8 (8)
Other	1 (1)
Formal education (years), mean (SD)	9.7 years (2.3)
Household wealth (US\$)	
Mean (SD)	688.50 (816.64)
Median (IQR)	311.54 (311.54–1141.35)
Earnings lost because of need to provide care for the child	
A lot	18 (19)
A little	63 (65)
Never/none	15 (15)
Missing	1 (1)
Residence, high density	67 (69)
Child demographics	
Gender male	55 (57)
Age (years), mean (SD)	5.6 (2.1)
No of siblings	
Mean (SD)	2.1 (1.8)
Range	0–10
Birth order	
1st	29 (31)
2nd	31 (33)
3rd	14 (15)
>3rd	23 (22)
School attendance	
If >7 years old, in school (n=37)	23 (62)
Not enrolled because of epilepsy-related illness	10 (71)

Values are no. (%) unless otherwise indicated.

Maternal proxy report of child stigma was associated with maternal stigma (OR: 5.4,  $p=0.04$ ), and with seizure frequency ( $p=0.03$ ) and seizure severity (OR: 9.3;  $p=0.01$ ), as shown in Table 5. Severe developmental delay was associated with more stigma (OR: 2.3;  $p=0.045$ ). Proxy report of child stigma was highly correlated with community and family rejection of the child (ORs: 21.6 and 12.1, respectively; both  $p<0.0001$ ) and with community and familial rejection of the mother (ORs: 6.0 and 8.8, respectively; both  $p<0.0001$ ).

Maternal stigma was significantly associated with lower familial and community support (ORs: 65.2 and 34.7, respectively; both  $p<0.0001$ ). It was also associated with less perceived effectiveness of epilepsy treatment (OR: 235.9;  $p<0.0001$ ) and lost earnings (OR: 7.4;  $p=0.009$ ). Formal education and epilepsy-specific knowledge were associated with decreased maternal stigma

**Table 2.** Clinical characteristics of 97 children with epilepsy attending four Lusaka-area clinics in Zambia

Development when compared to other children of the same age	
Delayed standing, sitting or walking	21 (22)
Difficulty seeing either at daytime or night	4 (4)
Difficulty learning new things	25 (26)
Appears mentally backward, dull, or slow	25 (26)
Problems understanding when told to do something	22 (23)
Difficulty with movement of arms or legs	16 (16)
Speech/naming problems	21 (22)
Difficulty with hearing	5 (5)
Disability score	
Mean (SD)	2.4 (1.0)
Median (range)	2 (0–6)
Severe disability, yes (%)	32 (33)
Nutritional status	
Underweight	3 (3)
Normal	91 (94)
Overweight	3 (3)
Epilepsy characteristics	
Seizure frequency	
Daily	6 (6)
Weekly	30 (31)
Monthly	27 (28)
Less than monthly	33 (34)
Missing	1 (1)
Seizure severity (mother's subjective rating)	
Mild	26 (27)
Moderate	64 (66)
Severe	7 (7)
How effective is the medication in controlling your child's epilepsy?	
Extremely	32 (33)
Somewhat	59 (61)
Not at all	2 (2)
Missing	4 (4)

Values are no. (%) unless otherwise indicated.

(ORs: 0.8 and 0.7, respectively; both  $p < 0.0001$ ). Mothers with higher stigma levels were more likely to experience psychiatric morbidity (OR: 1.2;  $p = 0.0002$ ) and be in need of additional psychiatric support (OR: 4.2;  $p = 0.0093$ ) than those with lower stigma levels. In addition, mothers with more stigma were more likely to limit their child's activities (OR: 0.5;  $p < 0.0001$ ) than those with less stigma. Adjusting for the child age and disability did not substantially change the relationship between affiliate stigma and child permissive score.

## Discussion

This study found that one in five mothers of children with epilepsy experiences substantial stigma as a result of their children's

**Table 3.** Knowledge, attitudes, and practices (KAP) regarding epilepsy of 97 mothers of children with epilepsy attending four Lusaka-area clinics in Zambia

Knowledge	
Thinks her child's epilepsy can be treated	74 (76)
Thinks her child's epilepsy is contagious	4 (4)
Believes epilepsy is a form of/caused by:	
Madness	2 (2)
Spirit or demon possession	9 (9)
Mental retardation	4 (4)
Brain injury	62 (65)
Runs in family	15 (16)
Witchcraft	44 (46)
Excessive worry	3 (3)
Not sure	24 (25)
Mean knowledge score (SD)	3.8 (1.3)
Attitude	
How difficult do you find it caring for your child?	
Not difficult	45 (46)
Difficult	31 (32)
Fairly difficult	16 (17)
Extremely difficult	5 (5)
Practices	
What do you do when your child has a seizure?	
Turn them on their side	56 (59)
Place an object in their mouth	19 (20)
Hold them down	20 (21)
Remain distant from them	3 (4)
What activities does your child participate in?	
Attends school	42 (44)
Participates in sports	56 (58)
Climbs trees	12 (13)
Swims	1 (1)
Plays with other children	83 (86)
Helps in the home	44 (46)
Mean permissive score for activities (SD)	2.5 (1.5)
Has used traditional medications to treat her child's epilepsy	75 (77)

Values are no. (%) unless otherwise indicated.

condition. Affiliate stigma describes self-stigmatization by caregivers of PWE in response to encountered or perceived discrimination because of their association with epilepsy. We found that both formal education and epilepsy-specific knowledge were associated with less affiliate stigma, whereas less familial and community support was associated with more affiliate stigma.

As previously reported, seizure frequency and seizure severity affects maternal proxy report of child felt stigma.<sup>10,11</sup> Severe developmental disability was associated with higher estimates of proxy child stigma. The strength of this relationship may have been underestimated in this study because 'The Ten Questions' screen has been validated only for children older than 2 years and, as a result, may have detected only gross disability in

**Table 4.** Maternal stigma and psychiatric morbidity in 97 mothers and their children with epilepsy attending four Lusaka-area clinics in Zambia

	Mother	Child
Rejected by:		
Community	10 (11)	20 (22)
Family	11 (12)	14 (15)
Other children	NA	15 (16)
Teachers (n=39)	NA	2 (2)
Because of my child's epilepsy:		
Some people are uncomfortable with me/my child	18 (19)	35 (37)
Some people would prefer to avoid me/my child	17 (18)	35 (37)
Some people treat me/my child like an inferior person	14 (15)	34 (36)
Three-item stigma score		
0	78 (80)	60 (62)
1	3 (3)	3 (3)
2	2 (2)	1 (1)
3	14 (14)	33 (34)
Mean three-item stigma score (SD)	0.52 (1.1)	1.1 (1.4)
Shona Symptom Questionnaire		
During the course of the past week:		
Thinking deeply or thinking about many things	85 (88)	NA
Failing to concentrate	42 (43)	NA
Lose your temper or get annoyed over trivial matters	8 (8)	NA
Nightmares or bad dreams	7 (7)	NA
See or hear things that others could not see or hear	1 (1)	NA
Stomach aching	2 (2)	NA
Frightened by trivial things	4 (4)	NA
Fail to sleep or lose sleep	77 (80)	NA
Cry or wanted to cry	43 (45)	NA
Run down or tired	73 (75)	NA
Feel like committing suicide	1 (1)	NA
Unhappy with things you were doing each day	7 (7)	NA
Work lagging behind	44 (45)	NA
Problems deciding what to do	13 (14)	NA
Mean (SD)	4.2 (2.1)	
Warranting additional psychiatric assessment and support <sup>a</sup>	39 (40)	NA

Values are no. (%) unless otherwise indicated.

<sup>a</sup>Scores >5 using the Shona Symptom Questionnaire; NA: not applicable.

younger children. However, as only 6% of our sample was under 2 years of age, the effect of this was probably minimal. This study also suggests that maternal proxy report of child felt stigma is largely associated with maternal perceptions of rejection by

**Table 5.** Characteristics associated with stigma in 97 mothers and their children with epilepsy attending four Lusaka-area clinics in Zambia

Characteristic	OR (CI)
Maternal proxy report of child stigma	
Mother's reported stigma	5.4 (1.1–27.7)
Community rejection of	
Child, yes	21.6 (7.4–59.9)
Mother, yes	6.0 (2.5–14.5)
Family rejection of	
Child, yes	12.6 (4.8–33.5)
Mother, yes	8.8 (3.5–22.4)
Severe disability, yes	2.3 (1.0–5.3)
Seizure frequency (1=less than monthly)	
Monthly	NS
Weekly	3.5 (1.2–10.0)
Daily	7.5 (1.6–35.4)
Seizure severity (1=mild)	
Moderate	NS
Severe	9.3 (2.0–44.3)
Mother's stigma	
Rejection by family, yes	65.2 (17.8–237.9)
Rejection by community, yes	43.7 (13.0–146.7)
Effectiveness of treatment (1=extremely effective)	
Somewhat effective	NS
Not at all effective	235.9 (29.3–> 999.9)
Report of lost earnings due to need to provide care for the child (1=never/none)	
A lot	7.4 (1.2–45.6)
A little	NS
Formal education, years	0.8 (0.7–0.9)
Knowledge of epilepsy score	0.7 (0.6–0.8)
Permissive score	0.5 (0.4–0.7)
After adjusting for child age and disability	0.6 (0.4–0.9)
Shona Symptom Questionnaire score	1.2 (1.1–1.3)
Among those needing psychiatric support	4.2 (1.4–12.1)

NS: not significant; OR: odds ratio.

family and community as well as maternal stigma. Because of this, proxy report of felt stigma may actually more accurately reflect maternal stigma than the stigma experienced by the PWE. Further research is required to determine how much caregiver beliefs and experiences impact proxy report of a PWE's felt stigma.

In our study, maternal affiliate stigma was associated with more psychiatric morbidity. Additional research into this relationship is necessary, as maternal depression has been repeatedly shown to adversely affect child behavior and quality of life.<sup>19,32</sup> This suggests that caregivers should be screened and



treated for depression and anxiety. Ideally, support should be routinely provided to caregivers, but in settings where healthcare resources are scarce, this may not be possible. In resource-limited settings like Zambia, where mothers often obtain medical care in the same healthcare facility as their child, it may be feasible to screen and treat psychiatric morbidity in caregivers while treating the child's epilepsy. Care for both epilepsy in the child and depression or anxiety, or both, in mothers can now be guided by the WHO's Mental Health Gap Action Program (mhGAP).<sup>33</sup> This study also suggests that affiliate stigma adversely affects child activities. Further investigations into this relationship are vital given the detrimental impact this may have on the child's future.

### Limitations

It is important to note that the participants selected for this study were drawn from a convenience sample of mothers seeking care for their child with epilepsy at four Lusaka-area clinics. As a result, when compared with the general population, this sample has a higher level of formal education and a greater percentage is married.<sup>34</sup> Because education and familial support were found to be associated with decreased affiliate stigma, the prevalence of affiliate stigma may be greater in the general population of caregivers of children with epilepsy than is reported here. In addition, the findings of this study may not be generalizable to all caregivers of PWE in Zambia due to the substantial disparity between the number of individuals in need of epilepsy treatment and those that have access to it.

This study is one of the first to assess the prevalence and role of epilepsy-associated affiliate stigma among caregivers of children with epilepsy. Our findings suggest that future interventions designed to decrease stigma in this setting should include caregivers of PWE.

**Authors' contributions:** CSS, GB, AH, and EC conceived the study; CSS, AH and GB designed the study protocol; CSS carried out data collection; ME, AH and CSS conducted data entry; GB and ME conducted data analysis. ME drafted the manuscript; ME, GB, and MA critically revised the manuscript for intellectual content. All authors read and approved the final manuscript. GB is the guarantor of the paper.

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