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Measuring the challenges of people with epilepsy in Harare, Zimbabwe

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Measuring the challenges of people with epilepsy in Harare, Zimbabwe

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Abstract

In this 6 months study the researchers measured the challenges of people with epilepsy who were all members of the Epilepsy Support Foundation in Harare, Zimbabwe. Possible challenges arising from the various aspects of life of 60 people with epilepsy were measured using a Problem Index Questionnaire for People with Epilepsy adapted from Dr. John Collings Problem Index method which was used at Leeds Polytechnic in 1990 to develop the British Epilepsy Association's Charter for Epilepsy. The method uses a short questionnaire that has a set of problem areas with three possible responses, 'no problem', 'some problems' and 'serious problems'. The index was found by combining 'some problems' and 'serious problems' and reflects the degree to which an aspect of life was problematic. Results from interviews and observations were also utilised. The study shows that the people with epilepsy's major life challenges are psychosocial, followed by economic and lifestyle. The most common issues regarded as problematic are: securing adequate income (93%), society's attitude (87%), stigma (87%), standard of living (83%), memory (83%), overprotection (78%), finding and maintaining employment (78%).

INTRODUCTION

The International Bureau for Epilepsy (IBE) believes that epilepsy affects 50 million people worldwide[1,2], a view supported by the World Health Organisation (WHO).[2] WHO further estimates that about 0.5% of any given population might have epilepsy.[2] However, as shown by the Global Campaign Against Epilepsy (GCAE), prevalence rates vary from region to region.[3] Prevalence for Africa, Europe and Western Pacific are given by WHO as 1.12%, 0.82% and 0.36% respectively.[2,3] With modern medicine, epileptic seizures can be controlled but not cured.[4]

In Zimbabwe, the Epilepsy Support Foundation (ESF) estimates a prevalence of one percent.[5] This estimate is in line with world estimates for African nations. However, advocates for epilepsy work in Zimbabwe, among them the late Nicholas George (founder of ESF) argued that prevalence could be over two percent[5], although no comprehensive prevalence study has been conducted in the country. This is supported by some of the other health professionals based in Africa.[4,6]

Societal attitudes may shape quality of life of people with epilepsy.[5,7] In Zimbabwe, to begin with, epilepsy is referred to as *zvipusha* in Shona, the main vernacular language. *Zvipusha* means a condition that is infectious.[8] There are other non-derogatory names though, like *pfari* (jerking), *kugwinha* (fitting) and *tsviyo* (minor sound) which all describe seizures.[8] The name of epilepsy really does matter. In their review, Lim *et al*. noted that some names add to stigma and misunderstanding on people with epilepsy in Asia.[7] This may also be true in Zimbabwe, given names like *zvipusha.*

With education, mainly promoted by the ESF, changes in attitudes have been seen mainly in urban areas.[9] However, this achievement seems to be eroded by high rural-urban migration which brings into urban centres rural residents who still harbour misunderstandings about epilepsy. As a result, people with epilepsy in Zimbabwe has to face numerous challenges, including poor understanding of the disease, impaired access to treatment, predisposition to burns and injuries; prejudice that affect socialisation, marriage, school and work, resulting in impaired quality of life and socioeconomic status.[10]

Since 1990, the ESF, a member of the International Bureau for Epilepsy (IBE) and a partner of the Zimbabwe League Against Epilepsy (ZLAE) has been promoting epilepsy awareness, treatment and providing back up support to people with epilepsy. The ESF has a centre in Harare that has social rehabilitation unit, a clinic and an EEG unit.

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This research sought to investigate the challenges people with epilepsy are facing in urban Zimbabwe in spite of them being on treatment.

METHODS

The study subjects were adult people with epilepsy who were members of the ESF. ESF had 150 active adult members in May 2012, 60 members were interviewed. Of the 90 members who were not interviewed, 30 did not consent, 45 were not available for various reasons, 12 had migrated and 3 were sick.

Data gathering involved interviewers asking respondents a set of questions from the Problem Index Questionare for People with Epilepsy. The questionnaire was adapted from Dr. John Collings Problem Index method, which was used at Leeds Polytechnic in 1990 to develop the British Epilepsy Association's Charter for Epilepsy. This was a short questionnaire that has a set of problem areas with three possible responses, 'no problem', 'some problems' and 'serious problems' was used. The index was found by combining 'some problems' and 'serious problems' and reflects the degree to which an aspect of life was problematic. Interviews were conducted in both Shona, the vernacular language and English. This helped clarify terms. An explanation was given by the interviewer to ensure that the respondent understands the question.

Data was gathered between May 2011 and June 2012 with the aid of 4 research assistants. Two of these research assistants were Social Work students on attachment at ESF, one was a Trainee Counsellor working for ESF and another was a Nurse Aid Volunteer at the ESF. Both the Trainee Counsellor and Nurse Aid Volunteer were living with epilepsy.

Findings from the study were analysed with the help of Microsoft Excel.

RESULTS

All the respondents were residing in Harare, Zimbabwe's capital city. Of the respondents, 24 were males and 36 were females. They were aged between 19 and 56 years with most of them falling within the range 27-34 years. Half of respondents had completed secondary school "O" level. Of the 54 respondents who consented to declare their marital status, two were widowed, 20 were single and 14 were married.

Table 1 shows the responses on psychosocial aspects of life. Of the responses, society's attitudes and stigma were regarded as the most problematic by 87% of respondents, followed by standard of living (83%) and memory (83%).

Table 2 shows the responses on lifestyle. Of the responses, overprotection was regarded as problematic by 78%, followed by driving (73%).

Table 3 shows the responses to the economic issues. As shown, the most problematic was securing adequate income (93%), followed by finding and maintaining employment (78%).

Table 4 shows the responses to the physical challenges. As shown, doing family chores was regarded as most problematic (67%), followed by sleeping (62%).

Table 5 shows the responses to health related issues. Overall, health related aspects of epilepsy

Table 1: Distribution of responses by psychosocial challenges

Aspect of Life	No problems	Some problems	Serious Problems	Problem Index n	Problem Index Percent
Society's attitudes	8	28	24	52	87%
Self image	14	28	18	46	77%
Stigma	8	34	18	52	87%
Friendships	31	16	13	29	48%
Courtship	22	19	19	38	63%
Standard of living	10	34	16	50	83%
Plans for future	16	19	25	44	73%
Memory	10	31	19	50	83%
Mean in percent	**25%**	**44%**	**32%**		**75%**

Table 2: Distribution of responses by lifestyle challenges

Aspect of Life	No problems	Some problems	Serious Problems	Problem Index n	Percent
Child care	18	19	23	42	70%
Bathing	37	10	13	23	38%
Driving	16	12	32	44	73%
Transport	28	22	10	32	53%
Overprotection	13	21	26	47	78%
Leisure	28	19	13	32	53%
Mean in percent	**39%**	**29%**	**33%**		**61%**

Table 3: Distribution of responses by economic challenges

Aspect of Life	No problems	Some problems	Serious Problems	Problem Index n	Percent
Finding and maintaining employment	13	19	28	47	78%
Schooling	22	22	16	38	63%
Further education	25	16	19	35	58%
Securing adequate income	4	22	34	56	93%
Social welfare	31	16	13	29	48%
Legal matters	34	13	13	26	43%
Mean in percent	**36%**	**30%**	**34%**		**64%**

Table 4: Distribution of responses by physical challenges

Aspect of Life	No problems	Some problems	Serious Problems	Problem Index n	Percent
Movement	36	15	9	24	40%
Sleeping	23	15	22	37	62%
Effective work speed	34	16	10	26	43%
Cooking on hot plate stove	38	12	10	22	37%
Sporting	38	9	13	22	37%
Travelling	35	12	13	25	42%
Family chores	20	30	10	40	67%
Child bearing	35	9	16	25	42%
Mean in percent	**55%**	**24%**	**21%**		**45%**

Table 5: Distribution of responses by health challenges

Aspect of Life	No problems	Some problems	Serious Problems	Problem Index n	Problem Index Percent
Medication	42	12	6	18	30%
Further diagnosis	51	6	3	9	15%
Specialist services	54	3	3	6	10%
Side effects of medication	39	12	9	21	35%
Triggers by computer/TV	48	12	0	12	20%
Mental/psychiatric	51	6	3	9	15%
Mean in percent	**79%**	**14%**	**7%**		**21%**

were reported to be less a problem by the respondents. As shown, side effects of medication was regarded as most problematic by 35%.

Table 6 is a summary of the mean responses to the different challenges. As shown, a mean of 53% respondents indicated they had problems with one or more aspects of their life, 28% had some problems and 25% serious problems. The aspects of life most problematic was psychosocial, (75%), followed by economic (64%), and lifestyle issues (61%).

DISCUSSION

In this study, we have confirmed that majority of people with epilepsy on treatment in Harare faced problems arising from their epilepsy. Their major challenges were psychosocial, followed by economic. By comparison, health related issues were the least of the challenges. For psychosocial issues, The findings in this study confirms that stigmatization and society's attitude were the most common problems faced by the people with epilepsy in Harare. This is similar to many other parts of the world, probably due to negative cultural and religious beliefs.[3,6] Misconception that epilepsy is contagious may also contribute to the stigmatization.[10] The video documentary *Pfari muZimbabwe*/Epilepsy in Zimbabwe by the ESF shows most of these negative attitudes.[10] In one episode, a young man with epilepsy is shown chained to a tree in a bush, alone. This was done to keep him away from the community. Many (83%) of our respondents also regarded memory as a problem. This may partly be due to effect of memory impairment on other aspects of life, such as work productively.

The economic aspect of life was identified by the respondents to be the second most important challenges overall. In fact, 93% of the respondents indicated securing adequate income as a problem, more than society's attitude and stigma (87%). This was probably related to the other problem of finding and maintaining employment (78%). This probably reflects the prejudice which reduces employment opportunities for people with epilepsy in Zimbabwe. Furthermore, because of the general socioeconomic situation of the country, employment rates in Zimbabwe remain very low

Table 6: Summary of the mean responses

Problem Area	No problems in percent	Some problems in percent	Serious problems in percent	Problem Indices in percent
Psychosocial	25%	44%	32%	75%
Lifestyle	39%	29%	33%	61%
Economic	36%	30%	34%	64%
Physical	55%	24%	21%	45%
Health	79%	14%	7%	21%
Mean %	**47%**	**28%**	**25%**	**53%**

even for people without epilepsy.[10] On the other hand, schooling (63%) and further education (58%) was regarded relatively as less problematic. This rating may be because the respondents have been long time members of the ESF, and they got assistance to navigate through this problem.

The lifestyle issues were the rated the next in overall problem faced by the respondents. Of the issues, overprotection was regarded as the most problematic (78%). This may partly due to most people with epilepsy in Zimbabwe remain under the care of their families and friends.[10] This is probably due to the unpredictable occurence of seizures, and the difficulties of securing adequate income to be independent. As for taking bath, although the ESF advices protective measures when a person with epilepsy is taking bath, e.g. not to take bath alone, do not lock the door and not to bath in deep water[8-10], this was considered to be relatively less problematic (38%). Driving was considered to be problematic in 73% of the respondents. There are no specific driving laws for people with epilepsy in Zimbabwe.[5,8]

For physical challenges, 62% had identified sleeping as a problem. It may partly be due to sleep as a precipitant of epilepsy. On the other hand, 67% of the respondents identified doing family chores as a problem. Lethargy from antiepileptic drugs side effect may possibly contribute to this problem. Although two third of respondents indicated that child bearing was not a problem, courtship and presumably marriage was identified as a problem in 63% of the respondents.

For health related issues, close to a third (30%) of our respondents identified medication as a problem. This could be contributed by the older antiepileptic drugs used by majority of patients, which has more side effects.[9] Only minority of respondents identified further diagnosis (15%) and specialist services (10%) as problems. This could be because the respondents were getting services from the ESF which has specialist services including an EEG machine.

In conclusion, we have confirmed that people with epilepsy in Harare encounter numerous problems arising from their epilepsy. Their major challenges were psychosocial, followed by economic and lifestyle issues, though these problems were likely to be closely related.

DISCLOSURE

Conflict of interest: None

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