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Individual resilience as a strategy to counter employment barriers for people with epilepsy in Zimbabwe


Abstract

Understanding individual resilience helps to improve employment opportunities of people with epilepsy. This is significant because, in Zimbabwe, as in many other countries in the Global South, people with epilepsy encounter several barriers in a context of less-than-ideal public services. Despite this disadvantage, some people with epilepsy have better employment outcomes for reasons including level of seizure control, social background, employment support services, and individual resilience. This article reports on data from participants (n=8), who were part of a larger study (n=30) on employment experiences of people with epilepsy in Harare. The study used in-depth interviews with the participants, who were all service users and members of the Epilepsy Support Foundation (ESF) in Harare. The eight resilient participants comprised four males and four females aged between 26-48 years, who were selected because, unlike the remaining 22 participants, they had overcome chronic unemployment. Seven of the eight participants were employed, while one had recently become unemployed. Views of service providers (n=7) were sought on the experiences of people with epilepsy through a focus group discussion. The service providers included two health workers, three social service workers, and two disability advocacy workers. Data were analysed using NVivo, a computer-assisted qualitative data analysis package. The study found that participants experienced barriers, such as a lack of medical treatment, yet this was important for education and training, lack of finances for training, and negative attitudes at workplaces. Despite these barriers, participants had overcome chronic unemployment due to their individual resilience characterised by: (i) a ‘fighting spirit’, (ii) being their own advocates, and (iii) having a mastery over, and acceptance of, their epilepsy. The research concluded that, where people with epilepsy faced barriers, as in Zimbabwe, individual resilience acted as a strong coping mechanism that resulted in better employment outcomes. This suggested service providers should strengthen resilience-building initiatives and make them more accessible to people with epilepsy. However, this is only a coping mechanism that should not stop service providers and service users from advocating for government-provided employment services.

Key words: Epilepsy; Individual resilience; Employment; Zimbabwe

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1. Introduction

A significant number of the 50 million people with epilepsy worldwide are of working age but most lack job skills, employment opportunities, and job security (1). People with epilepsy require employment support to overcome this disadvantage but, in Zimbabwe, as in many other countries in the Global South, such support is usually not available. Despite this, some people with epilepsy achieve better employment outcomes for reasons including level of seizure control, social background, employment support services, and individual resilience. This article reports on individual resilience, one of the themes that emerged out of a study of the employment experiences of people with epilepsy in Harare, Zimbabwe. Extant literature suggests that understanding individual resilience would help to improve employment opportunities for people with epilepsy in situations where public employment support services are not available. The next section presents the context of epilepsy in Zimbabwe, followed by a brief review of literature on epilepsy and resilience, the study methodology, and findings. The concluding section discusses some implications of the findings.

2. Epilepsy in Zimbabwe

A review of literature showed that there was limited research on epilepsy in Zimbabwe and none that directly and comprehensively addressed issues of employment and individual resilience. Nonetheless, existing studies provided a basis for understanding the general situation and context of people with epilepsy in the country (2-8). A theme running through these studies was misunderstanding of epilepsy resulting in high levels of stigma. These emanated mainly from traditional and religious beliefs among Zimbabwe’s indigenous African, and Christian religious adherents. They believed that epilepsy could be treated through faith, prayer, fasting, herbs, or tribal medicines, with the help of traditional, spiritual, or faith healers, depending on the religion in question (6). Biomedical treatment often competed with traditional
or religious healing (4, 5, 9). While traditional treatment was valued as part of Zimbabwean culture, it nonetheless did not offer a better seizure control option than biomedical treatment (4, 5). Adhering to traditional treatments resulted in people with epilepsy having to endure lengthier periods with uncontrolled seizures, a situation that only changed after they had initiated, and complied with, medical treatment (9).

A Zimbabwean study that measured possible life challenges for people with epilepsy (n=60) found that the major obstacles were psychosocial and economic and emanated from a lack of correct knowledge about epilepsy (3). Another study found that myths, misunderstandings, and incorrect knowledge relating to the condition were prevalent in Zimbabwean society and were barriers to the social and economic integration of people with epilepsy (4). The myth that epilepsy was contagious restricted the social interaction of people with epilepsy, supporting observations made in other studies that people with epilepsy were possessed by demons (5, 6). Ninety five (55.5%) of the 165 teachers surveyed in a peri-urban area near Harare said they would employ a person with epilepsy, while 12.6% thought epilepsy was a form of insanity; 0.6% thought evil spirits were a cause; 22.6% believed epilepsy was contagious; 82% would allow their child to play with a child with epilepsy; and 76% would marry a person with epilepsy (7). Researchers attributed these surprisingly favourable findings to the educational status of the respondents, though their study still highlighted the prevalence of negative attitudes towards people with epilepsy, even among educated people in Zimbabwe (7).

Education levels among people with epilepsy were found to be low, as was school attendance among children with epilepsy and the support levels families provided them (8). The researcher concluded that limited educational opportunities were a precursor to poor quality of life for people with epilepsy in Zimbabwe (8). Similar findings were reported in an earlier study (9). Reasons for low school attendance included uncontrolled seizures and
treatment visits, while some caregivers reported that their children faced challenges, such as stigmatisation and labelling in schools (8).

Another study that assessed the functioning of people with epilepsy in Zimbabwe found that the majority (36 of 38 respondents – people with epilepsy and their carers) reported their cognitive impairment had not interfered with their social functioning, work performance, or relationships with others (2). The research reported that respondents were unhindered by seizures. Although self-reporting and carer-reporting was used in this study, the results were crucial in building understanding of how people with epilepsy thought about their social functioning ability.

While these local studies said little about employment and nothing about individual resilience, they nonetheless showed that public services, such as education and health that help people with epilepsy overcome their disadvantage, were less than ideal and that there was a lack of correct knowledge of epilepsy in Zimbabwean society. This had direct implications for employment prospects because, without these services, people with epilepsy encountered difficulties in acquiring the knowledge and skills required for jobs. More so, misunderstanding of epilepsy reduced social interaction and increased isolation and stigma in society, including the workplace, making it difficult for people with epilepsy to gain and maintain work.

3. Epilepsy and resilience

Studies outside Zimbabwe have shown the importance of individual resilience in people with epilepsy (10-13). A number of studies showed that resilience helped people with epilepsy to adapt to, or survive, adversity associated with debilitating seizures and socioeconomic disadvantage and have a good quality of life (12-14) aided by fewer side effects of treatment and the absence of depression (14). Resilience facilitated employment but its absence meant that some people with epilepsy were vulnerable to biopsychosocial disruption (13). Advocates
of the resiliency model argued that individuals experienced biopsychosocial disruption after which they reintegrated in a manner that improved their quality of life and reduced their vulnerability (10, 13).

Studies showed that self-management was an important characteristic of resilient individuals. Resilient individuals depended on their psychological self-management abilities, such as resource seeking, acceptance of epilepsy, and environmental resources, including patient support networks, the positive attitudes of employers or co-workers, or strong family support (13). Resilient self-managers controlled their epilepsy by seeking and maintaining treatment (11). Seizure frequency had no significant impact on the quality of life of resilient individuals (12). This showed that better employment outcomes were achieved by those who were resilient despite seizures.

Prior research suggested that service providers were encouraged to integrate resilience-building factors into standard care practices (13, 15), including helping people with epilepsy build psychological self-management strategies to cope with adversity (14). It acknowledged that resilience could be only part of standard care practices, meaning that service providers did not need to rely solely on individual resilience to achieve better employment outcomes.

4. Methodology

As pointed out in the introduction, this article reports on individual resilience, one of the themes that emerged out of a study of the employment experiences of people with epilepsy. The study site was the Epilepsy Support Foundation (ESF) in Harare, Zimbabwe’s main urban area and capital. The ESF provides access to epilepsy treatment, psychosocial support, economic empowerment, disability advocacy, and awareness-raising services. Specific interventions at the ESF include counselling, support groups, information centre, dispensary, electroencephalogram (EEG) diagnosis, income-generating projects and epilepsy awareness
through *inter alia* National Epilepsy Awareness Week, International Epilepsy Day, Purple Day and the distribution of literature and information dissemination. The ESF was selected as a study site because it provided researchers with easy access to its service users and service providers being the only support organisation for people with epilepsy in the country. People with epilepsy in Zimbabwe often do not disclose their condition and it is difficult for researchers to identify them, except through institutions providing them with services, such as the ESF.

This article reports on data from eight participants, who were classified as resilient, out of 30 participants who took part in the in-depth interviews. The eight resilient participants comprised four males and four females whose ages ranged from 26 to 48 years. They had overcome chronic unemployment. Seven were employed while one had recently become unemployed. The eight participants were receiving medical treatment and described their seizures as controlled (n=2), partially controlled (n=3), and fully controlled (n=3). Four participants had experienced their first seizures during childhood and four during adulthood. The demographic characteristics of participants are presented in Table 1. Pseudonyms were used to ensure the anonymity of participants, while names of actual occupations were avoided in favour of more generic descriptive terms. Other demographic information, such as marital status, were also removed to ensure anonymity.

To supplement the in-depth interview data, a focus group discussion was conducted with service providers (n=7) employed by the ESF. The service providers included three social service workers, two health workers, and two disability advocacy workers. It was important to include service providers for two reasons. First, to focus their attention on employment issues, not usually a major preoccupation of their support work and, secondly, to get their opinions on the experiences of people with epilepsy with whom they worked.
### Table 1: Social demographic characteristics of participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Characteristics</th>
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<tbody>
<tr>
<td><strong>Resilient female participants (n=4)</strong></td>
<td></td>
</tr>
<tr>
<td>Saru</td>
<td>A 39-year old government worker. Worked at three different schools, dismissed at one school because of epilepsy. Adult onset fully controlled epilepsy.</td>
</tr>
<tr>
<td>Mucha</td>
<td>A 32-year old government worker. Childhood onset partially controlled epilepsy.</td>
</tr>
<tr>
<td>Grace</td>
<td>48-year old government worker in a public hospital. Dismissed from a similar job during internship. Teenage onset controlled epilepsy.</td>
</tr>
<tr>
<td>Tindo</td>
<td>A 33-year-old who was unemployed. Held a diploma. Worked in retail shops before but was underpaid and felt underrated. Adult onset controlled epilepsy.</td>
</tr>
<tr>
<td><strong>Resilient male participants (n=4)</strong></td>
<td></td>
</tr>
<tr>
<td>Munya</td>
<td>A 33-year old bank worker with a university degree and other qualifications. Missed a lucrative job opportunity after having seizures during probation. Dismissed from other jobs before due to seizures. Adult onset fully controlled epilepsy.</td>
</tr>
<tr>
<td>Lameck</td>
<td>A 28-year-old technician. Contract not renewed at immediate past job. Adult onset fully controlled epilepsy.</td>
</tr>
<tr>
<td>Edson</td>
<td>A 26-year old customer care worker. No ordinary level passes or any other qualifications. Not secure at present job because of seizures. Childhood onset with partially controlled seizures.</td>
</tr>
<tr>
<td>Farai</td>
<td>A 32-year old maintenance worker. Did not pass ordinary levels and an apprenticeship course. Childhood onset, partially controlled.</td>
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</tbody>
</table>

A semi-structured interview guide was used with people with epilepsy, while a focus group discussion guide was used with service providers. Service providers were first presented with a summarised report of findings from the in-depth interviews, which they read before the focus group discussion. Data collection involved audio recording of responses from people with epilepsy and service providers. The data was then transcribed verbatim. These two data sets were analysed separately using NVivo, a computer-assisted qualitative data analysis package. The analysis sought to understand the common and exceptional experiences of participants and how these experiences influenced their employment prospects. To achieve this, the transcripts were read several times to gain familiarisation with the data. Emerging codes were noted and the researcher added a few codes he had developed during fieldwork. The resultant codes were then loaded into NVivo to form initial codes that identified broad themes around experiences, barriers, and facilitators. Individual resilience was one of the themes. The next section presents the barriers to employment, experiences of resilience, and opinions of service providers.
5. Findings

5.1 Barriers to employment

5.1.1 Barriers encountered during job seeking

Participants’ experiences showed that lack of educational qualifications was a barrier to job seeking. Hence, participants like Grace, Tindo, Lameck, Edson, and Farai could not apply for jobs because they were underqualified. Asked why she did not have adequate educational qualifications, Grace said she had challenges acquiring basic education:

Epilepsy started in 1984 when I was at boarding school, [school name removed]. I stopped going to school … [when I resumed] I did not go back to boarding school. I went to a local school.

Grace withdrew temporarily from school but later continued, though at a school with poorer facilities. Grace said her family had not fully supported her education at the well-resourced boarding school believing she would not be accepted there or would not succeed because of her epilepsy. She had to sit the examinations several times to pass the five subjects required for a tertiary qualification. This affected her job seeking because most companies preferred candidates who had passed the examinations in the first sitting. Grace intended to train as a teacher or nurse to get a diploma, but the training colleges required candidates who had passed the examination the first time round. By the time of the interviews, she had not secured training, and was past the age limit set by most training colleges. However, she trained as a non-skilled worker, obtained a certificate, and got a job, but this was not the qualification or job she had desired.

Participants said delayed seizure control was another major reason why their education and training was not strong. All participants - Saru, Mucha, Grace, Tindo, Munya, Lameck, Edson, and Farai - reported challenges with acquiring initial medical treatment, mainly because
of the dominance of traditional and religious knowledge and beliefs geared towards non-medical treatment services. Resultantly, misunderstanding of epilepsy led to delayed treatment, which, in turn, led to poor educational and training outcomes.

Tindo and Grace reported that they had no access to government employment support services and, although they had relied on nongovernment organisations, such as the ESF and Ruwa Rehabilitation Centre, they had not received adequate employment services to assist with writing resumes, interview coaching, referral letters, and career guidance. Grace reported that there were few jobs available in the open labour market, largely due to Zimbabwe’s failed economy. This increased competition and, without support services, she was greatly disadvantaged.

Tindo and Mucha reported that they faced challenges in the home that prevented them from successful job seeking. They were both married. In the case of Tindo, her husband did not allow her to look for a job, fearing that she would face challenges in the workplace. Mucha said ‘my husband is very supportive’. Mucha’s challenges were that she had more chores at home and this impacted on her work, since she was already employed.

Farai and Edson said, although they were employed, they faced the challenge of having few social contacts necessary for job seeking. Farai said he had lost most of his friends when his seizures began. Farai’s brother got work at his father’s workplace, but Farai could not because of his condition. Farai was later employed by an organisations, where he had volunteered for about a year, while a relative had helped Edson to secure a job. Edson had not discloses his condition, while Farai did.

Job seekers often did probation or work-related learning. While on three-month’s probation, Munya had had three seizures at work and did not get the job. He said that, in normal circumstances, people were employed by the company following probation; given that he had worked so well, he had expected an appointment but was unsuccessful due to his epilepsy.
Grace was on work-related learning when she had a seizure and her contract was terminated instantly. Saru, Mucha, Lameck, and Edson said they had been able to get jobs because they had not disclosed; they were afraid that once they disclosed their epilepsy, they would lose their jobs or be treated differently.

5.1.2 Barriers encountered in the workplace

In the workplace, Lameck, Edson, and Saru encountered negative attitudes from managers and co-workers once they knew about their epilepsy. Tindo and Lameck had experienced unfavourable employment conditions followed by dismissal from work. Farai, Lameck, and Mucha reported that their employers feared that they would die at work or scare off customers. Edson reported that co-workers had doubted his capacity and ‘disagreed when management gave him the worker of the month award’. Saru, Munya, and Tindo were each dismissed from four jobs, while Mucha, Grace, and Ashley had been dismissed from two jobs because of their condition. Edson and Farai had each been dismissed once. Despite discrimination in the workplace, there was no recourse to justice because participants had no hope of winning the cases of discrimination in court, and lacked the resources for litigation.

Participants said employers had treated them unfairly once they had disclosed their epilepsy. While Edson had not disclosed his condition to his employer, Lameck and Munya had disclosed but their employers had not supported them, since they ‘viewed epilepsy as a spiritual rather than a health condition’. Lameck was not allowed time off to seek treatment, while Munya had been dismissed for spending a lot of time off work. Lameck had been ‘transferred from department to department’ and had been denied responsibilities at the factory where he worked ‘because they thought I would die at work’. Edson said he had not been ‘taken seriously at work’. At times, supervisors had brushed off Lameck in favour of ‘the next guy’. He added:
I think the way they took it they did not have full knowledge. They were not informed.

Management was saying I could die at work or have another seizure. I would feel the segregation when duties were shared but I could feel that I could do this and that.

Although Lameck had explained his situation, his contract had not been renewed. He had looked for another job and had not disclosed his condition. In his new job, he had worked from the top of construction scaffolds, something that he had feared, but had to do because he had no other option. He had then enrolled in a diploma course in preparation for leaving the construction job due to his discomfort with it. Tindo, too, had faced several challenges, as illustrated in the case vignette 1.

**Case vignette 1: Tindo’s employment experiences**

Tindo was 33-years old by the time of the study. Her epilepsy started when she was already a young adult. She had completed her secondary education but had not passed all the subjects required to proceed to high school or college. Her family pursued traditional treatments and only embraced medical treatment after four years. Tindo and her family faced negative attitudes, such as stigma from the community. She faced several challenges when she married and the marriage did not last. Some of the challenges had to do with gender roles and her husband’s refusal to allow her to work. After the failure of her marriage, she had looked unsuccessfully for work, even though she had acquired a diploma. She was unable to get any government or nongovernment employment support services. She eventually found work in a retail shop. The owner knew about her condition but was willing to hire her, though she was underpaid, despite having been dependable. She thought this would improve but did not. She approached the employer, who indicated that she had hired her because of her condition and that no one else would hire her. Frustrated, she had resigned and another company had hired her. She believed she was hired because of her impressive work performance at her prior workplace. Sadly, this new company had gone out of business and she was jobless once again. By the time of the study, Tindo had enrolled in a diploma program at a local college.
Tindo’s experience showed most of the barriers she and her fellow participants encountered, including a lack of education and delayed seizure control. Without employment support services, participants like Tindo resorted to self-management. Despite these barriers, all eight participants overcame chronic unemployment and had not abandoned hope of achieving better employment outcomes. Their resilience was characterised by a ‘fighting spirit’. They had been their own advocates and had mastered their epilepsy, as discussed in the following three sections.

5.2 Resilience

5.2.1 Adopting a ‘fighting spirit’ in society and in the workplace

Participants adopted a ‘fighting spirit’ in society and in the workplace. Acquiring an education and skills needed for jobs was extremely challenging for all eight participants. However, Munya, had a university degree and was enrolled in a professional course to improve his chances at his workplace. His epilepsy began during his final year at university, and he had overcome the pressures this put on him. He had acquired a driver’s licence, despite the lengthy process due to his condition, and had remained positive, as his story of resilience presented in case vignette 2 shows.

Case vignette 2: Munya’s story of resilience
Munya’s seizures had begun during his final year of university. The immediate explanation was that he had been bewitched to prevent him from graduating. As a result, his family had sought traditional interventions but these had not stopped his seizures. Munya could have dropped out of university but he had not. After graduating, he got a part-time job at the company where he had done his internship, but had been dismissed due to his seizures. He was not on medical treatment and had been taken to the hospital several times following seizures but had only received attention for injuries. He had not been properly diagnosed. He got a job at a parastatal (semi-government institution), where he was put on three-months’ probation. During the period, he had had two seizures at work and had not got the job. He said he was surprised because he had worked exceptionally well. As was the norm in Zimbabwe, due to a weak economy, Munya went to neighbouring country, Namibia, to find work. He found a job and worked well, remaining seizure free. The job in Namibia required him to have a driver’s licence so he had gone back to Zimbabwe to get one. He could not get the licence because he needed to be seizure free for at least two years. He could not go back to Namibia. Luckily, he attended an interview and got a job at a company he had worked with before. In his opinion, the main reason he got the job was that he had shown them that, despite his epilepsy, he was hard working and highly productive. He sought medical treatment at ESF and his seizures were reduced. After two years, he applied successfully for his driver’s licence and was allowed to drive company vehicles at his new workplace. He became an active member of ESF. By the time of the study, he was enrolled for a professional course to enhance his promotion prospects at work.

Munya’s story showed the challenges he faced and strategies he employed to overcome them. His story corroborated that of other participants. Similarly, Lameck and Tindo had enrolled in diploma programs to enhance their employment chances. Grace had moved from office to office, pestered government officials to provide her with a place to train or a job. She had finally found employment at a government hospital. At the time of the study, she was still pestered to provide her with college training so she could become a skilled worker. Mucha too showed that it was important to develop a positive attitude. He said a ‘fighting spirit’ was needed. Such a positive attitude to their seemingly hopeless situation allowed some
participants to overcome employment barriers. In the workplace, participants like Tindo and Edson had proved that they were hard workers. Due to her hard work, Tindo had gained her employer’s trust quickly, while Edson had been crowned worker of the month for his diligence.

Female participants, such as Saru and Mucha, had experienced challenges balancing work at home and their jobs. They often felt overwhelmed. Saru said duties at home usually impacted on her work. Mucha said that, being a female worker, wife, and person with a chronic condition was:

the boring aspect of epilepsy, especially for women like myself, is that after work you need to work at home again. You then need to sleep early and prepare for work again. At times, I feel like I should start my own company and control my timetable.

Mucha’s argument was that, with so many chores to do at home, she was deprived of the rest time needed before work the next day. Her employer was not flexible and she had contemplated self-employment so she would be able to control her work time.

5.2.2 Being own advocates challenging negative attitudes

Edson and Munya said people with epilepsy must act as advocates for sound employment policies. Munya noted:

I told my boss I have epilepsy. That is me. If you ask me to raise a policy [part of his job] I will do that. If you give me any job, I will do it. If I have a seizure in front of a client and you lost business, then I am sorry but that is my situation.

Munya, who could be interviewed at work, had faced several challenges in the past, but thought the best way was for people with epilepsy to challenge society to understand and accommodate them.
Other participants showed that it was important to be their own advocates. Tindo had unsuccessfully challenged her employer for underpaying her. Edson had challenged his co-workers for labelling him a ‘Sascam’, a derogatory term referring to a person with low intelligence unable to take care of themselves. At work, Saru insisted that she be given equal duties to her co-workers, because she could work just as effectively as they could without epilepsy.

5.2.3 Having a mastery and acceptance of epilepsy

The eight participants had been clear about their treatment, side effects, and the need for compliance with medication. Edson, Munya, and Mucha’s experiences showed that mastering and accepting epilepsy was necessary to achieve better employment outcomes. Asked to share experiences that improved his outcomes, Edson said:

   In most cases, I think it starts with you, the person with epilepsy. You should accept your condition and educate people around you. Know what your condition requires. If you educate someone and they do not understand, ask someone else who knows to further educate them.

Mucha said she had been able to comply with medical treatment and take charge of her situation:

   Get yourself treated, maintain yourself so that you can keep your work. Those not employed, do self-jobs like woodwork, welding, and just do not neglect yourself. Epilepsy is just a condition.

Asked to explain, Mucha said that she had been mindful of her treatment and had controlled the factors that could trigger her seizures. Saru had accepted her condition and complied with
medical treatment. Farai, too, had been cognisant of triggering factors, such as sun heat and often discussed these with his supervisor.

5.3 Views of service providers

When asked for their opinion on the work experiences of participants, the service providers agreed that people with epilepsy faced challenges in education and this affected their employment opportunities. Service provider 5, an advocacy officer, blamed the education system for the situation of people with epilepsy, saying society labelled them as incapable and limited their educational opportunities:

Those [people with epilepsy] who excel through it’s either by force or by God’s grace. If you look at the environment at schools, it’s not conducive for a person with epilepsy. One, teachers are not equipped to handle children with epilepsy. As an example, at one school the headmaster told the parents ‘take away your child; bring child when better’. What does that mean? Where will she take that child? You see, hence, it’s just a way in which the system is discriminating against the person with epilepsy…

This meant that success for people with epilepsy was difficult as they encountered several barriers. Service provider 5 said it was always important to have schoolteachers and headmasters who knew how to deal with children with epilepsy. He recommended improved teacher training. However, Service provider 3, a health worker, thought the parents were to blame for their children’s poor education:

The parents will say you are wasting our time, you can’t proceed with school. They (people with epilepsy) are asked to sit at home doing nothing. But they forget the person is taking medication, and is able to proceed with school. But they blame the person saying you are failing school, yet it’s because of seizures.
Service providers agreed that a lack of adequate medical treatment affected employment in several ways. They bemoaned the delays in receiving medical treatment and the lack of effective medical treatment services the interview participants had experienced but said this was a usual occurrence. Service provider 5 said many people with epilepsy delayed medical treatment as they did not know that epilepsy was a treatable condition: ‘There is lack of knowledge within communities’. Service providers 1 and 4 agreed, adding that health centres did not usually have an adequate supply of anti-epilepsy medicines and most lacked nurses trained to manage epilepsy, the unavailability of doctors notwithstanding. Although services were much better in urban areas, they were still basic and unaffordable for many, hence the attraction of the ESF. They seemed to agree that epilepsy was neglected both as a disability and a chronic health condition. Service providers 1 and 7 agreed that health services were poor, with an undersupply of medicines and inadequate personnel.

Focus group participants agreed with interview participants that self-management was important for improving employment opportunities. Service providers 1 and 3 emphasised that people with epilepsy needed the skills to manage their treatment, epilepsy triggers, and the side effects of medication or this would impact on their ability to work. Service provider 3 said issues encountered included work events or stresses that triggered seizures, such as the over use of computers or loud noises, the side effects of medication that made them dizzy, and ineffective treatments.

Service providers agreed that there was negativity and doubt in the workplace once it was known they had epilepsy though they debated the merits of disclosure. Service provider 4, a social service worker, supported the view that disclosure was a personal choice but, for those having seizures at work, that choice was not available. Service provider 5 was equally ambivalent, saying that given the stigma of epilepsy as a disability and chronic medical condition, people should not be forced to disclose, adding we also have ‘to protect my interests
as a person with the condition’. Among other service providers, there was consensus that disclosure was a personal choice.

While service providers said little about individual resilience, their views reinforced the fact that people with epilepsy faced extremely challenging employment situations and that services to reduce such disadvantage were limited. They seemed to agree that people with epilepsy, who succeeded against all odds, had an extra attribute, ‘force’, or ‘God’s grace’ not available in others, to use the words of Service provider 5.

6. Discussion

Despite the odds stacked against them, the findings showed that participants had demonstrated remarkable resilience by overcoming chronic unemployment. Employment barriers faced aligned with those reported previously (5, 16). Delayed medical treatment compromised education and vocational training – key factors for acquiring skills and for positive employment outcomes. As pointed out by service providers, in the absence of reliable public services, people with epilepsy were left to self-manage their adversity. Faced with adversity, participants used their individual resilience. Previous studies reached the same conclusion (12-14).

Resilient individuals acquired skills needed for jobs, despite the odds stacked against them. Findings showed that resilient individuals had skills and some were training to acquire more. The findings showed that skills were important if people with epilepsy were to have favourable employment outcomes. Service providers supported this view, pointing out that people with epilepsy lacked the skills required for employment. Those who acquired skills walked an extra mile, a show resilience.

Resilient individuals achieved in the workplace beyond expectations. Previous research in Zimbabwe showed that people with epilepsy did not perceive their cognitive impairment to interfere with their functioning and work performance (2). This could be true given that
participants in this research were able to work effectively. Workplace challenges emanated from incorrect knowledge about epilepsy, a situation found to be prevalent in Zimbabwe in previous studies (4, 6). Prior studies showed negative attitudes among educated people (7). A similar finding was reached in this study. Educated managers had incorrect knowledge of epilepsy, making the situation extremely challenging for workers with epilepsy.

Resilient individuals in this study had good seizure control and had a mastery of epilepsy. Previous studies reached the same conclusion (13, 14). As reported in other studies (16), health services were erratic and acted as a barrier to the employment chances of people with epilepsy. Resilient individuals were able to achieve greater control of seizures, perhaps because of the control they developed over their epilepsy. They were cognisant of side effects of medication and were able to control them effectively.

The findings of this research supported the argument that resilient individuals depended on their individual self-management abilities and environmental support systems (13). This study confirmed the role of social support systems in building resilience (13). An important support system for participants was the ESF. Service providers supported this view. Participants were members of the ESF who had benefitted from its medical and psychosocial interventions and often participated in support groups and advocacy work. This presented participants with an opportunity to manage their epilepsy and build the self-confidence to challenge negative attitudes. No doubt this was a factor that fostered their resilience. As members, they often interacted with service providers and other people in their situation. As one service provider said, their role was to misinform people with epilepsy of the notion that they had no potential. Further, the service providers advocated for opportunities for their members, and some members were exposed to employers who worked with the ESF.

Participants in this study showed that, despite the barriers to employment, they were able to overcome and achieve a better quality of life. This supports a view held by advocates
of the resiliency model that, after disruption, resilient individuals are able to reintegrate in a manner that improves their quality of life and reduce their vulnerability (10, 13). They bounce back. However, resilience alone was not enough, such factors as the economy and availability of services also impacted on employment opportunities.

Although the equal number of males and females did not necessarily mean that resilience was experienced equally between males and females in this study, the figures point in that direction. In this study, there were no noticeable differences between males and females regarding resilience. Service providers said women faced a ‘triple burden’ and, in light of this, their resilience was remarkable.

Inevitably, the research presented in this article had some limitations. First, it did not focus strongly on individual factors, such as vulnerability, personality, seizure type, treatment, or depression, as highlighted in previous studies (12, 14). The research focused mainly on structural factors. Secondly, experiences of vulnerability were not explored, and participants were not always resilient. Despite these limitations, the study’s conclusions have important implications for epilepsy work.

7. Conclusion and implications

Despite the barriers encountered in their journey towards gaining and maintaining employment, the eight people with epilepsy reported in this study, who demonstrated tremendous individual resilience, showed how this enabled them to overcome some of the barriers they had encountered. They exhibited a strong ‘fighting spirit’ in seemingly hopeless situations and ongoing shame associated with their condition. The research concluded that, where employment support services were weak to address employment barriers, as in Zimbabwe, individual resilience acted as a strong coping mechanism that resulted in better employment outcomes for many. These findings have implications for policy and practice. Service providers
in epilepsy work ought to add resilience building to their portfolio of strategies. Increasing people with epilepsy’s knowledge and acceptance of their condition could be a starting point. However, this is only a coping mechanism that should not stop service providers and service users to advocate for government-provided employment services.

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References


9. Mielke J, Madzokere C. Epilepsy care in rural Zimbabwe: A global campaign against epilepsy project. EPILEPSIA. 2005; 46 347-.


