



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



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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.

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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

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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 that 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 favorable findings to the educational status of the respondents, although their study still highlighted the prevalence of negative attitudes toward people with epilepsy, even among educated people in Zimbabwe [7].

Education levels among people with epilepsy were found to be low, as were 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 stigmatization and labeling 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 that 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 coworkers, 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 counseling, support groups, information center, 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 organization 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 favor of more generic descriptive terms. Other demographic information, such as marital status, was 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 second, to get their opinions on the experiences of people with epilepsy with whom they worked.

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