

## Title

Exploring the Lived Experiences of Students with Disclosed Epilepsy in Accessing Support Services at a Teachers' College in Zimbabwe.

Margaret Chimedza

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Centre for Disability and Rehabilitation Studies

Faculty of Medicine and Health Sciences

Stellenbosch University

Supervisor: Dr Chioma Ohajunwa

Co-supervisor: Dr Martha Geiger

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## Declaration

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## Dedication

This dissertation is a special dedication to my family. I appreciate the support they gave me while writing this dissertation. Special mention goes to my mother Mrs Catherine Chimedza for believing in me. You have always been my pillar of strength and inspiration.

## Acknowledgements

I wish to acknowledge the following significant people who supported me to realize my educational goal.

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I owe a lot to my wonderful fellow students and colleagues who supported me from the beginning up to the end of this academic journey. To my family and friends, thank you for the encouragement and for being there for me each step of this journey.

Lastly, I give thanks unto my Heavenly Father and Saviour Jesus Christ for without His grace none of this would have been achieved.

## Abstract (In English)

There is a marked increase in students with disabilities accessing higher education. A significant proportion of these students constitute students with chronic conditions such as epilepsy.

The purpose of this study was to gain an insight into the lived experiences of students with disclosed epilepsy in accessing support services at a Teachers' College in Zimbabwe. The main objectives were to identify the provisions that are available in the institution and the accessibility barriers students with epilepsy encounter in their learning. The study also intended to provide guidelines to stakeholders on how to assist students with epilepsy in accessing higher education based on their experiences.

The study employed a qualitative approach to answer the main research question. Four former students with disclosed epilepsy, recruited through snowballing, participated in the research. Data was gathered by responding to telephonic interviews and analysed through thematic analysis. Three themes were derived from the data which included facilitators to inclusion, accessibility barriers and reasonable adjustments that the participants suggested would improve their access to higher education.

Findings from the study indicated that the lack of mandatory disability policies, negative attitudes from the college community, inappropriate training of members of staff and lack of information acted as obstacles to accessing support services in the institution. The participants recommended that institutions draw up policies that guide their operations. They expressed the need for appropriate training for academic staff, psychosocial support, the need for disability awareness campaigns and self-representation at the college. The study outcomes recognized the need for institutions to adopt a Multi-dimensional support framework that values human rights and creates an inclusive and accessible learning environment.

Findings from this study may add to the information base about the support services appropriate for students with epilepsy in accessing higher education.

## Abstract (In Afrikaans)

Daar is 'n merkbare toename in studente met gestremdhede wat hoër onderwys toetree. 'n Beduidende deel van hierdie studente konstitueer studente met kroniese toestande soos epilepsie. Die doel van hierdie studie was om insigte te kry in die geleefde ervarings van studente met epilepsie om toegang tot steundienste by 'n Onderwyskollege in Zimbabwe te verkry.

Die hoofdoelstellings was om die beskikbare voorsienings by die instelling en die toeganklikheidsversperrings wat studente met epilepsie in hul onderrig ervaar, te identifiseer.

Die studie was ook bedoel om riglyne voor te stel vir belanghebbendes oor hoe om studente met epilepsie te ondersteun om toegang tot hoër onderwys te kry.

'n Kwalitatiewe benadering is geïmplementeer om die hoof navorsingsvraag te beantwoord. Vier voormalige studente, met bekend-gemaakte epilepsie, is gewerf deur 'n 'sneeubal'-steekproefnemingsmetode. Data is versamel deur telefoononderhoude met die deelnemers en dan tematies ge-analiseer.

Drie temas is afgelei en het die volgende ingesluit: fasiliteerders tot insluiting, toeganklikheidsversperrings en redelike aanpassings wat die deelnemers voorgestel het om hoëronderwys-toeganklikheid vir hulle te verbeter.

Bevindinge uit die studie dui op 'n gebrek aan verpligte gestremdheds-beleide, negatiewe houdings van die kollege-gemeenskap, ontoepaslike opleiding van personeellede en gebrekkige inligting, as hindernisse vir studente om steundienste by die instelling te bekom.

Die deelnemers het aanbeveel dat instellings beleide opstel wat die bedrywighede van die instellings reël. Hulle het 'n behoefte geïdentifiseer by die instelling vir toepaslike opleiding vir akademiese personeellede, psigososiale ondersteuning, gestremdheid bewusmakingsveldtogte en selfverteenwoordiging.

Die studie-uitkomst erken die behoefte daaraan dat instellings multidimensionale ondersteuningsraamwerke aanneem, wat menseregte waardeur en 'n insluitende en toeganklike leeromgewing steun.

Bevindinge uit hierdie studie mag bydra tot die inligtingsbasis oor toepaslike, toeganklike steundienste vir studente met epilepsie om toegang tot hoër-onderwys te verkry.

## Glossary of Terms

**Biomedical Model of Disability**- views disability as a problem within the individual that requires treatment as a form of intervention (World Health Organization) (WHO) (2001).

**Biopsychosocial Framework**- is based on the result of the interactions of individuals and their environments and the impact of their impairments on their functioning (World Health Organization) (WHO) (2001).

**Students with Epilepsy**- students with “a chronic neurological condition that is characterized by the recurrence of unprovoked seizures” (Rush, 2020:1).

**Disability** - is regarded as the outcome of the impact that a health condition has on a person’s functioning (Moriña & Orozco, 2021:160).

**Impairment**- refers to the underlying health condition, such as epilepsy or hearing impairment (Shakespeare, 2018:3)

**Inclusive Education**- is a philosophy based on the tenets of equity, equal rights and equal opportunities in accessing education (McKinney & Swartz, 2020:2).

**Lived Experiences**- how participants interpret their experiences of a phenomenon (O’Leary, 2017:149).

**Social Model of Disability**- views society as responsible for creating barriers that prevent people with disabilities (PWD) from accessing services (World Health Organization) (WHO) (2001)

**Support Services**- learning provisions or accommodations that respond positively to individual differences (Chitiyo & Muwana, 2018:103).

## Acronyms and Abbreviations

|        |  |
|--------|--|
| DRC    | Disability Resource Centre   |
| ICF    | International Classification of Functioning, Disability, and Health  |
| SDG    | Sustainable Development Goal   |
| SWD    | Students with Disabilities   |
| SWE    | Students with Epilepsy   |
| UNCRPD | United Nations Convention on the Rights of Persons with Disabilities |
| UNESCO | United Nations Educational, Scientific and Cultural Organization     |
| WHO    | World Health Organization  |



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## Chapter 1. Introduction

### 1.1 Background to the study

Several studies on accessing tertiary education are commonly focused on the needs of students with the more obvious categories of disabilities associated with sensory, mental and physical impairments (Collins, Azmat & Rentschler, 2019; Kisanga, 2017; Oats & Disele, 2019). McKinney and Swartz (2020:2) argue that students with chronic conditions who need psychosocial support receive very little attention although they constitute a significant proportion of students with disabilities (SWD) in tertiary institutions. Although less visible, chronic conditions such as epilepsy, diabetes and asthma comply with the criteria of the definition of disability set out by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) and the International Classification of Functioning, Disability, and Health (ICF), World Health Organization (WHO) (2001). Disability is conceived as the outcome of the impact that a health condition has on a person's functioning (Moriña & Orozco, 2021:160).

Students with chronic conditions constitute one of the vulnerable groups who are at risk of marginalization and exclusion in tertiary institutions (Sithole & Mafa, 2017:1232). Society has challenged the appropriateness of separate systems of education for persons with disabilities (PWD) from a human rights and effectiveness point of view (UNESCO, 2005:9). Consequently, educators in tertiary institutions will encounter students with diverse learning abilities. This calls for educational policies, initiatives and programmes that are responsive to students' access needs (Moriña & Orozco, 2021:161).

### 1.2 Problem statement

There are diverse understandings of inclusive education within various educational institutions and among practitioners. United Nations Educational, Scientific, and Cultural Organisations (UNESCO) (2005:13) defines inclusive education as a process of responding to the diverse needs of all learners through increased participation in learning and reducing barriers in education. In principle, students with disabilities (SWD) should have equal access to and be able to participate fully in tertiary education. Chitiyo and Muwana (2018:103) state that inclusive education focuses on adapting the system to meet the access needs of all learners and not expecting learners to adjust to the system.

In response to this push for inclusion, tertiary institutions in Zimbabwe have enrolled SWD in different programs. A substantial number of the students have also enrolled in teacher education colleges. By declaring their disability statuses, students expect the institutions to respond to their educational needs. Nevertheless, SWD continue to encounter barriers in accessing and adapting to the demands of education. James, Bustamante, Lamons, Scanlon, and Chin (2020:1) argue that tertiary institutions were not designed with SWD in mind because academic staff lack knowledge in supporting them. Many SWD have to work much more than their peers due to rigid curricula. Moriña and Orozco (2021) identify limited access to institutional support in the form of negative perceptions about the different types of impairments among SWD, unwillingness to provide reasonable accommodations, and insufficient information about the students' rights and available support services. Students with chronic conditions such as epilepsy face multiple barriers as a result of negative attitudes which lead to some of them dropping out of their studies.

Within the Zimbabwean context, existing inclusive, education-supportive, ministerial circulars focus largely on disability and not much on the removal of the barriers experienced by all learners (Sithole & Mafa, 2017:1235). Consequently, there is a lack of consensus on the meaning of inclusive education in tertiary institutions in Zimbabwe. One consequence is that there are different interpretations of the concept of inclusive education. Due to the lack of a comprehensive inclusive education policy, tertiary institutions end up chasing conflicting goals. For example, some institutions' perception of inclusive education focuses on just the removal of infrastructural barriers but not adjusting teaching strategies to widen access to tertiary education for SWD (Sithole & Mafa, 2017:1231)

Sithole and Mafa (2017:1231) assert that inclusive education has progressed from a narrow perspective of mainstreaming learners with special educational needs towards identifying and eliminating barriers to all students' learning and meeting their diverse learning styles. This implies employing holistic approaches to identifying accessibility challenges experienced by all learners in tertiary institutions.

### 1.3 The Context

Chronic conditions such as epilepsy and diabetes have an impact on an individual's functionality. Unlike physical or visual impairments there is rather no outward, visible sign for students with

epilepsy (SWE), which makes it challenging for institutions to understand the effects of this condition on academic performance. Accordingly, they do not seem to see the need to provide support services to these students (Oats & Disele, 2019:127). Studies highlight that learners with chronic conditions were considered as individuals who have health conditions that require medical attention (Mukhopadhyay & Musengi, 2012:16). Thus, SWE were not considered as having special educational needs and would therefore not require any support in their learning (Mukhopadhyay & Musengi, 2012:16). The World Health Organization (WHO) (2001) aligns such a perception to the biomedical understanding which views disability as a problem within the individual that requires treatment as a form of intervention. Such a conception also acquits institutions from their obligation to provide accessible accommodations for the students (Samkange, 2013:954).

The social model approach, on the other hand, is supported by several studies, such as those conducted by Redpath, Kearney, Nicholl, Mulvenna, Wallace and Martin (2013: 1334). The social model of disability views society as responsible for creating barriers that prevent people with disabilities (PWD) from accessing services due to its failure to consider their needs (Jung, 2003:93). Whilst it is true that society creates systematic barriers that hinder full participation of PWD, it is crucial to consider both: the effects of the impairment on an individual's performance as well as the environment. Hence, I adopted the definition of disability based on the International Classification of Functioning, Disability, and Health (ICF), a biopsychosocial and spiritual framework formulated by WHO (2001).

The ICF portrays functioning and disability as the result of the interactions of individuals and their environment. The impairment is also considered in this definition. Rush (2020:9) mentions that the ICF provides valuable information about persons with chronic conditions such as epilepsy and describes the impact of these conditions on daily living. Intervention based on the bio-psychosocial approach is critical to best practices in education because it stresses an all-inclusive model of service provision designed to meet individual needs and preferences (Davis, 2020:6).

Beghi, Giussani and Sander (2015:243) define epilepsy as “a chronic neurological condition that is characterized by the recurrence of unprovoked seizures”. Rush (2020:1) further suggests that epilepsy is a disease of the brain that is characterized by one or more unprovoked seizures. The risk of having epilepsy is high in individuals diagnosed with neurological conditions such as brain

tumours and cerebral palsy (Rush, 2020:4). It is observed that if individuals with epilepsy get appropriate treatment, prognosis shows the probability of full recovery.

Although epilepsy might not be associated with acute problems, it may impose restrictions that can significantly impact the individual's educational achievements and quality of life (Rush, 2020:4). This in turn may result in vocational impairments and loss of financial independence in adult life (Jung, 2003:100).

Chronic conditions such as epilepsy do not fit the more widespread understanding of disability whereby students may just require accessible infrastructure or assistive technology (Jung, 2003:92). Nonetheless, students with epilepsy (SWE) also depend on disability policies to access tertiary education. Regrettably, tertiary institutions in countries such as Zimbabwe, with no specific legal policies on inclusive education, are not consistent in the manner in which they provide educational support to SWE (Chireshe, 2013:224).

#### 1.4 Rationale and Motivation

There is an insufficient focus within the literature on the educational support services that can be provided to students with chronic conditions such as epilepsy and diabetes. Policies in Zimbabwe require tertiary institutions to support students with disabilities (SWD) and to guarantee that they are bestowed educational opportunities equal to those of their peers (Majoko, 2018:2). Given this, the Education Amendment Act of 2019 was introduced so that it complies with the Constitution of Zimbabwe Amendment Act of 2013 which promotes the rights of the learners in the education system. Nonetheless, the right to education is compromised due to a lack of funding from the government which makes it problematic for tertiary institutions to effectively serve the needs of diverse groups of students in their classes (Sithole & Mafa, 2017:1231). Hence, SWE drop out of college or end up with poor outcomes (Chitiyo & Muwana, 2018:103).

As an educator, I have observed that structural and institutional barriers that exist prevent students with epilepsy (SWE) from accessing educational provisions in tertiary institutions. While some of the students may trust in their capabilities, the institution may question their abilities in undertaking some of the study programs, which creates self-doubt and results in low self-esteem. I have witnessed some of the students with epilepsy (SWE) withdrawing from college. These SWE are



disadvantaged due to limited resources and an academic staff that lacks appropriate training in accommodating their needs.

According to Moriña and Orozco (2021:161), tertiary institutions may render students disabled due to institutional barriers created by inaccessible support services. This may affect their participation and achievement in tertiary level education. The lack of a mandatory inclusive education policy also means tertiary institutions cannot invest in the elimination of barriers that exclude SWE (Mutswanga & Mapuranga, 2014:38). It is against this backdrop that I wish to gain an understanding through this study on how best teachers' colleges in Zimbabwe can improve access and other support services that respond to the needs of SWE.

### 1.5 Significance of the study

Students with epilepsy (SWE) are increasingly enrolling into tertiary institutions yet few institutions are properly equipped to handle them. This study provides a platform for participants to narrate their experiences in tertiary education. It highlights the barriers SWE encounter during their training. Participants also made suggestions on what institutions can do to improve their services to SWE. The findings would assist heads of institutions, policymakers, academic staff and other stakeholders to gain an insight into what constitutes best practices with regards to providing accessible accommodations to SWE. Tertiary institutions with no specific policies may not find the reason to formulate policies that guide their operations. The study would also assist other students to understand their obligations towards the access needs of SWE in tertiary institutions. SWE may be empowered and be able to circumvent some of the challenges they encounter in accessing tertiary education.

### 1.6 Conceptual framework and methodology

This study is premised on the belief that all citizens have a right to education and lifelong learning. As such, the conceptual framework guiding this study is social justice, and equity embedded in the human rights-based approach (Magumise & Sefotho, 2020:544). The principles of social justice and inclusion are enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006), which aims at addressing social inequity and exclusionary practices in tertiary (Mutswanga & Mapuranga 2014:39).

Inclusive education is a philosophy based on the tenets of fairness and widening access to education. McKinney and Swartz (2020:2) underscore that inclusion respects human dignity and people's rights. This means that it is ethical that education policies and practices should serve natural justice by recognizing and putting into place appropriate strategies and accommodations that respond positively to individual differences (Chitiyo & Muwana, 2018:103). This is in tandem with my belief that best practices in tertiary education should be based on social justice, equal opportunities and equity.

This study is qualitative. Qualitative research was used to study the lived experiences of students with disclosed epilepsy (SWE) during their training at one of the teachers' colleges in Zimbabwe. The study design which I employed was phenomenology and the rationale for using this design was that it assisted me in gaining an insight into the underlying meanings of the participants' experiences. Semi-structured interviews were used to gather rich data from the participants about their lived experiences. I was interested in how participants interpreted their experiences so this design was appropriate to conduct this study (O'Leary, 2017:149). The goal was to try and understand how the participants made sense of their experiences in accessing support services at their institution. I used thematic analysis which uses coding to analyse and interpret data (Braun & Clarke, 2006:79). Next is the main research question and sub-questions, the main aim and objectives.

## 1. 7 Research Question

What are the lived experiences of students with disclosed epilepsy (SWE) in accessing support services at a Teachers' College in Zimbabwe?

### 1.7.1 Research sub-questions

- What are the support services participants were aware of at the Teachers' college?
- What are the challenges that SWE encountered in accessing support services during their training?
- What are participants' views on what constitutes best practices and appropriate support services for SWE in colleges?

## 1.8 Main Aim

To explore the lived experiences of Students with Disclosed Epilepsy (SWE) in accessing support services at a Teachers' College in Zimbabwe.

### 1.8.1 Objectives

- To identify support services SWE were aware of at the Teachers' college.
- To describe the challenges which SWE encountered in accessing support services in the course of their training.
- To describe the participants' viewpoints on what constitutes best practices/best support services for SWE at the college.

## 1.9 Conclusion

This chapter introduced the background and focus of this study, which is about finding solutions to access barriers in higher education for students with epilepsy (SWE). The study problem, rationale, context and significance of the study was also presented in this chapter. The conceptual framework is highlighted to position the study, and lastly, the design, research questions, aims and study objectives are given, to illustrate the methodology which informed the study. The study outline is presented in the next section.

### 1.10 Study outline

This study is organized into six chapters. Chapter 1 introduces the background to the study consisting of the barriers students with epilepsy (SWE) encountered in tertiary institutions and the support needs they require. It also introduced the problem statement, the motivation and the significance of the study. Chapter 2 reviews related literature, the conceptual framework, and the policy framework with a special focus on the experiences of SWE in accessing tertiary education. Chapter 3 provides the methodology which detailed the research design, the sampling procedures, data gathering and analysis procedures. Chapter 4 presents the findings using excerpts from the data and themes from the coding process. Chapter 5 and 6 discuss the findings, conclusions and recommendations respectively.

## Chapter 2-Literature Review

### 2.1 Introduction

In this chapter, I present a review of current literature related to my study focus. The conceptual and policy framework which influences the study, the models of disability aligned to this study and the prevailing context and discourses concerning the barriers to accessing tertiary education and inclusion of students with epilepsy (SWE) in tertiary education are presented here. The focus of the study is located within the literature, highlighting the gap which the study seeks to address within extant literature and current discourses about SWE inclusion in tertiary education. I will begin with a discussion of the policy and contextual framework of the study.

### 2. 2 Policy frameworks of the study

International conventions and instruments reaffirm the vision for making education universal and equitable for all. The Jomtien Declaration on Education for All (1990), The Salamanca World Conference (1994) and The Dakar World Education Forum (2000) have been influential on inclusive education policies guiding primary and secondary education worldwide. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) and the 2030 Agenda for Sustainable Development (2015) further promote the principle of inclusive education that is linked to accessing higher education (Sustainable Development Goal [SDG] 4) (UN, 2018:97).

In light of the above developments, numerous countries globally and regionally have shown their commitment and adherence to the statutes stipulated in the international conventions by adopting and ratifying the UNCRPD (2006) and other related instruments (Magumise & Sefotho, 2020:545).

Zimbabwe ratified the UNCRPD (2006) in 2013 and adopted a constitution that promotes the rights and fundamental freedoms of persons with disabilities (PWD). The Constitution of Zimbabwe Amendment Act of 2013 and the Education Amendment Act of 2019 state that all persons regardless of gender, ethnicity or disability have a right to education (Samkange, 2013:954). Sections 22 and 83 recognize the rights of PWD and require that institutions remove obstacles and provide special facilities for their education. The government should provide state-

funded education and training to enable PWD to achieve their potential (Constitution of Zimbabwe Amendment Act of 2013). The Education Amendment Act of 2019 specifies that Zimbabwe is working towards achieving SDG 4 which advocates for inclusive and equitable education and life-long learning for all by 2030.

Nonetheless, Magumise and Sefotho (2020:545) point out that although Zimbabwe has ratified the UNCRPD (2006) and adopted policies on inclusive education that promote equal opportunities in the provision of social services, students with disabilities (SWD) still encounter numerous barriers in accessing tertiary education. This notion is shared by Oats and Disele (2019:127) who postulate that SWD in different countries continue to experience barriers in their learning due to policies that are not comprehensive.

Inclusive education policy documents in Zimbabwe lack legal enforcement which makes it difficult for the government to enforce compliance (Chireshe, 2013:224). In addition, the Zimbabwe Council for Higher Education Act (Chapter 25-27) (2006) which oversees the operations of tertiary and vocational institutions in Zimbabwe, is silent about implementing inclusive education as a means to widen access in tertiary institutions. Thus, the absence of legal policies that promote access in tertiary education such as inclusive education policies is problematic because tertiary institutions lack supportive guidelines on the education of students with disabilities (SWD), making access problematic to students with epilepsy (SWE). Hlatywayo and Mapolisa (2020:406) confirm that the lack of mandatory inclusive education policies from the Ministry of Higher and Tertiary Education, Science and Technology Development (MHTESTD) may lead to a lack of cohesion in the provision of support services in teachers' colleges and other tertiary institutions in Zimbabwe.

### 2.3 Current Context of Higher Education Access of Students with Epilepsy in Zimbabwe

A study by Garwe and Thondhlana (2019:3) revealed that there are 51 institutions of higher learning in Zimbabwe. More than 15 of these are teachers' colleges responsible for training either primary or secondary education teachers. According to Garwe and Thondhlana (2019:3), these figures were last reviewed in 2018, which means currently they may be more than this. Sadly, no formal statistical records are available for students with epilepsy (SWE) enrolled in tertiary

education. I would like to believe that quite a substantial number of SWE have enrolled in Zimbabwe learning institutions.

Chitiyo and Muwana (2018:104) report that in Zimbabwe, superstitions and traditional beliefs influence people's attitudes towards individuals with epilepsy. Students with epilepsy (SWE) encounter unique challenges which are different from groups of students with other disabilities. For example, SWE may experience disorientation after a seizure which makes it difficult for some of them to remember what they have learnt due to a temporary memory loss. Due to lack of knowledge and cultural beliefs, lecturers treat SWE differently and their peers tend to avoid them. Majoko (2018:3) supports these sentiments, by stating that there is a lack of support in most of the learning institutions. Thus, SWE experience attitudinal barriers and continue to encounter challenges in accessing tertiary education due to inappropriate information about their impairment (Jung 2003:92).

SWE are required to self-disclose their condition and even negotiate for reasonable accommodations. According to Griful-Freixenet, Struyven, Verstichele, and Andries, (2017:1628) this type of approach used to secure disability support services is a by-product of the biomedical model which views disability as a problem situated within the individual which needs to be treated or normalised. This approach also assumes that SWE can articulate their learning needs, which may not always be the case. As a result, SWE may choose not to disclose their condition due to fear of appearing different from their peers. Hlatywayo and Mapolisa, (2020:417) assert that stigmatization and discrimination make the social environment intimidating, resulting in some of the students concealing their impairments. Members of staff are also sceptical about teaching SWE due to a lack of appropriate teaching methods (Griful-Freixenet et al, 2017:1628).

Dalton, Lyner-Cleophas, Ferguson, and McKenzie (2019:1) postulate that the framework of the Universal Design of Learning provides practical tools to assist education professionals in designing universally accessible and inclusive learning environments. The framework attempts to remove discriminatory practices, as the diverse learning needs of students are taken into account. Dalton, et al, (2019:3) further explains that instruction is designed, in such a way that eliminates the need to 'fit' teaching strategies with specialised accommodations for learners.

In addition, the absence of a mandatory inclusive education policy in tertiary institutions, and an agreed interpretation of the concept of inclusive education in Zimbabwe, creates barriers for SWE in accessing educational opportunities (Hlatywayo & Mapolisa, 2020:407-8). Tertiary institutions experience inadequate funding, limited resources and lecturers' lack of expertise. Lecturers have a limited knowledge base and inappropriate skills for working with SWE (Sithole & Mafa, 2017:1238).

Despite the limitations on inclusive pedagogy, a rigid curriculum and assessment methods, tertiary institutions in Zimbabwe, including some teachers' colleges, have made notable progress in providing support for SWE. Institutions have built infrastructure and disability resource centres that are manned by staff members trained in inclusive education. Disability coordinators liaise with both SWE and academic staff on issues concerning access to educational support (Moriña & Orozco, 2021:167).

Sithole and Mafa (2017:1231) assert that for the country of Zimbabwe to drive the concept of inclusive education forward and enable access to tertiary education, there is a need to make significant changes and modifications in teaching and learning policies and approaches. This should be done to ensure that SWE have access to support services and participate in tertiary education in the same manner that other students with disabilities are supported. The Education Amendment Act of 2019 is the first step in the right direction of advancing the rights and access needs of all learners in the education system.

This study intended to address the gap within literature related to how tertiary institutions in Zimbabwe could better support SWE to access educational opportunities and to fully participate and learn on an equal basis with their peers. The study also aimed to address an additional gap: The dearth of literature reporting on these narratives from the perspectives of SWE in a Teachers' College themselves. As these students aim to become educators, it becomes critical that their experiences are documented to inform the educational sector in terms of disability inclusion, participation and access for SWE.

## 2.4 Conclusion

The studies reviewed show that inclusive education promotes social justice. Hence, it should be the bedrock to accessing equal learning opportunities for all learners regardless of their differences. The government, educational institutions and other stakeholders need to be aware of their responsibilities to provide learning support and develop policies that address issues of access that affect students with epilepsy (SWE). The next chapter presents the research methodology used to conduct this study.



## Chapter 3: Methodology

### 3.1 Introduction

In this chapter, I discuss the methodology used in the gathering and analysis of data. The main aspects described are the research design, sampling and recruitment procedure, the data gathering and analysis procedures, and precautions to optimize rigour and ethical considerations guiding this study. It begins with a discussion of my study aims and objectives, and methodological framework.

### 3.2. Aim

The study was aimed at exploring the lived experiences of students with disclosed epilepsy in accessing support services at a Teachers' College in Zimbabwe. The research question was "What are the lived experiences of students with disclosed epilepsy in accessing support services at a Teachers' College in Zimbabwe"?

### 3.3 Methodological framework

The epistemological theory informing the study was subjectivism. According to O'Leary (2017:7), this is a post-modernist worldview, aligned to qualitative approaches which accept multiple realities and complexities. O'Leary (2017:8) points out that this approach accepts that people are complex and that personal experience is the foundation for real knowledge.

Since my study was explorative and sought to find out the lived experiences of students with epilepsy (SWE), I employed a phenomenological research design. Khan (2014:300) and O'Leary (2017:149), clarify that phenomenology is an interactive process that provides multifaceted literal descriptions of people's experiences of phenomena from their perspectives. O'Leary (2017:149) further spells out that to understand the students' experiences with access to educational provisions offered at the teachers' college, all the information provided has to be examined through the 'lens' of the participants involved.

### 3.4 Research Setting

According to Akhtar (2016:81), a good research design is flexible, feasible and considers the setting. The context of the study was a teachers' college in Zimbabwe with approximately two

thousand students (de-identified for confidentiality). I interviewed the participants telephonically, in their different locations.

### 3.5 Population and recruitment of participants

The study population consisted of students with disclosed epilepsy (WE) who attended the teachers' college in Zimbabwe from 2016 to 2019.

#### 3.5.1 Inclusion and Exclusion criteria

I included former students with disclosed epilepsy who did their training at the teachers' college in Zimbabwe. To avoid recall bias, I selected participants who had left the college not earlier than 2017. My initial plan was to gather data from current students at the teachers' college, but due to the COVID-19 pandemic, students had left the college to learn from home. I had to apply to Stellenbosch University for an ethics amendment in adherence to the recommendations made by WHO which discouraged face to face interviews and emphasized social distancing. I, therefore, chose to work with former students fitting to the study criteria of students with disclosed epilepsy. The limited scope, time frame and resources that were available for this study also informed the need for the above change.

All the participants provided me with the most relevant information. Former students with disclosed epilepsy in addition to concomitant disabilities (multiple disabilities) or comorbidities were excluded, to further eliminate bias due to the additional conditions (Patino & Ferreira, 2018:84). To avoid recall bias, I also excluded former students with epilepsy who enrolled at the college before 2016.

#### 3.5.2 Sampling and Recruitment of participants.

I used snowball sampling to recruit the participants. Snowballing involves recruiting participants through referrals (O'Leary, 2017:211). When I identified the first participant through purposive sampling, he assisted me with identifying the others. For this study, I worked with a sample of four participants, consisting of three males and one female, who were all former student teachers with epilepsy at the institution. Their ages ranged from 23 to 31 years of age. Their characteristics met the selection criteria stated above. Creswell (2012:215) justifies this decision by asserting that

phenomenological methodology permits us to understand the lived experiences of human beings through studying a small number of participants.

### 3.5.3 Logistics

After receiving full ethics approval, I obtained permission from the institution to access students' information. (See Appendices B and C).

Due to COVID-19 related restrictions regarding face-to-face research, I had to apply for ethics approval for amendments to change my data gathering strategy. After permission for amendments was granted, I explained the purpose of the study to the participants as well as the contents of the informed consent forms over the phone. Thereafter, we set up the appointment dates. I also requested the participants to read and only sign the informed consent forms if they were willing to voluntarily participate in the study. The study commenced after the signed consent forms were returned to me via email.

## 3.6 Data Gathering Strategies

Data gathering for this study was utilizing telephonic interviews. I used open-ended questions and prompts to gain an in-depth understanding of issues of access affecting the SWE.

### 3.6.1 Data gathering tool

I chose to interview as the best method to answer my research questions. Hence, I designed an interview guide with semi-structured and open-ended questions (See Appendix D) to allow participants to freely share their experiences without being constrained by my perceptions (Creswell, 2012:218). O'Leary (2017:244) and Creswell (2012:248) postulate that it is crucial to design an interview schedule that guides the process, contains general questions from research questions to be asked and space for writing responses from participants.

### 3.6.2 Pilot Study

Before the actual data collection, I conducted a pilot study with my colleagues to test my instrument and the feasibility of the data collection plan. According to Kim (2013:191), a pilot study is a feasibility study consisting of trial runs that will guide the researcher in data collection and analysis. The feedback from the pilot study assisted in modifying the interview schedule where

I had to rephrase and fine-tune some of the rather ambiguous interview questions. For example, question 3 initially read:

‘To what extent were the support services at your institution accessible’?

This was amended to;

‘So, tell me about your experiences in accessing the support services provided at your former institution.’

### 3.6.3 Data Gathering Procedure

I used telephonic interviews to gather data in observance of the recommendations from Stellenbosch University and regulations set out by the WHO on the prevention of the spread of the coronavirus.

According to Tracy (2020:208), one of the strengths of telephonic interviews is their ability to reach participants distributed in a wide geographical area who may desire to stay at home, as in this case, to avoid contracting and spreading the coronavirus. This approach provided an opportunity to conduct my study with a population that might otherwise have been difficult to reach. The approach yielded rich data because participants were open and shared information on stigmatized and intimate issues.

However, Tracy (2020:188) also criticizes telephonic interviews for their lack of non-verbal cues and participant distraction. Farooq and De Villiers (2017:294) nonetheless point out that the lack of visual cues compels both the interviewer and interviewee to listen carefully and to clearly articulate the messages they wish to communicate, resulting in rich data collection. On the issue of distraction, I advised the participants to find spaces with fewer distractions such as empty rooms away from noisy places.

The participants decided on a day and time which was convenient for conducting the interviews. I sought their permission to record the calls and saved the interview recordings and transcripts in a folder on my laptop, which is locked with a code. I provided each participant with 1 Gig of data, part of which was used to send back their signed consent forms via email.

We conducted the interviews in both English and Shona because all the participants were familiar with these two major official languages used in Zimbabwe. The duration ranged from 50 to 65 minutes with the longest taking about 65 minutes. I translated the recordings into English and a translator cross-checked the translations I had made by listening to the recordings and reading the transcripts as a way of confirming credibility (Ohajunwa, 2019:130).

### 3.7 Data Analysis

I analysed the data thematically aided by everyday software programs such as Microsoft Word and Excel to organize the data. According to Braun and Clarke (2006:79), Scharp and Sanders (2018:1) thematic analysis is a method for identifying, analysing, reporting and interpreting qualitative research findings.

#### 3.7.1 Thematic Analysis

The thematic analysis aims to identify important and interesting themes and patterns from the data, also interpreting the underlying ideas and assumptions drawn from the data that would be used to answer the research questions (Maguire & Delahunt, 2017:3353; Creswell, 2012:252)

I adopted an iterative analysis approach that draws from predetermined research questions or objectives (Huffman, Tracy & Bisel, 2019:6). Analysis was mostly driven by my objectives. I repeatedly moved back and forth between my research questions and emerging findings. Although I identified unexpected themes, my focus was driven by data that was of the greatest significance and value to my study.

I was guided by Braun and Clarke's (2006:87) suggested steps in conducting thematic analysis. All data were transcribed. I listened to the interview recordings and immersed myself in the data to become familiar with the details. I filled in the omissions and jotted down notes that captured my first impressions of the transcripts.

#### 3.7.2 Codification of data

According to Tracy (2020:212), to make the most of the data analysis, one needs to systematically organize the data. The data was organised in a more meaningful way through generating and assigning initial codes from the transcripts to segments of text that were relevant and spoke to my objectives.

### 3.7.3 Codes into subthemes-

I created an Excel spreadsheet and Word documents to assist in categorising recurring codes from the transcripts into themes under relevant columns, as informed by the study objectives (See Appendix E) I added quotes from the participants that supported the codes which informed each subtheme (Creswell 2012: 244).

After scrutiny of the subthemes, I managed to identify emerging patterns and underlying themes. Themes are patterns that identify and explain something significant or interesting about the research question (Maguire & Delahunt, 2017:3356). I reviewed the subthemes by collapsing and re-grouping some and creating new subthemes and themes. Braun and Clarke (2006:96) assert that subthemes are themes found within themes that give structure to an otherwise large and complex theme.

I also recorded unexpected and unanticipated concepts and ideas from the data and built new themes that would be included in the report (O’Leary, 2017:332). To preserve the richness of the narratives from the participants, I included direct quotes in my report to allow the audience to “hear the participants’ voices”.

## 3.8 Rigour

In qualitative research, indicators of credible research include trustworthiness, confirmability, dependability, and transferability (O’Leary, 2017:56).

### 3.8.1 Trustworthiness

To ensure good research I had to self-reflect and manage my subjectivities and biases by acknowledging their presence and influence (O’Leary, 2017:332). According to Berger, (2015:220) self-reflection is an essential element that demonstrates trustworthiness in conducting research. To demonstrate credibility, I conveyed supporting evidence to the readers by using quotes from the participants that the findings accurately represented what was studied. Trustworthiness of qualitative research is an important indicator of the quality of research findings which gives a detailed description of the study (Meena, Jakhetiya & Pandey, 2020:6)

### 3.8.2 Dependability

Another indicator for rigour and credibility in my research was dependability, which is attained by using consistent data collection procedures. This was accomplished by supervisor and peer debriefing which entailed sending the research findings to my supervisors and colleagues, who are experts in the area, for verification (Scharp & Sanders, 2018:4). To ensure dependability, I described the research design in great detail so that if a different researcher repeated the same study processes, they would be able to gain the same results and make similar inferences. By leaving an audit trail that gives a record of the research design, the processes that were used can be replicated (Johnson, Adkins, & Chauvin, 2020:143; Ataro, 2020:21).

### 3.8.3 Confirmability

Confirmability requires that a detailed explanation is given to link the data to the findings (Scharp & Sanders, 2018:4). I have described the methodologies and methods used to conduct my research. According to Johnson, Adkins and Chauvin (2020:143), confirmability necessitates that the researcher ensures and communicates to the reader that the results are based on and reflective of the information gathered from the participants and not from the interpretations or bias of the researcher.

This endeavour provides evidence of the approaches and methods which were employed in the research to other readers. Data gathering and analysis processes were systematic and well designed. O'Leary (2017:64) states that the methodology should be well-documented to illustrate the connection between the findings and the original data.

### 3.8.4 Transferability

Transferability refers to the extent to which the research findings can be applied to other circumstances. Johnson, Adkins, and Chauvin (2020:143) postulate that in such a case the researcher provides detailed information such that readers can determine whether the findings apply to other situations. The findings of this study may apply to participants in similar situations. The purpose of the study was to gain an in-depth understanding of the experiences of students with epilepsy (SWE) in accessing support services in higher education and not to try and generalize findings.

### 3.9 Ethical Considerations

This study is guided by the World Medical Association (WMA) Declaration of Helsinki Ethical Principles for research involving human participants (World Medical Association, 2013). I obtained approval to conduct my research from the Health Research Ethics Committee (HREC) of Stellenbosch University (SU) with HREC Reference No: S19/10/251 (See Appendix A). Below are the precautions that were taken in compliance with basic research ethics principles in conducting my research with the participants.

#### 3.9.1 Preserving Confidentiality

I used codes such as BB and GM which were initials from their names to protect the identity of my participants (Ohajunwa, 2019:143). I locked hard copies of notes and consent forms in my filing cabinet. I saved transcriptions and notes on my personal computer and laptop which is password protected. All the information was cloud-saved to further preserve the confidentiality of the participants. Voice calls and documents sent via the internet were encrypted to restrict access to them. I emphasised that telephonic interviews be conducted in private spaces by reminding participants to ensure that no one overheard their conversations during the interview sessions. After completion of the study, data will be safely kept for the specified period of five years, and then destroyed.

#### 3.9.2 Beneficence and non-maleficence

Beneficence is an ethical principle in research whereby researchers are expected to take into consideration the interests of the participants by promoting what is best for them and minimizing harm, also known as non-maleficence (Department of Health, 2015:14; O’Leary, 2017:70). This means the benefits of being involved in the research should outweigh the risks to the participants. In keeping with this principle, I ensured that no unnecessary tension was created by asking insensitive questions that would result in psychological harm to the participants (O’Leary, 2017:71). When one of the participants indicated that he was not feeling well, we rescheduled the interview to a different date suggested by the participant.

#### 3.9.3 Distributive justice (or equality)

The principle of distributive justice states that there should be a fair distribution of benefits to those who will be involved in conducting research (Department of Health, 2015:14). Furthermore,



O’Leary (2017:69) asserts that the researcher should practice fairness in the recruitment of participants. The recruitment was gender-sensitive because I managed to recruit three male students and one female student. The interview questions were made available to all the participants via the internet before the date of the interview so that they would be prepared for the actual interviews. Participants, therefore, had more time to think and reflect on their responses to the questions on the interview guide I had emailed them.

I created rapport with the participants by phoning them before the interview date to discuss issues of privacy and confidentiality. I also responded to questions they had about the study which also helped to build trust (O’Leary, 2017:59). Participants were happy to receive a gigabyte of data as promised in the consent form.

Tracy (2020:209) claims that virtual interviews level out power imbalances as compared to face-to-face interviews. The fact that participants were in familiar environments made them feel safe, confident and less apprehensive. The issue here is self-awareness and acknowledging the power differentials between the researcher and participants in the construction of knowledge (Karnieli-Miller, Strier, & Pessach, 2009:282).

#### 3.9.4 Respect for persons (dignity and autonomy)

The principle of respect for persons (dignity and autonomy) incorporates the elements of respect and independence in participants (Department of Health, 2015:15). According to O’Leary (2017:70) participants must make informed decisions on whether to participate in a study or not, in keeping with the right to autonomy. On the day of the interview, I explained the purpose of the study once again which gave room for the participants to ask questions about the study. I reminded them that they had a right to withdraw from participating in the study if ever they felt they wanted to terminate and that they would not be prejudiced in any way (Khan 2014:306).

#### 3.10 Conclusion

In this chapter, I discussed the methodology I employed in gathering data. I utilized the qualitative approach and adopted the phenomenological research design and in-depth conversations to elicit participants’ perceptions about the support services institutions should provide to students with epilepsy (SWE). Participants were recruited using snowballing, a purposive sampling procedure.

I also discussed ethical issues such as preservation of confidentiality and respect for participants' dignity and autonomy. The findings of this study are presented in the next chapter.

## Chapter 4 – Research Findings

### 4.1 Introduction

In this chapter, I present the outcomes of the data analysis process and findings from the study. The findings reflect the perspectives and lived experiences of students with epilepsy (SWE) in accessing tertiary education in Zimbabwe. Participants identified both challenges and facilitators of inclusion under the following overarching themes: 1) Facilitators of inclusion 2) Accessibility barriers 3) Reasonable adjustments measures.

### 4.2 Presentation of study themes

The emanating themes from the study are:

1. Facilitators of inclusion, these are the accommodations that were provided by the institution which supported access and inclusion of students with epilepsy (SWE).
2. Accessibility barriers are the challenges SWE encountered that restricted their opportunities to access their learning on an equal basis with their peers.
3. Reasonable adjustments measures are the adaptations or obligations suggested by the participants that the government and the institutions should fulfil to make higher education accessible to everyone.

Under each theme are subthemes as reflected in table 4.2 that further express the participants' narratives related to each theme. I used excerpts from the interview transcripts to present participant voices as relevant to the social justice influence of the study. The facilitators of inclusion are presented first, followed by barriers to accessibility and finally, the various reasonable adjustments that support accessibility of SWE within HE as indicated below.

An overview of these themes is presented in Table 4.2 below. First, the research questions are presented as follows;

(A) What are the support services participants were aware of at the college?

(B) What are the challenges that SWE encountered in accessing support services during their training.

(C) What are participants' views on what constitute best practices and appropriate support services for SWE in tertiary education?

Table 4.2 above presents the themes and subthemes from the findings.

| AIM  | OBJECTIVES   | THEMES                            | SUBTHEMES   |
|--|--|-----------------------------------|---|
| To explore the lived experiences of Students with Disclosed Epilepsy in accessing support services at a Teachers' College in Zimbabwe. | A. To identify support services participants were aware of at the college  | 1.Facilitators of Inclusion       | Self-disclosure<br>-eligibility to support services<br>-Disability services<br>Holistic support systems/services<br>-Curriculum & adaptations<br>-Social support<br>-Psychosocial support<br>-spiritual support<br>-Positive self-perceptions   |
|  | B. To describe the challenges participants, encountered in accessing support services in the course of their training. | 2.Barriers to Accessibility       | Social exclusion due to stigma and negative attitudes<br>-Non-acceptance from lecturers and peers<br>-Impact of cultural belief systems<br>-Non-disclosure due to perceived discrimination<br>Limited resources<br>-Lack of training of staff<br>- Financial challenges<br>Challenges of self-representation<br>-Problems in negotiating for accommodations<br>-Difficulties in advocating for rights |
|  | C. To describe participants' views on what constitutes best practices for learners with epilepsy at the college.       | 3.Reasonable Adjustments measures | Policy formulation<br>-Access to disability grants.<br>-Improved information dissemination strategy<br>Partnerships<br>-Government partnerships<br>-Non-governmental partnerships<br>-Institutional partnerships<br>-Peer partnerships  |

#### 4.2.1 Facilitators of Inclusion

This theme speaks to factors that support inclusion, with two subthemes which are self-disclosure and holistic support.

##### 4.2.1.1 Self-disclosure

One participant disclosed their medical condition to the institution on application. Although the other participants were initially hesitant to disclose their health conditions, they all acknowledged receiving support services after disclosing their conditions. When students with epilepsy (SWE) disclosed their health conditions, they automatically became eligible for support services such as, curriculum adaptations, appropriate accommodation, medication and other essential services from the Disability Resource Centre (DRC) which facilitated their learning during training.

*“My lecturers understood my condition. When I explained to them that I had had an attack, they would always allow me to write my test after the condition had stabilized; after a day or two”. NC: Line 24-25.*

*“I was happy with the support that I got especially the special arrangement on accommodation”. BB: Line 57*

Participants described how the services they received from the Disability Resource Centre (DRC) responded to their needs and facilitated their learning.

*“I explained my condition that I had epilepsy and also told them that I was taking medication. The DRC staff registered my name and referred me to the clinic”. BM: Lines 24-25.*

*“The DRC educated people on how to handle SWE”. GM: Line 172.*

*“The staff there encouraged me to participate in sports. So, I got to participate in different kinds of sporting activities with other SWD from other institutions”. BB: Line 61-63*

#### 4.2.1.2 Holistic Support

Providing only academic and social support without psychosocial support for students with epilepsy (SWE) is not enough. Generally, SWE need holistic support which, in addition to academic support, should include psychosocial support and spiritual support.

It emerged from the findings that participants valued the psychosocial support they received from the nurse, the lecturing staff, peers, and spiritual support groups. Participants acknowledged the benefits of counselling services they received at the college. It was evident that they experienced stressful encounters in their interactions which required psychosocial support.

*“I always received counselling from the nurse and this helped because most of the time I would be stressed due to this condition”. NC: Line 31-32.*

*“Lecturers would also try to counsel me and try to cheer me up if they saw me withdrawn in a corner by myself. This would prevent me from getting into a seizure”. GM: Line 127-128.*

Participants also gained solace from the support of their small circle of friends and participation in religious activities.

*“The support I got was important, very important. It transformed me from what I was in the past when I enrolled at the institution. My friends helped me to view my condition like just any other ordinary condition. They transformed my life by counselling me and encouraging me. They did a good job”. GM: Line 132-135.*

*“..... Religion gives me hope. It helps me create strong relationships with other people when I interact with them in church and they treat me with respect. It feels good to hear someone calling you ‘sister G.... It is motivating and helps to build your self-confidence. It plays a great role in the realm of socialization even though it is just for a few hours.....” GM: Line 239-243.*

It is also evident in the data collected that the academic and psychosocial support that the participants received helped to shape their perceptions about their condition which positively

impacted their learning and how they felt about themselves. They developed positive self-perceptions and psychological well-being.

*“The first thing I acquired was an education about epilepsy. ... I was so excited when we were taught this topic. It made me understand my condition more than the way I used to do in the past. --- I can easily handle my condition and even avoid unnecessary seizures”. GM: Line 64-66.*

*“Lecturers from my subject area encouraged me to actively participate in all activities like every other student. They said I was not different from other students. I found this quite helpful and I began to enjoy my subject very much”. BB: Line 42-44.*

*“Religious activities assisted me to be more confident..... It makes one mentally stable”. GM: Line 239,243*

The inputs they received motivated them to continue with their studies and strengthened their self-confidence. However, participants also identified certain barriers and challenges to their learning as highlighted below.

#### 4.2.2 Barriers to Accessibility

The subthemes that emerged are social exclusion due to negative attitudes and stigma; limited resources and challenges with self-representation. Findings reflected that participants encountered several challenges that interfered with their learning during training.

##### 4.2.2.1 Social exclusion due to negative attitudes and stigma

The participants experienced a lot of stigma due to negative attitudes. While a few of their peers assisted them in different ways, some of them avoided them due to their condition which led them to become overly self-conscious and withdrawn. The signals that students with epilepsy (SWE) received from their peers and academic staff influenced the way they viewed themselves, leading to low self-esteem and self-isolation.

*“I remember one of the members of staff from the Disability Resource Centre (DRC) suggesting that I write my examination in the DRC alone. So, I was*



*kind of asking myself whether I needed to write on my own. Why would I be excluded? Am I not like other students? It's a question that remained unanswered". GM: Line 190-193.*

*"They would say, 'She is the one who always falls due to 'pfari' (a vernacular and derogatory term which means epilepsy) and ... stuff like that. It also made it difficult for me to be in a relationship. They looked down upon me. This condition has disrupted my social life. So, I ended up isolating myself and I was left with no one to talk to or socialize with me". GM: Line 40-43.*

*"-----they would discriminate against me due to my condition and look down upon me". BM: Line 293.*

Participants felt unease about their peers knowing their condition due to a lack of understanding of their impairment. They believed that the stigma they suffered from both peers and lecturers was a result of cultural beliefs and ignorance. Thus, there was a need for staff development as well as peer and student training.

*"Some of the lecturers did not accept my condition. It appeared some were not aware of the condition because they made comments such as 'leave him he is mad/insane. So, they need to be educated about epilepsy so that they do not mistake it for mental illness". BB: Line 130-132.*

*"Some of them are still 'primitive' (superstitious). The students come from different cultural backgrounds and view epilepsy differently. Some view epilepsy as an ordinary condition but others believe that the condition is somehow demonic". GM: Line 146-148.*

Segregation from past experiences had taught the participants that society held negative perceptions about students with epilepsy (SWE). Therefore, some of them could not just declare their impairments during application out of fear of being denied admission at the college.

*"I didn't declare my disability status because I was afraid that I could fail to get a place due to my condition". BB: Line 49-50.*

*“Some people discouraged me from disclosing my impairment because they thought I might fail to get enrolled due to discrimination because of my disability”. BM: Line 19-20.*

#### 4.2.2.2 Limited resources

The participants also experienced financial challenges. With the additional burden of having to buy medication for the participants, parents faced challenges in raising college fees and buying assistive technology (TA).

*“The majority of students are suffering because parents cannot afford to buy medication, supplementing food and paying school fees. Parents cannot afford it. We are economically challenged and living a very difficult life”. GM: Line 268-270*

*“I felt that a person with limited resources like me, becoming a member of the Students Representative Council (SRC) and carrying out all those responsibilities ---- would be too much for me. The other students owned laptops and other gadgets that I didn't have”. BM: Line 139-142.*

#### 4.2.2.3 Challenges of self-representation

Participants felt that there was no space for them for self-representation. They believed that the college should give them room to express their views. Findings revealed that they wanted to be actively involved in decision-making about their access needs as a way of advocating for their rights.

*“We want to be recognized as individuals who have special needs. We require safe accommodation, medication and other services. We can engage in awareness campaigns strategies such as those employed in HIV/AIDS campaigns”. GM: Line 276-278.*

*“We should be involved because an affected person like me knows what happens after one gets into a seizure, that it is difficult to take an exam because even sentence construction would be a problem”. NC: Line 105-106.*

*“They can also give SWE opportunities to explain their condition and experiences because they are knowledgeable about their condition. First-hand information is better than second-hand information which may be shallow”.*

*GM: Line 178-180.*

#### 4.2.6 Reasonable Adjustments Measures

Reasonable adjustments measures emerged as a subtheme too. The major aspects supporting this theme was the importance of policy formulation, information dissemination, funding, and partnerships.

Participants proposed several improvements that would facilitate their learning. They felt a strong need for the institution to come up with a policy that would guide the operations of the college with regards to accessing provisions for students with epilepsy (SWE). Participants identified that the college community lacked adequate knowledge about epilepsy and suggested that the institution hold regular awareness campaigns on how to handle SWE.

Due to financial challenges participants also requested that they should also benefit from disability grants in the same manner in which students with impairments (such as visual and physical impairments) received grants from the government. Participants also highlighted the need for government and institutions to create partnerships with non-governmental organizations (NGOs) and civic organizations and the community. Findings indicated how SWE benefitted from peer support and suggested the need for peer partnerships.

##### 4.2.6.1 Policy Formulation

The participants perceived the lack of a disability policy as the root of all the challenges they encountered during their training. The participants conceptualized that the availability of a legal framework would assist them to make their demands met and holding the institution accountable. The participants highlighted some of the benefits of having a disability policy as shown below.

*“Having a disability policy brings a sense of alertness on the requirements of students with disabilities. The policy would spell out what type of assistance the institution should provide. Students with epilepsy (SWE) will also get to know about the kind of assistance the college provides”.* BM: Line 115-117.

*“When you have such a policy at school you feel protected just like you would feel at home with your family and friends around you. Having a documented policy will guide the institution in handling SWE”. GM: Line 207-208.*

To improve information dissemination participants suggested that qualified personnel in the Disability Resource Centre (DRC) should be responsible for propagating information to the college community in a systematic manner and guided by the institutional policies. The DRC had an obligation to provide SWE guidelines on negotiating for academic support services and disability grants.

*“The DRC should sensitize students and lecturers on matters of disability so that everyone is aware of how to handle all types of disabilities and especially epilepsy”. BB: Line 199-101.*

*“DRC staff should hold frequently awareness campaigns so that everyone becomes aware of the services offered the DRC and other support from the clinic. At times students may not be aware of services offered at the institution”. BB: Line 76-78.*

*“---There were times when it was very difficult for my parents to raise fees for me that I wished I also would benefit from the social welfare grant”. BB: Line 194-195.*

#### *4.2.6.2 Partnerships*

The participants felt that the government had an obligation to fund their education. To lessen the burden of the institution’s dependence on government funding, participants proposed that both the government and the institution should partner with other stakeholders such as Non-Governmental Organizations (NGOs) and civic organizations if their goal is to provide education that is accessible to everyone was to be achieved.

*“The government may also assist. I am not sure how they should do it, but the institution could request the government to assist”. BM: Line 258-259.*

*“I think some organizations can also be involved in assisting the institution”.  
NC: Line 123.*

*“NGOs could also assist with funding for procuring drugs. If the institution partners with an NGO it may be assisted”. BM: Line 263-264.*

Participants depend upon peer support in their academic endeavours. One of them suggested that the college should introduce the buddy system so that they benefit from peer partnerships. She seemed unsure about whether the institution should shoulder the responsibility of recruiting assistants for students with epilepsy (SWE).

*“Students should be taught about this condition as soon as they get admitted at college. Personnel from the Disability Resource Centre (DRC) should advise SWE that they look for someone who they can coach on how to look after individuals with epilepsy”. BM: Line 148-150.*

*“The institution should enforce that each SWE must bring an assistant who should enrol with the college and also stay on campus”. GM: Line 278-279.*

#### 4.3 Conclusion

In this chapter, I presented the participants’ experiences and narratives about the facilitators and barriers to accessing support services within tertiary institutions and their thoughts on reasonable adjustments. Participants highlighted the relevance of holistic support systems and disability policies, as facilitators of inclusion and access. They equally noted the detrimental impact of social exclusion and negative attitudes, lack of resources and challenges of self-representation on their capacity to learn with their peers. In the next chapter, these critical outcomes are discussed in terms of current literature and discourse in this area.

## Chapter 5: Discussion

### 5.1 Introduction

This chapter applies the conceptual framework of social justice and equity embedded in the human rights approach as a lens to discuss the findings of this study. The findings highlighted the importance of providing holistic support for students with epilepsy (SWE). The study revealed the benefits of formulating a national and institutional inclusive education policy that should guide the operations of the institution. Mandatory policies ensure that SWE have equal access to tertiary education and that their right to education is honoured and respected.

From the analysis of participant narratives, some areas emerged as critical to the capacity of SWE to gain access to educational support and to be included in tertiary education on an equal basis with their peers. These areas include a multi-dimensional approach to support provisions; policy guidelines for implementation; disability sensitization; self-representation; and partnerships for inclusion.

### 5.2. Multi-dimensional support system

This section provides reflections on the support services required by students with epilepsy (SWE) to access higher education.

#### 5.2.1 Staff development

Participants enjoyed some level of social and academic support services provided at the institution. However, they highlighted some of the barriers they encountered in the teaching and learning processes that prevented them from fully engaging in their education. Due to their unique condition, students with epilepsy (SWE) require a holistic approach to service provision. McKinney and Swartz (2020:7) assert that academic staff members play a critical role in either facilitating or preventing students' learning in tertiary education.

If academic staff are not well equipped to handle the needs of SWE, Moraña and Orozco (2021:161) point out that SWE continue to experience access barriers in their education and fail to fulfil their aspirations of economic independence and community integration. Students with epilepsy may experience learning challenges imposed by the nature of their impairment. This calls for qualified personnel equipped with skills in curriculum adaptations or differentiation. James,

Bustamante, Lamons, Scanlon and Chin (2020:3) posit that most lecturers lack the knowledge of how to support students with epilepsy in higher education. They thus fail to design accommodative curricular in their different study areas.

Institutions of higher learning should train lecturers utilizing staff development or in-service training to ensure that all students benefit from accessible and fair educational programs. Svendby (2020:275) suggests that tertiary institutions should provide training in inclusive approaches to academic personnel to ensure that students with disabilities (SWD) have equitable opportunities in accessing tertiary education. It is understood that training professionals and staff who work at all levels of education guarantees the right to education for individuals with special education needs.

In Zimbabwe, only a few teachers' colleges are responsible for training teachers in inclusive education. The limited number of professionals qualified in inclusive education is mainly employed in primary or secondary schools. Only a limited number of vacancies for academic staff trained in inclusive education are available in tertiary institutions. According to Clouder, Karakus, Cinotti, Ferreyra, Fierroa, and Rojo (2020:16), there is a gap in the number of academic staff trained in inclusive education in tertiary institutions. Hence, students with epilepsy (SWE) continue to experience barriers in accessing higher education.

Clouder, et al (2020:16) and Moraña and Orozco (2021:173) suggest that the application of a Universal Design for Learning (UDL) framework, serves the purpose of adjusting the curriculum to suit students with various learning styles. Dalton, et al, (2019:3) also point out that the UDL applies the concepts of accessibility and inclusion that includes designing teaching and learning resources in ways that are accessible to students with differing learning needs. This helps to remove the barriers established by rigid curricula, which restrict participation and make it problematic for SWE to engage in meaningful learning. Social justice and equity in education can be achieved by employing the UDL which also support non-disabled students in tertiary institutions. (Wilson, 2017:1).

### 5.2.2 Psychosocial support

Seizures can be disruptive to one's social and academic life. Participants described how they experienced memory loss after seizures, which immensely affected their concentration in their studies. High levels of stress trigger seizures, thus, creating a vicious circle. According to Reid (2017:4), stress is a major issue that students with epilepsy (SWE) grapple with. Lecturers, the college nurse and peers played a vital role in providing psychosocial support to SWE, as also indicated in the current study where participants esteemed the counselling services they received from the institution. According to Alqahtani (2015:163), a multidisciplinary approach to managing epilepsy is recommended which calls for cooperation among professionals.

Participants benefited from counselling services offered on campus, they also benefited much from engaging in religious activities. Participants believed that spiritual healing could treat health conditions such as epilepsy. This could have originated from the traditional belief that epilepsy is a result of witchcraft or is demonic. Chitiyo and Muwana (2018:106) postulate that traditional beliefs often impact the health-care seeking strategies employed in African countries such as Zimbabwe. The same view is shared by Oumer, Girma and Ayeligne (2020:1) who state that in most African countries, individuals with epilepsy preferred indigenous or spiritual treatments rather than allopathic medical treatments. Findings here, however, indicated that spiritual healing complemented medical treatment. Thus, participants used both ways to seek healing.

Participants derived satisfaction from attending faith healing churches. They confessed that attending these churches stabilized them mentally and made them feel good about themselves. Spiritual support services improved their mental well-being. This is an area where institutions need to improve. Spiritual support services could complement other psychosocial support services offered at the institution. The college needs to strengthen spiritual support services on campus to accommodate all religious affiliations.

While the institution is commended for putting up structures that facilitated the inclusion of SWE, findings highlight a substantial number of obstacles that still obstructed SWE from accessing higher education.



### 5.3 Prevailing attitudinal challenges and self-representation

Disclosing one's condition is a ticket to benefitting from support services available at an institution. Participants in most cases, however, chose not to disclose their impairments for fear of discrimination during application. They expressed fear of non-admission due to their health condition and thus forfeiting support services that facilitate inclusion and access to higher education. McKinney and Swartz (2020:7) observe that there is too much stigma associated with epilepsy, and as such students with epilepsy (SWE) avoid disclosing their impairment due to fear of labelling. It is understandable why SWE do not reveal their impairment in the initial stages of their application.

All SWE have a right to admission and should not be excluded due to their impairment. According to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) individuals with disabilities cannot be denied entry to any course of study based on their impairment. The Constitution of Zimbabwe Amendment Act of 2013 dictates that all citizens have a right to education. Chitiyo and Muwana (2018:104) argue that superstitions and cultural beliefs influence people's attitudes towards the inclusion of individuals with epilepsy in tertiary education in Zimbabwe.

Negative attitudes from society perpetuate the marginalization and social exclusion of SWE. Onwuakagba, Okoye, Obi, Okoye, Akosile and Akobundu (2020:1) concur with this assertion by stating that individuals with epilepsy, in developing countries, experience human rights violations and segregation in education. This suggests why some students with epilepsy choose to forgo the benefits of self-disclosure despite the negative repercussions on their learning. Hlatywayo and Mapolisa (2020:417) declare that stigmatization and discrimination make the social environment intimidating, resulting in some students concealing their impairments. Concealing their health condition creates more barriers for SWE as they will fail to get the support, they need to access education. This undermines policies and practices which promotes the principle of social justice and equity.

Participants requested that SWE be involved in decision-making about issues that concerned their learning at the college. They declared that they understood their condition better than anyone else and should be involved in crafting institutional policies and leading awareness campaigns.

McKinney and Swartz (2020:1) advocate for the inclusion of the students' voices in decision-making. In line with the statement: 'Nothing about us without us' participants advocated for full participation in their education communities. It is their fundamental right according to the UNCRPD (2006). While students with epilepsy (SWE) need to collaborate with the institution for support. It is equally justified that they make decisions on the kind of support they need.

For students to be fully included, they need to advocate for themselves. Vergunst and Swartz (2020:4) argue that the most effective way of assessing the needs of students with disabilities (SWD) is to have direct consultation with them. SWE need a voice to air their views about what constitutes appropriate accommodations for them. This implies that institutions should impart advocacy and social skills to SWE in an endeavour to empower and build their self-confidence. They need to speak out for themselves to gain the respect and recognition they deserve as espoused in the human rights approach UNCRPD (2006).

Individuals with epilepsy can lead normal lives as long as they can manage their health conditions. However, from their study, Moriña and Orozco (2021:171) found out that lecturers in countries such as Spain were prejudiced about SWE, and even had doubts about their suitability of becoming teachers after completing their studies. Most of the lecturers in Zimbabwe hold the same perceptions about SWE, thus challenging their ability to attain educational success (Chitiyo and Muwana, 2018:105).

Educating the college community by undertaking intensive awareness campaigns about epilepsy could remove some of the myths and misconceptions that are deeply rooted in most people's minds in Zimbabwe. This will help shift negative attitudes towards SWE that act as barriers in accessing tertiary learning, as indicated in the subsequent sections.

#### 5.4 Information dissemination & disability sensitization

This study indicates poor methods of information dissemination at the institution. The institution lacks proper channels of communication and, as a result, students with epilepsy (SWE) had to struggle to get the information they needed about the kind of support available at the institution. Moriña and Orozco, (2021:167) proclaim that lack of information and advice about requests for help were some of the major challenges that SWE grapple with.

Participants could not access support services in time due to a lack of information. Access to information and understanding the available support services assist SWE to negotiate reasonable accommodations that facilitate their learning in tertiary education (Murray & Sotardi, 2020:12). Being equipped with correct information assists SWE to make the necessary adjustments and reduces anxiety.

Understanding epilepsy and how it manifests itself is key to students, lecturers, administrators, and every member of the college community. It is therefore vital to raise awareness amongst lecturers and the whole community, as this could change the negative traditional attitudes of stakeholders towards epilepsy. The study reveals that lecturers lacked critical information about managing epilepsy. Majoko (2018:4) points out that the lack of awareness by lecturers of the diverse needs of SWE is a barrier to participation for the students. Alamri and Thobaity (2020:2705) concurred with this observation when they highlighted that knowledge concerning epilepsy was scanty and that prompt mediation through educational awareness campaigns was required to develop a responsive and sensitive community.

All the information on how to respond to the needs of SWE should be made available to everyone. Personnel in the Disability Resource Centre (DRC) could help sensitize lecturers, administrators, and other students about epilepsy and how to manage it. The disability resource centre (DRC), due to its strategic position in the institution, should take this critical role seriously so that students have access to available support at the institution. Participants complained about the delay they had getting this information. Moriña and Orozco (2021:167) earlier also acknowledged the view that the DRC has an essential role in offering critical information involving the lives of SWE at the institution.

Ensuring that each student undertakes some training sessions in inclusive education helps to sensitize everyone on disability issues (Sithole & Mafa, 2017:1231). Moriña and Orozco (2021:171) suggest that not only should students be trained but also the whole college community. Awareness-raising campaigns will help fight against negative attitudes. A review of the literature shows that the negative perceptions that society holds in general concerning disability, are associated with beliefs embedded in the biomedical model which perceives disability as a deficit and not as originating from one's interactions with their environment (ICF) (WHO, 2001).

Tertiary institutions can mitigate all the exclusion and injustices experienced by students with disabilities (SWD) by adopting the human rights model. The model utilizes inclusive approaches that can foster inclusive participation by removing barriers, widening access and transforming attitudes in higher education. This means that all vital information and policy documents should be readily available on websites or printed copies in modes of communication that can be accessed by all (for example, in Braille or Sign Language).

### 5.5 Policy guidelines and relevant implementation

The institution lacked policies that guided its operations. There was no admission policy for SWE. As a result, students were confused and uncertain and foresaw potential challenges during their training (Manuel, Machakanja, & Jeranyama, 2019). No written document was available which specified existing support services at the institution. The United Nations Convention on the Rights of People with Disabilities (UNCRPD) (2006) stipulates that individuals with chronic disabling conditions such as epilepsy depend on disability policies to enjoy their rights to education by effectively accessing tertiary education.

Hlatywayo and Mapolisa (2020:407-8) observe that the absence of a mandatory disability policy in tertiary institutions and an agreed interpretation of the concept of inclusive education in Zimbabwe creates barriers for SWE in accessing educational opportunities. By adapting their systems and responding to the students' needs and not vice versa, institutions would be upholding principles of equity and social justice enshrined in the UNCRPD (2006) and the SDGs.

The formulation of an inclusive institutional policy would help dismantle barriers to access and address the needs of SWE. The institution will be well-positioned to implement inclusive education according to the policy guidelines for accessible tertiary education. Teacher education is recognised as vital for equipping teachers with efficient knowledge to teach students with diverse learning abilities (UNESCO, 2009). Medina-García, Doña-Toledo and Higuera-Rodríguez' (2020:6) confirm that at the end of the day, student teachers need to be educated and knowledgeable about all aspects of equity and non-discrimination in education.

Participants did not question why they were not benefiting from the Social Fund as students with other categories of impairments were. One reason could be attributed to ignorance or that they did

not see themselves as disabled and deserving of this grant. For some unknown reason, students with chronic conditions in Zimbabwe are not benefitting from the social grant as those with sensory, mental and physical impairments are. Issues of disability grants should be stipulated in policy documents so that students are aware of who is eligible or not. This issue warrants further investigation.

Setting up a legally binding policy would hold tertiary institutions accountable for their conduct. Tertiary institutions in Zimbabwe have conflicting definitions and interpretations of inclusive education. A policy document would stipulate its meaning, the roles, scope and responsibilities of institutions and the government. Mukwambo (2020:1258) observes that in the absence of policies and limited consultation, lecturers themselves mostly determine what constitutes quality educational practices that may not be equitable to SWE.

A policy document would inform tertiary institutions about accessible support services and what their implementation entails. Students with epilepsy (SWE) have the right to receive an education that accommodates their needs. Moriña and Orozco (2021:173) postulate that providing supportive education is not a question of preferential treatment for SWE but rather one way of effecting social justice and respect for the diverse forms of learning styles.

Enacting a legal framework will certainly have a positive impact on the inclusion of individuals with disabilities in sectors such as education, health and other social services. At the time of writing the new Bill on the National Disability Policy in Zimbabwe was in its final stages before being passed into law. This is something worthy of mention, although it has taken quite some time to be enacted. If the policy is implemented, institutions will be bound by this enactment and students will be in a position to question institutions if their demands are not met.

## 5.6 Partnerships for Inclusion

It is necessary to create partnerships and collaborations at institutional levels, district, provincial, national and even international levels to facilitate access to education for students with epilepsy (SWE)

For the institution to be accessible, structural and institutional barriers need to be removed. This means that institutions need funding to make them accessible for SWE. Tertiary institutions also

need funding to purchase learning and teaching resources and to offer staff development in inclusive education, both for academic and administrative staff. The allocations that institutions receive from the government are inadequate. Sithole and Mafa (2017:1238) proclaim that institutions suffer from a lack of adequate funding, and thus fail to fulfil their obligations to SWE. The same sentiments are expressed by Vergunst and Swartz (2020:4) who state that it is established that tertiary education is poorly funded in low- and middle-income nations compared to high-income states. This means that putting up structures that support the implementation of inclusive education approaches also differs from country to country.

The Zimbabwe Education Amendment Act of 2019 stipulates that funding depends on the availability of funds. With dwindling economic resources in the country, it becomes problematic for institutions to raise adequate funding for their projects. During the time of writing, countries were under lockdown due to the COVID-19 pandemic. Gains that had been made towards providing accommodations will all be lost due to the economic hardships experienced by low-income countries. Funding will be diverted to other critical areas such as basic health services and food security. Whenever there is a crisis in the country, the social fund is affected which in turn affects the disadvantaged groups which depend on it.

There is a need for the government and institutions to partner with other organizations that would assist with the much-needed resources in the education of students with epilepsy (SWE). The college has partnered with several non-governmental organizations (NGOs) through the Ministry of Higher and Tertiary Education that have introduced varied educational programs which assist individuals with disabilities. They focus mainly on providing assistive technology to support students with different impairments in their learning. Students with epilepsy (SWE) would benefit from such endeavours by getting improvements in medical supplies and financial assistance.

The major challenge with these partnerships is that NGOs have their own, set objectives when they introduce programs. The projects are designed from the top down and beneficiaries have very little say in their implementation. My personal experience as an academic staff member in tertiary education was that some of the programs are not sustainable and end as soon as the organizations terminate their funding. This means barriers to access will continue to exist in learning institutions in Zimbabwe.

Tertiary institutions still have a long way to go for them to be able to remove barriers that prevent access for SWE. The suggestion that they mobilize and team up with local industries, civil organizations and communities and draw up sustainable educational programs that will benefit and support every learner in accessing education is commendable. Failure to provide equal opportunities and accessible support services militates against the spirit of social justice and equity which advocates for equal access to educational opportunities (UNCRPD, 2006).

In this study, it was evident that participants relied heavily on peer support. According to Moraña and Orozco (2021:161), peer support is important to SWE in that it brings positive experiences to their learning. SWE need other people to assist them throughout their learning period. In developed countries, assistants are paid for their services by the state. Depending on the policy, some institutions in Zimbabwe advise students experiencing challenges in their learning to bring someone who would enrol at the institution and become an assistant to the SWE. In other institutions, the assistant is exempted from paying boarding fees as an incentive. This way SWE would greatly benefit from the buddy system and would be assured of getting assistance whenever they need it. The college policy would specify all the benefits that SWE are supposed to enjoy at the institution. A laid out institutional policy such as, for example, the one at Stellenbosch University would assist in such endeavours.

Support groups can also serve as a centre for bringing together students with epilepsy (SWE) who seek communal support from one another (Bromley, Murray, Rochelle & Lombardi, 2020:10). Peer support helps reduce a sense of isolation as well as providing the opportunity to share similar concerns and propose solutions that can be shared among peers and the college community at large (Chiang, 2020:1184). This fosters a sense of belonging among SWE and boosts their self-esteem. The Disability Resource Centre (DRC) can take a leading role in organizing SWE who wish to mobilize their efforts and campaign for change.

## 5.7 Conclusion

Participants suggested steps that institutions could take to widen access and improve participation in tertiary institutions. Students with epilepsy (SWE) have a right to education just like everyone else. Capacity-building should include the professional development of lecturers and sensitization of students and the college community as a whole. Policies that advocate for social justice and

equity should guide the implementation of disability awareness, provision of grants and support services that enable SWE to access higher education.

Institutions need to adopt a framework that facilitates access and equal opportunities in tertiary education. Learning support needs to be multi-dimensional for it to be meaningful and beneficial to SWE. The framework is discussed in the succeeding chapter.



## Chapter 6: Conclusion

This chapter presents the conclusions, limitations, recommendations and suggestions for future research.

### 6.1 Introduction

The main research question guiding this study is: ‘What are the lived experiences of students with disclosed epilepsy in accessing support services at a Teachers’ College in Zimbabwe? The sub-questions derived from the main research question are:

- a) What are the support services participants were aware of at the institution?
- b) What are the challenges that students with epilepsy (SWE) encountered in accessing support at the institution?
- c) What are participants’ views on what constitute best practices and appropriate support services for SWE in tertiary education?

Participants shared their perceptions concerning their current service provisions, barriers they have experienced and suggestions for improvements to the support services. Key issues raised in this study comprised of the need for a multi-dimensional support system, prevailing attitudinal challenges, need for policy guidelines, and partnerships for inclusion.

### 6.2 Summary

This section answers the first research question which investigated available support at the institution. The study highlighted that, despite the numerous challenges the institution encountered, it managed to provide tertiary education to students with epilepsy (SWE). Participants made use of the available support services at the institution and have managed to complete their studies. This proves that institutions are not only aware of their obligation to educate all students but are determined to fulfil this social obligation.

The institution not only responded to the participants’ academic needs but also their psychosocial needs. SWE have managed to succeed in their academic pursuits and realizing their dream of leading independent lives and community integration. Findings revealed that holistic support from the government, non-governmental organizations (NGOs), students and the whole community would assist the institution to carry out its mandate successfully. For SWE to enjoy equal rights to

education there is a need for collaboration between the government and non-governmental organizations, civil organizations and institutions, tertiary institutions and the community.

Responding to the second research question the study illuminated numerous individual and institutional barriers to students' participation in tertiary education. Evidence reveals that SWE do not disclose their impairment due to negative attitudes. A well-established support system would encourage SWE to disclose their conditions on registration as this guarantees their support throughout their whole training period.

Some SWE do not disclose their health condition for fear of stigma, this reflects society's negative perceptions about epilepsy and persons with this condition. There is a need to carry out intensive awareness campaigns to rid society of such negative and culturally-based perceptions about epilepsy which act as barriers to providing accessible support services. How society perceives individuals with epilepsy determines the way it will treat them.

Lecturers and peers play a vital role in the academic and psychosocial development of students with epilepsy. The study revealed that SWE benefitted from spiritual support. Their involvement in religious and spiritual activities was good for their mental wellbeing.

This study highlighted the shortcomings of academic staff in handling SWE and suggested staff development workshops and in-service training for lecturers, and disability awareness campaigns for the whole community. It is evident from the study that the general student populace also have misconceptions about epilepsy and correct information would help dispel prejudice against SWE. This in turn would increase the social acceptance and integration of individuals with epilepsy into the college and community at large.

In response to the third research question about improvement on provisions for SWE in higher education, the study highlighted the need for a disability policy that would detail all the information about the support services available for learners with epilepsy. An institutional policy that advocates for the support services and provides spaces for SWE to voice their concerns enhances participation in tertiary education. It also enables SWE to make informed decisions about appropriate learning support services. Developing legislation and appropriate policies is a political endeavour that is meant to redress the human rights issues of social injustice and exclusion that

SWE have experienced for a long time. Disability policies advocate for equity and the widening of students' access to tertiary education. Thus, the government and tertiary institutions should provide services guided by such policies.

The findings of the study highlighted the need for adequate funding for tertiary institutions to acquire resources needed to facilitate the education of students with epilepsy (SWE). The institution lacks adequate funding to buy resources. Hence, participants proposed that the institution considers collaborating with public and private organizations and other stakeholders in the community. The partnerships would help the college source funds for its projects. SWE should also benefit from the social fund as other students with physical, intellectual and sensory impairments. The college should move towards providing more inclusive learning spaces by adopting the principles of Universal Design for Learning (UDL) so that everyone can access and participate in tertiary education. It is important to develop a more universal approach to disability support systems in tertiary institutions.

Provisions in tertiary institutions should be holistic, inclusive and reflexive. A multidimensional approach to student support relates to diverse support systems that include psychosocial support, staff development, policy development, information dissemination, and the creation of partnerships. The framework considers all aspects of support needed by SWE in accessing tertiary education in line with the principles of social justice and equity.

### 6.3 The Multi-dimensional Support System Model

The model shown in figure 6.1 below reflects the interconnectedness of different aspects of support for students with epilepsy (SWE) in higher education as these emerge from this study

The framework promotes partnerships and communication between SWE and lecturers, peers, and the government, institutions, civic society and other stakeholders. It values the creation and implementation of a national and institutional disability policy and the professional development of lecturers. Lecturers need to be equipped with knowledge, competencies and skills that meet the diverse needs of SWE. The skills would be used to educate administrators, students, other stakeholders about the needs of SWE and belief systems that prevent them from accessing tertiary education.

The multi-dimensional approach values human rights and promotes the social interaction of all the students. This means placing the SWE in a space of socialization and learning. Students with epilepsy could be inserted at the heart of all discussions and involved in all decision-making, which culminates in creating an inclusive and accessible learning environment.

Aspects of inclusion that are based on my belief system of social justice, equity and non-discrimination are embedded in the multi-dimensional approach to support. Service providers continue to consult with SWE and other stakeholders to provide the universal design for learning (UDL) that is accessible to everyone.

## The Multi-dimensional Support System Model

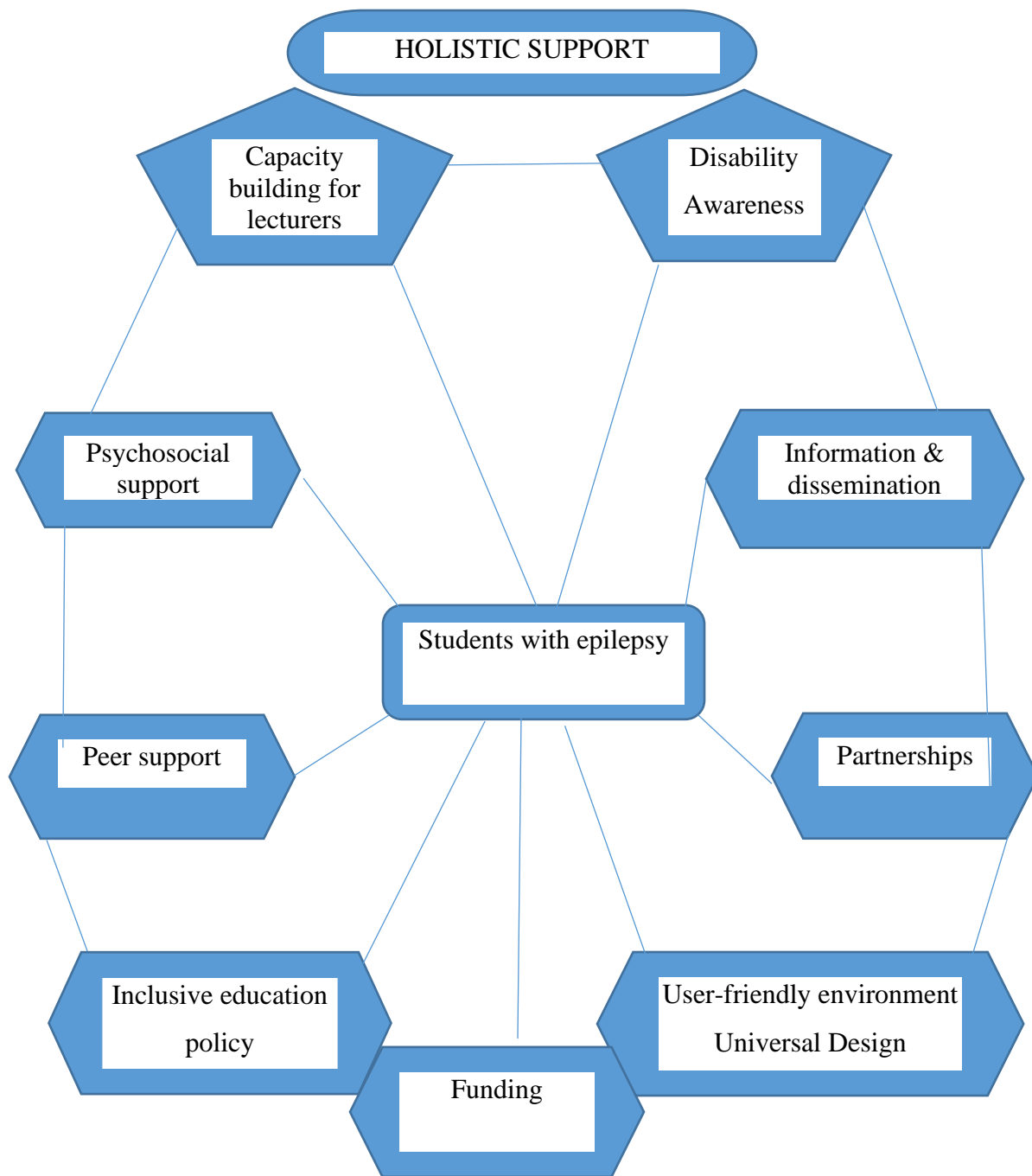


Figure 6.1 Multi-dimensional Support System Model

## 6.4 Study Limitations

The study had a limited timeframe since it is an academic requirement. This was compounded by restrictions caused by the COVID-19 pandemic. I had to make several amendments to my study to align my study with the recommendations made by Stellenbosch University and also to abide by the World Health Organization (WHO) regulations to prevent the spread of the Coronavirus.

This was a retrospective study that employed self-reports from past experiences of students with epilepsy (SWE). Recall bias was probable. This was minimized by involving only those participants who had left the institution after 2016. The sample was limited to a few participants. As a result, findings may only apply to students in similar settings. There may be a need to carry out further studies with current students with epilepsy examining how COVID-19 has impacted their studies.

I shifted my data collection procedures from face-to-face interviews to telephonic interviews which enabled me to contact participants who were located in different geographical locations. Although I managed to collect rich data there were no visual cues during the telephonic interviews. To curtail this limitation, I framed my interview questions carefully so that the participants were very clear of what was required of them. I used active listening which enabled me to detect any changes in the tone of the participants' voices.

The other limitation was the result of translating data from vernacular into English. Although I used a translator to verify the translations some of the meanings might have been lost during the translation process. Paying for the proofreading and editing of the document in forex caused some financial strain.

## 6.5 Recommendations

Examination of the findings led to the following recommendations:

1. There is a need to capacitate academic staff and equip them with competencies to meet the needs of students with epilepsy (SWE). Institutions can offer their lecturers college community in-service training, hold staff development workshops and disability awareness campaigns in handling SWE. Professionals manning the Disability Resource Centre (DRC) can assist with imparting knowledge and skills to the lecturers and students.

2. Working in conjunction with members in the Disability Resource Centre (DRC), students with epilepsy (SWE) could be given opportunities to share their experiences. This will assist in promoting positive attitudes towards individuals with epilepsy. The institution can also arrange for public seminars on inclusive education to remove psychological and social hurdles that limit access to social and academic support services for SWE.
3. The college could work in partnerships with other institutions, non-governmental organizations (NGOs), academic and non-academic staff, students and other stakeholders. The institution could cross-pollinate ideas with other institutions and civic organizations to improve access for students with epilepsy (SWE) in higher education. It can also embark on joint projects that will assist with funding of projects targeting improving resources for SWE. Although the government is responsible for funding tertiary institutions, it works on a tight budget due to depressed economic resources especially with the prevailing conditions of COVID-19. Collaborations with other stakeholders could assist SWE to secure grants from the government and civic organizations as students with other impairments do.
4. The government could develop a mandatory Inclusive Education Policy that will enforce the implementation of inclusive education at all tertiary institutions. Institutions could draft their policies guided by the national policy that promotes equal access to tertiary education. All stakeholders could be consulted in the formulation of these policies. The students with epilepsy (SWE) should be at the centre of these consultations. Open communication should exist that encourages dialogue between all stakeholders with an interest focused on the well-being of SWE. The institution could create a forum to make suggestions on good practices. The Disability Resource Centre (DRC) should be the centre for information dissemination that ensures that individuals with epilepsy have all the relevant policy knowledge. They should be involved in all decision-making processes. 'NOTHING ABOUT US WITHOUT US' should be the guiding principle in making access arrangements for SWE in tertiary education.

## 6.5 Conclusion

The chapter highlighted the key findings and the extent to which each research question was answered or not answered. Students with epilepsy (SWE) still encounter barriers in accessing tertiary education due to lack of comprehensive policy guidelines, lack of information, negative attitudes and inexperienced staff in handling SWE.

Limitations of the study were also discussed, and recommendations were given. There is a need to avail appropriate support for SWE for them not to encounter obstacles in accessing higher

education. They could employ a multidimensional support system that upholds human rights for SWE. The support system includes the following aspects: information dissemination regarding available support, policy guidelines, psychosocial support, qualified personnel, funding, and the implementation of a universal design for learning (UDL) framework which promotes social justice and equity in accessing tertiary education.



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## Tables & Figures

Table 4.2: Themes and subthemes

Figure 6.1: Multi-dimensional Support System Model

## Appendix A: Ethics Approval



Approved with Stipulations

New Application

09/04/2020

Project ID: 12938

HREC Reference No: S19/10/251

**Project Title:** Exploring the Lived Experiences of Students with Disclosed Epilepsy (SWE) in Accessing Support Services at a Teachers' College in Zimbabwe.

Dear Ms Margaret Chimedza

We refer to your response to modifications **received** on 17/12/2019. Please be advised that your submission was reviewed by members of the **Health Research Ethics Committee** and was approved with a stipulation.

Please note the following information about your approved research protocol:

Approval date: 9 April 2020

Expiry date: 8 April 2021

The stipulation of your ethics approval is as follows:

1. The PI requires permission from the institution to access student information if the students in question did not give consent for their information to be stored in the database and for it to be accessible to third parties.

We wish you the best as you conduct your research.

Yours sincerely,

Mrs Melody Shana

Coordinator: HREC1

## Appendix B: Application to the Principal

The Principal  
Mutare Teachers' College  
P O Box 3293  
Paulington  
**Mutare**  
21 September 2020

Dear Sir/Madam

RE: REQUEST FOR PERMISSION TO ACCESS STUDENTS' INFORMATION FROM THE  
INSTITUTION'S DATABASE

My name is Margaret Chimedza, a student at Stellenbosch University in South Africa. My Student Number is 23374608.

I am conducting research entitled: Exploring the lived experiences of students with disclosed epilepsy in accessing support services at a Teachers' College in Zimbabwe. I am seeking permission to have access to students' information from the institution's database. The information will assist me in identifying potential participants who are former students with epilepsy. I will take into account ethical considerations such as informed consent and voluntary participation. The study is part of the requirements for the Master's Degree in Human Rehabilitation I am undertaking at the university.

Your institution has demonstrated its commitment to Inclusive Education (IE) by enrolling students with disabilities to train as secondary school teachers. The purpose of this enquiry is to investigate the availability and accessibility of educational support or provisions for students with epilepsy (SWE) at the institution. Since the college is rendering support to students with epilepsy and other disabilities, I expect the institutions to benefit from this study as it is aimed at gaining an understanding of the nature of support services (SWE) expect from colleges.

I have already obtained approval from Stellenbosch University Health Research Ethics Committee (HREC) to conduct this research. The information I will get will be used for academic purposes only. I expect to share the findings of this study with the institution and the participants.



I look forward to hearing from you soon.  
Thank you  
Yours faithfully

*M Chimedza...*

Margaret Chimedza

## Appendix C: Response to Application

### APPENDIX C

Attention: Ms M. Chimedza

Dear Ms Chimedza

**RE: PERMISSION TO ACCESS STUDENTS' INFORMATION FROM THE INSTITUTION'S DATABASE**

Reference is made to your letter dated 21 September 2020 in which you sought permission to access students' information from the institution's database. You stated in your application you that needed the information to assist you in carrying out your research entitled: Exploring the lived experiences of former students with disclosed epilepsy in accessing support services at a Teachers College in Zimbabwe.

We write to grant you permission on the condition that:

- The confidential information you will gather is used solely for the purposes of this study and that,
- The final report of your thesis is availed to the college for institutional benefits.

Wishing you the best in your endeavours.

Yours sincerely



Mrs Mandabva

pp Ass. Registrar (Academic)



## Appendix D: Interview Schedule

Research question:

What are the lived experiences of students with disclosed epilepsy (SWE) in accessing support services at a teachers' college in Zimbabwe?

Objectives:

- I. To identify support services participants were aware of at the college.
- II. To describe the challenges SWE, encounter in accessing these support services in the course of their training.
- III. To describe the participants' views on what constitutes best practices/best support services for SWE in colleges.

Time: TBA

Date: TBA

**Setting:** Participants will be in their different locations.

**Interviewer:** Margaret Chimedza

Interviewee:

- Call the participant and start with a general talk to put the participant at ease and build rapport.
- Acknowledge receiving signed consent forms and confirm that participation is voluntary and that participants can still withdraw even after signing the consent form.
- Explain the need for the participant to be at a place where no one can overhear their conversation to safeguard confidentiality.
- Explain objectives of the study, procedure and duration of interviews. (30-60 mins)
- Allow questions for clarification.
- These will be telephonic interviews so the investigator and participants need to listen attentively and be able to be articulate in their conversations.
- Refrain from being judgmental.

Semi-structured and open-ended Interviews

1. May I know what made you disclose your condition to the institution?

- When was that? (Probe)

Let's talk about the support services that you were aware of at your institution.

2. What type of education provisions did you have at your institution? (Infrastructure, specialized equipment, qualified personnel, peer support groups, counselling services, medical services, etc.)

- May you explain further? (Prompting)

If I have heard you correctly, you mean .....

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(Summary of responses in own words and asking for further clarification and affirmation)

3. So, tell me about your experiences in accessing the support services provided at your former institution.

- May you elaborate further on ... (Prompting and probing)
- Give examples from your experience.

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4. How did you negotiate for support services suppose they were not readily available?

- What strategies did you use when seeking assistance from the institution?
- How successful were these methods in getting you the kind of support that you wanted?
- If you encounter any challenges in seeking assistance, how did you resolve these?
- How do you rate the support services that you received? (Quality, adequacy, accessibility etc.)

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5. What was the role of the Disability Resource Centre (DRC)? Explain further (prompts)

- How can the DRC improve its services to SWE?
  - May you elaborate further?
- -----

6. What was the position of the institution as far as disability awareness is concerned?

- How can sensitization on disability issues be enhanced among students and staff?
  - May you give examples? (Prompting)
  - Were you aware of any disability policy at your institution? (Prompts for further clarification)
    - What is the need for a disability policy at an institution?
    - Who do you think should be involved in crafting the disability policy?
    - Explain why. (prompts)
- -----  
-----  
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7. How did the institution cater for your mental or psychological well-being?

In which social events did you participate?

- Explain your answer (prompts and probes)
- -----

8. Which stakeholders should be involved in the support of SWE in institutions?

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9. What do you think would be the ideal situation as far as providing reasonable accommodations for SWE in institutions of higher learning is concerned?

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10. Do you have any suggestions or any additional information you would like to share?

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11. Winding off and thanking the participants.

Reflective notes on insights and emerging themes for later analysis.

## Appendix E - Data Analysis Grid

| OBJECTIVES   | CODES  | SUPPORTING TEXT   | COMMENTS/THEMES                               |
|--|--|-------------------|---|
| Identifying support services which participants were aware of at the institution |  |                   | Facilitators of inclusion                     |
|  | registered disability at DRC                 |                   | benefits from college resources               |
|  | received peer and lecturers' support         | Line 14-16, 23-25 | Accommodation, Psychosocial support           |
|  | received drugs from the clinic               | 31-33, 35         | appreciating available services               |
|  | had access to computers, some counselling    | 38-40             | Disability services                           |
|  | accommodated on the ground floor             | 43-44             |   |
|  | services were quite good                     | 179-185           | Happy with service provisions                 |
| Describing challenges faced by participants during training                      |  |                   | Accessibility barriers                        |
|  | poor counselling services                    | 48                | unhappy about counselling services from DRC   |
|  | no information on managing my condition      | 51-53, 59-61      |   |
|  | DRC staff not providing adequate information | 63-65, 72-75      | Problem with the dissemination of information |
|  | did not disclose condition on enrolment      | 18-19             | Afraid of stigma and discrimination           |

|  |   |          |  |
|--|---|----------|--|
|  | did not disclose his condition to lecturers   | 84       | Negative attitudes   |
|  | Peer and lecturers had negative attitudes     | 90       | Lack of awareness  |
|  | responsible for monitoring other SWE          | 108-111  | Lack of knowledge  |
|  | delayed dissemination of critical information | 124-127  | Lack of training for academic staff                            |
|  | peers failed to get medication on time        | 148      |  |
|  | lack of assistants to monitor the condition   | 148-151  |  |
|  | had few friends                               | 164-165  | Lack of social skills  |
|  | lack of knowledge to handle SWE               | 173      | The institution not playing its role well.                     |
|  | No disability policy                          | 190      | Cannot hold the institution accountable due to lack of policy. |
|  | Chances are you miss critical information     | 193      |  |
|  | refused to join SRC due to lack of resources  | 247=251  | low self-esteem  |
|  | was afraid to have a seizure during lectures  | 297-298  |  |
|  | was afraid of students' reaction              | 292, 301 | feared stigmatization and discrimination                       |
|  | Paid own fees assisted by parents             |          |  |
|  | Did not benefit from Social Welfare grants    |          | institution relegating its duties to students                  |



|  |  |          |  |
|--|--|----------|--|
| Participants' views on what constitutes best practices |  |          | Reasonable accommodations                            |
|  | students to be taught about epilepsy                 | 154-156  | Disability awareness                                 |
|  | SWE to find assistants, the role for the college     | 167-170  | Introduce buddy system                               |
|  | DRC and nurse staff to train assistants              |          |  |
|  | involve SWE in crafting policy                       | 199      | ownership of the document, nothing for us without us |
|  | SWE are more knowledgeable of their condition        | 201-203  |  |
|  | improve on accommodation                             | 207-209  | pre-planning on accommodation                        |
|  | improve channels of communication                    | 224-227  | institution to cascade information                   |
|  | consistent supply of drugs at the clinic             | 230-233  | partnerships with stakeholders                       |
|  | improve on socialization among students              | 236      | institution to involve SWE in social activities      |
|  | encourage a spirit of oneness                        | 257      |  |
|  | discourage looking down upon other people            |          | Acceptance from the college community                |
|  | Government and NGOs to assist with funding for drugs | 265, 271 | Build partnerships                                   |
|  | DRC to improve on communication with SWE             | 276-279  | Improve on information dissemination                 |
|  | Government to offer financial assistance             |          | need the policy to back up Disability grants         |

