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FACULTY OF SOCIAL SCIENCES AND HUMANITIES

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CAREGIVERS' EXPERIENCES IN MANAGING CHILDREN WITH EPILEPSY IN WARD 8, CHITUNGWIZA

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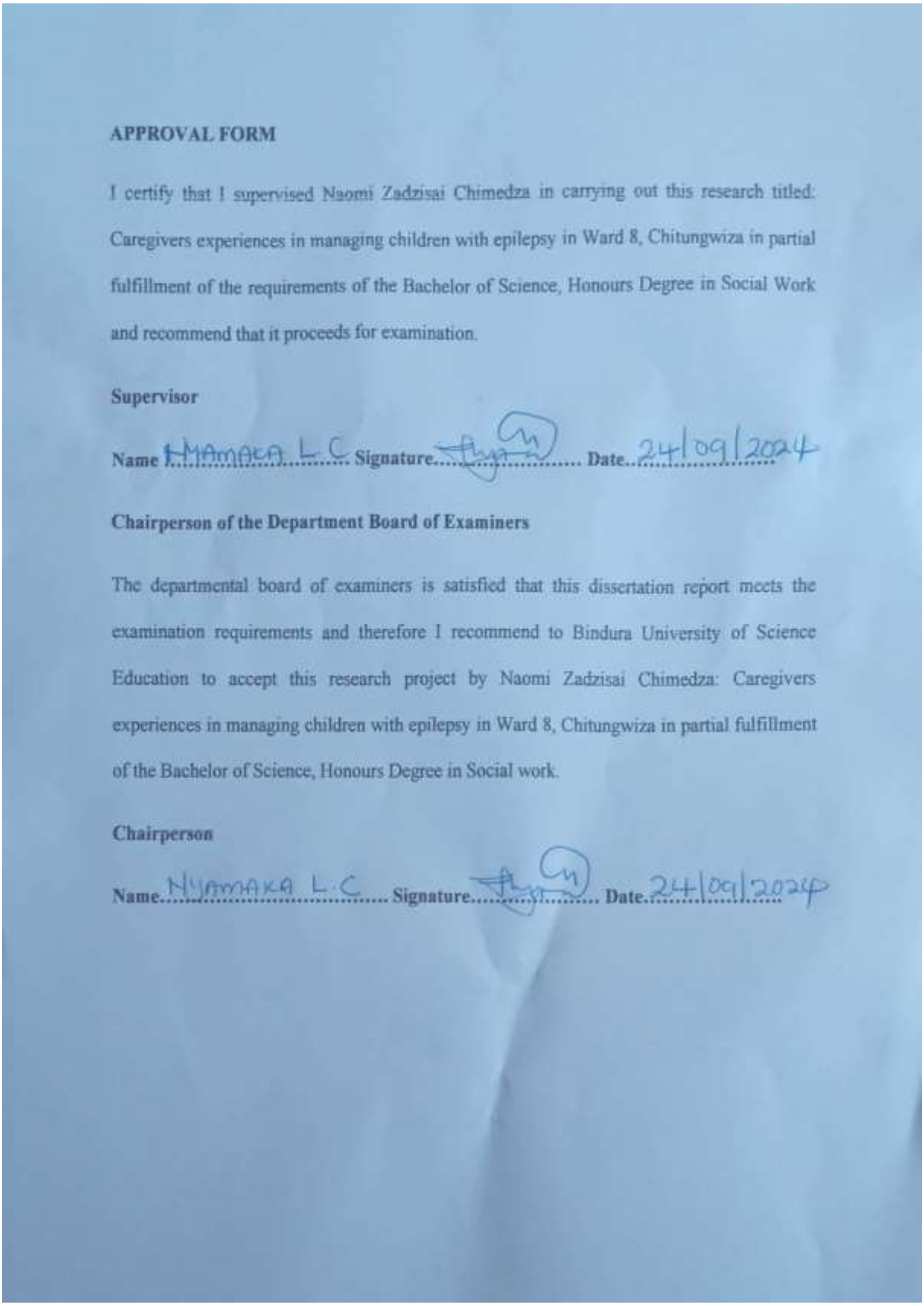

APPROVAL FORM

I certify that I supervised Naomi Zadzisai Chimedza in carrying out this research titled: Caregivers experiences in managing children with epilepsy in Ward 8, Chitungwiza in partial fulfillment of the requirements of the Bachelor of Science, Honours Degree in Social Work and recommend that it proceeds for examination.

Supervisor

Name NYAMAKA L.C Signature.......... Date 24/09/2024

Chairperson of the Department Board of Examiners

The departmental board of examiners is satisfied that this dissertation report meets the examination requirements and therefore I recommend to Bindura University of Science Education to accept this research project by Naomi Zadzisai Chimedza: Caregivers experiences in managing children with epilepsy in Ward 8, Chitungwiza in partial fulfillment of the Bachelor of Science, Honours Degree in Social work.

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DECLARATION RELEASE FORM

I, Naomi Zadzisai Chimedza studying for a Bachelor of Science Honours Degree in Social Work, aware of the fact that plagiarism is an academic offense and that falsifying information is a breach of the ethics of Social Work research, I truthfully declare that:

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Dedication

I dedicate this project to my parents, Mum and Dad, for their unwavering support and encouragement throughout my academic journey. Your belief in me has been a constant source of motivation, and I am grateful for all the sacrifices you have made to ensure my success. To my sisters, Leah Yeaukai Chimedza and Gamuchirai Chimedza, thank you for always being there for me with your love and understanding. Your presence in my life has brought joy and strength during both challenging and joyful times. Lastly, I dedicate this project to my son, Matipaishe. You have been a beacon of light in my life, inspiring me to push through obstacles and strive for excellence. Your love fuels my determination, and I am forever grateful for the bond we share. This project stands as a testament to the support and love I have received from my family, who have been pillars of strength in my life. Thank you all for being my rock and guiding me towards achieving my goal.

Abstract

The aim of the study was to investigate and analyse the primary obstacles faced by caregivers in the management of children with epilepsy, as well as the coping strategies employed by caregivers of children with epilepsy in Ward 8, Chitungwiza. The primary objectives of the study were to examine the firsthand experiences of caregivers of children with epilepsy in Ward 8, Chitungwiza. A narrative research design was utilized in the study, which was qualitative in nature and involved in-depth interviews and a focus group discussion for data collection. The study utilized a sample size of 33 participants, selected from the target population to gather the necessary information. Ubuntu Philosophy Framework was applied in the research. This investigation successfully identified the key issues faced by caregivers of children with epilepsy, encompassing the fundamental care they provide to these children along with the associated challenges. The research revealed that caregivers of children with epilepsy encounter difficulties such as social stigma and isolation, financial limitations, mental health issues, and the overall burden of care. Furthermore, the study uncovered that the essential care provided to children with epilepsy involves the management and regulation of seizures, basic caregiving tasks like bathing and feeding, and ensuring the child's adherence to prescribed medication. Additionally, it was observed that caregivers of children with epilepsy employ coping mechanisms such as seeking support from organizations like the Epilepsy Resource Centre Zimbabwe and the Epilepsy Support Foundation, although the availability of support systems remains limited. The study also proposed recommendations to address these challenges effectively.

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LIST OF ACRONOMYS

AEDs	**Anti-epileptic drugs**
CWE	**Children with Epilepsy**
CSWZ	**Council of Social Work**
COF	**Code Of Ethics**
EEG	**Electroencephalogram**
ERCZ	**Epilepsy Resource Centre Zimbabwe**
ESF	**Epilepsy Support Foundation**
ILAE	**International League Against Epilepsy**
NASWZ	**National Association of Social Workers**
WHO	**World Health Organisation**
MF	**Mufudzi Wakanaka**
UNCRPD	**United Nations Conventions On the Rights of a Person with Disabilities**

CHAPTER 1: BACKGROUND OF THE STUDY

1.0 Introduction

The purpose of this study was to explore the lived experiences of caregivers of children with epilepsy in Ward 8, Chitungwiza. This chapter will illustrate the back ground of the study focusing on the concern for this study. The main concern for this study was that caregivers encounter a lot of problems in caring and managing children with epilepsy in Ward 8, Chitungwiza. The study's statement of the problem justification of the study, aim, objectives of the study, key research questions and definition of terms and conclusion are also presented in this chapter.

1.2 Background of the study

The International League Against Epilepsy (ILAE 2005) defines epilepsy as a neurological disorder characterised by a persistent predisposition to produce epileptic seizures. The ILAE (2005) further goes on to state that epilepsy is not a singular entity but rather a spectrum of disorders that reflect an underling dysfunction in the brain, which can have various causes. WHO (2020) estimates that 50 million individuals globally are impacted by epilepsy encompassing all ages groups and genders. The condition epilepsy is marked by recurrent seizures, which manifest as episodes of involuntary movements involving either a specific body part(partial) or the entire body (generalized) and they can be accompanied by periods of unconsciousness and a loss of control over bowel or bladder movement. Berghi *et al* (2016) goes on to further support that epilepsy is a condition that can affect any person despite the race, culture, ethnicity, country, time and space. Wirrel & Fine (2020); Long (2021) postulates that epilepsy is regarded as one of the most common chronic neurological disorders in children. Schuwerk (2019); Keykhosravi *et al* (2019) asserts that epilepsy is most frequently diagnosed in children, with genetic factors, hypoxia (that is oxygen deficiency) during pregnancy or birth, infections being the primary cause and all these lead to chronic epilepsy in children. Furthermore, Holmes (2009); Bajaj *et al* (2022) suggests that new-born babies are particularly vulnerable to seizures due to potential trauma, infections, intra cranial bleeding, and the in the inherent susceptibility of the developing brain include birth asphyxia, febrile seizures, perinatal and neonatal complications, while in developed countries, epilepsy commonly stems from brain tumours, traumatic head injuries, and cerebrovascular diseases. According to Bhalla *et al* (2014), further asserts that African countries such as Zimbabwe among others relate the prevalent belief of epilepsy as a supernatural cause and not correctable with biomedical methods. The anti-epileptic drugs vary and in Zimbabwe drugs commonly used are sodium valproate, phenobarbital and carbamazepine.

Globally the prevalence of epilepsy varies from developed countries to developing countries. According to Rabie *et al* (2016) asserts that globally more than 11 million children aged less than 15 years have active epilepsy. Soare *et al* (2022) further postulate that 25% of the global population of epilepsy are children below the age of 15 and they have active epilepsy. Camfield & Camfield (2015) further goes to state that the prevalence of epilepsy is disproportionately concentrated in low and middle income countries that is 139 per 100,000 compared to high income countries which is 48,9 per 100,000. According to the WHO (2004) state that epilepsy is a major public health challenge representing about 1% of the total burden of morbidity and mortality globally. WHO (2019) postulates that the high burden of epilepsy in low and middle income countries is largely attributed to inadequate medical services, poor socioeconomic conditions and traditional beliefs regarding the treatment of epilepsy. Oluwole *et al* (2015) further supports that the disease burden from epilepsy has been reported to be higher in developing regions of the world. According to Carter *et al* (2012) further alludes that the burden of epilepsy is more pronounced in resource limited countries, particularly in Africa where prevalence of drug resistant /complex epilepsy is higher due lack of access and non-adherence to prescribed medication, poor reporting of seizure occurrence, and limited health facilities resulting in a worrying treatment gap of up to 100% in some communities thus making the incidence higher in lower income economies (Kampara *et al* 2017. Voitiuk (2019) and Oguni (2023) suggest that epilepsy is more prevalent in males as compared to females but when it comes to children, epilepsy in children has nothing to do with children. According to Camfield & Camfield (2015) state that the incidence of epilepsy in children is reportedly high during the early ages of a child's life and it declines as they age and go into adulthood. Paul *et al* (2012) thus draws the conclusion that more than 90% of epileptic cases in the Sub- Saharan countries have been reported to be in children and adolescents aged less than 20 years.

Caregivers globally experience many difficulties in caring for children with epilepsy for instance Yang *et al* (2019) Southern China highlights that the experiences of caregivers of children with epilepsy are complex and heavy, with the caregivers of the children with epilepsy bearing a heavy burden of care and psychological burden. Wu (2013) have indicated that caregivers lack the information pertaining the condition which therefore highlights where the problem of caregivers ignite from. According to Harden *et al* (2016) state that a certain study found out that parents of children with epilepsy were shown to have higher rates of depression, anxiety and stress because one child with a chronic illness had an additional burden and care needs. John and Reily (2016) alludes that epilepsy becomes a family problem and should be adapted by all and parents feel anxious when and guilt when their child feels seek hence affecting the whole family's performance.

An epidemiological report done in 2013 on Sub Saharan Africa, state that epilepsy is the fourth most common neurological disorder condition among regions of Africa, with prevalence rate estimated to vary from 49 to 215 per 100,000 people (Boling *et al* 2018). In Africa, epilepsy is highly stigmatized and also there is a huge treatment gap towards epilepsy hence this does not spare children with epilepsy. According to Mac et al (2007) state that in developing countries of Sub-Saharan Africa and Latin America, up to 90% of people with epilepsy have been reported to receive inadequate treatment or no treatment at all. According to Nsengiyumva et al (2004) state that in Burundi a child with epilepsy in low resource family frequently cannot participate in the activities of family life such as collecting water for fear of drowning and cooking for the fear of falling in the fire and also the financial security of the parents being at risk due to the cost of medication and treatment. According to (Matuja 1994) further goes on to highlight that in East and South-central Africa, children with epilepsy are often prevented from attending school due to stigma, maybe shunned from family meals and the stigma creates an environment that leads to few or no childhood friends or play. According to Reis 1994 and Birbeck (2000) state that the common themes identified that contribute to treatment gap in Zambia and formerly Swaziland include poverty, a lack of access to AEDs, inadequate access to physicians trained to manage epilepsy, poor knowledge about epilepsy among the community and healthcare providers, failed models of healthcare delivery, as well as stigma of epilepsy arising largely from common misconceptions about epilepsy that it is contagious or has supernatural origins. A study conducted in Rwanda highlighted that epilepsy in Africa is highly referred to as something that is spiritual or obtained from a religion for example through the study it was found that 55,3 of the people contested to this (Sober et al 2005). This can further allude that caregivers in Africa face a lot of stigma with the condition being spiritualised rather than being medicalised.

In Zimbabwe, epilepsy is a condition that is usually associated with a lot of myths and misconceptions due to it nature, with a lot of people with the condition being stigmatized because of the nature. In the context of epilepsy, myth and perceptions together with incorrect knowledge contribute to stigma (Mushi et al 2011) and promote the discrimination of people with epilepsy for example in Zimbabwe epilepsy is associated with names such as zvifaifa, and a study had been done which also highlighted that myths and misconceptions lead to stigma (Birbeck et al 2007). To add to this, epilepsy is also referred to as zvipusha meaning a condition that is infectious (Mugumbate 2011) while some refer to it as kugwinha (fitting), *pfari* (jerking), and tsviyo (minor sound) (Mugumbate 2011). The quality of a person with epilepsy in Zimbabwe is shaped by societal attitudes (Lim et al 2012). In zimbabwe studies towards epilepsy have been conducted by a number of researchers for instance Mugumbate but none of them have been specifically focused on the experiences of the carers caring for the child with epilepsy.

Caregivers of persons with epilepsy experience severe emotional, physical and economic burdens resulting from the nature, chronicity, disability and stigma affiliated with epilepsy ‘condition (Hansen et al 2018). According to Kwon and Jacoby et al 2022 further supports this, the burden of epilepsy does not arise from seizure activities but other factors like social and cultural stigma affiliated with epilepsy. More so, caregivers of children with epilepsy can face several issues including fatigue, headaches, physical pain, family conflict and financial problems whilst helping their children to cope with numerous challenges, including poor academic performance, lack of physical activity and reduced social participation (Jones et al 2019). Caregivers experience a lot of challenges caring for a child with epilepsy. According to Wood et al 2008, parents of children with epilepsy are required to make decisions concerning the care and future of their child and usually mothers are at high risk for psychological distress, such as depression and anxiety norms (Wagner et al 2006).Given the above information, it highlights that caregivers lived experience have existed since the 1990s up to date but with all the solution that have been put in place, none of them have been fully able to absorb all the challenges that caregivers experience in caring for a child with epilepsy hence there is the need of improved healthcare systems, social support and all the necessities that are needed in caring for a child with epilepsy. In an attempt to do so, there is the need to address the issues that the caregivers face hence the research is aimed at bringing out the lived experiences that all caregivers undergo through in caring for a child with epilepsy. More so caring for a child with epilepsy requires a lot, and in all researches conducted no specific attention has been bought towards Chitungwiza ward 8, yet the area has caregivers struggling with issues to do with epilepsy and stigma hence catching the attention of the researcher.

1.3 Statement of the problem

Caring for a child with epilepsy can be a challenging and demanding task that requires a lot of inputs from the carer. Caregivers of children with epilepsy take up different roles in trying to cater for a child with epilepsy but in it all the condition ends up affecting both the carer and the child being cared for negatively. In Zimbabwe studies pertaining epilepsy have been researched quite a lot with various researchers focusing on the persons with epilepsy. However, there is limited knowledge on caregiver's experiences in managing children with epilepsy particularly in dormitory towns such as Chitungwiza. Whilst there exist policies and legislation to promote the inclusion of persons with disabilities, not much has been reviewed concerning the challenges faced by caregivers and their predicaments. Therefore, given the above, there is the need to analyse the nature of care given to children with epilepsy, explore the challenges being experienced by caregivers and examine the copying mechanism that they are adopting in caring for children with epilepsy in Ward 8, Chitungwiza.

1.4 Aim

To explore the lived experiences of caregivers of children with epilepsy in Ward 8, Chitungwiza.

1.5 Objectives

1. To analyse the nature of care given to children with epilepsy in Ward 8, Chitungwiza.

2. To explore the challenges experienced by caregivers in providing care to children with epilepsy in Ward 8, Chitungwiza

3. To examine the copying mechanisms adopted by caregivers in caring for children with epilepsy in Ward 8, Chitungwiza

1.6 Research questions

1. What is the nature of care given to children with epilepsy in Ward 8, Chitungwiza?
2. What challenges are the challenges experienced by caregivers in providing care for children with epilepsy in Ward 8, Chitungwiza?
3. What copying mechanism can be adopted in caring for children with epilepsy in Ward 8, Chitungwiza?

1.7 Assumptions of the study

The study assumes that caregivers have a significant role to play on the well-being of children with epilepsy. This assumption recognizes that caregivers play a major role when it comes to children with epilepsy that is they support, care and experience together with the children with epilepsy therefore the knowledge that they have is important in understanding how epilepsy as a condition is managed. It also assumes that most of the challenges in managing the children with epilepsy, caregivers face challenges and difficulties in managing children with epilepsy. This assumption recognizes the demanding characteristics of epilepsy as a condition with its challenges such as seizure management and monitoring, emotional stress and accessibility of the health care system. Another assumption is that in trying to manage children with epilepsy, caregivers adopt mechanism in which they use to cope up with the difficulties of the condition when caring for a child with the condition. It assumes that caregivers develop strategies to reduce the impacts of the challenges these may include seeking psychosocial support, researches on the condition and also adopting to the self-care practices suitable for them. Lastly it assumes the focus on how the society and cultural context influence the impact of the conditions and the policy systems that help in promoting the well-being of persons with epilepsy. This assumption recognizes the myths and misconceptions surrounding epilepsy, it tries to figure out how these factors increase the impacts of the condition. In the last assumption it also seeks to ensure the inclusivity of persons with epilepsy in the policies that stand up for the rights of persons with epilepsy for example the Disabled Persons Act (chapter 17:01) stand up for the protection of persons with disability, inclusion and equal treatment, it has not been effective enough in addressing the specific needs of persons with epilepsy hence the study assumes for the inclusiveness of epilepsy.

1.8Significance of study

The study seeks to provide a deeper understanding through the insight in the lived experiences of caregivers in the challenges, the copying mechanism and needs, it then helps in acquiring the aid that can be given by the health care sector and policy makers and all support organizations to develop tailor made interventions and support systems that address the needs of caregivers. The study is also significant in that through understanding the lived experiences of caregivers, there is the improvement of the support given to caregivers that is through the identification of the of the challenges that they face hence leading to the development to the support that they need for examples resources in the form of EEG scans, medication and psychosocial support .According to Mugumbate et al (2017) " people with epilepsy in Zimbabwe has to face numerous challenges, including poor understanding of the disease, impaired access to treatment, predisposition to burns and injuries; prejudice that affect socialization, marriage, school and work, resulting in impaired quality of life and socioeconomic status." This highlights the significance of the study which is to explore the challenges faced by caregivers and interventions that can be employed in order to assist them. To add on to this, the significance of the study also lies in its ability to bridge the gap between medical and social components of epilepsy thereby acknowledging the vital role that the caregivers have in their child's health and wellbeing. This can lead to the creation of a more inclusive and empathetic approach to addressing the special need of families afflicted by epilepsy.

1.9 Key definitions

1.9.1Seizure

A seizure is the manifestation of abnormal, excessive, or synchronous neuronal discharges predominantly located in the cerebral cortex and this is a typical paroxysmal activity is sporadic and typically self-restricted, with a duration ranging from seconds to a few minutes (Huff & Murr 2024).

1.9.2 Anti-epileptic drugs

AEDs are a group of drugs mad for and used for the controlling of seizures in people with epilepsy. These drugs are also known as anti-convulsions (Brodie 2021).

1.9.3 Burden of care

According to Schulz & Sherwood (2020) defines burden of care as the financial, social, emotional and physical struggles felt by carers within a family when assisting and caring for people with disabilities, children or age related essentials.

1.10Limitations of the Study

Acquiring the necessary information may prove challenging due to privacy regulations and constraints. To address this issue, the researcher intends to solicit a letter of recommendation from the academic institution. The study will centre on the experiences of caregivers managing children with epilepsy in Ward 8 Chitungwiza. It is plausible that caregivers' perspectives may be influenced by prevalent myths and misconceptions surrounding the condition, potentially leading to the dissemination of inaccurate information to mitigate societal judgment and exclusion. Some participants may lack the stamina for extensive discussions, emphasizing the importance of organizing brief interviews. Certain individuals express a preference for being interviewed at their workplace due to time constraints arising from their social commitments. In the event of scheduling conflicts with respondents, the researcher is prepared to prioritize research commitments over lectures, subsequently catching up on missed classes by reviewing PowerPoint presentations shared by instructors. Challenges may arise in data retrieval from interviewees without official university authorization, prompting the researcher to secure a permission letter to facilitate the research process. Furthermore, the presence of Cholera outbreaks could constrain the study's ability to forecast future occurrences, instead focusing on proposing strategies to mitigate such challenges.

1.11Delimitations of the Study

This study will focus on the Chitungwiza Ward 8 which is situated in Seke, Chitungwiza which is under Harare Metropolitan Province. The study for physical and interactive research might stretch to Unit N, Unit P and Unit G.

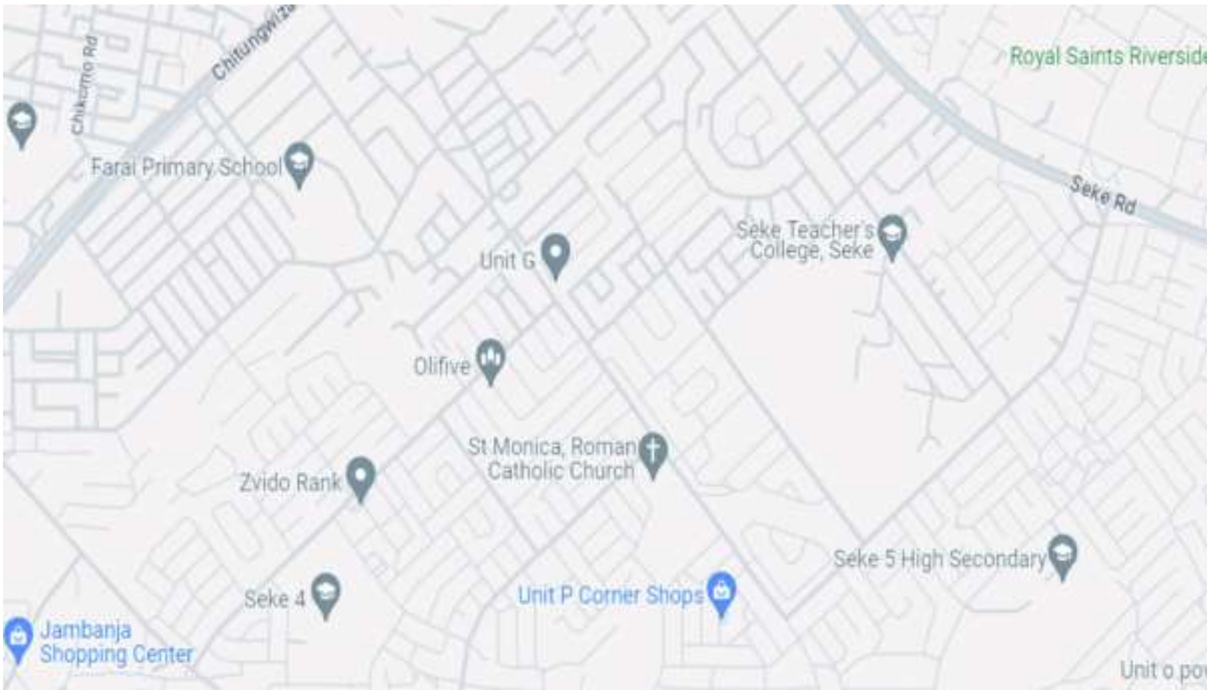


Figure 1.1: Aerial view of Chitungwiza Ward 8 extracted from google earth pro. (Source Author)

The study is also limited to caregivers of children with epilepsy hence the researcher is only going to be focused on caregivers lived experiences in managing their children with epilepsy and a child is someone below the age of 18aand residing in ward 8, Chitungwiza. It is also limited to qualitative approach in that it is going to adopt a research design that is qualitative in nature for instance the use of the interviews and focus groups allowing them to obtain detailed data. To add more the study is also limited to the caregiver being the real mother of the father.

1.12Summary of the chapter

This chapter provides background information for the research. The background information included the meaning of epilepsy, causes, prevalence and definition of key concepts. The statement of the problem as well as the research objectives and aim were provided. Chapter 2 seeks to highlight the literature review of the study.

CHAPTER 2: LITERATURE REVIEW

INTRODUCTION

The researcher reviewed literature from existing studies on databases such as African Journals Online, Directory of Open Access Journals and Google Scholar. From the literature reviewed, the researcher found various key themes about the lived experiences of caregivers in managing children with epilepsy and among those were lack of information to demonstrate how caregivers manage children with epilepsy. This chapter reports on the literature review and then highlight the short coming of the existing literature.

2.1 Theoretical Framework

According to Barbour (2014) theoretical framework is a structure utilised in defining and observing obtained data in a research study. In this research a theory is being used to provide a sound meaning of the research and an understanding of the research topic. Creswell and Creswell (2018) posit that a theory provides lens that shape research.

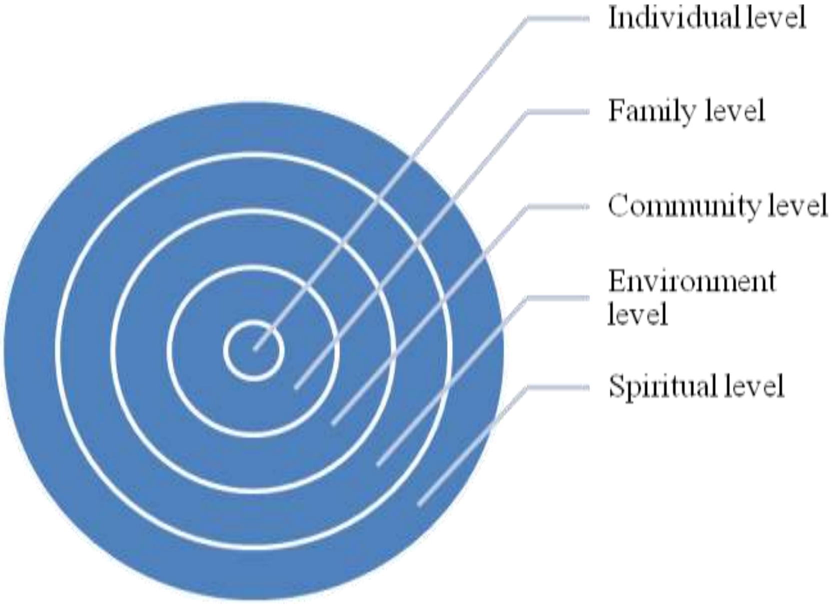
2.2 An Integrated Framework of Ubuntu by Mugumbate and Chereni (2019)

The study is uses the Ubuntu philosophy framework, which has been selected because of its applicability to the study setting, its relevance to the researcher and its strengths in explaining the role of family, community, society, environment and spirituality in care. The relevance of this Ubuntu is seen in adoption by the Council of Social Work in Zimbabwe in its Code of Ethics and its use by the National Association of Social Workers Zimbabwe. The framework is ingrained in the adage or aphorism that conveys ethical standards or beliefs, known as *umuntu ngamuntu ngabantu* in the Zulu and other Nguni languages, signifying that a person's essence is shaped by others. This framework emphasizes the traditional method of nurturing a child within an African household. Ubuntu is a concept that has its roots in sub-Saharan Africa, where the Bantu communities reside. Ubuntu is a term in Zulu that corresponds to *hunhu* in the Shona dialect. Samkange and Samkange (1980) defined hunhuism or Ubuntuism as African humanism classified into three maxims, that is valuing human wellbeing, respectful relationship and people centred leadership. The main three pillars of Ubuntu are interpersonal values (regard for others), intrapersonal values (regard for self) and environmental values (regard for the environment) (Maphalala 2017). The integrated Ubuntu framework by Mugumbate and Chereni (2019) was an approach that had been put into account by African researchers such as Mbiti (1969), Samkange and Samkange (1980). In an African context Ubuntu is embedded in every culture hence we see Ubuntu being utilised even in social work practice. This can be highlighted through the Code of Ethics of Social Workers in Zimbabwe which describes Ubuntu as humanness, it includes the values of human solidarity, empathy, human dignity and humanness in every person (CSW, 2012, p,1). Under the theory of Ubuntu as proposed by Samkange and Samkange (1980) who brings out that to be human involves the affirmation of one's own humanity through the acknowledgment of the humanity of others, leading to the establishment of respectful human interactions with them, this act of one individual showing care towards another person, encompassing kindness, politeness, consideration and warmth in interpersonal connections is capsulated in Hunhu or Ubuntu therefore this highlights the importance of *hunhu* as part of the African ethics and part of our culture.

2.3 Key Features of the Integrated Framework of Ubuntu

The principal characteristics of the Ubuntu framework entail the notion that an individual's identity is shaped in relation to others. As Metz (2016) contends, within the family unit, children cultivate their sense of self through interactions with fellow individuals, underscoring the importance of fostering communal and harmonious bonds. This fundamental concept serves as the guiding principle of the entire framework, particularly within an African context, where enhancing an individual's well-being contributes to the collective well-being of the community, emphasizing the interconnectedness prevalent in such a setting. The reciprocal nature of influence is evident, whereby the fortunes of the individual impact the group as a whole, and vice versa. Echoing Mbiti's (1969) assertion on communal identity, individuals acknowledge their existence through the collective "I am because we are; and since we are, therefore I am" (p. 106). This underscores that the key objectives of the Ubuntu framework revolve around nurturing interconnectedness, compassion, and solidarity among African societies.

Mugumbate and Chereni's framework



On the individual level, according to Mugumbate and Chereni(2019) integrated framework, an individual person belongs to a family hence forming *ukama*. Individuals belong to the of the system and all parts of an individual become meaningful if they contribute to the betterment of self together with the family and communities. The individual part refers to the body, the mind, knowledge and possessions. Individuals and their family belong to the community and they respect the communal relationships (Mugumbate and Chereni 2019). Achild under goes various stage until he or she becomes an adult.

The subsequent tier pertains to the family level, which assumes a crucial role in the life of the child. As outlined in the framework, the child is considered part of the family unit, bonded by regulations, lineage, and selfhood. The concept of family extends beyond one's spouse and offspring to encompass all interpersonal connections within a given society. Furthermore, the framework elaborates on family as comprising extended kin who contribute to the welfare of orphaned and vulnerable children in African communities. The philosophy of Ubuntu places significant emphasis on parental involvement in the upbringing of children. Concerns often arise among parents regarding the ethical principles their children might internalize from the Westernized educational system (Maphalala, 2017). Tusasirwe (2020) contends that the family institution remains a cornerstone of African society, whether in rural or urban settings. Nevertheless, the ongoing process of modernization has led to the adoption of Western customs by African populations, thereby diminishing the emphasis placed on extended family networks. Evidently, the ubuntu framework in African societies underscores the pivotal role of the family within its cultural milieu. While familial ties are esteemed, the significance of extensive kinship networks is not consistently upheld in urban locales (Dziro and Rwufurwunokuda, 2013).

The community is the third level, according to the framework, the community values the environment and spiritual wellbeing of its people. Individuals, families, leaders and knowledge holders make up the community. The major role of the framework is to protect children, which is strengthened by the belief that children become humans through others.

Environmental level is the fourth level of the framework, which is the provider of the main resources required by an individual. The individual is part of a natural system comprised of the land, animals, vegetation and other elements from which basic needs are met. Africans use Ubuntu to conserve the environment so as to achieve a balance between current and future needs (Mugumbate and Chereni 2019). The environmental level, the relationship with nature however has been negatively impacted by colonization which immediately landed African societies in western customs.

The framework values the spirituality as it plays a huge role in the lives of children (Seehawer 2018). Spirituality refers to the awareness of a transcendent dimension to human existence and he search for meaning, purpose, and connection in life (May 2002). According to the framework, the child is part of a whole, comprised of God, Ancestors, elders, family and communities. the level of spirituality, foreign beliefs tried to displace African beliefs on which the Ubuntu philosophy flourished (Van Breda 2019). This shows that in the Ubuntu framework, the spirituality has to do with one's beliefs but due to the colonisation and globalization these beliefs are becoming distorted. Thus the spiritual level represents the people's beliefs.

2.4 Applicability of Mugumbate and Chereni's framework

The framework is mainly focused in the protection of children within the African context through the use of the indigenous knowledge systems. Social workers according to the article can challenge their own knowledge base through the application of the indigenous knowledge systems in protecting children. The main objective of the article goes hand in hand with this research that is caregivers experiences in managing children with epilepsy, in this there is need for the understanding of the lived experiences of caregivers to children who have epilepsy, and in so doing it is highlighting the main challenges and obstacles that they face in the management of this condition and how they are being able to protect their children from it. Hence through this the main objective of the article then comes into place that is the protection of the children .According to Mugumbate and Chereni (2019) assets that it takes a village to raise a child, meaning that meaningful interactions among the child, family members and those outside the family circle are necessary for children to realise human excellence Interestingly, from this optic, adults play a critical role to create the relational conditions that enable children to realise their personhood. Thus its applicability to this research as it seeks to protect the child.

The integrated framework talks about the individual level where it stresses the importance of self-growth within an African context. According to Mugumbate and Chereni (2019) it talks about the different stages that a child undergoes in until he or she reaches adulthood, hence it also highlights the important role which is played by the family in nurturing the child into an adult but however in this case the child represents the caregiver who is at the centre of the child's life providing all the basic needs and attention required by the child. At individual level the caregiver is applying the holistic approach to care when it comes to children with epilepsy. Holistic approach to care is the consideration of the person including their physical, emotional, social, and spiritual needs (Watson 2005). The holistic approach to care further highlights the roles that the caregiver plays with the aim of increasing the self-growth of a child with epilepsy and this can be highlighted through the emotional support they give to children with epilepsy, medical management, lifestyle considerations and in all other aspects of life.

On the family level, according to the framework, family refers to all the relations within a community. Caregivers managing children with epilepsy can draw their strength from family members, that is they can be assisted though care giving, assistance in medical bills to mention but a few. In this research, be it extended or not represent the caregivers who are able to care for the child with epilepsy hence family just like in the Ubuntu theory plays a pivotal role in the caring for a child with epilepsy. The family level highlights the principle of respect for elders that is caregivers can offer respect for those that have more wisdom than them, they can seek advice and support to elders who have witnessed similar situations and lastly

The integrated Ubuntu framework by Mugumbate and Chereni(2019) describes the 5 levels that exist in an Ubuntu society with the levels being the individual level, the community level, the family level, the environmental level and lastly the spiritual level. All this levels highlight the interconnectedness that exist within an African setup, thus it acknowledges interdependence. Interconnectedness talks about people being a part of a network of interactions and that a person’s wellbeing is influenced by the wellbeing of others. this is significant to the research in that it helps in the understanding of the connection between the medical experts and the larger community in the context of caring for a child with epilepsy. This further denotes the importance of the community aid and assistance is important to caring for child with epilepsy. This also highlights the Ubuntu principle of I am because we are, which talks about interconnectedness with other and that we all belong to a large system hence caregivers feel a sense of connectedness through shared experiences and support systems.

The third level of the integrated approach framework is the community level, where the community offers protection to children. According to the framework (Mugumbate and Chereni 2019) individuals, families, leaders and knowledge make up the community. Therefore, ubuntu places a strong emphasis on the support, understanding, and empathy that the community can offer. Ubuntu places a strong emphasis on the support, understanding, and empathy that the community can offer. This is applicable to the research in that a stigma-free, knowledgeable, and supportive community can be beneficial to parents of children with epilepsy, offering both practical and emotional assistance. Ubuntu inspires the community to come together in support of caregivers, providing help, pooling resources, and fostering a feeling of community. This also highlights the Ubuntu principle of I am because we are, which talks about importance of community and shared experience. Caregivers experience a sense of community belonging and connection to other care givers within the community.

The fourth level is the environmental level. The environmental level refers to the physical environment and social context in which people live. It is the arena within which life is lived and a world is perceived (Ingold 2000). The environment in the case of the research refers to the accessibility of the major services that are required in caring for a child with epilepsy, that is easy access to the medical care, the presence of support system, socioeconomic circumstances, cultural norms and beliefs. All these aspects have contributed to the provision of care that is done to children with epilepsy. Hence the environmental level becomes important in providing another view to how the caregivers manage caring for children with epilepsy and the factors that affect caregiver's experiences and capacity in caring.

The last level is the spiritual level. According to the integrated framework, the spiritual level includes values, beliefs and the idea that all beings are interconnectedness. Spirituality entails the belief that people who are caregivers uphold in caring for the children with epilepsy.in this research, spirituality entails the assessment of how upholding spirituality impacts coping mechanisms, how caregivers get resilience and strength from their belief, or how culture affects the way they perceive epilepsy and treat people with epilepsy. Hence the spiritual component plays a huge role in the provision of care to children with epilepsy.

There are many theories that apply to this research topic, including the social model of disability, the health belief model, caregiver stress theory, attachment and the systems theory. However, these theories do not fully address the social issues in African communities because they are not holistic.

2.5 Limitations of the applicability

The framework entails of interconnectedness but in reality caregivers often face the stigma due to the misconceptions surrounding epilepsy**.** Epilepsy is surrounded by a number of myths and misconceptions hence people often discriminate. Another limitation is that Ubuntu has eroded in some families and communities, especially in urban areas because of competing values from philosophies, especially Western philosophies of individualism as opposed to family hood and communalism.

2.6 Existing literature on caregivers

Epilepsy is defined as to having more than one unprovoked seizure (WHO 2019; Trinka et al 2015. Zhang et al (2020) further goes on to highlight that epilepsy is something that is unexpected, occurs continuously, something for a lifetime and with consistent drug intake and a lot of side effects of drugs. Caring for a child with epilepsy is a multi-tasked job which comes with the alterations of the family function and more focus on the child with the condition (WHO 2010; Santo et al 2011). The caregivers of persons with epilepsy encounter a number of challenges including financial and psychological problems due to the stigma and nature of the condition (Cianchettie et al 2015; Senthil 2016). Both the caregiver and the child face the consequences of epilepsy. In most cases parents are in a dilemma of decision making concerning the future of their children (O’toole et al 2015). Grady & Rosenbaum 2015; Javalkar et al 2017 noted that caregivers have perceived low quality of life caused by the social, physical and the psychological burden of caring for a child with epilepsy, fatigue, loss of sleep and high levels of depression. Many studies conducted have been highlighting that many caregivers of children with epilepsy suffer a lot in caring for children with epilepsy through mental health problems, monetary issues among others (Jakobsen et al 2020, Zhang t al 2021)

The condition epilepsy negatively impacts a child in all the aspects of his or her life and among these include in terms of individuality, school attendance, participation and also performance and lastly the core relationship with other children. Children who are often afflicted with epilepsy tend to have other medical health conditions which affects them psychological and social wellbeing. According to Amudhan et al (2015) state that when a child is diagnosed with epilepsy, it brings a lot of mixed emotions for the parents of the child with epilepsy and at most of them may think they have lost a perfect child due to seizure type. According to Elsakka et al (2021) &Yang et al (2020) limited knowledge on epilepsy usually results in the caregivers of children with epilepsy being the sole providers of care to a child with epilepsy. Apart from seizures, a lot of children with epilepsy face difficulties in learning, side effects of medication, stigma and learning problems (Upton et al 2005; Agniar et al 2007). Caregivers of children with epilepsy also align with health professionals in providing care for children with epilepsy as highlighted by a study conducted by Samia (2019). Zhichao et al (2022) highlighted that the nature of care given to children with epilepsy also involve.

2.7Understanding caregiving

Primary health caregivers may include parents, relative's other adults who live with the child-care providers, offering direct care, daily management of the child's condition, medical care condition and crisis management and there is need for comprehensive understanding of the condition and its mangement (Barth et al 2010). Caregivers can be referred to as family members, paid helper who regulars cater for a child or a sick, elderly or disabled person. Caregiving can be simply defined as the process or act of rendering care services to other people, who as a result of illness or disorder, have a deficit in or have lost the independent capabilities of carrying out certain fundamental activities on their own (Schulz and Patterson 2004). A caregiver is the active person who renders the care to the passive care recipient who is the receiving end, and usually this is an ongoing process, involving execution of duties and routines (Schulz and Patterson 2004).

According to Epilepsy Support Foundation (2022) state that caregivers should be people who are well versed with different types of epilepsy, the symptoms of epilepsy and the type causes of the child's epilepsy whether it is genetic or not thereby allowing them to detect potential triggers which are likely to cause a seizure. According to Arjun 2017 further alludes that caregiving involves a multidimensional role, varying from daily routine activities such as household management, checking and monitoring tasks, providing transportation and physical care to recognizing reportable symptoms. Camfield and Camfield (2015) alludes that caregivers should be possessive of comprehensive knowledge on the availability of treatment such as anti-seizure drugs, dietary interventions and potential surgical procedures along with an understanding of how each method can influence a child's wellbeing. Studies done have highlighted that mostly caregivers of children with epilepsy are women. This goes in line with a study conducted by Rahba et al (2021) in Sudan which highlighted that most of the caregivers were the mothers of children with epilepsy. Another research conducted in Egypt which highlighted that most of the study participants were females and these were the mothers of the children with epilepsy (Samia 2019). Nhunzvi et al (2019); (Choruma 2007) cited that caregivers of children with epilepsy mainly manage the adherence to drugs, seizure chats and doctor's appointments. Russ *et al (*2015), Ferro (2017) & Adnams(2010) highlighted that studies conducted in countries such as Canada, United States and South Africa cited the importance of a comprehensive understanding of holistic assistance for caregivers and the nerd for the education of people for the needs and advocacy for the rights of their children. In Zimbabwe, Mugumbate and Nyguru (2013) further goes on to highlight that caregivers of children with epilepsy in Zimbabwe are mainly affected by stigma thereby reducing the quality of care that thy provide which is further alluded to by Chimedza & Peters (2001) who state that society disrupt the type of care which is supposed to be delivered by caregivers therefore increasing the caregiver burden.

2.8 Understanding epilepsy

According to the World Health Organisation (2012) and from a medical perspective epilepsy is a disorder of the brain which is characterised by a recurrence of unpredictable interruptions of the normal function called epileptic seizure, a person should at least have two or more unprovoked seizures before the diagnosis of epilepsy. Epilepsy Foundation (2017) further describes epilepsy as a condition that causes recurrent seizures and is treated using anti-epileptic drugs (AEDs). According to Bhalla et al 2014, further asserts that African countries such as Zimbabwe among others relate the prevalent belief of epilepsy as a supernatural cause and not correctable with biomedical methods.

The anti-epileptic drugs vary and in Zimbabwe drugs commonly used are sodium valproate, phenobarbital and carbamazepine. According to the Epilepsy Support Foundation of Zimbabwe (ESF 2009) the names of the condition in the local language are *pfari*, *tsviyo* and also *zvipusha*. ESF (2009) further goes on to allude that epilepsy is more common in children (Fine & Wirrel 2020) and is commonly caused by hpoxia (lack of oxygen at birth, infections and head injury. According to the Epilepsy Support Foundation (2021) defines an epileptic seizure is as a result of an irregular discharge of activity produced by the nerve cells in the brain and that seizures differ from one person to another. Milligan (2021) state that epilepsy has different types which include status epilepticus, generalized epilepsy and also partial epilepsy. Milligan (2021) further goes on to highlight that epilepsy can be treated through maintaining a ketogenic diet which is high in fats and lower in carbohydrates.

Chimedza & Peters (2001); Mugumbate (2020) & Nhunzvi et al (2019) highlight that epilepsy in Zimbabwe is often alluded to spirituality with most of the people and communities linking it with witchcraft. Mugumbate (2020) further goes on to highlight that stigma in epilepsy is not only limited to the social life but also to other aspects such as employement.

2.9Nature of care given to children with epilepsy

A study conducted in China in 2020 by highlighted that caregivers take care of children with epilepsy through particular diets, adherence to drugs for a life time, dealing with the side effects of drugs, strict monitoring of children on some of the activities that they are doing on a daily basis to ensure maximum protection of children with epilepsy. A study conducted by Ankash & Piya (2019) in India further goes on to highlight that parents of children with epilepsy take care of their children through the management of and adherence to medication, hospital visits, informed consent and decision making when it comes to medicals, seizure chats and also being there for the child in all the process, this thus highlight the nature of care that is given to children with epilepsy which ranges from medication taking to seizure chats. e provision of basic care to children with epilepsy. A study conducted by in 2022 which highlighted that the mothers of children with epilepsy were the ones who did the caring for their child with epilepsy which at times held heavy burden to them. The study by Rozensztraunch & Koltuniuk (2022) also highlighted that the family is the basis which shows the child with epilepsy the first support that he or she need leading to the formation of bonds and security for the child with epilepsy, burden of caring for a child with epilepsy. According to Ankash & Piya (2019) also highlighted that children who have multiple disabilities relay on their parents for care in terms of issues to do with bathing, eating, adherence to medication and physical movement for their own safety.it also reflects that the job of nurturing CWE. Research by Ankash & Piya talks of the fathers playing an assistive role whilst in this study care-givers are mostly women and they struggle in caring for the children alone and some have even divorced due to the condition of the child. Elemandor study (2018) goes in line with the findings of this study in that it states that most of the carers to children with epilepsy are the female housekeepers who care for long hours leading to their increased levels of stresses. According to Choruma (2007) & Peters (2001) have highlighted that when it comes to Zimbabwe, the nature of care given to children with epilepsy is mainly affected by the spirituality given to children with epilepsy that is the linking of epilepsy with witchcraft. This is further alluded to by Mugumbate (2020), who highlights that in Zimbabwe a lot of misconceptions exist thus this affect the nature of care given to children with epilepsy. High levels of stigma having a negative impact on caregivers of children with epilepsy reducing the quality of care delivery in Zimbabwe (Nyaguru 2013)

2.10 Challenges faced by caregivers in caring for a child with epilepsy

Caring for a child with epilepsy often involve a lot of negative impacts on the caregivers, and some of the impacts involve need for continued observation, state of uncertainty and uneasiness. In all studies that have been conducted have highlighted that caregivers of CWE are more focused on the all things to do with seizures that is the hesitation they have and the occurrence of seizures and possibility of being injured whilst still in seizures which leads to high levels of emotional burden on the part of caregivers (Berg et al 2019; Chiou& Hsieh 2008).

2.10. 1Multi-disability in children

A study conducted by Campbell 2018 highlighted that the problems of caregivers of CWE are issues to do with caring for them especially when they have multiple disabilities for instance severe form of epilepsy and Dra vet Syndrome. A study conducted by Aaberg t al 2016 in the United States highlighted that CWE usually experience other medical conditions and are usually at high risk of these conditions for instance gastrointestinal disorders, musculoskeletal disorders and also neurological disorders such as cerebral palsy.

2. 10.2Age of child with epilepsy

A study conducted by Ankash & Piya (2019) in India brought out that epilepsy in children is more prevalent in boys as compared to girls with a rate of 66.7 % of boys affected and 33% of girls affected and mostly children who had the most seizures were not yet going to school and some had also dropped out of school due to seizures. The study further goes on to highlight that caregivers of children with epilepsy may end up with school dropout children due to the fact that they fear that teachers in schools may fail to handle their children.

2.10. 3Stigma

A study conducted in India by Ankash and Piya (2019) brings out that caregivers or parents of children with epilepsy suffer a lot due to the perceived stigma around epilepsy. This stigma is brought about as a result of friends and relatives way in treating the child with epilepsy, the perceived meaning of epilepsy within the society which leads to the aggravated stigma felt by the caregivers and also when caregivers of children with epilepsy face a lot of stigma due to their social status and thus the study brought out that those parents who are not well established and are poor have a high possibility of being stigmatized within their society. Another study done by also highlighted that friends and relatives of children with epilepsy many at times stigmatized the children due to limited knowledge in relation to epilepsy, that the basic care when a child has a seizure. Studies have revealed findings regarding the phenomenon of stigma associated with epilepsy. The stigmatization of epilepsy has persisted over time, leading individuals with epilepsy to encounter social stigma within their respective communities. As indicated by Lee (2020), research has demonstrated that a significant proportion of caregivers of individuals with epilepsy encounter stigma, which in turn has adverse effects on their psychological well-being, manifesting as feelings of shame, diminished self-worth, anger, and challenges in disclosing the disorder. According Rahba (2021) highlighted that in Sudan, caregivers experience stigma due to the association of epilepsy with spirituality and lack of knowledge on the condition. In Northeast Ethiopia a study done by (Kassie *et al* 2021) highlighted that caregivers of children with epilepsy face a lot of stigma when it comes to epilepsy with it being related to witchcraft. Report conducted in Zimbabwe on shortage of drugs in Zimbabwe also highlighted that people with epilepsy undergo a lot of stigma and isolation New Humanitarian Report (2024). Studies and reports obtained in Zimbabwe highlights the isolation that people with epilepsy undergo in in Zimbabwe but in most researches done none of them have been completely focused on the challenge of stigma towards caregivers of children with epilepsy for instance the New Humanitarian report on the shortage of drugs (2024) highlights the way people with epilepsy succumb to stigma and isolation and mocking with their communities but the main focus of the research was persons with epilepsy rather children with epilepsy.

2.10. 4Fear

Ankansh & Piya (2019) conducted a study in India which highlighted that due to the pronounced stigma that is around epilepsy, the parents of children with epilepsy often live in fear, which is highlighted by the way they conceal the condition of their child from relatives and society. According to Bernie *et al* (2022) conducted a study and highlighted that caregivers of children with epilepsy the fear that caregivers have go beyond themselves that is it extends to the family members and this also has a negative impact on the family of caregivers. Mekonnen et al (2022) also conducted a study and highlighted that caregivers of children with epilepsy have fear as a result of the pattern of seizures that their child face and this thereby has a negative psychological impact on them.

2.10. 5 Limited self-time and family time

Ankansh & Piya (2019) conducted a study in India which highlighted that caregivers of CWE were more concerned with the health of their children more than their personal lives hence thy end up unemployed or living at home in order to effectively care for their children leading to no social life or activities with relatives or friends. Another study conducted in **scholar** also highlighted that caregivers of children with epilepsy spend most of their time taking care of children with epilepsy than taking care of themselves. Caring for a child with epilepsy can result in both positive and negative consequences for the family. Research conducted in Austria by Hames et al (2009) involving children with epilepsy and abnormal cognition revealed that 26% of families showed dysfunction in family dynamics, in comparison to 6.5% of control families as indicated by the FAM-III assessment. Similarly, a study conducted in India by Tsuchie et al (2006) also pointed out that 42% of families experienced adverse effects of epilepsy. Factors identified to exacerbate these effects included shorter time since diagnosis, increased frequency of seizures, multiple medications, and an escalation in behavioral issues in children with epilepsy.

2.10.6 Lack of knowledge on epilepsy.

Eileen in Portland (ILAE 2019) who highlighted that parents of CWE have a lot of special needs due to the number of things they do for children with epilepsy and this can lead to stress disorders. A study conducted by Zhang (2021) in China also highlights the absence of knowledge in caregivers in on the condition hence which also leads to poor delivery of care due to the absence of the essential information to care and a study by Samanta (2021) in

Arkaans also highlighted the unavailability of disease related information on the caring for a child with epilepsy in the black children. Moreso, Varghese in 2019 who highlighted that most parents lacked the knowledge which basic even the basic steps of providing first hand care (first aid when in a seizure), they did not even know it hence there is need for the education of the caregivers. A study conducted by Yu et al (2022) in China goes in line with this study in that it also cited that caregivers have a lot of needs which they are not able to get them all and among the needs that they want Is the access to knowledge. . A study carried out by Kissani, Moro, and Arib in Morocco (2020) revealed that only 5% of caregivers were knowledgeable about the basics of first aid. Caregivers lack the technical knowhow when it comes to epilepsy and the limited knowledge they have when it comes to epilepsy result in different practices in Sudan (Rahba et al 2021). Studies on caregivers have indicated that caregivers frequently have insufficient knowledge regarding epilepsy and generally hold negative attitudes towards this condition (Elaska et al., 2021). Liu (2017) further asserts that the lack of disease management skills among caregivers underscores their unmet need for knowledge in disease management. This emphasizes the global inadequacy of information available to caregivers concerning epilepsy, thereby compounding their challenges

2.10.6 Shortage of drugs

A report conducted by the New Humanitarian in 2024 in Zimbabwe highlighted that shortage of anti-epileptic drugs is a major challenge that is faced by people with epilepsy in Zimbabwe. Given this it also highlights that caregivers to children with epilepsy are not left out in shortages of drugs in Zimbabwe. Shortage of anti-epileptic drugs is another major challenge faced by caregivers in Zimbabwe. Although existing studies done pertaining epilepsy did not specify about children with epilepsy, they highlight the issue of shortage of drugs for people with epilepsy. a report conducted by the New Humanitarian in 2024 highlighted that people with epilepsy succumb to drug default as a result of the shortage of drugs and the high cost of medication on the other side it highlighted the unavailability of drugs due to financial constraints within the country. Studies conducted pertaining the shortages of drugs have been well researched upon globally, but when it comes to Zimbabwe most researchers have been more focused on people with epilepsy but when it comes to caregivers of children with epilepsy in Zimbabwe hence a research gap exists when it comes to the stigma and isolation that caregivers of children with epilepsy face in Zimbabwe.

2.10.7 Mental health problem

Mental health problems in caregivers caring for children with epilepsy have been reported to be high, a study conducted in China reported that caregivers undergo emotional burden in providing care for a child with epilepsy due to its complexity (Yang et al 2020 and Rani 2019; Zhang and Hu et al 2021). According to King et al 2020 has also supported the view that caregivers of children with epilepsy face a huge burden mentally when managing children with epilepsy. In Uganda, a study conducted there also highlighted that caregivers perceived epilepsy as a he burden and caring for a person with epilepsy does not make it any better (). A study conducted by Kathrine also highlighted that caregivers of children with epilepsy report higher levels of stresses compared to other caregivers of children with other disabilities.

2.10.7 Financial constraints

A study conducted in Uganda by Linda et al 2022, highlighted that caregivers faced a lot of challenges in managing CWE, and caregivers perceived epilepsy as a condition associated with huge financial constraints due to the uniqueness of the seizures that a child is likely to face hence they end up being with them to ensure that they are safe which is also cited in a study conducted in 2013 by Mahrer on the Quality of life in adult patients with epilepsy and their family members. A study by Karakis et al 2011 further goes on to point out that income is a difficult thing to find as most of the caregivers had to be at home caring for children with epilepsy which is also in line with the study conducted by Linda et al in 2022 in Uganda which bring out that the most challenges of caregivers also state from resources which decreases the quality of care they give to their children as a result of lack of resources.

2.10.8 Burden of care and lack of acceptance

Studies conducted have highlighted that caregivers of children with epilepsy have very complex and substantial challenges. A study conducted in Southern China have highlighted that caregivers of children with epilepsy bear a heavy burden of care and psychological burden (Yang et al 2020 and Rani 2019). Another study emphasized on this, a majority of caregivers reported heavy burden of care and negative emotional experiences, which was constant with other studies that suggested that epileptic caregivers had a high burden of disease socially, emotionally, functionally and economically (King Stephen et al 2020). To add to this another research by Zhang, Zhang and Hu et al (2021) in China also highlights that nearly half of all caregivers' experience depression and anxiety. Caregivers at times fail to accept the condition of their children this is highlighted by a study conducted by Bapat and Shankar (2021) in India who highlight that negative emotions are primarily due to difficulty in accepting and epilepsy diagnosis and inadequate coping skills which lead to other issues such as poor sleep quality and this is also highlighted in another study Liu, Yin and Zhu et al in China (2021). this further alluded to by Zhang, Zhang and Hu et al (2021) in China which state that 49% of caregivers do not get adequate sleep which was noted in the study.

Primary health caregivers may include parents, relative's other adults who live with the child care providers, offering direct care, daily management of the child's condition, medical care condition and crisis management (Barth et al 2010). Understanding Caregiving

2.11 Copying mechanisms adopted by caregivers ibn caring for children with epilepsy

Resilience have been highlighted as method that has been used by caregivers in managing children with epilepsy and this was noted by a study conducted by Zhao 2016 in China. The study by Zhao (2016) in china highlighted that caregivers who made us of resilience have been able to overcome the burden of care which they face that is the emotional and psychological stress. A study by Joling *et al* (2016) goes on to further cite that resilience work hand in hand with the support that is given to caregivers by their families hence they are able to cope with the burden of care they face in caring for CWE. Another study that was done in the British highlighted that caregivers cope to the challenges they face of caring for children with epilepsy through the support the get from the family (Roberts 201). Rebekah et al 2021 further highlights that caregivers of children with epilepsy rely on the paediatric who offer them support. In Zimbabwe caregivers of children with epilepsy heavily rely on the extended families for care and support and the communities that they rely on their families for support (Mugumbate 2013). Chimedza et al (2001) cited that caregivers of children with epilepsy in Zimbabwe rely also on spirituality for their copying mechanism.

2.12 Legal frameworks that exist for caregivers of children with epilepsy

These can be referred to the legal documentation or the existing policies or frameworks that are used to advocate for the inclusion and the social support of caregivers of children with epilepsy (Gordon & Tavera-Salyutov 2018). This part discusses the existing the frameworks which offer the support to caregivers of children with epilepsy, globally, regionally, in SADC and lastly in Zimbabwe.

2.12.1 Global frameworks for caregivers of children with epilepsy

Among the global frameworks is the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which upholds the rights and dignity of people with disabilities, especially young children with epilepsy. Principles like non-discrimination, accessibility, and full inclusion in society are highlighted in the CRPD. In order to defend the rights of children with epilepsy, such as their access to social services, healthcare, and education, caregivers might make use of the CRPD. For instance, Article 25 of the CRPD affirms that people with disabilities have the right, free from discrimination, to the best possible level of health, which includes having access to epilepsy diagnosis, treatment, and rehabilitation services. CRPD principles into national policy and practices, governments can guarantee that children with epilepsy receive the necessary support. This legal framework supports for the rehabilitation and supporting of persons with disabilities thus also including children with epilepsy (article 25). According to Kirtane &KaIra (2015) posits that Article 25 promotes for the psychosocial support of children with epilepsy through access to services and also non-discrimination which goes in line with the Ubuntu integrated approach by Mugmbate and Chreni (2019) which advocates for the social protection of children with epilepsy hence the UNCRP stands for the rights of children with epilepsy as well as goes in line with the social work values which allows for the inherent dignity and worthy of a person. Martinovic &Simic (2013) further goes on to allude that the framework supports for the provision of support and knowledge which help caregivers on how to care for a child with epilepsy thus the legal framework is of importance in this research through its advocacy for caregivers of children with epilepsy. However, one can note that caregivers of children with epilepsy face a lot of stigma when caring for a child with epilepsy, although the UNCRPD supports for non-discrimination thus showing that the legal framework lacks credibility since caregivers still face stigma due to lack of implementation, lack of awareness and also cultural barriers (BIeberck 2010; Ngwena 2010 & Mugumbat & Nyaguru 2019)

One more crucial piece of legislation that safeguards children's rights, including those of those who have epilepsy, is the United Nations Convention on the Rights of the Child (CRC). Among other rights, the CRC recognizes every child's right to health, education, and freedom from discrimination. In order to ensure that children with epilepsy have access to proper medical care, educational support, and protection from discrimination and stigma, caregivers can utilize the CRC as a tool to advocate on their behalf. For instance, Article 24 of the CRC highlights a child's right to the best possible quality of health and requires nations to take action to lower new-born and child mortality, including treating and preventing conditions like epilepsy. the UNCRC also advocates for the right to health for children with epilepsy, non-discrimination, right to pleasure and leisure time and also right to education. These thereby goes in line with the Ubuntu framework which seeks for the protection of a child in an African context but one can note that children's rights are not really being preserved due to the communities that we live in, that is societal norms are leading to a lot of stigma and children are not left out especially when they have epilepsy (Mugumbate 2020) in Zimbabwe. This is noted also in a study conducted by Samia (2019) in Egypt where careers of children with epilepsy face stigma and discrimination within the communities that they leave in. to add on, this can also be highlighted in a study conducted in Indi, where children with epilepsy are failing to access the affordabl health services that they need (Manasi & Veena 2018). This can be noted also in a study conducted in Brazil by Juliana & Antoni (2018) which highlight that children with epilepsy fail to access the basic education due to stigma of epilepsy.

2.12.2 Regional frameworks for caregivers of children with epilepsy

Under the regional frameworks of caregivers of children with epilepsy there is the African Charter on the rights of the Child (ACRCW) that is a legal frame work which contribute to the well-being of a child, the framework advocates for the non-discrimination towards children with epilepsy thus also children with epilepsy. it advocates for the rights of a child and also access to necessities such as the health and also advocates for the rights to health. The important of the framework goes in line with the study in that it helps in the advocating of the right of children with epilepsy leading to the complete access to services and the psychosocial support of children. This goes in line with the Ubuntu Framework by MUgumbate and Chereni (2019) which advocates for the use of our own approaches which are not westernized. According to Samkange and Samkange (1986) which highlights the needs for the use of the Afrocentric methods of dealing with a child. However, one can note that the ACRCW has been effective to a lesser extent in that it lacks enforcement to ensure that it is being properly adhered to within

African countries. This is highlighted by Fatima (Fatima 2017) in Nigeria who state that access to quality healthcare in Nigeria remains a challenge despite the provisions of the charter. To add to this many African countries lack the resources to implement hence the charter becomes of little to no use for instance in South Africa where those in rural areas cannot access their rights as well as in Zimbabwe (Jadesola 2018).

2.12.3 Zimbabwe frameworks for caregivers of children with epilepsy

Caregivers are crucial in the management of epilepsy in children through close collaboration with healthcare professionals and adherence to treatment plans. It is imperative to have a deep understanding of the legal framework that pertains to the protection and rights of children with epilepsy. According to Children Act (5:06) a child, as articulated in Section 2 of the Children Act, pertains to any individual under the age of eighteen years. The obligations of parents or guardians to cater to their children's physical and emotional necessities, encompassing access to essential medical care, are detailed in Section 31 of the Act. For a child contending with epilepsy, this provision underlines the legal responsibility of parents or guardians to ensure the provision of suitable medical attention and supervision. Additionally, Section 48 of the Children Act mandates obligatory medical treatment for children in specific scenarios, including epilepsy as a chronic ailment necessitating regular medical intervention. Nevertheless, it specifies that such treatment must prioritize the child's best interests and avoid causing harm to their physical or mental well-being. It is crucial to acknowledge that while the Children Act furnishes a legal structure for the protection and advocacy of children with epilepsy, there exist constraints in its execution. This goes in line with the Ubuntu framework by Mugumbate which seeks for the social protection of a child within an African home, it also advocates for the social workers to assist with children but however the scarcity of resources within Zimbabwe's healthcare system can pose obstacles for caregivers in consistently obtaining essential medications and specialized medical services for their children.

2.13 Research gap

Given all the above studies that have been highlighted, one can tell that caregivers face a lot of challenges when they are caring for children with epilepsy. caring for a child with epilepsy ranges from the nature of care that they give for instance the administering of medication up to doctors' appointments but in all these many studies have been focused on the children or the lived experiences of caregivers in other countries but no particular attention has been made for the caregivers in Zimbabwe particularly, those in Ward 8, Chitungwiza. Legal frameworks exist for the protection of a child but none have been effective in providing support of the child thus the research gap. To further highlight on this one can note that many studies concerning epilepsy have been focused on the person with epilepsy in Zimbabwe, but no particular attention has been given to the caregivers who care for those with epilepsy hence the need for this study to view the lived experiences of caregivers in Zimbabwe. Furthermore, the studies reviewed in this chapter have relied on theories from the countries they were conducted, and none applied an African perspective to understand issues of care. Lastly legal frameworks which guide the provision of care for children with epilepsy are there but their effectiveness has been to a lesser extent.

2.14 Summary of chapter

This chapter reported a review literature on the topic caregiver's experiences in managing children with epilepsy and the research was able to view existing literature on the nature of care, the challenges and the copying mechanism that is used by caregivers in managing children with epilepsy. At the end, the gap in the literature was highlighted. The next chapter provides the methodology used in the study.

CHAPTER 3: RESEARCH METHODOLOGY

3.0 Introduction

This chapter is centred on how the study was conducted. It discusses the methodology utilised in the research. This chapter delves into aspects such as the research design, study population, sample selection, methods of sampling, techniques for data collection, presentation and analysis of data, as well as the ethical considerations adhered to. At the end, the limitations of the methodology are provided.

3.1 Research approach

Research approach is the overall strategy, perspective, or framework that guides the selection of specific research methods (Creswell & Cresswell 2018). This research employed the qualitative research methodology due to its efficacy in comprehending the experiences of individuals (Parse 2014). Within the qualitative research framework, the researcher utilized focus group discussions with caregivers, enabling the exploration of caregivers' shared experiences and fostering a sense of community and social learning. These discussions allowed for the simultaneous gathering of data from various participants, providing insights into their thoughts, experiences, and attitudes through group dynamics (Hesse-Biber 2015). Additionally, interviews were conducted to delve deeper into the subject matter, offering the researcher a more profound understanding through one-on-one interactions, thereby uncovering individualized caregiver concerns. Interviews present opportunities to gain a profound insight into the interviewees' lives (Kvale 2007).

The research also made use of the Ubuntu research approach which is driven by the ontological interactive and is an epistemological co-creation, theoretical humanism, methodological collaboration (Mugumbate 2020). The research made use of the local language that is Shona to obtain informed consent, collect data and used the local language in verbatim thus making the research language used which was accessible to every. It also made use of the Ubuntu philosophy, ethics and techniques. The approach was chosen on the basis that the research solemnly involved mixed caregivers thus there was need for the acceptance of each individual as they are thus also adopting the local language for the respect and dignity of the worthy of a person in their own ways within the research.

3.2 Research design

Research design is a framework or plan for a study that guides the collection and analysis of data, covering the steps that will be taken to conduct the research (Creswell & Creswell 2018). he current study employs a narrative research design, which is characterized by its reliance on individuals' narratives, reflecting how individuals interpret and contextualize their experiences over time (Riessman, 2008). This narrative approach offers a unique perspective on individuals' lived experiences, emphasizing the significance of storytelling in shaping individuals' understanding and interpretation of their own lives (Andrews et al., 2013; McMullen & Braithwaite, 2013).

The application of the narrative research design allows for the understanding of the situations that come from the people being investigated, so as to get a better understanding of the situation. In this case caregiver's experiences in managing children with epilepsy brought about the understanding of the experiences of the caregivers of children with epilepsy and through observations the researcher was able to identify specific data which was in relation to the study. the caregivers will be able to adapt to the condition, develop copying mechanism towards dealing with the condition. Narrative integration are the processes of self-definition, self-interpretation, and self-alteration that occurs as individuals work on the stories of their lives (Tannus 2023).

The application of the narrative research design was to allow for the enhanced teaching about the condition for example when it comes to epilepsy they are certain myths and misconceptions towards the condition, which results in a lot of stigma and social exclusion within our societies, hence through the application of the narrative approach, it enhances the literacy of people as to all issues about the condition thus reducing stigma. Narrative research is used to enhance teaching and learning for students and educators in health and social related science related disciplines (Clandinin and Connelly 2000).

Narrative research design was more critical to the research in that it allows for the formulation of a trustworthy relationship between the research and participants. In carrying out narrative research, researchers form a close bond with participants where participants may feel their stories are heard and important (Creswell 2012). By doing so it gives a sense of trust to the participant that they are also included and to also bring the gap that is between the people with needs and how they can be met. Narrative research in this study allowed for the connection between the integrated Ubuntu philosophy framework and the methods being applied to the research therefore allowing for individuals to freely express their lived experiences (Laher and

Fyn, 2019) whilst the Ubuntu framework brings out the cultural aspects of the African communities (Mugumbate & Chereni 2019). This therefore highlights that the use of the Ubuntu framework brings out the unpopularity of the caregivers experiences and the experiences thus challenges the existing social system for the functioning of the caregivers with children with epilepsy in ward 8, Chitungwiza.

This therefore highlights the importance of the narrative research in this study, in that through the expression of lived experiences of caregivers of children with epilepsy, caregivers are able to identify their strengths and copying mechanisms and leading to the fully understanding of epilepsy which goes in line with what is stated by Laher and Fyn (2019) that narrative approach allows for individuals to view their experiences and grow from the challenges that they face and also develop copying mechanisms suitable for each and every one.

3.3 Study setting

Study setting is the time and place in which a study is conducted and in which data are collected (Yin 2018). The research is going to be carried out in Seke Chitungwiza in Ward 8. Born and bred in the study area, obtaining her working experience in the same place, the researcher has been closely observing the suffering of her fellow community members who work as caregivers yet encounter numerous challenges. Lack of medical health services is one of the reason as to why the researcher also chose this area. Baskind and Birbeck (2005), Duggan (2013) and Mushi et al (2011) asserts that “Previous studies in Zimbabwe and other African countries have reported issues of poor health services and inadequately trained nurses. As a result of this the researcher was able to identify only a few places where persons with epilepsy can get medical attention and this being Epilepsy Resource Centre Zimbabwe and also Chitungwiza hospital, but at times there maybe be lack of resources. Public services are available in urban areas but the quality is erratic (Mugumbate and Gray 2021) Therefore, the purpose of selecting the research location was to allow the community to propose measures that would improve wellbeing as people with epilepsy are not fully included. The main issues concerning people with epilepsy in Zimbabwe are lack of appropriate treatment, drug unavailability, high cost of medication, stigma and discrimination (Chiyangwa 2019). The focus of the study setting is to understand the lived experiences of caregivers in caring for persons with epilepsy.

3.4 Target population

A target population contains members which the researcher is interested in studying and the results of the findings are mostly generalized (Vonk, 2016). The study in question targeted caregivers who provide care and manage children with epilepsy. The targeted population provided a deeper understanding of the lived experiences of care provision to children with epilepsy in Ward 8 Chitungwiza. The target population provided the present issues to be addressed, making the data collection manageable and that the data provided were relevant to the main issues of concern. Caregivers within this area range around 30.

The population of the study constituted of the caregivers of children with epilepsy who were the mothers or fathers of the children with epilepsy primarily caring for the child with epilepsy in Ward 8, Chitungwiza. These caregivers were targeted as a result of the experiences that they face that is all of them manage children with epilepsy hence they give a better lived experience of managing children with epilepsy. The study also targeted professionals who deal with children with epilepsy such as a doctor from the hospital, a teacher from any organization who deal with children with epilepsy, the study made use of one from Mufudzi Wakanaka and also any organization that assist people with epilepsy from Epilepsy Support Foundation and Epilepsy Resource Centre Zimbabwe. Professionals were targeted population also provide information as to how epilepsy in children can be managed be it in schools or in their day to day activities through interactions with the children and all.

3.5 Sample size

A sample is a segment of the population that is selected for the investigation (Bryman, 2012:187). Sample size refers to the number of units that are selected for the study (Babbie 2012). The research involved of 20 caregivers who were the key participants pertaining managing children with epilepsy. The participation of the caregivers was based on a freewill that is if a person is not interested he or she is able to quit at any time. According to Babbie (2012) “Participants have the right to withdraw from a study at any given time without penalty, even after the study has begun”. The study included 3 key informants that is 1 doctor, 1 teacher, 1 organisation who offer assistance and lastly the extended family. Key informants were chosen on the bases that since doctors specialise in epilepsy, they can offer important insights into the disorder and how to manage it and also valuable perspectives on the daily management of children with epilepsy and the difficulties faced by those providing care. Information regarding resources and support available to carers and children was obtained from organisations that deal with epilepsy. Having these important informants helps the researcher to have a thorough and well-rounded grasp of the subject. Key informants provided in-depth, first-hand knowledge that which was valuable for understanding a phenomenon (Lokot 2021).

3.6 Sampling technique

Sampling is the process of selecting a statistically representative sample of individuals from the population of interest (Kamangar et al 2013). A good sample is a statistical representation of the population of interest and is large enough to answer the research question (Browner et al 1988). The research used purposive sampling technique and snowball sampling when choosing participants for the study. These are explained below.

3.7 Purposive sampling

Purposive sampling involves deliberately selecting participants who possess specific characteristics or experiences relevant to the research topic. According to Bryman (2012) purposive sampling is a form of non-probability technique whereby participants are selected in a tactical way so that the sample is relevant to the research questions. Key informants in this research comprised of a doctor, a teacher from an organization and lastly an organization who deal with children with epilepsy. Key informant in depth interviews were used by the researcher in conducting the research and only three key informants were used because those were the ones available due to the nature of their jobs and one of the 3 key informants opted for the use the email rather than conducting a face to face in-depth interview due to her tight schedule. The other two key informants were interviewed by the researcher through in-depth interviews and she recorded the interviews and noted the responses given, interviews were done at their work places. The researcher used purposive sampling to target key informants who were the professionals. She adopted the purposive sampling as a result of its uniqueness in selecting participants who possess special knowledge which is unique for the study.

3.8 Snowballing sampling

The researcher used snowballing sampling which involves initially identifying a few participants through the help of Epilepsy Resource Centre Zimbabwe who met the inclusion criteria and then asking them to refer other potential participants which she was referred to by both the participants and the organization. It is a technique of data collection that begins with one or more informants and relies on them to identify others who meet the eligibility criteria for the study (Brannen 2017). This method can be useful when reaching out to a specific population of caregivers who may be difficult to locate through traditional sampling methods. The researcher chose to adopt the snowball sampling due to the complexity of the issues to do with epilepsy hence snowballing was used on the key participants of the study. In most cases, in Zimbabwe it is characterized by a lot of myths and misconceptions on epilepsy. In the context of epilepsy, myth and perceptions together with incorrect knowledge contribute to stigma (Mushi et al 2011). As a result of the stigma a lot of people tend to hide these conditions hence it becomes hide to find research participants who can voluntarily show the lived experiences they have hence the need to apply the snowball sampling. Due to the complexity of the condition and social stigma, the researcher applied snowball sampling because most people who have the condition tend to hide it because of societal perceptions, the researcher applied snowball sampling on key informants, hence through snowball sampling, the researcher can be able to get help from those who have participated rather than having those who will volunteer on their own as it may be hard due to the issues surrounding epilepsy.

3.8 Data collection techniques and methods

Data collection methods in qualitative research are designed to capture meaning and understanding which is to be discovered by the researcher to create a context that will make sense of data (Creswell 2013). The research adopted utilized these techniques to collect data which included in depth interviews for key informants and key participants and also focus group discussions on key informants.

3.8.1 In- depth interviews

Interviews are a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspective on a particular idea, program, or situation (Sloan 2019). On key informants, interviews offered a unique opportunity to explore the experiences, perspectives, insights of individual who possesses extensive knowledge or who have directly experienced the condition. In-depth interviews allow researchers to enter into participant world and gather rich, detailed data (Gubrium and Holstein 2015). For caregivers, as the key participants, in depth interviews provided a platform where caregivers are able to express themselves without the fear of being judged or stigmatised. Epilepsy is a condition that leads to the isolation of those that have it and a lot of myths and misconceptions tend to lead to stigma and discrimination. Therefore, with this in mind, the researcher applied the in depth interviews as a method that allows the caregivers to express themselves without thinking of what is going to happen next within their community. The researcher conducted 30 in-depth interviews with caregivers and 3 in depth interviews with professionals. For instance, the key informants comprise of a teacher, a community health worker who works with children with epilepsy and also the organization that works with children with epilepsy. Hence the researcher made use of in-depth interviews with the 3 key informants. Yin (2009) posits that in-depth interviews with key informants, helps to gain rich detailed data that can help to understand complex phenomena. With the key informants who are people who are well educated in issues to do with epilepsy, it becomes of paramount importance to make use of in depth interviews.

3.8.2 Focus group discussions

Caillaud and Flick (2017:3) contain that a focus group discussion can be conducted ahead of one on one interview to establish how participants construct their perceptions on a certain phenomenon during social interactions. It is a research method that brings together 6 to 12 people for an hour or two to talk about a specific set of topics, with the goal to get a variety of perspectives and insights on a topic (Kruger and Casey 2015). The focus group discussion is to allow the caregivers of children with epilepsy to have different perspective as to how each one of them can deal with the challenges and cope up with dealing with children with epilepsy. Each one of the caregivers provided a different perspective on the management that they have used and experienced with their children hence focus groups become important. To add on, epilepsy is a condition that is often associated with stigma due to different views within societies hence some of the caregivers are not comfortable talking about it or seeking help for the conditions of their children, hence by conducting a focus group discussion caregiver can have a sense of belonging to a common group, thus with other people who have the same formalities. Dr Bennets (2011) assets that the social stigma of epilepsy may prevent individuals from seeking help, and result in a cycle of isolation and shame for people with epilepsy and their carers. Therefore, the focus group discussions then allowed for the researcher to get a better understanding of epilepsy and also find ways in order to help the caregivers in also managing children with epilepsy. The researcher was given permission form the organisation where she was attached at to conduct a focus group discussion with the caregivers since she also dealt with caregivers during the time of her attachment. After obtaining the permission the researcher recruited participants and developed a guide with open ended questions which opens the floor for each one of them to participate. The focus group is going to compromised of 8 caregivers taken on the group of the key participants. On key informant's the researcher applied the in-depth interviews as well as a discussion and the discussion involved 8 caregivers who were conducting a support group at Mufudzi Wakanka, this helped the researcher to utilize the support group to conduct a focus group discussion as it is hard to bring caregivers together as a result of the complexity of epilepsy.

3.9 Data collection tools

These are strategies for systematically gathering qualitative information from the study participants (Creswell 2012). In this research the researcher made use of interviews and focus group discussions. On interviews the researcher is going to look for participants, recruit them and schedule appointments for the interviews. Once the interviews are done the researcher then made use of the follow-up questions based on the responses given by participants. The interview is a uniquely powerful means of entering the private word of the interviewee, the research interview is not only a data gathering technique, but also a human interaction and an influence process (Kvale 1996).

3.9.1 In-depth interviews guides

An in-depth interview is a dialogue between an interviewer and an interviewee characterised by extensive probing (Coghlan and Brannick, 2014). The researcher adopted in depth interviews for her research, and in doing so she selected the respondents for her research. The justification for employing the use in-depth interviews is that it allows the researcher to gain a more nuanced and in depth understanding on issues to do with epilepsy and in-depth interviews were used on the caregivers of children with epilepsy. In depth interviews created an environment where the researcher is able to pay attention attentively to the participants, ask deeper questions. The researcher is made use of open ended and close ended questions. Key informants were interviewed with in depth interviews because of their profession for example a doctor due to the complexity of his or her work the researcher can only conduct in depth interviews. The researcher adopted in-depth interviews for key informants because it allowed the researcher to get the professional side of the experience that are faced by caregivers in caring for children with epilepsy. She also used open ended questions. Key informant's in-depth interviews were necessary in that they offered medical knowledge to the conditions and aspects they have perceived from caregivers. Some of the professionals were interviewed through online platforms due to the nature of their jobs. In-depth guide shown on appendix 1and 2.

3.9.2Focus group discussions guide

On focus group discussions, the researcher recruited participants for the focus group discussions then used a discussion guide with open-ended questions to stimulate conversation and explore the participant perspective. Through the focus group discussions of the key participants, the researcher is able to adopt different perspectives surrounding epilepsy and how unique each caregivers experience differs from the next one. The researcher was able to then facilitate the focus group discussion, allowing participants to share their experiences and perspective while also making sure that the conversation stays on track. The process of collecting data through focus group discussions involves recruiting participants, developing a discussion guide and facilitating the discussion (Krueger and Casey 2014). The researcher was able to conduct the focus group through the assistance of the organisation Mufudzi Wakanaka where they conduct support groups for caregivers of children with disabilities, she was then able to maximise the support group through the assistance of the organisation. Shown on appendix 3.

3.10 Ethical issues

As noted earlier, the research was informed by an Ubuntu approach, and this also applied to ethics. The researcher valued respect, non-harm, getting permission and keeping information confidential. This ethical issues are also stated in the CSWZ Code of Ethics.

3.10.1 Informed consent

Caregivers should be appropriately briefed to ensure their fully informed consent, comprehending the study's objectives, methodologies, potential hazards, and advantages. It is crucial to uphold their independence and guarantee their voluntary involvement. O'Leary (2017:70) stresses the significance of participants' informed decision-making regarding study participation, emphasizing the principle of autonomy. Participants were further informed about the study's objectives to facilitate inquiries, ensuring their right to discontinue participation without any biases (Khan 2014:306). The principle of respect for individuals (including dignity and autonomy) integrates notions of respect and self-sufficiency among participants. The NASWZ also advocates for the practice of informed consent.

3.10.2 Confidentiality and Privacy

Safeguard the confidentiality and privacy of caregivers' personal information and data collected during the study. Use secure storage and data management practices to protect their identities and maintain anonymity when reporting findings. According to the National Association Social Workers Code of Ethics (NASWZ 2021) “social workers should respect clients right to privacy, social workers should not solicit private information from clients unless it is essential to providing services or conducting social work evaluation or research. Once private information is shared, standards of confidentiality apply.” In the research, the researcher is going to apply confidentiality and privacy that is when conducting one on one information, if given sensitive information the researcher should keep it confidential, when referred to other clients the social worker should also keep the information private.

3.10.3 Respect and dignity

Treat caregivers with respect, empathy, and cultural sensitivity throughout the research process. Avoid stigmatizing language or actions that may further burden or marginalize caregivers. According to the National Association of Social Workers (NASWZ 2021), "social workers respect the inherent dignity and worthy of a person. They treat each person in a caring and respectful fashion, mindful of individuals and difference and cultural and ethnic diversity". The researcher considers the inherent dignity and worthy of a person during the research.

3.10.4Beneficence and Non-maleficence

As per the ethical principle of beneficence within research (Pieper & Thomson 2016; O'Leary, 2017:70), researchers are obligated to prioritize the welfare of participants by advocating for their best interests and minimizing potential harm, commonly referred to as non-maleficence. This necessitates that the advantages of involvement in the research project should surpass any risks posed to the participants. Adhering to this principle, the researcher ensured that no unnecessary stress was induced through the avoidance of insensitive inquiries that could potentially affect an individual's emotional well-being. Furthermore, it guarantees that the research endeavours to enhance the overall quality of life and level of care rendered to children diagnosed with epilepsy.

3.11 Limitations of the study

The limitation to the study can be the unavailability of caregivers that is most people can be a bit reluctant to participant in the research due to the stigma and misconceptions surrounding epilepsy. According to Langan (2011) asserts that "misconceptions about epilepsy can lead to a lack of understanding and even discrimination, which can discourage people from seeking treatment and disclosing their condition to others". Another limitation can be on the type of epilepsy, that is it can depend on its severity from one child to another. Epilepsy can manifest in many different ways, with varying symptoms and severity, and this can make it difficult to find a one size fits all approach to treatment Sillanpaa (2012). And lastly another challenge can be that ward 8, Chitungwiza can be a limited area to find a number of caregivers in that area hence limiting the study.

3.12 Validity and reliability

Validity refers to the extent to which study measures what it intends to measure. The degree of the rigor included in the research process establishes the legitimacy of a qualitative research topic (Shenton 200). The researcher has to employ suitable techniques for gathering data, demonstrate the reliability and authenticity of the information, and guarantee that the conclusion is trustworthy and transferable in order to assure validity. By making sure that the participants are the representative of the larger community of caregivers, the researcher ensures that focus group and interviews are credible methods of gathering information about caregivers. The researcher also ensures that the study is carried out ethically and takes into account the main focus of it and possible emotional impact it has on individual when examining experiences.

3.13 Feasibility

According to Neuman (2014) state that feasibility as the capacity to execute, achieve or realised. The study viability was demonstrated by a range of factors which precipitated its necessity. One the major reason being the area of focus is the area that the researcher resides in and did field work placement, Ward 8, Chitungwiza hence enabling her to conduct the research because she knew the place. Further, the researcher’s placement was on the Epilepsy Resource Centre Zimbabwe in the same area, this provided access to community organisations and reading source.

3.14Summary of the chapter

This chapter highlighted the research methods that were used by the researcher when she conducted her research. The research also highlighted the ethical considerations, limitations and the delimitations of the study. The coming chapter is going to focus on the presentation of data and its analysis and discussion of findings.

CHAPTER 4
DATA PRESENTATION, ANALYSIS AND DISCUSSION

4.0 Introduction

This chapter focuses on the data presentation, interpretation and discussion of the findings of the research on the lived experiences of caregivers in managing children with epilepsy in Ward 8, Chitungwiza. The major focus of the study was to answer the objectives of the research which were the nature of care given to children with epilepsy, the challenges being faced by caregivers in managing children with epilepsy and the copying mechanisms adopted by caregivers in managing children with epilepsy. The data was collected from 30 caregivers who had children with epilepsy and 3 professionals who also deal with children with epilepsy. Analysis and presentation of data was done through themes led by the research objectives which were to highlight the lived experiences of caregivers of children with epilepsy. Verbatims were utilised in the research and further translated to English.

4.1 Demographic characteristics of participants

Demographics play a huge role in research in that they are useful in the analysis of data which is going to help the researcher to interpret data collected thereby leading her to draw meaningful conclusions of the research which are tailor made towards the age, gender of the participants and economic level as the disparities that exist within their societies (Ferreira 2017). The main participants of the study were caregivers of children with epilepsy who reside within Ward 8, Chitungwiza and most of them were parents to the child with epilepsy.

The demographics of the caregivers are summarised in the table 1 below:

Table 1: Demographics of caregivers

Variables		Caregivers with children below the age of 5	Caregivers with children below the age of 10	Caregivers of children below the age of 15	Caregivers of children below the age of 18	Frequency	Percentage
Range of age	20-25	6	1	0	0	7	27%
	25-30	7	3	0	0	10	33%
	30-35	5	4	1	0	10	33%
	35-40	0	0	0	1	1	3%
	40-45	0	0	0	2	2	1%
Marital status	Married	9	6	1	2	18	60%
	Single	7	5	0	0	12	40%
Economic activity	Formally Employed	0	0	0	1	1	3%
	Unemployed	8	2	1	3	14	47%
	Self employed	10	3	3	0	16	53%

Level of education reached	Primary	5	4	1	1	11	37%
	Secondary	8	7	3	0	18	60%
	Tertiary	0	0	0	1	1	3%
Gender	Females	18	8	1	3	30	100%
	Males	0	0	0	0	0	0%
Relationship to the child	Parent	15	7	2	2	26	87%
	Guardian	0	1	0	1	2	6%
	Other relationship	2	0	0	0	2	6%

n = 30 participants

Results from the research indicate that all caregivers of children with epilepsy are women and mothers to the children with epilepsy, with little to no male involvement in the assistance of caring for child with epilepsy. this goes in line with a study conducted by Rahba et al (2021) in Sudan which highlighted that most of the caregivers were the mothers of children with epilepsy. The findings of the research also go in line with the findings of the research conducted in Egypt which highlighted that most of the study participants were females and these were the mothers of the children with epilepsy (Samia 2019)

The researcher conducted a focus group with caregivers of children with epilepsy but from the respondents that she found, the caregivers who were presented were women, here were no males involved highlighting that caregivers of children with epilepsy mostly in ward 8 are women hence they are the ones who endure the burden of care of children with epilepsy. to add on to this, the researcher noted that the challenges that were faced by caregivers of children with epilepsy varied depending on the gender of the caregivers and also their age and the age of the child, for instance caregiver's who were a bitter younger with children below the age of 10 faced more challenges as compared to older caregivers with children of the same age group or with older children.

4.1.1 Demographics of caregivers age of children with epilepsy by age

Out of the thirty participants of the study, 6 caregivers were under the age group of 20-25 and they had children under the age of five years, one had a child under the age of ten. In the 25 to 30 years' group of caregivers 7 had children below the age of 5 and 3 had children under the age of 10. In the 30-35 years' group of caregivers 5 had children under the age of five, 4 had children under the age of 10 and 1 had a child under the age of 15.1 caregiver had children under the age of 18 and is in the 35-40 age group. Lastly under the age of 40 -45 years' group 2 caregivers had children under the age of 18.

The purpose of the age in the study was to investigate the depth of the challenges that is faced by caregivers in managing children with epilepsy as challenges may vary according to the age of the caregivers. Young caregivers face a lot of challenges as compared to older caregivers this is because young caregivers are still growing their resilience towards the condition hence they are likely to face more emotional burden as compared to older people. Compared to older caregivers, younger caregivers may feel a bit more overwhelmed and isolated with little to no social support from others whilst older caregivers may have a lot of support from various sides such as the family and all.

The findings of this research is similar to the finding of Eyong (2021) who found that caregivers who are above the age of 40 face years have a higher burden of care compared to younger caregivers of children with epilepsy. This is because older caregivers succumb to a lot of health problems such as high blood pressures which increases the strain on their physic and thereby leading to poor delivered care to children with epilepsy.

As noted above age is very important in the study in that it allows for the comparison between the different ages to see the depth of their challenges as all caregivers face unique challenges caring for a child with epilepsy. For instance, older caregivers in age groups such as 35 to 45 years have their own physical burdens such as high blood pressure, heart problems to mention but a few hence caring for a child with epilepsy increases the physical burden that they face. When it comes to the physical burden, older caregivers may face a huge challenge as compare to the younger caregivers as caring for a child with epilepsy is both demanding and tiresome.

Lastly age is also important in that, it helps again in telling the complexity of the challenges faced by caregivers in that children below the age of ten are considered to have more seizures as compared to children who are a bit grown. To add to this, these children face stigma from other people within their society hence they may be denied playtimes with other children within the society.

4.1.2 Distribution of caregivers by employment

From the research it is indicated that 2 out of the 30 participants of the research are formally employed and one of them have a child in the age group below 18 and also below the age of 18. 14 caregivers are unemployed with the highest number of the caregivers with children below the age of 5. Lastly 16 caregivers are of children with epilepsy are self employed

The employment variation seems to determine the extend the monetary stability of the caregivers so as to see how their challenges vary, while in this research caregivers who were unemployed faced more financial constraints compared to those who are self-employed as some of them may be assisted by their families, younger caregivers are more vulnerable as compared to children with epilepsy. Unemployed caregivers are likely to face more challenges a s compared to caregivers who are employed.

This goes in line with a study conducted in Sudan which highlighted that 51,4 % of caregivers were unemployed, with less than 31.8 % formerly employed leading to the conclusion that most caregivers were not educated.

4.1.3 Distribution of caregivers by level of education

The distribution of caregivers through the level of education is important in the study in that, it helps in investigating the knowledge that caregivers hold in caring for children with epilepsy, how they carry it. Lack of knowledge when it comes to caregivers of children with epilepsy, can help them in caring for their children but if they lack knowledge pertaining epilepsy they face a challenge in caring for children with epilepsy.

4.1.4 Distribution of caregivers by gender

The research highlighted that 100% of the caregivers of children with epilepsy are women and men are usually not involved in participating in caring for children rather caregiving for children with epilepsy is a women's job and at times women complain of being blamed for the condition of their baby.

This research finding goes in line with what was highlighted by the Epilepsy Society (2024) that the number of unpaid carers in the United Kingdom is so high and 6/10 of the unpaid workers are women thereby highlighting that women hold the mot responsibility of caring for CWE. A study in China (Wang *et al* 2024) also cited that among the caregivers of children with epilepsy 78.35% were the mothers with fathers representing only 21.65% as caregivers, this goes in line with the demographics in this study that most of the caregivers of children with epilepsy are the females or the mothers to the children with epilepsy. this is also cited by Etemadifar et al (2018) who conducted a study and pointed out that fathers only play the role of assisting mothers in taking care of CWE but the main role of caregiving is undertaken by the mothers of CWE and they undertake care for very long hours and they are mainly focused on house cores which also lead to their high levels of mental health problems. This study also brings out that caregivers (mothers) have an overprotective nature and worried for the safety of their child. The findings of this study also differs from the findings of a study conducted by Joling (2016), which highlighted that they are also male caregivers in caring for children with epilepsy.

4.1.5Distribution of caregivers by marital status

Most of the children in the study are children who are not yet going to school with some others dropping out of school due to the condition and mostly parents tend to avoid their children from going to school due the uncertainty of their seizures. This goes in line with a study conducted by

4.1 The nature of care given to children with epilepsy in Ward 8, Chitungwiza.

From the research conducted, it showed that caregivers of CWE had various ways of providing care to their children. Out of the 30 participants of the study, the nature of care provided to the children with epilepsy seemed to vary, but all of them had their own various ways in which they all catered for their children with epilepsy. Out of the 30 participants 5 caregivers had children with other disabilities such as autism and cerebral palsy hence the care varied from the one given to children with just epilepsy. Caregivers highlighted that the nature of care they give to their CWE varied from one caregiver to another but basically caring for a child with epilepsy included provision of basic care, drug compliance and adherence and seizure controls. The caregivers of children with other disability highlighted the provision of basic care including bathing the child because of their age and also due to having multiple disability.

4.1.1Provision of basic care.

Under the provision of basic care, respondents highlighted that caring for a child with epilepsy involves managing and controlling the taking of AEDs by children, seizure monitoring and writing up of chats to monitor them, bathing of young children as water can be a trigger or when they are disabled and cannot do things own their own. Caregivers also cited that children with epilepsy need a good diet for the taking up of their medication as they require a lot of food hence children with epilepsy overeating due to the side effects of the medication hence, it was noted in the study that the AEDs of CWE also required a good diet. To add on, the caregivers brought out the issues that seizures mostly do not have a specific time of when they are likely to occur rather it is uncertain hence under the provision of care caregivers also have to be alert every time for the safety of their child so me seizures may occur at night hence as part of care that they provide for their children they also sleep with their babies. Another caregiver also noted that caring for child with epilepsy has a lot of complexities which range from seizure management up to avoiding what may trigger the seizures. Lastly on the issue of bathing children with epilepsy, the provision of care brought out by the study also highlighted that children with epilepsy may also have multiple disabilities thus they are not able to take care of themselves hence their mothers pitch in assisting them in bathing and all the care routine and this was also highlighted by the key informant to the study who cited that provision of basic care goes overall to the child as a whole that is there is seizure management and writing up of seizure chats and adherence to drugs although they might be unavailable and expensive to caregivers.

One caregiver said that

"Mukuchengeta *mwana anodonha, ndinomupa chikafu chaicho zvakaita sesadza nekuti dzimwe dzenguva akasanyasodya mwana anoramba achitaura kuti mama ndine nzara, saka ndakatoona kuti mapiritsi anoda mwana anyasodya chikafu chakanakaa. Zvakare mwana wangu anodonha chero nguva asi kazhinji zvinoitika husiku saka ndinotorara naye kuitira kuti kana aripedyo neni ndinokasika kuzvinzwa ndomubatsira. Nenyaya yekuti ane cerebral palse* *haazokwanise kugeza ega saka ndinozomugezesa*" (**Female caregiver mother to a 6-year-old boy)**

Translated to English as follows:

"*In caring for my child with epilepsy I make sure that I give him solid food like sadza because the kind of pills that he take(carbamezapine) usually exacerbates his hunger and he ends up eating a lot so I make sure that I give him solid food before his medication, on the part of seizures usually they happened at any time but during the night at times it gets worse so I end up sleeping with him so that I will be alert when his under seizure and I can be able to assist him immediately and I end up bathing him because he will not be able to do it alone because he has cerebral palse".*

Another caregiver highlighted that

"*Kuchengeta mwana ane pfari kunoti netsei, kazhinji pakumuchengeta mwana ndinotarisa kuti hapana zvinomukuvadza here, kuti anonwa mushonga nenguva dzakafanira here nekuona kuti anodonha kangani uye kuti mushonga yacho iripo hre kana pasina totsvaga nekusaita zvinoita adonhe, kazhinji akafarisa anodonha. Pakumuchengeta kazhinj ndinozongorara naye husiku kuitira kufita asi masikati anotoswera zvakanaka uye panyaya yekumugeza kazhinji ndongomugeza nekuti achiri mudiki* ***(Female caregiver mother to a 4-year-old girl)***

"Providing basic care for a child with epilepsy comes with a lot of challenges, due to fact that I have to monitor the safety of the environment so that whenever he has a seizure he will not be hurt, in caring for him I ensure that there's drug adherence at the right time and that the supply of drugs is well stocked to reduce drug defaulting. I sleep with my baby so that whenever his seizures are triggered I can easily help him but during the day he is always okay and playing with other kids. When it comes to him taking a bath, I just do it because he is still young ***(Female caregiver mother to a 4-year-old girl)***

A key informant stated that:

> *Well I can't say there is anything special but it comes with a territory just like any teacher providing teaching or providing support to children in a classroom. But the uniqueness is that a parent has to know the type of medication their child is taking, have to know the time they have to take their medication, they should know where to take the child in the event of a seizure and in the event that the child has severe reactions towards medication, in the event that the child has continuous seizure what we call status epilepticus. These are things that we try to educate the parents, we also give what we call a seizure record. A seizure record this is where the number of seizures are recorded per day, the time, duration and what the child was doing and at what time and so forth, does it happens twice a day or more, is it once and then they record and we track those. the issue of adherence, we also try to educate parents that on week before the medication is about to finish, they need to find the medication as we know that the most of the medicine is not easily accessible, is very expensive and majority of times it's not available in clinics and hospitals. (Director Epilepsy Resource Centre Zimbabwe).*

The above findings indicate the nature of care given to children with epilepsy by caregivers and this means that caring for a child with epilepsy can be a significant strain to caregivers of children with epilepsy considering the various demands that are highlighted in caring for a child with epilepsy whilst some of them lack the financial strength to effectively care for their children with epilepsy , caregivers are highlighted as people who do not have the right resources, the right information to caring for a child with epilepsy which therefore leads to them provide the general care that they afford which may not be sufficient to a child with epilepsy. Hence there is the need for social workers to conduct assessment of the strengths and the weakness of the family caring for a child with epilepsy and ensure that they can be able to link them with the access to the resources which they need in caring for a child with epilepsy to increase their copying mechanisms. The above findings also highlight for the need for the counselling and strong support systems for caregivers of children with epilepsy in that provision of basic care increases the rates of burden of care hence there is need for the assistance of caregivers in dealing with caring for children with epilepsy. one can also note that, caregivers should also be assisted on the obtaining of the basic education required in caring for a child with epilepsy, in that they get to know the basic information needed in caring, the first aid measures to conduct when a child is in a seizure and also the diets suitable for their children hence social workers should advocate for the awareness of epilepsy and caregiving. Caring for a child with epilepsy is presented as a multitask with a lot of complexities which varies from diet to medications. Caregivers, as highlighted by the findings are the ones who have the major responsibility for the welfare of children with epilepsy so as to ensure that they are well taken care of in Ward 8, Chitungwiza. This is supported by the Ubuntu Philosophy Framework by Mugumbate and Chereni 2019 which highlight that a child should be protected within the African context through the already existing indigenous knowledge system. Therefore, the findings go in line with the Ubuntu Theory in that it stresses the protection of the child which is highlighted within the study through the various ways in which caregivers are providing care for children with epilepsy. caregivers are highlighted as the sole providers of children with epilepsy. the provision of basic care to children with epilepsy is in line with a study conducted by in 2022 which highlighted that the mothers of children with epilepsy were the ones who did the caring for their child with epilepsy which at times held heavy burden to them. The study by Rozensztraunch & Koltuniuk (2022) also highlighted that the family is the basis which shows the child with epilepsy the first support that he or she need leading to the formation of bonds and security for the child with epilepsy, which differs from the findings of this study in that caregivers are the sole protectors of children with little to no male involvement of men. This is reflective to the result of the study that main participants of the study were women hence they are the ones who endure the major burden of caring for a child with epilepsy. According to Ankash & Piya (2019) also highlighted that children who have multiple disabilities relay on their parents for care in terms of issues to do with bathing, eating, adherence to medication and physical movement for their own safety, it also reflects that the job of nurturing CWE is undertaken by the mothers and the findings of the research also differs from the findings of this research in that the research by Ankash & Piya talks of the fathers playing an assistive role whilst in this study caregivers are mostly women and they struggle in caring for the children alone and some have even divorced due to the condition of the child. Elemandor study (2018) goes in line with the findings of this study in that it states that most of the carers to children with epilepsy are the female housekeepers who care for long hours leading to their increased levels of stresses. The investigation done by the researcher was able to highlight that caregivers in offering care to children with epilepsy they also partake in the administering of medication to their children which is done at a certain time on a daily basis as prescribed by the doctor. This therefore goes in line with the research objective which is to bring out the nature of care given to children with epilepsy. The findings of the research goes in line with the findings of a study conducted by Ankash & Piya in India (2020) which brings out that parent of children with epilepsy also administer medication to their children as a way to curb seizures with the adherence of medication.

4.1.2 Understanding of epilepsy and caring for a child with epilepsy.

The research was able to find out that most caregivers had the general idea of the condition epilepsy but most of them lacked the further information of the first aid conducted when a child as a seizure and all that is surrounding epilepsy. Caregivers cited having the general idea of what is epilepsy, how to protect their children from epilepsy, what may trigger the seizures, but all in all this knowledge that the caregivers have is generally obtained from their own understanding of the condition, but they lack the basic education for the proper care. The key informant in the research highlighted that mostly caregivers of children with epilepsy have their own ways and methods that they already know but some of them may cause harm to children with epilepsy hence which may end up doing more harm than good to children with epilepsy for instance drug default or reducing the milligrams so as to extend days giving the child medication as a result of its shortage or financial constraints.

A caregiver noted that:

"Zvine chekuita nepfari tavakunzwisisa tavakuziva kuti mwana ane pfari ndomuchengeta sei. Ini ndonzwisisa kuti mwana akawanda mushonga yake yakakwanaa nechikafu chekuti chinovaka miri anenge aribhoe asi ndakaona kuti akashaya chikafu chinovaka miri, anoperezeka miri"

Another caregiver also highlighted that:

"Ehe tavakunzwisisa ndavakuziva kuti kana mwana akafarisa kana kutsamwisa anogwinha saka zvave zvinhu zvandave kuziva pamwana ane pfari uyu wangu munhu ane miri saka handigone kusamupa chikafu because mapiritsi aanonwa chaiwo anoda munhu akadya iye anotora masodium valproate"

A key informant also noted that:

"Yes, each and every parent is unique to the child's type of epilepsy because in most cases caregivers will respond positively or negatively to the each and every child with epilepsy. One some may not be supportive or very encouraging to assist their children, some are very proactive and some may be overprotective assuming that they are helping the child whilst they are not, they are doing more harm than good. So yes they come with their own methods, for instance like on medication some would break the medication into half when they are about to finish and give the child to prolong or stretch the days but in actual fact it does more harm than good, secondly others would ask from other parents medication , borrowing tablets which is wrong and some especially when administering first aid , I think I mentioned earlier, some would rub oil or kumubatisa mugoti whilst being in a seizure are some of the ways they use, some just lock up their children in their homes regardless of seizures or not and all and leave them all day long whilst being at work. So yeah”

The research findings bring out that caregivers lack the medical knowledge of the epilepsy, first aid measures and the basic information which is related to epilepsy which lead to harmful care practices which may negatively impact the baby hence this highlight that caregivers of children with epilepsy lacks the right information towards caring for a child with epilepsy need to be educated on what is epilepsy, through support groups of even capacity building trainings where they are equipped with the right with the right information for instance caregivers can be taught the basic stages of conducting first aid when a child is in a seizure that way they can be properly assisted. The research findings highlighted that caregivers in ward 8, Chitungwiza only understood the basic meaning of the condition but most of them do not have the basic information of the condition and the research findings on this goes in line with the research findings by Zhang (2021) in China who cited that most caregivers lack the knowledge when it comes to epilepsy and this affects the provision of care to children with epilepsy. a study conducted in South Africa by Musekwa (2023) also support the view of this research, it states that caregivers of children with epilepsy show low levels of knowledge pertaining the conditions in the rural areas of Limpopo hence the lack of knowledge of the caregivers also affects the nature of care given to children. However, the findings of the research conducted by Varghese contradicts the findings of this research in that, the study found that half of the caregivers in the research knew the causes of the seizures whilst in this study the researcher was able to note that the majority of the caregivers in her study had the knowledge only on what is epilepsy but relating to the causes of seizures they had no idea.

To add on, the findings of this research is similar to the findings of a study conducted by Elham 2021 which highlighted that caregivers of children with epilepsy lack information with percentage of 89,7 without the knowledge pertaining epilepsy. According to a study done in 2019 by Epilepsia Open highlighted that parents of young children with epilepsy suffer from a huge burden caused by seizures leading to traumatic stress disorders. This goes in line with what is stated by the Eileen in Portland (ILAE 2019) who highlighted that parents of CWE have a lot of special needs due to the number of things they do for children with epilepsy and this can lead to stress disorders

4.1.3Overprotective nature of caregivers

The research study was able to highlight that caregivers of children with epilepsy develop an overprotective nature towards their children with epilepsy due to the fear they have about the condition and the safety of their children. Caregivers in the study highlighted that they are always with their children in trying to protect them against seizures, against discrimination in areas that they live in, this way it brings a sense of peace to them to know that their child is safe and some caregivers end up with school dropout due to the fear of the safety of the child. A caregiver highlighted that

" Kazhinji kacho ndinoti kana mwana wangu akanotamba panze ndinotobudawo kungoendawo panze oaye kuti ndioene kuti aribhoe here, hapana vakumushungurudza here nekuti vamwe vemunharaunda havanyasogamuchire chirwere. Pamwe pacho ndinotomurambidza kuntamba oanze pacho otambira hake mumba zvinova zvinhu zvekuti unenge wakagadzikana uchiziva pane mwana wako".

Another caregiver also highlighted that:

"Mazuva aakatanga kunyasodonha ndakaita kuti ambomira kuenda kuchikoro nekuti ikoko kwacho unege usingazive kuti zvinozoita sei uye nenyaya yekuti vanhu vari ikko havatonya-sonzwisise zvehchirwere ichi, unenge wakutyira kuti mwana wangu zvingaende nepamwe ariko kuchikoro ikoko"

A key participant highlighted that:

“mothers of children with epilepsy are usually protective of their child because of the motherly love that they have, and the fear of the implications of the condition of the child. Stigma and discrimination that they face within communities makes it worse hence they end up over protecting their children and some may even become school drops out which is a negative effect on the development of the child”

The above findings of the study highlight the overprotective nature of caregivers to children with epilepsy but this negatively impacts the growth of a child in that the child develops a dependency syndrome that is the child may have developmental issues in not participating with peers of his age and also the reduce the child’s self-determination skills. For instance, in the study a 17-year-old boy is used to his mother that much and has no friends and is always with his mother, this affects his growth as an individual, he might lack confidence in whatever he does and also in terms of issues to do with sexual orientation which is really not appropriate leading to a lot of mother and child attachment or through the social learning theory one can note that the child may not be able to develop rather he or she may leave in the comfort that his mother is solely responsible for themselves leading to the lack of sustainable development of an individual. To add to this, overprotectiveness of caregivers may also increase chances of dysfunctionality of a family in that a mother can be more devoted to a child that is regarded as being sick thus limited attention to other children. The study findings go in line with the research framework in that the Ubuntu framework seeks for the provision of protection of a child to the transition into adulthood hence the overprotective nature of caregivers ensures the safety of children into adulthood. The findings goes in line with the findigs of the research conducted by Elemandor(2018) further goes on to highlight that mothers of CWE are more cautious due to the uncertainty of the seizures of their child thereby developing an overprotective nature this also goes in line with the findings of the study conducted By Ankash & Piya (2019) which also highlighted that mothers of CWE also tend to their children in playing with others, school activities which may be assumed as harmful and also out of their sight and in doing activities which may also pose a threat or expose them to seizures . Doron *et al* (2018) also conducted a study which also highlighted that caregivers develop a nature of over protectiveness due to the fear of having their children succumbing to seizures whilst they may not be able to take care of them or in watching their children in agony thereby leading them to take full control of their children's life as a way to avoid the danger their children are likely to have. A study conducted by Doron et al (2018) highlighted that due to the nature of seizures that happen to children with epilepsy and the uncertainty of when and where they may happen, caregivers usually tend to develop an overprotective nature when it comes to their children with epilepsy, this may lead to some of them dropping school due to the fear of them getting attacks whilst they are not around.

4.2 Challenges faced by caregivers in managing children with epilepsy in ward 8, Chitungwiza

The major challenges faced by caregivers in managing children with epilepsy were investigated. The participants highlighted the major challenges to caregiving as mental health problems, financial constraints, stigma and social isolation, lack of knowledge pertaining epilepsy.

4.2.1 Stigma and isolation

Stigma and isolation was highlighted by the participants as one the challenge that they face in caring for their child with epilepsy. Respondents cited that stigma and isolation has become a life time concern be it within the family or within the societies that they reside in. People within communities that caregivers reside in often discriminate caregivers leading to isolation due to the myths and misconceptions surrounding epilepsy, hence the caregivers end up isolated due to the misconceptions. One can note that caregivers suffer a lot from stigma and this end up negatively affecting even their participation within the community. Most of the participants highlighted that they faced stigma and isolation, one participant highlighted that

“Munharaunda matinogara havanyasogamuchire mwana anofita, pamwe pachoakada kunotamba nevmwe muraini chaimoo unomuona adzoswa kana nevepamba panext door kuti torai mwana wenyu pamwe pacho unotozoona kuti rega angogare hake mumba nenyaya yezvine zvichiita vana muraini”

Translated to English:

“Within the societies that we live in children with epilepsy are stigmatized, even by other parents whom forbid their children from playing with my child because of his condition so I just end up confiding him in our house because of the treatment he is given even by other children”

Another participant cited that

“Vanhu vakaziva kuti pane mwana anodonha kazhinji kacho chero uchitsvaga imba vanotongokuti hapana chero vavamboti iripo, saka kazhinji kacho kana tave kutitsvga pekugara handiende naye vanotozoziva kuti mwana akaremara kana tavepo sewangu uyu anogwinya plus ane cerebral palse”

A key informant cited that:

“Within the communities, the main challenges of caregivers are stigma and from my experience I have been able to note that people have different knowledge pertaining epilepsy hence this is one of the major reason why caregivers end up being stigmatized. Although stigma isn’t the only problem that they face, they are any others but because of stigma they end up without anyone to share the burden with, they endure it all alone” (Doctor)

These responses confirmed that stigma and isolation is a challenge being faced by caregivers in caring for their children with epilepsy. this entails that epilepsy is a highly stigmatized condition which leads to a lot of judgemental attitudes within the societies hence this highlight that there is limited knowledge when it comes to epilepsy hence there is the need for the awareness of the condition within the urban and rural areas because caregivers of children with epilepsy are being side lined because of the lack of knowledge of the condition and that no particular attention has been given to them. with epilepsy are being. In Africa, due to the different spiritualties that different people hold, they have their own believes when it comes to epilepsy hence the myths and misconceptions (Mugumbate 2018) thereby directly affecting caregivers of CWE within their societies. Stigma and isolation of caregivers lead to them keeping their challenges to themselves and not seeking assistance because they are scared of the discrimination that follows when they open up about the condition of their child which therefore contrast with the Ubuntu Theory by Mugumbate and Chereni 2019 which speaks about oneness, social support and sympathy towards children whilst they are growing. To further highlight this on can note that, stigma goes against what exist in our African culture in Ubuntuism which was highlighted by Samkange and Samkange (1980), instead of people showing empathy and kindness towards caregivers of children with epilepsy people end up discriminating them thereby going against the values embedded in the African roots which value kindness and care in human relationships. The study findings go in line with a study conducted in China by Wang *et al* in 2024 which highlighted that parents of children with are affected by affiliate stigma because of the lack of the correct information pertaining the epilepsy and also the existing myths and misconceptions of the condition. A similar scenario is also highlighted by a study conducted in Korea by Sang- Ahm et al (2020) that stigma is not only felt by children with the condition rather their carers are also afflicted by stigma as well with a lot of people being uncomfortable with them be it in work places or in any other areas. In Morocco a study by Kissani et al cited that people lack the basic knowledge of epilepsy which therefore leads to the misunderstanding of the condition including the relatives of the CWE hence also leading to stigma and the marginalization of persons with epilepsy. Stigma as a challenge of caregivers goes against the theory of Ubuntu in that the theory suggests of togetherness and unity but within the community people are stigmatizing persons with epilepsy. Ankash & Piya in India also cited that families of CWE face a lot of stigma even from friends and relatives due to the existing issues surrounding epilepsy, hence family and friends becom evn scared of the child with epilepsy leading to them being affiliated with stigma.

4.2 .2Mental health problems

Mental health problems were recognized as part of the challenges that the caregivers face in caring for CWE. The majority of the caregivers highlighted mental health challenges as a major challenge that they face. Caregivers are mentally disturbed due to the circumstances that they face and amongst this is stigma, feelings of worry for the safety of their children within homes, societies and also within the family and also due to the overthinking nature for the future of their children. Carers pointed out that the fact that their children have epilepsy does not make it any better, mostly they tend to accuse themselves of where they went wrong for their child to have the condition. A caregiver cited that

“Matorero anoita vanhu vana vane pfari ane kakusarura saka pamwe pacho unopedzisira wavakunetseka kuti mwana wangu akakura akadai ndian achazodawo kuva naye, vamwe nekuda kwekuti munharaunda vanoramba kana kutamba naye ndochimwe chezvinhu zvinonetsa wobva wati kumba kwacho murume wangu ane achiti chirwere chakabva kumusha kwenyu kwedu hakuna zvakadai, ndezvimwe zvevzinhu zvinondinetsa pakuchengeta mwana ane pfari" (Female caregiver 30 years old, mother of 2)

Translated to English:

"People discriminate and stigmatize people with epilepsy so much that you end up stressing about the future of your child because even in the society that we live, they don't even allow their children to play with mine which is so heart-breaking to add to this I get blamed all the time by my husband for the child's condition" (female caregiver 30 years old, mother of 2)

Another caregiver noted that:

"Kuchengeta mwana ane pfari chinhu chakangooma zvekuti paanoda mishonga nezvese zvinodiwa uku uchikiya kiya zvinhu zinongonetsa, saka pamwe pacho unopedzisira wava nestress nenyaya yekutoomerwa chaiwo, woti pamwe pacho chero ukada kukiya kiya hapana anosara nemwana nekuda kwekuti vanofunga kuti pfari inotapuriranwa".

Translated to English

"*Caring for a child with epilepsy is a very hard and hectic job considering the basic needs of the child which range from medication up to his or her welfare whilst I don't have a job which is very depressing and stressful because of the many hardships that I face, sometimes when you want to work for the child you don't have any person who is willing to care for the child in your absence"*

A key informant highlighted that:

> "Sometimes when we get to talk to the caregivers and in my experience working with them, I have come to notice that most of them are depressed with the burden that they carry of caring for CWE, some say their relatives have a lot of negativity towards their children which at times may end up even affecting their marriages and others end up divorced which leads to a lot of stress on their part". (community health worker)

The above findings highlight that caregivers face a lot of mental health problems due to the complexity of caring for a child with epilepsy hence this entails for the need for the social support network which can be used by caregivers in attaining services such as counselling, emotional support and also financial support as most of the challenges of caregivers include those of finances to be able to purchase medication and hospital scans. One can note that there is the need for the development of policies and enforcement of the existing laws which assist caregivers of children with epilepsy in reducing the burden of care that they face. The findings of this research goes in line with a study conducted by Yu et al (2022) in China which highlighted that caregivers of CWE have a lot of mental burden in caring for children with epilepsy. this study further goes on to cite that depression and anxiety were rampant in China among caregivers of CWE with a percentage of 23.5% in Southern China (Yang *et al* 2020) and 25% in Western China (Yang *et al* 2020)

4.2. 3Reduced value of life expectancy and lack of knowledge pertaining epilepsy

The study result was able to highlight that caregivers of children with epilepsy have reduced quality of life in that due to the various concerns of caregivers caring for a child with epilepsy caregivers end up negating their own health thus reducing the quality of their lives. Lack of knowledge was also noted within the study, many caregivers highlighted to have to rely to the indigenous knowledge they have when it comes to epilepsy. A caregiver noted that

“ hupenyu hwemwana anepfari ndewekungogara wakatarisa vochireva izvo kuti pamwe acho unotozosiyaa zvaunoda iwe samai vemunhu nekuda kwekuti unenge uchiitira hutano hwemwana zvinova zvkuti chero ukarwara unongoti ndinopora hauzotsvake zvakawanda”

Another one noted that

“ kurwara kwangu kazhinji ndotsvaga mushonga wechibhoyi nekuda kwekuti unenge uchiitira mwana sakaa zvizhinji hauzozvitarise”

A key participant noted that

“caregivers usually ignore their own well-being being worried for the health of their child which thereby leads to the reduced life, they also lack information thus burdening them”

Reduced quality of life expectancy is another challenge that was highlighted by the results of the research. Most carers to CWE tend to invest all that they have in maintaining the lives of their children and by so doing they end up exhausting all the things they have including their valuables and money in trying to promote the well-being of their child which leads to an increased level of stress leading to poor quality of life. This shows the need for the social support for people with epilepsy as they lack the support they need hence leading to their problems emanating.This goes in line with the study conducted by Duggan (2010) in Uganda and also Kwalevag (2015) which also cited that parents who lack education and are not well established in terms of finances spent all they have in trying to improve the quality of life of their children which thereby results in a lot of depletion of the available resources thereby negatively impacting their lives. In India a study was conducted by Akanksha & Piya (2019) which also highlight that parents report more mental health problems when their children are failing to respond to the medication and have more seizures.

4.2.4Burden brought by care and financial constraints

The research was able to find out that caregivers of children with epilepsy are often burdened by caring for a child with epilepsy considering the financial constraints they face, the stigma within the societies that they leave in and also the amount of care they give which gives them limited time for themselves, for their families of with other children. Financial constraints also exacerbate the burden of care that is faced by caregivers leading to the development of a number of ailments thus reducing their quality of live. Burden of care often leaves the caregivers with no social lives, with them investing most of their lives to the wellbeing of their child which may lead to strained family bonds and relationships with other children.

" chinotinetsa kazhinji mari dzemishonga nemascans zvekuti kana mwana asinawo kukwanisa kubatsirwa nezvaanoda dzimwe nguva mishona yake chaiyo inogona kungoramba achidonha, saka zvingu zvekuti unogara uchinetseka nazvo uye zvinoita kuti uve nekufungsisa kuti mwana achovei".

"nekuda kwekuti mwana ane dambudiko repfari uye nezvaanenge achida kazhinji kacho haumbowane nguva yekuonana neshamwari kana hama nekuda kwekuti unenge wakugadzirira kuti uve unowana zvinhu zvinodiwa nemwana".

Another key informant stated that:

"interpersonally, care giver of children living with epilepsy tend to develop coping strategies to help them overcome the vast number of challenges posed by looking after individuals with epilepsy socially, the care giver tends to be excluded from social participation egg., family, religious gathering economically. Time spend looking after children with epilepsy disadvantages caregivers as they fail to participate fully in economic activities, eg farming, small scale mining vending, professional employment."

The study found out that caregivers of children with epilepsy are constantly tired due to the burden caring for CWE, that is some children they are not able to leave them with anyone due to the stigma and the isolation that they are given due to their kids with epilepsy which goes in line with the findings of the research by Linda et al 2022 in Uganda. Related study done in the United Kingdom by Hussain et al 2020 who highlighted that caregiving is associated with a lot of physical burden. Children with more seizures are likely to display more burden to their caregivers and this is because they need to be carried be it from places where they have their seizures to places of safety or because the caregivers do not have any helper to assist them in caring for their child with epilepsy which goes in line with the study done by Hussein et al 2020. A study conducted in Uganda by Linda et al 2022, highlighted that caregivers faced a lot of challenges in managing CWE, and caregivers perceived epilepsy as a condition associated with huge financial constraints due to the uniqueness of the seizures that a child is likely to face hence they end up being with them to ensure that they are safe which I also in line with a study conducted in 2013 by Mahrer on the Quality of life in adult patients with epilepsy and their family members. A study by Karakis et al 2011 further goes on to point out that income is a difficult thing to find as most of the caregivers had to be at home caring for children with epilepsy which is also in line with the study conducted by Linda et al in 2022 in Uganda.

4.3 Copying mechanisms adopted by caregivers in managing children with epilepsy in Ward 8, Chitungwiza.

The research conducted was able to note that in order to overcome the problems that they are facing caregivers adopt various methods to deal with their struggles, among the various ways, caregivers get support from local non-governmental organisations, support groups and also counselling services. To add to this, the researcher was able to note that caregivers do not only rely on support from organisations but also from spirituality which is mostly highlighted from in the religion that they go to.

4.3.1 Support from the local non-governmental organisations.

Support from local organisations was highlighted by the majority of the caregivers who cited that they mostly get their support from organisations such as Mufudzi Wakanaka which is located at Chitungwiza Central hospital where they find information related to conditions such as epilepsy and cerebral palsy, the organisation also provide clothes for both the caregivers and the children when they have them. Caregivers also get support from organisation such as Epilepsy Resource Centre Zimbabwe where they get medication if available and counselling services and also Epilepsy Support Foundation which also give the same services. Caregivers also get assisted by the general hospital Chitungwiza Central Hospital where they don't pay to get their children to get treated and also get medication for epilepsy free of charge.

One caregiver cited that:

"Mufudzi Wakanaka ndiyo inotibatsira mukuchngeta vana vedu uye vanotibatsira zvekare nenhumbi kana mapamper kana ariko. Mishonga tinopihwa pahospital kana iripo pasina kutengaa uye vana vanokwanisa kurapwa pasina kubhadhara ndozvimwe zvatikubatsirikana nazvo" (25-year-old caregiver)

Translated to English:

"The General hospital together with Mufudzi Wakanaka have been working tirelessly to assist us in our attempts to care for our children with epilepsy. the hospital provides medication if it available free of charge and also consultation for the child to see a physician is free of charge so these are some of the copying mechanism that we have been using" (25-year-old caregiver)

Another caregiver also cited that:

"ERCZ ndoinotibatsira kuburikidza nemazano uye neruzivo maringe nezvepfari. Patakaziva nezve pfari pamwana ndiiko kwatakatanga kuenda vaazotipa tsamba kuti tiende kuhospital uko takazonobatsirwa pachena pasina muripo nekupihwahwo mishonga asi pamwe pacho vanenge vasina yatoda as tinombowana imwe ikoko" (27-year-old caregiver)

Translated to English:

"We get support from organisations such as ERCZ, that's where we first went when we knew about the condition of the child, from there they wrote a referral letter to Chitungwiza hospital where we go for the child's check-ups and we get medication free of charge which has been helpful a lot although at times we don't find the drugs because of their unavailability" (27-year-old caregiver)

A key participant also highlighted:

> "I think to engage whenever they have issues with organisations that deal with children with epilepsy for possible suggestions or support and creating peer support groups in communities of parents or caregivers of children with epilepsy, through this they can share their challenges, we talk of these are all copying mechanism they have taken aboard, we talk of physio therapy as some may just be given medicine and fail to care for such issues. In terms of the support we are limited as we provide more of the adult than children but in terms demographics 0-18 years, we provide counselling but in terms of favour and need there is the |CRU, Children Rehabilitation Unit, where they undertake or deliberately support parents of children with various impairment including caregivers with children with epilepsy."(Director ERCZ)

The findings by the research noted that caregivers are able to deal with the challenges that thy are facing because of the assistance of the local Organisations that exist within their communities which have been aiding them to a greater extent. This also highlight that the support systems for caregivers of children with epilepsy in Ward 8, Chitungwiza is very low hence there is the need for the increased support networks for caregivers. Caregivers have been able to administer medication to their children as a result of the availability of free drugs. This copying mechanism goes in line with the Integrated Ubuntu philosophy by Mugumbate and Chreni (2017) which advocates for the interconnectedness of the social system in the protection of the child. In this case the environmental level has been highlighted to have been acknowledging the safety and well-being of the child in that the hospitals are offering, thy have been able to access the major services that thy need hence the copying mechanisms that the caregivers are using go in line with the theory which advocates for the provision of the basic care for a child ensuring that they are protected. The research findings also go in line with the findings of a research conducted by Samia (2019) who stated that caregivers of CWE are able to cope with the challenges they face of dealing with children with epilepsy because of the of the emotional support that they get and also through the awareness by education of the condition epilepsy

4.3.2 Religious support

The research was able to highlight that caregivers of children with epilepsy rely on religious support as they get prayers and counselling services also from their religions. This highlighted that caregivers get supported through the religions that they are affiliated to.

A caregiver highlighted :

“ Rumwe rutsigiro tinowana kuchurch seni pandoenda kuchurch kwedu ndoenda kuMasowe saka paanonamatirwawo pamwe chete nemiteuro zvinototibatsirawo mumatambudziko atosangana nawo ekudonha kunoita mwana uye paatinodzidziswa zvinotibatsira zvekare”

Another caregiver highlighted that

“church inobatsira zvekare pamatambudziko seni ndinoenda Pentecostal ndinowanawo maannointing oil uye nemawrist bands zvinova zvinotibatsira zvekare pakumuzora paanenge achidonha kana kugwinha”

A key informant also highlighted:

“spirituality is a huge copying mechanism that is mostly used by caregivers of children with epilepsy, they tend to belief that prayers also assist in dealing with epilepsy thus they are able to cope with the condition”

These responses confirmed that religion is used as a copying mechanism by caregivers in dealing with the children with family thus highlighting that belief is a strong hold that caregivers use thus clearly highlighting the role of spirituality in an African society. This goes in line with the Ubuntu Integrated framework (Mugumbate and Chereni 2019) which stipulates the main role of spirituality in dealing with caregivers of children with epilepsy. this goes in line with the study that was conducted in Zimbabwe by Chimedza (2001) which highlight that religion is used as a copying mechanism used by caregivers of children with epilepsy in devicing strategies.

4.4 Chapter summary

This chapter has presented the findings on the caregivers’ experiences in managing children with epilepsy in Ward 8, Chitungwiza. The exposition of the results was grounded in the data collected in Ward 8, Chitungwiza, with the analysis being interconnected with the research aim and objectives via thematic content analysis. The following section delves into the overview of the findings, conclusions, and recommendations.

CHAPTER 5

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.0 Introduction

This chapter presents the summary of the research and the findings of the previous chapters of the research. The chapter also highlights the analysed and obtained data from all the previous chapters and it also gives sound conclusion of the research and the recommendations on the presented data on the caregiver's experiences in managing children with epilepsy in Ward 8, Chitungwiza. Recommendations highlighted in this chapter intend to address the major concerns that were brought by this research in chapter 4 in order to ensure that the welfare of the caregivers are also taken into consideration in Ward 8, Chitungwiza.

5.1 Summary

The research adopted the Ubuntu framework by Mugumbate and Chereni (2017) which highlighted the importance of the values embedded in our African culture of hunhu and Ubuntu. The framework advocated for the protection of the child within the cultural set up of the society with each and every one playing a particular role to the welfare of the child. Through the use of the use of theory, the study was able to bring out the major concerns of the caregivers and how some of them are even caused with the system that is supposed to offer protection to children.

5.1.1 To analyse the nature of care given to children with epilepsy in Ward 8, Chitungwiza.

The study was able to observe that in caring for children with epilepsy caregivers do so through the administering of medication, monitoring of seizures through avoiding triggers and monitoring of seizure chats, ensuring children eat nutritious food and also provide basic car such as bathing the child, performing first aid procedure if the child was to get into a seizure and to ensure they are protected from things that causes harm when in seizures (overprotectiveness) in Ward 8, Chitungwiza. Most of the caregivers including key participants were able to note this as the key aspects of the nature of care given to children with epilepsy. The study was able to highlight that there little to no involvement of men in the caring of a child with epilepsy, it is mostly done by women and the blame is mostly theirs as to why the child has epilepsy including stigma within their families and also stigmatized within the families that thy live. More so, the study also highlighted that in the nature of care given to children with epilepsy, caregivers only possess the meaning of what is epilepsy and how to care for their children but they do not possess the medical knowledge of epilepsy and this may also lead to them conducting harmful practices in trying to care for their children.

5.1.2 To explore challenges faced by caregivers in caring for children with epilepsy in Ward 8, Chitungwiza

The study was able to explore the challenges that are faced by caregivers of children with epilepsy in Ward 8, Chitungwiza. From the objective, the research was able to highlight the major challenges of caregivers as to financial constraints and burden of care where the caregivers are facing high cost of scans and reviews in EEG which they end up not being able to access to due their expensive nature. Another challenge highlighted by the study is the burden of care that is the financial constraints faced by caregivers include high cost of scans, cost of medication and sand appointments, this increase the burden of care in that caregivers struggle with feelings of despair, guilt and fear of the unknown which exacerbate mental health problems of depression, grief and high levels of stress due to the complexity of their child's condition. To add to this due to the burden of care, caregivers end up without a social life, that is they isolate themselves from friends and families in an attempt to ensure that the child is well taken care of. Other challenges highlighted by the research include social isolation and stigma, and in this case this is as a result of myths and misconceptions surrounding epilepsy which leads to the unacceptance of those who involve with the persons with epilepsy hence the caregivers are denied a chance to effectively participate within the community thus making it more difficult for them.

5.1.3 To examine the copying mechanisms adopted by the caregivers in managing children with epilepsy in Ward 8, Chitungwiza

The study was able to examine the copying mechanisms used by caregivers of children with epilepsy in Ward 8, Chitungwiza. Caregivers of children with epilepsy cope through the assistance they get in support groups which are conducted by organisations that aim to assist with disability for instance it was noted in the research that Mufudzi Wakanaka in Zengeza 4 assist caregivers of children with epilepsy through cooperatives (mukando) where they seek to empower women so that they can be able to sustain themselves and their children and this has been quite effective in assisting caregivers of children with epilepsy. To add on, caregivers of children with epilepsy are assisted through Epilepsy Resource Centre Zimbabwe which offer psychosocial support to caregivers of children with epilepsy and counselling services thereby uplifting the challenges faced by caregivers of children with epilepsy. Lastly caregivers of children with epilepsy get assisted through free medical assistance which is done by the Chitungwiza General Hospital in Zengeza 4, where they get medical checks up frequently free of charge and readily available medication free of charge at the hospital.

5.1.1 Bringing care issues together using Ubuntu Framework

The Ubuntu framework foretells the use of the AFroccentric approachs in caring for children and protecting them, hence the framework explains the role that is played by people around the community in bringing care to children, one can note that the Ubuntu framework stipulates the embracing of the African ways in the protection of a child, thus as a social worker there is the need for competence, in Afrocentric literature and approaches since they work within our own community.

5.2 Conclusions

5.2.1 Nature of care given to children with epilepsy in Ward 8, Chitungwiza

To conclude given the summary of the research objective one can note that caregivers presented possessing little knowledge of what is epilepsy when it comes to epilepsy thus there is the need for the awareness on issues to do with epilepsy and epilepsy management so that caregivers are equipped with the right and medical knowledge which can help them in caring for the children with epilepsy in Ward 8, Chitungwiza.one can also note that there is the need for the emancipation or access to education of caregivers to basic health ways for assisting a child with epilepsy and the research also concluded the lack of education by the caregivers as shown by the use of mugoti in trying to help the child in a seizure thus minimizing harm to their children. Social workers can also advocate for caregivers for children with epilepsy to be included or have access to funding which can help them with providing healthier food for their children thereby; reducing malnutrition as a result of a non-nutritious diet which is needed by children with epilepsy (ketogenic diet). Another conclusion that can be drawn from the research is, caregivers of children with epilepsy lack access to social incentives or assistance that can help them in caring for their children these include access to stakeholders such as the Department of Social Development thus there is the need for the inclusion of persons with epilepsy as the study has already highlighted the lack of knowledge of the assistance which can be given to caregivers of children with epilepsy through the government.

5.2.2 Challenges faced by caregivers of children with epilepsy in Ward8, Chitungwiza

Caregivers of children with epilepsy face a lot of challenges in caring for a child with epilepsy to a greater extent which end up affecting their own lives. Caregivers face a number of challenges such as stigma and isolation which limits their social functioning of caregivers due to the judgemental attitudes which exist within the society thus they lack the social interactions which also increases their reduced quality of life through feeling of fear of what people say and fear of judgement from others, to add own challenges have huge impact on the lives of caregivers of children with epilepsy as presented by the research like dysfunction of family relationship through the realization of myths and misconceptions of the condition epilepsy leading to increased mental health problems such burnouts, high levels of depression and stresses.

5.2.3 Copying mechanisms adopted by caregivers of children with epilepsy in Ward 8, Chitungwiza

Copying mechanisms for caregivers are still low, they mainly rely on organisations for the support they get hence they are still limited. The available organisations although still low, have been able to help caregivers cope with the challenges they face positively. This leads to the conclusion that caregiver’s challenges are high because they lack the social support and the networks that can effectively assist them in overcoming the challenges they face while dealing with children with epilepsy. One can conclude that for the social functioning of caregivers there is the need for the development of strategies that can help them mitigate their problems for instance social workers can advocate for the social inclusion of caregivers of children with epilepsy in existing incentives which seeks to help people with challenges to enhance their well-being. They can also advocate for the policies which include caregivers and also lobby for the effectiveness of existing policies.

5.3 Implication to social work

The study caregivers’ experiences in managing children with epilepsy has a number of implication on social work as a profession and these include:

5.31 The need to understand caregivers of children with epilepsy

There is the need for the social work profession to pay particular attention to caregivers of children with epilepsy through the conducting of researches on carers of children with epilepsy. in doing researches there is the need for the social work profession to take into account the uniqueness of the condition epilepsy and to develop possible solutions for caregivers of children with epilepsy such as the advocating for the inclusion of them in policies which may help them in decreasing the burden of care for example funding for them to be able to assist children with epilepsy as it is also a disability. Social work can also advocate for the enforcement of the existing laws such as well as their access to services such as medical care, physiotherapy of children with epilepsy, thus as a profession it can take into considerations the highlighted lived experiences of children with epilepsy thus advocate for policies and policy change in addressing issues to do with epilepsy. to add to this understanding of caregivers can inform social works into advocating for the intermediations that’s address the challenges of caregivers such as stress managements.

5.3.2 Coordination and enhanced accessibility to basic needs

The research highlighted the major gaps that are faced by caregivers of children with epilepsy and these include the limited access to healthcare services and the expensive medical facilities, in this case there is the need for the social work as a profession to coordinate and increase the accessibility of caregivers to social services that are cheaper and affordable for them or free so that they can enhance their functioning. To add this social worker can collaborate with donor of the government in the increased accessibility of free services such as the ones done at Chitungwiza General Hospital.

5.3.3 Development of community based approaches

Social workers can engage with the local caregivers building on their strength therefore leading to the sustainable development of caregivers. Through the engagement with the caregivers, social workers can assist in the developing of strength based approaches of each caregiver thereby leading to them to be capacitated and skilled through each person’s strength thus leading to sustainability.

5.3.4 Engaging with the families of caregivers

This research highlights the experiences of caregivers in dealing with children with epilepsy, thus through this social worker can conduct family counselling services educating people on what is epilepsy and this can lead to the social integration of the caregiver and the child with epilepsy and their inclusivity within the family and to get supported by the family. Social workers can also make use of the integrated approach in addressing the challenges of the whole family in order to restore social functioning.

5.4 Recommendations

The outcomes of the research outlined in the previous chapter regarding the experiences of caregivers in managing children with epilepsy in Ward 8, Chitungwiza prompted the researcher to develop the subsequent suggestions:

5.4.1 To the government

- There is the need to offer incentives and financial assistance per month to caregivers of children with epilepsy so that they can be able to buy the essential things they need for caring for their children considering the fact that these people cannot go to work or get employed because of the burden of care that they face hence there is the need for incentives this way they can also afford medication for example.

- Formulation and implementation of policies which advocate for caregivers of children with epilepsy, taking into consideration the major challenges they face so that they can also be able to get assistance from department of social welfare like any other disability. Policies should also be implemented which advocate for the inclusion of children with epilepsy in social system as well as the enforcement of policies which already exist ensuring they are being uphold in the best interest of children with epilepsy like other disabilities (for example Education Act, Childrens Act) ensuring equal opportunities so there is the need for social workers to advocate for children with epilepsy.

- The need to build healthcare centres which offer affordable scans like CT scans and EEG to ensure inclusive care for children with epilepsy, essential services such as scans also need to be free of charge so that people can easily access them this way it can reduce the impacts of the seizures in children.

5.4.2To the community

- Awareness on epilepsy and epilepsy management not only in urban areas but also in remote areas to increase the knowledge base of what is epilepsy within the communities, this way it leads to the social inclusion of caregivers and children with epilepsy and also reduce the stigma that they feel so there is the need for social workers to educate the community and disability.

- Communities based support networks for caregiver this way they can also get what they need through the assistance of the people they live with hence there is the need for social workers to research on community based strengths.

- Advocate for the inclusion of caregivers and the community to offer support to caregivers of children with epilepsy so that they can be able to prioritize themselves hence there is need for social work counselling services and advocating for caregivers of children with epilepsy so that they feel safe within their communities.

5.4.4 To caregivers

- There is the need for the education of caregivers so that they prioritize their well-being and health as well while caring for children with epilepsy, this can be done through the advocating of the shared roles of caring for a child with epilepsy within family that way caregivers can be able to take time to themselves and also care for their health knowing that they are being assisted as well. There is need for social workers to advocate for the development of programs that give relief to caregivers in caring for children with epilepsy or government based interventions.

- There is the need for the education of caregivers on the awareness and the education for them to properly provide care for children with epilepsy. Conducting of awareness by social workers can bring overall awareness which reduces the stigma and they can be able to participate within the community. Awareness leads to reduction of myths and misconceptions about epilepsy.

- Caregivers should not solely rely on what they know when it comes to caring for a child with epilepsy rather there is the need for them to work hand in hand with different sectors which offer medical team and the physiotherapy teams, social support to the wellbeing of their child.

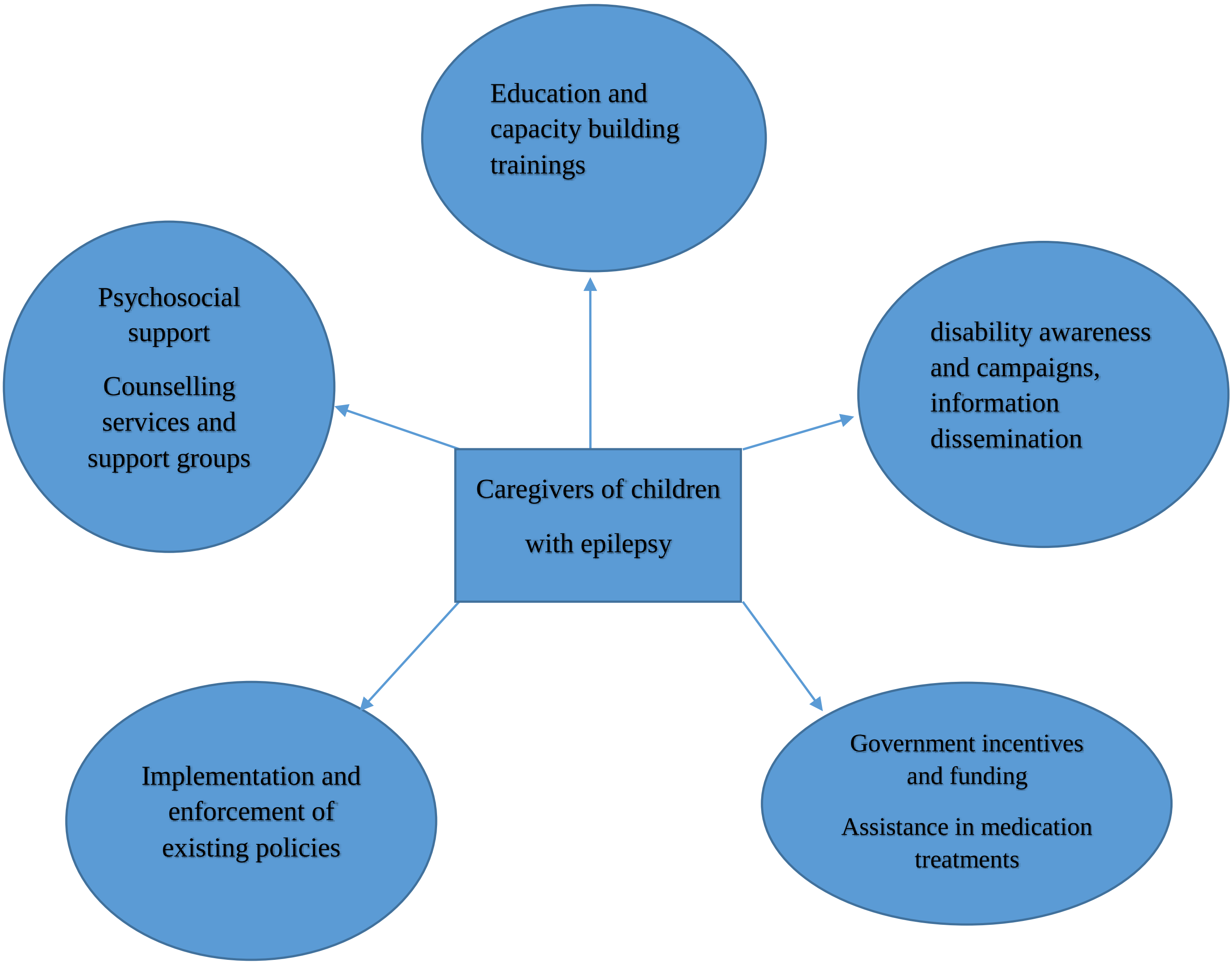
- Caregivers should also make use of support groups where they help each other overcome the challenges of caring for a child with epilepsy, that way they can have shared experiences thereby building on their resilience and strengths in dealing with the challenges of caregiving.

5.4.5 For further research

- There is the need for further research on the effectiveness of existing policies and frameworks on epilepsy and how effective there have been in addressing the challenges of persons with epilepsy and the ways in which they can be integrated for increased effectiveness.

- There is also need for the examination of the support systems that help people with epilepsy and how to mitigate further challenges that are faced with persons with epilepsy and children with epilepsy.

5.5 Holistic support system for caregivers of children with epilepsy



5.6Chapter summary

This chapter presented a summary of the results, included a segment on conclusions, and a segment on the suggestions for addressing the gaps found in the study. The suggestions focused on strategies that could be utilised in order to assist caregivers in the various experiences they get in Ward 8, Chitungwiza.

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Appendix 1 :In depth interview guide for key informants

INTRODUCTION

My name is Naomi Zadzisai Chimedza, I am a fourth-year student at Bindura University of Science Education, pursuing a Bachelor's degree in Social Work. As part of completing the degree programme, students are required to conduct individual research. Therefore, I am conducting a research study on the topic 'Caregivers experiences in managing children with epilepsy in ward 8, Chitungwiza'. The research focuses on exploring the lived experiences of caregivers of children with epilepsy. You are kindly requested to participate in this study. Be reminded that your responses will be kept confidential and anonymous and will be used strictly for academic purposes. Also, your participation in this study is voluntary. I am going to engage you in an interview that will not last for more than 30 minutes as part of data collection. You may choose to excuse yourself at any part during the interview.

Start Time: ………………………………….

Date: ………………………………………

Section A: Biographic Information

Respondent…………………………………………………………………………

Age 20-25 [ ] 25-30 [ ] 30-35 [ ] 35-340 [ ] 40-45 [ ]

Marital status Married [ ] Single [ ] Divorced [ ] Widowed [ ]

Religious affiliation…………………………………………………………………

Economic activity……………………………………………………………….

Level of education reached………………………………………………………..

Research question 1: What is the nature of care given to children with epilepsy in Ward 8, Chitungwiza?

1.What is caregiving in respect to children with epilepsy?

2. What kind of care do you teach caregivers of children with epilepsy?

3. What do you teach them as part of caregiving?

4.What kind of methods do caregivers say they use for children with epilepsy, that is their own methods

Research question 2: What challenges are experienced by caregivers in providing care for children with epilepsy in Ward 8, Chitungwiza?

1. In your own experience in working with caregivers of children with epilepsy what are the challenges that they are experiencing?

2.. From your own experiences with caregivers, how does caregiving affect the lives of caregivers of children with epilepsy, be it interpersonally, socially, economically and within the community?

3. from your own experience working with caregivers, do challenges also involve drug defaulting and do they perhaps fail to buy drugs?

Research question 3: What copying mechanism can be adopted in caring for children with epilepsy in Ward 8, Chitungwiza?

1. *What copying mechanisms do you think caregivers can adopt in caring for children with epilepsy?*
2. *In your own experience whilst working with caregivers of children with epilepsy, what are caregivers doing in copying with the condition?*
3. *What copying mechanism do you think caregivers should also adopt in order to reduce the impacts of the condition or to improve how they care for children with epilepsy?*
4. *Which support system are available for caregivers of children with epilepsy?*

Appendix 2: In depth interview guide for key participants / caregivers

BINDURA UNIVERSITY OF SCIENCE EDUCATION

FACULTY OF SOCIAL SCIENCES AND HUMANITIES

DEPARTMENT OF SOCIAL WORK.

INTERVIEW CONSENT FORM

Dear Participant

My name is Naomi Zadzisai Chimedza. I am fourth-year student at Bindura University of Science Education pursuing a Bachelor of Science Degree in Social Work. As part of the degree requirements, the student is expected to conduct a research project, which I cordially welcome you to engage in. Before deciding to engage in the research, you are welcome to engage with anyone that you feel comfortable with. If there is anything that you don't understand you are free to ask and I will explain it to you. I am thus humbly asking you to assist me in carrying out my research by sparing a few minutes of your time to respond to the following questions openly as possible. I am undertaking a research on the topic: Caregivers experiences in managing children with epilepsy in Ward 8, Chitungwiza

Date …………………….

Start time ………………….

Section A understanding the nature of care

1. What do you understand when it comes to epilepsy?
2. How do you conduct your day to day routine care for your child with epilepsy?
3. What do you do as part of caring for your child during the day and night?
4. How do you bath your child with epilepsy?

.

Section B Challenges experienced by caregivers

1. What challenges are you facing in caring for a child with epilepsy?
2. How does caregiving affect your personal life in general and your participation within the community that you live I n?

3. How does caregiving affect your marriage or your interactions with others?

4. How does caregiving affect you economically?

Section C Copying mechanisms

1. What strategies do you employ 2 manage the emotional and psychological stresses associated with caring for a child with epilepsy?

2. In caring for a child with epilepsy how do you manage to take care of your own well-being?

3. Which organizations or well-wishers assist in caring for your child with epilepsy?

Appendix 3: Key informants guide in Shona

BINDURA UNIVERSITY OF SCIENCE EDUCATION

FACULTY OF SOCIAL SCIENCES AND HUMANITIES

DEPARTMENT OF SOCIAL WORK.

INTERVIEW CONSENT FORM

Dear Participant

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Date

Time

MIBVUNZO

1. **Chii chamunonzwisisisa maererano nezvepfari?**

2. **Mungatitsananguririrawo here kuti munochengeta sei mwana ane pfari mumararamiro enyu epazuva nepazuva?**
3. **Chii chamunoita kuti mubatsire mwana ane pfari husiku kana masikati?**
4. **Munomugeza sei?**

5. **Ndeapi matambudziko amuri kusangana nawo mukuchengeta mwana ane pfari?**
6. **Mukuchengeta mwana anodonha/pfari, munosangana nematambudziko api muhupenyu hwenyu pamwe nemunharaunda yamunogara ?**
7. **Mukuchengeta mwana anodonha/ ane pfari zvine here zvazvinokanganisa mumhuri yenyu, nevana vamwe pamwe nehama neshamwari kana vavakidzani?**
8. **Mumararamiro enyu anhasi, nekuchengeta mwana , pane zvirikurema here kana kuti murikukunda sei?**
9. **Inzira dzipi dzamungashandisa mukurwisana nematambudziko amunosangana nawo pakuchengeta mwana anodonha?**
10. **Pakuchengeta mwana anodonha , munozvigona sei zvekuzochengeta vamwe vana kana varipo pamwe chete nekuzvichengetawo?**
11. **Ndeapi masangano or vane chekuita nezvekubatsira vana vanodonha arikukubatsirai kuchengeta vana vanodonha uye nei?**
12. **Zvii zvamunofunga kuti zvinofanira kuitwa kuti mubatsirikane mukuchengeta mwana anodonha?**
13. **Pangava nezvimwe zvamunoda kuwedzera?**

Appendix 4 Focus group discussion for key participants guide.

Research question 1: What is the nature of care given to children with epilepsy in Ward 8, Chitungwiza?

1. *Can you explain what you understand when it comes to epilepsy and how you provide care to a child with epilepsy?*
2. *Can you explain to me how you conduct your day to day routine care for your child with epilepsy?*
3. *Can you share what you do as part of caring for your child during the day and night?*
4. *How do you bath your child with epilepsy?*

Research question 2: What challenges are the challenges experienced by caregivers in providing care for children with epilepsy in Ward 8, Chitungwiza

1. *Can you tell me what challenges are you facing in caring for a child with epilepsy?*
2. *Can you share a bit on how does society view you and your child with epilepsy? Are there challenges you face that comes from the community?*
3. *How does caregiving affect your personal life in general and your participation within the community that you live I n?*
4. *How does caregiving affect your marriage or your interactions with others?*
5. *How does caregiving affect you economically?*

Research question 3: What copying mechanisms are adopted by caregivers of children with epilepsy in ward 8, Chitungwiza?

Probing questions

1. *What have been helping you cope in managing your child with epilepsy.*
2. *What strengthens you in providing care to your child with epilepsy*
3. *Do you receive any kind of support from well-wishers or organizations, and if so how has been the assistance so fa?*

Appendix 5: Consent Form

BINDURA UNIVERSITY OF SCIENCE EDUCATION

FACULTY OF SOCIAL SCIENCES AND HUMANITIES

DEPARTMENT OF SOCIAL WORK.

INTERVIEW CONSENT FORM

Dear Participant

My name is Naomi Zadzisai Chimedza. I am fourth-year student at Bindura University of Science Education pursuing a Bachelor of Science Degree in Social Work. As part of the degree requirements, the student is expected to conduct a research project, which I cordially welcome you to engage in. Before deciding to engage in the research, you are welcome to engage with anyone that you feel comfortable with. If there is anything that you don't understand you are free to ask and I will explain it to you. I am thus humbly asking you to assist me in carrying out my research by sparing a few minutes of your time to respond to the following questions openly as possible. I am undertaking a research on the topic: **Caregivers experiences in managing children with epilepsy in Ward 8, Chitungwiza**

The study is going to be confidential and any responses given will be solely used for the research study. Any person that is going to be participating is going to do it on the voluntary basis that is at any point the person feels like he or she is uncomfortable, the person has the power to withdraw at any time and the discussion will not take more than 30 minutes.

Contact details

If there is anything more that you feel like adding or asking you can contact me on

Email; naomizadzisaichimedza@gmail.com, Phone number; 0771530381

If you are willing to contribute and participate in the study, please enter your information in the sections provided below.

Participant Signature……………………………………….... Date………………………

Signature of researcher ……………………………………
Date………………………... Thank you

Appendix 6 REARCH APPROVAL FORM

FACULTY OF SOCIAL SCIENCES & HUMANITIES
DEPARTMENT OF SOCIAL WORK

P. Bag 1020
BINDURA, Zimbabwe

Tel: 263 - 71 - 7531-6, 7621-4

Fax: 263 - 71 - 7534

BINDURA UNIVERSITY OF SCIENCE EDUCATION

Date: 05 April 2024

TO WHOM IT MAY CONCERN

RE: REQUEST TO UNDERTAKE RESEARCH PROJECT IN YOUR ORGANISATION

This serves to introduce the bearer, Naomi Z Chimedza, Student Registration Number B200955R, who is a **BSc SOCIAL WORK** student at Bindura University of Science Education and is carrying out a research project in your area/institution.

May you please assist the student to access data relevant to the study, and where possible, conduct interviews as part of a data collection process.

Yours faithfully

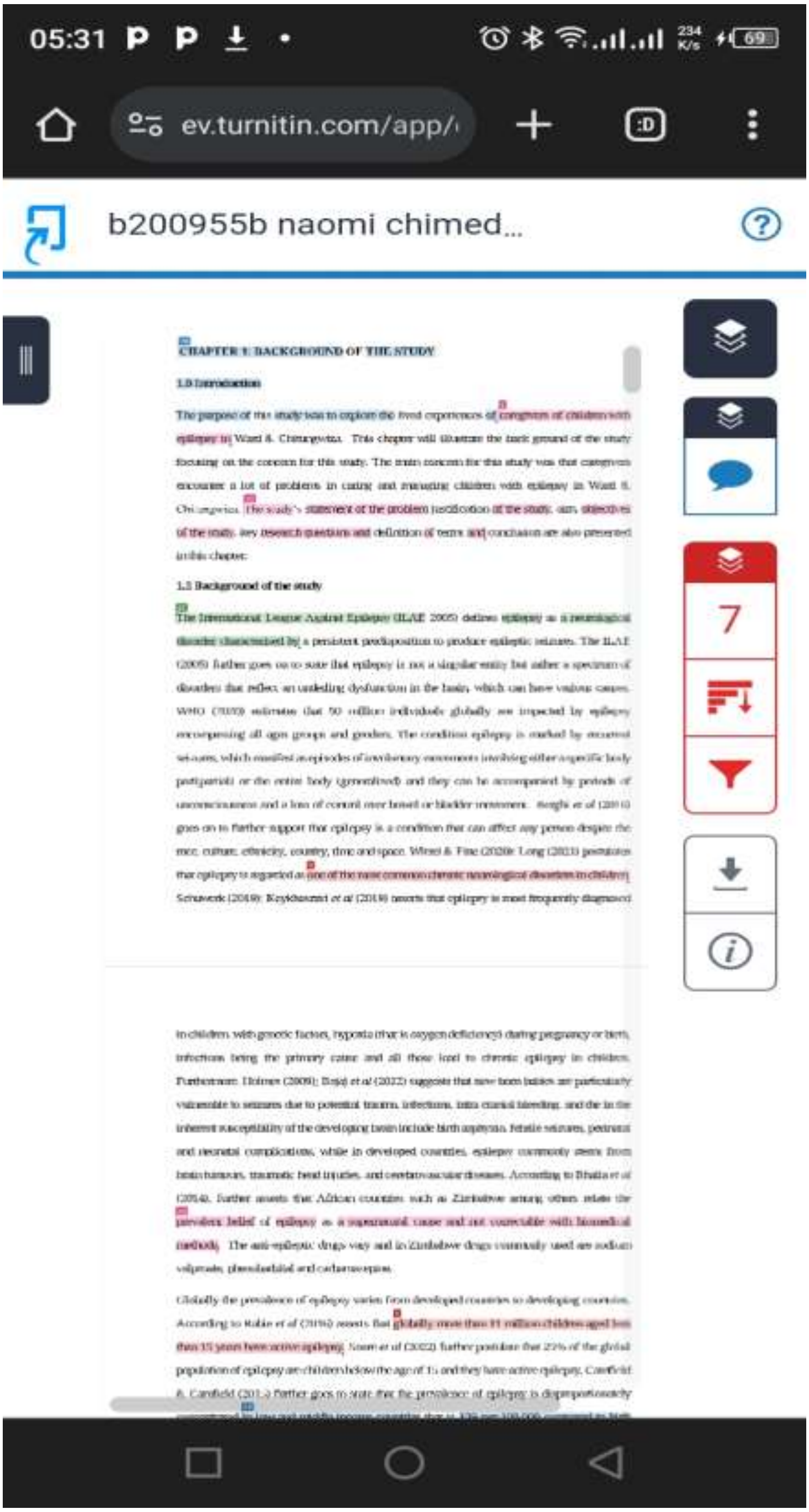
MR L.C Nyamaka
Acting Chairperson - Social Work

BINDURA UNIVERSITY OF SCIENCE EDUCATION
SOCIAL WORK CHAIRPERSON
22 NOV 2023
FACULTY OF [illegible] EDUCATION
PRIVATE BAG [illegible] BINDURA, ZIMBABWE

MUFUDZIWAKANAKA PARENT[illegible]
CARE FOR CHILDREN WITH DISABILITIES
AT PAEDS UNIT
CHITUNGWIZA CENTRAL HOSPITAL
0772 700 973 / 0773 633 224

EPILEPSY RESOURCE
CENTRE ZIMBABWE
(ERCZ)
05 APR 2024
12899 [illegible] Chitungwiza
0781 [illegible] / 0713 079 544
Signed

Appendix 6: Plagiarism report



Appendix 7: focus group discussion in picture