

**THE SOCIO-ECONOMIC EXPERIENCES OF PEOPLE WITH
EPILEPSY EMPLOYED IN THE OPEN LABOUR MARKET IN
THE EKURHULENI REGION**

BY

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DECLARATION

I, Dominic Alpheus Kandawire (Kandas), hereby declare that this research report is my own original work. Where secondary material is used, this has been carefully acknowledged and referenced in accordance with university requirements.



Signature

11 February 2016

Date

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ABSTRACT

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People with epilepsy (PWE) remain the most marginalised sector of the community. The rationale is that epilepsy is an invisible psychosocial disability. The stigma attached to epilepsy and PWE has a negative impact on their socioeconomic status, psychosocial functioning and well-being. PWE are often discriminated against and isolated by the broader community in all spheres of life, for example, in schools, families and in particular, in the employment sector. Further PWE also face attitudinal barriers and limitations towards obtaining socioeconomic justice. PWE have demonstrated that they have the capacity to reach their maximum potential if they are exposed to a barrier free and non-discriminatory environment. The socioeconomic context of South Africa's history of apartheid has effectively excluded PWE from participation actively in socioeconomic activities and, as a result, there is lack of knowledge about epilepsy and other disability related issues. PWE are faced with challenges to manage their condition and to ensure that they have resources to sustain their livelihoods through engaging in economic activities.

PWE struggle to complete their education and this leads to unemployment because of lack of the necessary skills required in the open labour market. In addition, the negative attitude displayed by some employers does not contribute towards creating realistic employment opportunities for PWE to achieve their social developmental goals.

Based on the above-mentioned background, the study sought to explore the socio-economic experiences of PWE employed in the open labour market in the Ekurhuleni region within the legislative framework and different work environments.

The study was conducted from a qualitative research approach. The study was applied and exploratory in nature. The phenomenological design was used for the study.

The researcher used the purposive sampling method to select the participants for the study. Ten participants participated in the study. A pilot study was conducted with two participants who were not included in the main investigation study. Data collection was done by using a semi-structured interview schedule. The researcher utilised the Creswell's spiral method of data analysis.

The findings indicated that PWE have the potential to work in the open labour market and that they have insight on their personal ability; PWE are coping, experience no frequent seizures; if they do; the seizures do not compromise their work capabilities and that PWE have the right to work in the open labour market. Most PWE have insight into their strengths and weaknesses, have the ability to deal with seizure occurrence, have knowledge about their rights as workers employed in the open labour market.

Key words:

Epilepsy

Person (s) with epilepsy

Open labour market

Socio-economic development

List of acronyms

DHET	Department of Higher Education and Training
DSD	Department of Social Development
DPLG	Department of Provincial and Local Government
EDD	Economic Development Department
EEA	Employment Equity Act
ESA	Epilepsy South Africa
ESF	European Social Fund
DWCPD	Department of Women, Children and People with Disabilities
ILAE	International League Against Epilepsy
ILO	International Labour Organisation
INDS	Integrated National Disability Strategy
LRA	Labour Relations Act
NDSD	National Department of Social Development
NDP	National Development Plan
NSA	National Skills Accord
NSDS	National Skills Development Strategy
PWE	People with epilepsy
STATSA	Statistics of South Africa
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VR	Vocational Rehabilitation
WHO	World Health Organization

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CHAPTER 1

GENERAL INTRODUCTION AND ORIENTATION OF THE STUDY

1.1. INTRODUCTION

People with disabilities are among the most vulnerable in any society. Epilepsy Ireland (2013) states that this is worse for people with hidden disabilities such as epilepsy. Further, it is argued that this can be attributed two reasons: firstly, epilepsy does not manifest itself continually in the way other physical disabilities do for instance, cerebral palsy and blindness and secondly, many people choose not to inform others about their epilepsy due to the stigma and discrimination attached to the condition (Epilepsy Ireland, 2013). Disability was described as a moderate to severe limitation in a person's ability to function and perform daily activities as a result of physical, sensory, communication, intellectual or mental impairment (Department of Social Development, 2005:4). In support, the Disability Framework for Local Government 2009-2014, (DPLG, 2009:58) explains that the South African Parliament in 2005 adopted the following definition of disability: "Disability is the loss or elimination of opportunities to take part in the life of the community equitably with others that is encountered by a person having physical, sensory, psychological, developmental, learning, neurological or other impairments, which may be permanent, temporary or episodic in nature, thereby causing activity limitations and participation restriction with mainstream society."

The Department of Social Development's *Harmonised Assessment Tool Training Manual* (DSD, 2011:5) describes activity limitation as a participation restriction that is mainly determined by external factors beyond the person's control, and is combined with a health condition that places a severe restraint on activities. These factors and people's perceptions may lead to discrimination and stigmatisation against people with epilepsy (PWE) in the workplace or society. In support, the World Health Organisation (WHO) (2012) states that although the social effects vary from country to country, the discrimination and social stigma that surround epilepsy worldwide are often more difficult to overcome than the seizures themselves. The stigma associated with epilepsy and PWE plays an important role in the social integration of PWE in the society.

The Epilepsy Foundation (n.d.:1) maintains that most PWE have the capabilities to effectively perform their work, just like any other person, and neither the condition nor the treatments for epilepsy will affect their performance. Lee (2005:1) states that the employability of PWE is significantly affected by factors such as the frequency and severity of seizures; the age of onset; inter-seizure psychosocial disabilities including self-esteem; personality and problem-solving style; and social discrimination. Further, Lim, Wo, Wong and Tan (2013:130) contend that seizure frequency and severity, social cultural factors may also impact on the employability of PWE. The Epilepsy Talk (2012) agrees that, based on these factors, employers may discriminate against PWE because of the stigma associated with the condition, misconceptions about its medical and social aspects, unfounded fears of legal and medical liability, and the misconception that PWE are not as productive as others.

Ramnarace (2012) contends that the real facts about the condition that PWE in possession of the necessary qualifications, knowledge and skills were as capable as their non-epileptic counterparts and had a right to access employment opportunities without discrimination if they met the prescribed criteria for the job. Further, the author states that the competence of a person should be a deciding factor rather than the person's epileptic condition. Ramnarace (2012) cited that a person who worked as a lawyer developed epilepsy, progressing from an aura to a shaking grand-mal, loss of consciousness seizure, but the person managed to recover and continued with the job in the legal field. In other employment positions, it was suggested a person with generalised absence seizures might work as a cook or chef, office assistant or welder while another person with the generalised tonic-clonic seizure type might also work as an office assistant (Epilepsy South Africa Employment Manual, n.d.:13). However, this should not be construed to imply that all PWE should be relegated to lower job categories as Swart (2012:33) contends that a number of disabled people are members of the Republic of South Africa's parliament and hold high office, up to minister and deputy minister levels.

Parfene, Stewart and King (2009:465) state that PWE are often stereotyped as being aggressive, anti-social, mentally retarded, unattractive, introverted, overly anxious, and undesirable employees to work with. Such conduct contradicts the United Nations

Convention on the Rights of Persons with Disabilities and Optional Protocol (UNCRPD) (2008), which mandates member states to recognise the right of people with disabilities including PWE to work on an equal basis with able-bodied people. This includes the right to the opportunity to gain a living by work or acceptance in the open labour market where the environment is open, inclusive and accessible to PWE. Ramnarace (2012) highlights that the stigma and misconception surrounding epilepsy might result in inequality and the unfair treatment of PWE in the workplace.

Lai (2007) states that a study conducted in Korea revealed that 25 percent of employed PWE experienced unfair labour practices and the working conditions did not improve, despite an increased access to employment opportunities. Baskind and Birbeck (2005:1) agree that stigma associated with epilepsy has a profound negative impact on the quality of life of PWE in that some lose their jobs and income while others opt to resign due to unfavourable employment conditions. Further, Bautista and Wludyka (2007:89) assert that the consequences of the perceived stigma and fear of discrimination make PWE not to seek employment. As a result, PWE were reduced to surviving through social assistance benefits in the form of Disability Grants, which are far less than their previous income. The transition from employment to unemployment also had an impact on their epilepsy management as they were not able to afford medical aid, but relied on ailing public hospitals (Birkbeck & Rockwell 2007). Lai (2007) states that 31 percent of PWE were unemployed in Korea. This figure was found to be five times higher than the general public.

South Africa is one of the signatories of the United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol (2008). The Convention is a human rights instrument with a developmental dimension that clarifies how all categories of rights apply to people with disabilities including PWE. The Constitution of the Republic of South Africa, 1996 has enshrined a human rights perspective aligned to the UN Convention (2008) that protects people from discrimination and establishes their inalienable right to dignity and participation in society.

Gathiram (2008:258) emphasises the aspects of the Constitution and the UN Convention (2008) supported by the adoption of anti-discriminatory and affirmative

legislation, such as the Labour Relations Act (LRA) (1995) and the Employment Equity Act (EAA) (1998). The position of the Constitution, LRA and EAA is based on the notion that people with disabilities including PWE have an enormous contribution to make in society and their participation in the open labour market is one mechanism to fulfil this realisation (Epilepsy South Africa Employment Manual, n.d.:5). Employed PWE face a significant number of challenges in the workplace, such as limited access to health and life insurances, the opportunity to obtain a driving licence being withheld, as well as other environmental barriers (WHO, 2012). As a result, advocacy efforts were crucial to increase the employment opportunities and pressurise employers to comply with relevant legislation in addressing issues of PWE in the workplace.

It is against this background that PWE can perform and compete with others in the open labour market to better their lives, if necessary legislation and procedures that protect the rights of PWE are implemented and monitored. Where non-compliance is detected, correct measures must be taken against such employers. Patel (2005:103) asserts that the integration of social and economic development needs macro-economic policies to promote employment and attain people-centred economic development outcomes. In support, Baillie (2011) states that the ability to engage in employment allows PWE to lead fulfilled and independent lives, and the outcomes of their participation not only creates financial independence and security, but also promotes social inclusion, self-esteem and individual's productivity. This implied that addressing human needs was a national collective responsibility. However, to achieve such objectives, a collaborative partnership was crucial if PWE are to be integrated into mainstream society.

It was therefore concluded that social inclusion would not benefit all sectors of the population, unless PWE were employed in positions of authority, and with real decision-making powers. The rationale was that the employment of PWE played an important role in improving their quality of life.

The key concepts relevant to the research study were as follows:

- **Epilepsy**

According to Hermann and Jacoby (2009:1) epilepsy is defined by the presence of recurrent seizures, epilepsy can be so much more and can include a very wide range of difficulties in cognition, psychiatric status, and social adaptive functioning. Mehta, Tyagi and Kumar (2014:1) suggest that epilepsy is a chronic neurological disorder that can have profound physical, social and psychological consequences.

Person (s) with epilepsy

WHO Epilepsy Fact Sheet No.999 (2015) indicates that to say a person has epilepsy it effectively means that the person has experienced recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized), and are sometimes accompanied by loss of consciousness and control of bowel or bladder function. Therefore, when a person has a single seizure this does not necessarily mean that he or she has epilepsy. It is also important to note that a person should have repetitive seizures to confirm the epilepsy diagnosis (Hermann & Jacoby 2009:1).

Beletsky and Mirsattari (2012) mention that seizure-like activity, at some intervals experienced by PWE, may not necessarily represent a seizure disorder per se. In the case where the clinical manifestation continues to unfold over time with a repeated pattern of the neurological manifestation of consciousness, unbalanced regulation of an autonomic nervous system, affective, behavioural changes, or a combination of all, this will confirm epileptic seizures (Beletsky & Mirsattari, 2012). The International League Against Epilepsy (ILAE) (2014) states that for a person to be considered to have epilepsy, the person must have at least two unprovoked seizures occurring greater than 24 hours apart. Further, it suggested that a person should at least have one unprovoked seizure with a probability of further seizures similar to the general recurrence risk. In this context, the researcher defines a PWE as a person who has epileptic seizures as a

result of the brief brain dysfunction leading to impaired consciousness. This presentation of events will qualify a person as living with epilepsy.

- **Open labour market**

The *McMillan Dictionary* (2009-2014) defines open labour market as the number of people who are available to work, considered together with available jobs. This refers to the capacity of the labour market to absorb people to work in places where jobs are available. This implies that PWE with the necessary capabilities and skills have the potential to be absorbed in the workplace like any other citizens.

- **Socio-economic development**

According to Martinelli, Moulaert and Novy (2013:3), socio-economic development can be defined as “the process of human emancipation for everybody and involves the mobilisation of human potentials to achieve it. It has to consider economic activities as embedded with the institutional ensemble of the social dynamics of working, housing, living together, caring and learning” (Martinelli et al., 2013:3).

The definition implies that a holistic approach is necessary to achieve optimal social functioning of human beings in a particular social environment. Further, in the context of this study, socio-economic development implies creating an enabling environment for PWE to be recognised as an integral part of the society and afforded equal opportunities to actively participate in social and economic activities.

1.2. THEORETICAL FRAMEWORK

The researcher chose the developmental approach as the theoretical framework of this study. The adoption of a developmental approach to social welfare in South Africa in 1997 earmarked a commitment by the South African government and the welfare sector to transform social welfare within the context of the broader transformation agenda of South African society. The White Paper for Social Welfare (RSA, 1997:7) states that the developmental approach to social welfare evolved from the country’s unique history of inequality and the violation of human rights. Further, it suggested that “the goal of the developmental social welfare approach is to bring about a humane, peaceful, just and caring society which will uphold welfare rights, facilitate the meeting of human basic

needs, release people's creative energies, help them achieve their aspirations, build human capacity and self-reliance, and participate fully in all spheres of social, economic and political life" (RSA, Ministry for Welfare and Population Development, 1997).

Lombard (2008:161) suggests that the developmental approach to social welfare embraces the right to have access to socio-economic opportunities. The rights of PWE in all spheres of life should be upheld. The Department of Social Development (DSD, 2005:13) agrees that the developmental approach puts more emphasis on the empowerment of people in society. Patel (2005:160) states that when people with disabilities including PWE are empowered, they will be able to determine their own development and actively participate in economic activities. Ife (2012:76) highlights that the human rights-based and developmental practice approach has a strong element of empowerment and promotes the idea of enabling people to define their rights and act to have them realised and protected. In this context, empowerment implied a strategy aimed at development and removal of barriers to ensure equal participation of PWE in all activities.

The researcher indicated that the relevance of the developmental approach in this study emanated from the integration of key economic and social policies through the creation of organisational arrangements at national level.

These arrangements entailed that social agencies and economic development work together within a unified framework to fulfil the following objectives:

- The adoption of policies that ensure people's active participation in the economy through job creation and self-employment opportunities for all and the removal of racial and discriminatory barriers;
- The government must mobilise major institutions of society to promote full participation of PWE and equitable distribution of resources; and
- The introduction of social programmes that generate high returns on social expenditures and contribute directly to economic development.

Based on these three highlighted objectives, the researcher asserted that the developmental approach would be meaningless if it was not accompanied by significant improvements to the well-being of PWE employed in the open labour market.

1.3 RATIONALE AND PROBLEM STATEMENT

Birbeck, Chomba, Atadzanov, Mbewe and Haworth (2007:1) state that PWE in Africa are socially and economically disadvantaged due to poor compliance and implementation of legal instruments. In agreement, Graham, Moodley, Ismail, Munsaka, Ross and Schneider (2014:11) that despite the existence of policies in South Africa, people with disabilities including PWE are still disadvantaged far worse their non-disabled counterparts. The Twenty Year Review, South Africa (1994-2014) indicates that the people with disabilities including PWE continue to experience high levels of exclusion and discrimination.

Although Epilepsy South Africa (ESA) had a programme aimed at improving the equalisation of opportunities for people affected by epilepsy, PWE are still victims of discriminatory practices in the workplace. In some instances employers were informed about employment conditions that exacerbated or triggered epileptic seizures. However, employees with epilepsy were assigned jobs that were risky and unsuited to their condition and, thus perpetuated the stereotype that PWE could not be gainfully employed in the open labour market.

ESA had promoted employment of PWE with full benefits, especially in the private sector. However, the organisation had not conducted a study to ascertain the socio-economic experiences of PWE employed in the open labour market.

This study sought to explore the socio-economic experiences by PWE employed in the open labour market in the Ekurhuleni Region. It was envisaged that the study would contribute to the body of knowledge regarding the socio-economic experiences of PWE by providing proposed solutions and practical educational guidelines to both employers and PWE on issues relating to epilepsy.

1.4 GOAL AND OBJECTIVES OF RESEARCH STUDY

The goal and objectives of the study were as follows:

1.4.1 Goal of study

The goal of the study was to explore the socio-economic experiences of people with epilepsy employed in the open labour market in the Ekurhuleni region.

1.4.2 Objectives of the study

To reach the goal, the following objectives were examined:

- To explore and describe various types of epilepsy;
- To explore the influence of epilepsy on PWE's social functioning and well-being;
- To explore and describe the socio-economic benefits enjoyed by PWE employed in the open labour market.
- To explore and describe the challenges PWE experience in the workplace;
- Based on the research findings, the researcher made recommendations for improved employment conditions to the benefit of both the employer and PWE.

1.5 RESEARCH QUESTION

Brink (2010:52) states that the research question serves as a guideline to implement the appropriate research process in relation to the identified problem. Based on the fact that the researcher wanted to explore the socio-economic experiences of PWE employed in the open labour market, the study was guided by the following question:

What are the socio-economic economic experiences of PWE employed in the open labour market in the Ekurhuleni Region?

Lack of research by ESA, poor enforcement of legislation and marginalisation of PWE are indicative of challenges experienced by PWE in the open labour market. This research report will serve as a valuable body of knowledge on epilepsy literature; while findings and recommendations will serve as additional guidelines to employers and organisations on the employability of PWE.

1.6 RESEARCH METHODOLOGY

The qualitative approach was utilised as an appropriate research approach in the context of this study to answer questions of a complex nature related to phenomenon, with the purpose of describing and understanding the phenomenon from the participants' point of view (Leedy & Ormrod, 2005:94). Brink (2010:113) states that the qualitative approach elicits the experiences of participants with regard to the thinking, feelings and behaviour, the importance of the experience, and how it impacts on their lives.

The study was exploratory in nature. Bless, Higson-Smith and Kagee (2006:76) describe exploratory research as the study arising out of a lack of basic information on a new area of interest to the researcher. Terre Blanche, Durrheim and Painter (2006:43) agree that the goal of exploratory research is to make a preliminary investigation into relatively unknown areas of research and attempt to gain new insight into the phenomenon in question.

Little was known about the socio-economic experiences of PWE employed in the open labour market in the Ekurhuleni region. As a result, the researcher was of the view that both descriptive and exploratory research approaches could assist to achieve the goal of the study.

Brink (2010:12) states that applied research focuses on problem-solving and seeking a solution to an immediate, actual problem. The study highlighted the socioeconomic experiences of PWE employed in the open labour market.

The researcher used non-probability sampling, which is the purposive sampling technique. Purposive sampling is a procedure based on the judgment of the researcher regarding the characteristics of a representative sample (Strydom, 2011:232). The researcher selected ten participants for the main investigation by analysing ESA and recruitment agencies' respective databases. The researcher chose this method on the basis that it would allow reasonable access to the participants of the study. Data was gathered through the use of a semi-structured interview schedule.

The pilot study, ethical issues, and trustworthiness and data analysis will be discussed in detail in chapter 3.

1.7 LIMITATION OF THE STUDY

The researcher experienced time delays in accessing selected participants due to strict security checks and protocol measures in some workplaces. The process was time consuming in that the researcher had to sign security registers, sign a declaration form for the personal computer and had to wait for the researcher's vehicle to be searched and cleared by the security. The researcher was then escorted by the security personnel to different participants' work stations.

This rigorous exercise had a negative impact on the time allocated for the interviews by management. Further this situation may have had an influence on the richness of the data obtained during the interviews as some of the participants were anxious to return to their respective work posts.

1.8 CONTENTS OF THE RESEARCH REPORT

Chapter 1 provides an introduction and a broad orientation for the study. It outlines the theoretical framework, rationale and problem statement; indicates the goal and objectives of the study; the research question which guided the study; and briefly highlights the research methodology; indicates the ethical considerations; and the limitations of the study.

Chapter 2 presents definition of concepts, theoretical framework, legislative framework; types of seizures, causes of epilepsy, effects of epilepsy, socio-economic benefits and challenges experienced by people with epilepsy in the open labour market; the challenges; and interventions to promote the rights of people with epilepsy.

Chapter 3 outlines the research approach; type of research; the research design; the population of the study, the data gathering method and analyses; the pilot study; and the ethical aspects that guided the study. Furthermore, it presents and discusses the empirical findings of the study.

Chapter 4 concludes the study by indicating how the goal and objectives of the study were achieved. Conclusions drawn from the research results are discussed and linked to the key findings of the study. Finally, recommendations are made based on the conclusions derived from the study.

CHAPTER 2

THEORETICAL AND LEGISLATIVE FRAMEWORKS, TYPES OF SEIZURES, CAUSES AND EFFECTS OF EPILEPSY; AND SOCIO-ECONOMIC BENEFITS AND CHALLENGES EXPERIENCED BY PEOPLE WITH EPILEPSY IN THE OPEN LABOUR MARKET

2.1. INTRODUCTION

The chapter elaborates on the theoretical framework and legislative framework; types of seizures, causes of epilepsy, effects of epilepsy, socio-economic benefits and challenges experienced by people with epilepsy in the open labour market and interventions to promote the rights of people with epilepsy.

2.2. THEORETICAL FRAMEWORK

Arfana and Mentz (2006: xxvii) describe the theoretical framework as empirical or quasi-experimental theories of social or psychological processes, which exist at different levels and are applied to understand the phenomenon under investigation. The diversity and richness of a theoretical framework gives the researcher a valuable opportunity to see what could seem familiar through a new and distinct perspective. Therefore, a theoretical framework provides the researcher with a chance to observe and perceive certain aspects of the phenomenon under study that appear obvious at face value. The researcher has chosen the developmental approach as the theoretical framework of this study.

The Department of Social Development (DSD) Framework for Social Welfare Services (DSD, 2013:14) states that the South African developmental approach to social welfare evolved from the country's unique history of inequality, human rights violations due to colonialism and apartheid, and a long history of social agency and social action to transform the society. Further (DSD, 2013:14) suggests that the developmental approach is intended to bridge the micro-micro divide in various aspects of individuals' lives. This strengthens the argument that PWE have a right to participate actively in economic activities appropriate to their capabilities without any form of discrimination.

Gathiram (2008:251) agrees that the developmental approach ensures the advancement of people with disabilities including PWE in all spheres of society, including the right to gainful employment. The author further states that where these rights have been denied, or their disability and epileptic condition have inappropriately or excessively restricted them in accessing these rights, corrective actions need to be implemented to fulfil these rights.

Midgley (2010:15), in support, agrees that investing in individuals implies strengthening their capabilities and phasing out oppression. Gathiram (2008:252) emphasises that the significance of a human rights and the developmental approach is the recognition of the fundamental needs of people with disabilities including PWE and to have these needs met by society. The author argues that South Africa faces excessive poverty and structural unemployment; improving the developmental landscape is one of the country's most pressing challenges.

The central tenet of the developmental approach is to integrate economic and social policies as these are considered to be important components of the development processes. The National Policy on the Provision of Social Development Services to People with Disabilities (2013:13) acknowledges that the approach plays a major role in promoting social development, social justice, social functioning and the wellbeing of people. The researcher suggests that the relevance of the developmental approach in this study re-affirmed that and signified the integration of economic and social policies to promote inclusivity and social integration of PWE in the workplace. The adoption of policies that ensure people's active participation in the economy through job creation and self-employment opportunities for all, and the removal of racial and discriminatory barriers, signify the importance of social cohesion for PWE.

The Framework for Social Welfare Services (2013:13) highlights that socioeconomic programmes are important for the development of opportunities and skills for individuals. The researcher believes that the developmental approach will not benefit PWE if they are excluded from mainstream economic activities. Jacoby, Gorry and Baker (2005:1978) argue that, despite marked advances in clinical management of epilepsy and the introduction of legislation for social inclusion, PWE remain

marginalised. de Boer, Mula and Sander (2008:544) assert that legislation can be used as a tool to legally enforce the goals and objectives of policies and programmes related to epilepsy. The following section addresses the status of the legislative framework pertaining to PWE.

2.3. LEGISLATIVE FRAMEWORK

Patel (2005:176) states that the enabling legislation to overcome discrimination in employment led to the enactment of the Employment Equity Act of 1998, which provides for the affirmative employment of black people, women and people with disabilities including PWE. In support, Howell et al. (2006:58) articulate that the significance of the human rights and the developmental approach to disability is centred on the fundamental needs for people with disabilities including PWE to participate in all spheres of the society

In the international arena, legislative imperatives require employers and government authorities to comply with the provisions of the UNCRPD. The Convention prohibits discrimination on the basis of disability for all matters pertaining to all forms of employment, including conditions of recruitment, hiring and employment, conditions of employment, continuance of employment, career advancement, and safe and healthy working conditions (UNCRPD, 2008:20).

Although international instruments are in place and an anti-discrimination provision in the Constitution of the Republic of South Africa makes specific reference to disability, implementation remains a challenge. The Commission for Employment Equity Annual Report 2012-2013 (Department of Labour, 2013:3) recognised the importance of employers' compliance with inclusive labour legislation. However, Nhlapo et al. (2006:101) argue that having such principles present in law does not mean that the rights of people with disabilities including PWE are secured on the ground. It is significant to identify policy gaps that prevent the implementation of labour legislation. This means that the anti-discriminatory legislation may not necessarily be upheld by all organs of government, the private sector and the broader community.

Further, Gathiram (2008:265) states that people with disabilities including PWE in South Africa have been awarded many rights within a developmental approach to disability. However, discrimination against PWE and negative social attitudes towards epilepsy plays an important role in their employability (Pahl & de Boer, 2005). In support, (Nhlapo et al., 2006:101) state that the actual change in the lives of people with disabilities including PWE is based on the upholding of the South African legislation of disability and human rights. This implies implementing the practical monitoring and evaluation mechanisms to ensure accommodation and equal opportunities for PWE.

The Skills Development Act (1998) offers persons with disabilities various forms of assistance for bridging the gap between learning and working opportunities in order to satisfy their social and economic development needs. The provision espoused by this Act minimises the divide between those who work and those without work. The Act also provides an enabling environment for people with disabilities including PWE to access education and training, acquire skills, and obtain employment and/or retain employment in the open labour market.

It is recognised that, despite enabling legislation establishing reasonable accommodation mechanisms and targets for the economic empowerment of people with disabilities including PWE, there has been insufficient progress in translating these into economic independence for people with disabilities including PWE due to persistent attitudinal and communication barriers (Patel, 2005:174). In support, the National Policy on the Provision of Social Development Services to People with Disabilities (DSD, 2013:20) states the despite the significant strides made in addressing the rights of people with disabilities including PWE, income poverty amongst people with disabilities including PWE remains a serious concern. Howell et al. (2006:58) articulates that people with disabilities including PWE continue to face barriers that prevent them from enjoying their full socioeconomic rights and fundamental human rights.

In agreement, de Boer (2010:634) highlights that PWE still experience serious limitations to their enjoyment of economic, social and cultural rights. DSD (2013:21) further, argues that the status quo regarding the overall economically active population of people with disabilities including PWE implies that the quality of life of South Africa's

people with disabilities including PWE remain low with limited access to basic, social and economic rights. The following section will address some of the different types of seizures that may contribute to challenges experienced by PWE and employment agencies.

2.4. TYPES OF SEIZURES

This section discusses the types of seizures, namely generalised, absence or petit mal, generalised tonic clonic, simple partial and complex partial and secondary generalised seizures.

2.4.1 Generalised Seizures

The seizures include absence, atonic, tonic- clonic and myoclonic, which affect the whole brain (Epilepsy Foundation, 2009). In agreement Senelick (2012) indicates that all areas of the brain are affected in a generalised seizure. Senelick further suggests that the person experiencing such a seizure may cry out or make some sound, stiffen for several seconds and then have rhythmic movements of the arms and legs. Eyes are generally open. The person having a generalised seizure may appear to experience breathing problems and turn blue. The person also loses his or her consciousness. Senelick (2012) asserts that the return of consciousness is gradual and the person may be confused and have no knowledge of what had happened. The Epilepsy South Africa Employment Manual (n.d.:12) states that the person may feel extremely exhausted, as such it will be important for the employee and employer to discuss remedial steps before and after the seizure onset.

2.4.2. Absence Seizures (formerly known as Petit Mal seizures)

These type of seizures usually last between 2 to 15 seconds and may occur a few times a day, or more than 100 times in a single day. Senelick (2012) agrees that these types of seizures are most common in childhood. The author further states that impairment of consciousness exists with the person staring blankly. Joseph and Shafer (2014) state that it is also possible for older teens and adults to have absence seizures, but it is less common. Beletsky and Mirsattari (2012) agree that these seizures are characterised by sudden impairment in awareness, often with a motionless blank stare and cessation of

ongoing activities. Absence seizures are a mild seizure type compared to generalised tonic clonic seizures as the person becomes unconscious for a short time (Epilepsy Society (2014). In support, the Epilepsy Foundation of Michigan (2011a) states that a person is unaware of what happened during the seizure, but will quickly return to full consciousness when the seizure has stopped. Senelick (2015) affirms that the person may resume his activities right after the seizure.

2.4.3. Generalised Tonic Clonic Seizures

The generalised tonic clonic seizures were formerly known as grand mal seizures. When a person has a tonic clonic seizure, his or her arms and legs will first stiffen. This is a tonic stage. His or her limbs and head will then begin jerking, which is the clonic phase (Epilepsy Foundation, 2009). During the seizure, the person might bite his or her tongue or the inside of his or her mouth, experience incontinence, or even decrease or cease his or her breathing (Epilepsy Foundation, 2009).

In this case, his or her breathing should return to normal during the tonic (jerking) portion of the seizure. Depending on the person, it can take minutes to fully recover from the seizure. As consciousness returns, the person may be confused, drowsy, agitated or depressed. Epilepsy Foundation of Michigan (2011b) state that this type of seizure lasts for a few minutes followed by a return of full consciousness. The individual may continue with his initial activities in his work environment.

2.4.4 Simple Partial Seizures – consciousness not impaired

Senelick (2015) states that a person having a simple partial seizure will stay awake and be aware throughout the seizure. Although the person's consciousness is not impaired the person may have involuntary movements, sensations, psychic experiences such as awareness of a smell lasting for a few seconds (Senelick, 2015). Schachter and Sirven (2013) affirm that the person experiences sensory distortions, hallucinations, unusual physical or emotional feelings and other symptoms that are not visible to the people around him. The person may continue with his activities that he was performing prior to the seizure onset.

2.4.5 Complex Partial seizures – with impaired consciousness.

Senelick (2012) state that this type of seizure involves only one part of the brain and only one part of body is affected. These seizures affect a greater part of the brain than simple partial seizures and they also affect consciousness. Although they can affect any part of the brain, they generally take place in one part of the brain's two temporal lobes. (Epilepsy Foundation, 2009) explains that as a result of this seizure onset, people prone to complex partial seizures have temporal lobe epilepsy. When a person has a complex partial seizure, they will stop what they are doing and stare blankly at nothing in particular this means that, at the seizure onset, the individual cannot continue with his immediate activities until consciousness has been fully regained. Furthermore PWE might appear conscious and normal because they usually move about and remain standing with their eyes open but they will be experiencing an altered consciousness. In other words, it will be rather like they are dreaming or in a trance. If they talk, which is a possibility, they will likely not make sense and they will not be able to respond appropriately to others (Epilepsy Foundation, 2009).

However, it is important to note that these types of seizures usually last for one to two minutes but the person may be confused and drowsy for some minutes to several hours after the seizure and have no memory of the seizure or the events just before or after it. Sirven and Devinsky (2013) state that some PWE may behave in a dangerous or embarrassing manner and they would need to be redirected from hazards and reoriented about their current state and activities after recovering from the seizure.

2.4.6 Partial seizures evolving to Secondarily Generalised Seizures

These seizures occur when only a part of one side of the brain is affected. The activity can start in one part of the brain, and then move to another, or it could just stay in the one area. Partial seizures affect the control functions on the part of the brain where they are occurring. Epilepsy Foundation (2009) states that if the seizure happens in the brain's speech area, a person's ability to talk will be affected. If a seizure starts off as a partial seizure, then spreads to include the whole brain, it is referred to as a partial seizure secondarily generalised). This means that primarily it started as a partial seizure, in one locality of the brain and then progressed to the whole brain area to

become a generalised seizure. It is further argued that PWE retain consciousness during partial seizures.

PWE can even continue conversations through the seizure, and they will usually remember what happened after the seizure (Epilepsy Foundation, 2009). The following section addresses the causes of epilepsy.

2.5. CAUSES OF EPILEPSY

Eastman (2005:8) states that some common causes of epilepsy are likely to include infectious diseases, such as neurocysticercosis and HIV/AIDS, trauma and alcohol consumption. However, Schachter, Shafer, Joseph, and Sirven (2013) contend that some people with no known cause of epilepsy may have a genetic form of epilepsy. Further it is argued that one or more genes may cause the epilepsy or epilepsy may be caused by the way some genes work in the brain. The relationship between genes and seizures can be very complex and genetic testing is not available yet for many forms of epilepsy (Schachter et al., 2013). Epileptic seizures are the result of intensive electrical discharges within the brain. These activities result in a person having epileptic seizures and consciousness is lost or impaired. The Annual Report of the Epilepsy Foundation of Victoria (2007-2008) states that epileptic seizures are induced by the lack of proper co-ordination and communication among nerve cells. This indicates that communication between cells becomes scrambled and PWE's thoughts, feelings or movements become momentarily confused or uncontrolled.

It was further believed that the main causal agent of idiopathic epilepsy was heredity. In agreement, Smith (2012:1) indicates that epilepsy with onset in children and adolescents is predominantly genetically determined, whereas the onset of epilepsy in adults results from mainly acquired structural causes. Fisher (2014a) highlights that genetics or heredity is most relevant to generalised seizures, including absence, generalised tonic-clonic and myoclonic seizures. Smith (2012:1) argues that individual genetic disposition underpins all causes of epilepsy. Furthermore, the author asserts that Japanese encephalitis and West Nile virus encephalitides remain largely untreatable and a cause of subsequent epilepsy.

de Boer et al. (2008:541) assert that epilepsy associated with head trauma, the central nervous system, infections, and tumours may occur at any age. The type of injury that can lead to a seizure is age-dependent. Seizures in children are often caused by birth traumas, infections such as meningitis, congenital abnormalities or high fevers (Fisher, 2014b). The WHO Fact Sheet on epilepsy (WHO, 2012) suggests that the most common type for six out of ten people with the disorder is called idiopathic epilepsy and has no identifiable cause.

It is estimated that 60 to 70 percent of people have epilepsy without any causative explanation. A person could be subjected to various tests and other medical investigations for an appropriate diagnosis. However, the outcome is negative and the person continues to have seizures. WHO (2012) explains that in cases of symptomatic epilepsy, causative factors such as the brain tumor, stroke and degeneration could be identified in a positive manner. It is further suggested that common chemical imbalances that can produce seizures include drugs such as alcohol, cocaine and others, low blood sugar, low oxygen, low blood sodium and low blood calcium in adults. Nakagawa (2015) indicates that in symptomatic epilepsy there are justifiable indicators for a person to develop epilepsy such as brain dysfunction, mental retardation or delayed development and cerebral palsy. The following section addresses the effects of epilepsy on the overall well-being of PWE:

2.6 THE BROADER EFFECTS OF EPILEPSY

de Boer et al. (2008:1) assert that the impact of epilepsy rests not only on the individual PWE, but also on the family and indirectly on the community. They further suggested that the burden of epilepsy may be due to the physical hazards of epilepsy resulting from unpredictability of seizures, the social exclusion as a result of negative attitudes of others toward PWE, and the stigma, as children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe (de Boer et al., 2008:1).

This section is divided into four subsections, namely: effects on psycho-social functioning, family functioning, and the quality of life for PWE, and employment:

2.6.1 Effects of epilepsy on psycho-social functioning

Aydemir, Ozkara, Unsal and Canbeyli (2011:679) acknowledge that the impact of epilepsy on social functioning was found to be profound and greater than, for example, migraine even though both are chronic neurological conditions and both observe elements of episodic, but complete disability. In agreement Lin, Wood and Yung (2013:1) indicate that impaired psychosocial functioning could be aligned to the result of social and psychological factors associated with the onset of epilepsy. Schachter (2006:1) argues that having epilepsy may also induce mood disorders, stigma, seizure worry, lower self-esteem and challenges in self-mastery.

Smelts, Van Lierop, Vanhoutvin, Aldenkamp and Nijhuis (2007:358) confirm that the uncertain and unpredictable nature of epilepsy can cause a variety of psychosocial difficulties for PWE. However, the impact of the diagnosis of epilepsy can be mediated by factors such as personality, social support and intellectual abilities (Smeets, et al., 2007:358). The PWE whose epilepsy has been newly diagnosed may be uncertain whether or not to disclose his or her epilepsy to the employer. Birbeck and Rockwell (2007) assert that the ultimate disclosure of epilepsy may lead to PWE being stigmatised in all spheres of life including employment.

It is further suggested that stigma accentuates inequities and disparities because it is mostly directed at the socially disfranchised and disempowered, in particular PWE (Birbeck & Rockwell, 2007). Swartz, Schneider and Rohleder (2006:109) emphasizes that people with disabilities including PWE are more stigmatised in the public domain because of the negative attitudes displayed against them. Further Birbeck and Rockwell (2007) assert that the stigma attached to PWE may be as a result of any form of distinction, exclusion, or restriction affecting a person by virtue of some character he or she possesses. In support, Moselhy (2011) maintains that social attitudes towards the disorder often cause more distress to PWE and the near ones than the disease itself.

Hills (2007:10) emphasises that although epilepsy is a medical condition, PWE also have to cope with psychological and social consequences. England, Liverman, Schultz and Strawbridge (2012:1) indicate that having epilepsy is about much more than having seizures. Smeets et al. (2007:358) assert that the uncertain and unpredictable nature of

epilepsy can cause a variety of psychosocial difficulties for PWE. In agreement, Thompson (2013) emphasises that the unpredictability of the majority of seizures is sufficient to erode self-confidence and self-esteem, even when the episodes are infrequent. It is further argued that diagnosis and prognosis aside, individuals have to cope with ongoing seizures (Thompson, 2013).

Further, Hills (2007:10) agrees that grief at the realisation of being disabled goes through stages of shock, anxiety, bargaining and denial, mourning and depression, internalised anger, acknowledgement and adjustment. PWE might expose themselves to unjustified guilt feelings and have a negative perception of life in general. Privitera, Haut, Shafer, Joseph and Sirven (2013) mention that too much stress experienced by some PWE cause worry, depression, frustration and anger resulting in increased frequency of seizure and reduced quality of life. The end result is that PWE feel inadequate and depressed about trying to live a normal life like other people without epilepsy. de Boer et al. (2008:1) assert that depression, anxiety, psychoses, and attention deficit disorders are common features among PWE.

Beletsky and Mirsattari (2012) agree that anxiety in humans is a natural response required for adaptation and as such is not pathological by itself. Flatt (2005) explains that anxiety is a common human experience; however, some PWE may find it difficult to engage in long-term activities. In agreement, Beletsky and Mirsattari (2012) indicate that when the sense of worry or apprehension becomes excessive, compared to what would be experienced by most PWE under the circumstances or uncontrollable, it starts to affect the quality of life and from that point requires professional attention.

de Boer et al. (2008:1) argues that epilepsy has a considerable psychological and emotional impact. However, self-management of the condition is highly dependent on affected PWE. Smeets et al. (2007:359) contend that coping strategy, self-efficacy and social support play an important role in accepting and managing psychosocial consequences and the effects of having epilepsy.

2.6.2 Effects of epilepsy on family functioning

Thompson (2013) argues that PWE do not live in a vacuum; the attitudes and experiences of family members will greatly influence how PWE cope. In agreement, the Epilepsy Ontario (2014) emphasises that epilepsy affects not only the individual with epilepsy but also has a great impact on all members of the family unit. Hung (2009) agrees that the impact of epilepsy extends to the whole family. It can be extremely difficult for parents to fully admit and accept that their children are diagnosed as having epilepsy. They are overwhelmed by enormous worries and concern about their child's prognosis, unpredictable epilepsy, the side effects of anti-convulsants and the impairment to the brain functions as well as their future career and marriage (Hung, 2009). Thompson (2013) asserts that families may harbour misconceptions about epilepsy and thus become socially isolated for fear of adverse public reactions. The family may also be overprotective in relation to the PWE and impose social interaction restrictions on the individual.

2.6.3 Effects of epilepsy on the quality of life

England et al. (2012:1) maintain that the negative effects on quality of life of PWE can be severe and could extend to family and social relationships, academic achievement, and opportunities for employment, housing, and the ability to function independently. In support Kerr, Turkey and Huber (2009:1) indicate that epilepsy has a pervasive impact on the quality of life of PWE. Moselhy (2011) agrees that to be a PWE means being exposed to the fear of having attacks, being at a disadvantage in terms of employment and personal relationships, and being open to prejudice.

It is further argued that it is frightening to see a person having an epileptic attack and losing control of himself (Moselhy, 2011). Hills (2007:11) suggests that the quality of life for PWE may be reduced by higher psychological sickly rates, anxiety and depression, lower self-esteem, increased helplessness, defensive aggression, poorer educational achievement and higher unemployment or underemployment. In support, Lim, Wo, Wong and Tan (2013:130) assert that PWE may experience multiple social, psychological and economic challenges. Chung, Liu, Ivey, Huang, Chung, Guo, Tseng and Ma (2012:256) state that PWE may also experience lower quality of life due to a

variety of factors. These factors may include the sudden onset of seizures, side effects of anti-epileptic medication, worries about psycho-social functioning, impaired learning and cognitive abilities, loss of employment opportunities, loss of independence, and stigma. This increases the stigma attached to PWE and the epileptic condition. Baskind and Birbeck (2005:1) affirm that the stigma associated with epilepsy has a profound impact on the quality of life of PWE. Hesdorffer, Beck, Begley, Bishop, Cushier-Weinstein, Holmes, Sirven and Austin (2012) argue that reductions in social, health and in employment opportunities often have a negative effect on the quality of life for PWE.

2.6.4 Effects of epilepsy on employment

Flatt (2005) asserts that getting and keeping employment is an important aspect of sustaining one's self-worth and self-esteem. Employment is vital to anyone's mental health, including PWE. Thompson (2013) explains that work has many functions aside from financial rewards as it provides a way of structuring time and more importantly, contributes to a person's identity and feelings of self-worth. Graham et al. (2014:18) assert that employment and occupation are important mechanisms through which people may earn in income, thus achieving economic independence. Baillie (2011) in support, states that the ability to engage in employment allows PWE to lead fulfilled and independent lives. Baillie (2011) articulates that when PWE participate in the workplace the outcome not only creates financial independence and security, but it also promotes social inclusion, self-esteem and individual productivity.

However, if the onset of epilepsy occurs during a person's working life, it can and often does lead to long-term and sometimes permanent unemployment (de Boer, 2005). In support, Graham et al. (2014:18) contend that lack of participation in employment result in income poverty. Patel (2005:16) suggests that employment insecurity leads to income insecurity and poverty. Ife (2012:9) agrees that people with disabilities including PWE find it especially difficult to obtain and retain employment. This means that PWEs' rights to decent work and the denial of those rights to participate actively in economic activities is equivalent to gross violation of their human rights (United Nations, 2008:20).

In a study conducted by Bautista and Wludyka (2005) it was established that employment-related information, belief in the importance of work for personal growth

and fulfilment impacted on PWE in that they would be discriminated against at work because of their epileptic seizures. In support Thompson (2013) argues that PWE in general are vulnerable to employment difficulties, particularly at times of economic recession. Ionescu (2012:829) suggests that PWE are pushed by their economic situation towards badly paid jobs, while the real value of social benefit lags behind the value of the average wages. This implies that desperation of PWE to obtain employment will force them to accept any job available not equivalent to their skills. Holland, Lane, Whitehead, Marson and Jacoby (2009:1030) agree that manual workers with epilepsy are at a greater risk of unemployment than their professional counterparts.

Despite the negative effects epilepsy on PWE, the following section addresses the socio-economic benefits enjoyed by PWE employed in the open labour market.

2.7. THE SOCIO-ECONOMIC BENEFITS OF THE OPEN LABOUR MARKET EMPLOYMENT

Bautista and Wludyka (2007) affirm that psychosocial factors such as a high self-perceived importance of work and decreased fears of workplace discrimination are significantly associated with the improved quality of life of PWE. A positive workplace environment will enable PWE to know and understand their rights in the same manner as their counterparts without epilepsy. Shouri (2013:1) agrees that employee socio-economic rights are of concern to any employed individual, but become of even greater concern when a person has a disability, such as epilepsy.

The White Paper on Integrated National Disability Strategy (INDS) (RSA, 1997:43) recommends that people with disabilities including PWE should be accommodated in the equitable provision of employment benefits such as Unemployment Insurance Fund (UIF), pension and health insurance schemes in the same manner like their counterparts. In support, the Employment Equity Act (1998) justifies the measures to ensure that designated groups such as people with disabilities including PWE enjoy equal opportunities in the workplace without any form of discrimination.

WHO Fact Sheet (2012) indicates that legislation based on internationally accepted human rights standards can prevent discrimination and rights violations, improve access

to health care services, education and employment for PWE. Further it is argued that PWE have special financial needs such as sourcing a healthy diet and medication (Ionescu, 2012:829). These basic needs could be met through employment like any other citizen. It is imperative for PWE to receive economic benefits like their co-workers without epilepsy to achieve inclusivity and social integration in the workplace. This will bring about self-confidence in PWE and feelings of belonging to the broader society. Baillie (2011) emphasises that when PWE participate in the workplace, the outcome not only creates financial independence and security, it also promotes social inclusion, self-esteem and individuals' productivity. The following section focuses on the challenges faced by PWE in the workplace.

2.8. THE CHALLENGES EXPERIENCED IN THE OPEN LABOUR MARKET

Epilepsy Foundation (n.d.:1) indicates that people with epilepsy are reluctant to tell their employers they have epilepsy or seizures because they learn through bitter experiences as this can be used against them. The attitudes of employers play an important role in the employment of PWE. Thompson (2013) highlights that employment problems of PWE are characterised not only by seizures but other factors such as discrimination and stigma. Employers, however, feel that their workplaces are not geared for the employment of PWE. The particular challenges experienced by persons with psychosocial disabilities, which flow from the stigma and ignorance pertaining to reasonable accommodation measures required, are also acknowledged. Baillie (2011) indicates that getting into and staying in the workforce is not always easy for PWE because of barriers that continue to make it difficult to obtain, and hold on a job. Further, (Baillie, 2011) explains that this is caused by lack of information and understanding by employers and co-workers who express attitudes of anxiety towards epilepsy.

In a study conducted in Korea it was revealed that more than half of those who disclosed their health condition to their employers reported that they had been refused a job because of epilepsy (Lai, 2007). In another study involving 543 adult PWE, results showed that 75 percent of the PWE never disclosed their disease when applying for employment (Lee, 2005:1). Hills (2007:11) agrees that disclosure to an employer is a difficult decision to implement as it might have undesired consequences for the PWE in

the workplace. This means that PWE withdrew their right to disclose their epilepsy diagnosis to prospective employers. The consistent dilemma facing PWE is about whether or not to disclose their epileptic condition to employers. Graham, Selipsky, Moodley, Maina and Rowland (2010:15) assert that the end result is that people with disabilities including PWE may be excluded from employment and remain poor and therefore unable to support themselves.

Birbeck and Rockwell (2007) state that stigma accentuates inequities and disparities because it is mostly directed at the socially disfranchised and disempowered. WHO (2012) argues that PWE experience reduced access to health and life insurance, withholding of the opportunity to obtain a driving licence, and barriers to enter particular occupations, among other limitations. Baskind and Bierbeck (2005:1) agree that PWE's productive activities may be limited to avoid seizure related injuries. Such limitations may place further restrictions on other important social and economic functions due to epilepsy associated stigma, passive coping styles and low self-efficacy interacting with one another in a complex manner Baskind and Bierbeck (2005:1). In agreement, the Human Resource Development South Africa (2010-2030) indicates that illiteracy and skills shortage contribute to individuals' low levels of finding and retaining employment.

In a study conducted by Tedrus, Fonseca, Oliveira, Fonseca, Carneiro and Carvalho (2010:136), it was established that the low scholastic level, professional qualifications and the stigma restricted the employment opportunities of PWE, contribute to their social exclusion. Jacoby et al. (2005:1978) confirm that one area of quality of life known to be compromised by having epilepsy is employment. Other factors contributing to the unemployment of PWE were employer attitudes and stigmatisation (Jacoby et al., 2005:1978).

Smeets et al. (2007:357) assert that not only does stigma result in discriminatory reactions, PWE might also have internalised negative community attitudes and come to expect rejection from employers and co-workers. Somavia (2009) argues that people with disabilities including PWE are less likely to be in permanent employment as a result of a negative attitude by employers. Birbeck and Rockwell, (2007) state that the burden of epilepsy associated stigma rest heaviest upon PWE who are subjected to social and

economic inequities. This implies that PWE would have serious challenges in retaining employment on a permanent basis as a result of frequent or uncontrolled seizures.

However, The Epilepsy Talk (2012) argues that it is a myth that individuals with epilepsy are less capable than others when it comes to job performance. Nhlapo, Watermeyer and Schneider (2006:101) explain that it is crucial to promote actual change in the lives of people with disabilities including PWE through upholding of the South African legislation for disability and human rights. This implies implementing practical monitoring and evaluation mechanisms to ensure reasonable accommodation and equal opportunities to PWE. Epilepsy South Africa (2013) indicates that people from designated groups including PWE must be accommodated with equal opportunities in the work environment. Further, the Epilepsy Employment Manual (Epilepsy SA, n.d.:1) takes the argument further and suggests that particular challenges and ignorance pertaining to reasonable accommodation measures required are also in existence. It can also be emphasised that despite the comprehensive policy landscape and the extensive work of the disability rights movement in South Africa and other countries such as Korea, America and Australia, people with disabilities including PWE still face a range of challenges that are compounded by poverty (Graham et al., 2010:14).

The Epilepsy SA Employment Manual, (Epilepsy SA, n.d.:5) states that people with epilepsy and other disabilities in South Africa are significantly under-represented in the workforce. Graham et al. (2010:15) assert that the reality is that persons with disabilities including PWE in particular remained poor and therefore unable to sustain themselves. The following section focuses on possible intervention strategies to promote the socio-economic rights of PWE and address these challenges.

2.9. INTERVENTIONS TO PROMOTE THE SOCIO-ECONOMIC RIGHTS OF PEOPLE WITH EPILEPSY

Parfene et al. (2009:465) recommend that education-based organisational programmes designed to address challenges faced by PWE in the workplace such as inequality and discrimination, are imperative in the promotion of the socio-economic rights of PWE. Further, Hersdorffer et al. (2012:5) argue that the employability of PWE involves epilepsy education of employers. Patel (2005:157) indicates that it is vital to also

promote rights through educating people including PWE about their rights within the work environment. In agreement, Midgley (2010:19) emphasises that advocacy for social justice is critical when community members face inequalities in resources and power or when they are exploited or discriminated against. Sherraden (2009:6) maintains that advocating for social justice or fairness on behalf of the poor and powerless, and challenging economic and political elites are central to the promotion of socio-economic justice. Mount, Johnstone, White and Sherman (2005) assert that because PWE experience numerous problems in securing and retaining employment, it is imperative to engage them (PWE) in Vocational Rehabilitation (VR) programmes. In a study conducted by Mount et al. (2005), it was established that VR programme can assist PWE in becoming successfully employed, increasing personal income and decreasing reliance on state grants. Hesdorffer et al. (2012:207) state that there is a clear need to implement community-based intervention to evaluate the efficacy of approaches to promote employer knowledge and to improve attitudes about epilepsy. Flatt (2005) emphasises that education and discussion are the keys to eliminating wrong assumptions about PWE. In agreement, Fernandes, Noronha, Sander and Bell (2007) assert that education and training programme will assist in increased knowledge, create positive attitudes and perceptions towards PWE.

It is further argued that employers need to strive to create an environment that addresses everyone's individual needs and this will help to eliminate feelings that one employee is getting preferential treatment (Flatt, 2005). In support, the Gauteng Provincial Government Disability Rights Policy (GPG, 2010:28) commits to ensure that people with disabilities including PWE employed in the private sector enjoy fair pay, full employment benefits and career development. The (GPG, 2010:28) undertakes to prevent exploitation of people with disabilities including PWE through anti-discrimination measures and inspection of workplaces. This will ensure that employers comply with the overall labour legislation and international instruments to uphold the socio-economic rights of PWE employed in the open labour market. The following section addresses another strategy in creating and increasing open labour market employment opportunities for PWE.

2.9.1 Skills development Internships

According to the Twenty Year Review (RSA, 1994-2014:16) skills development and employment opportunities have been recognised as important components of a fundamental right for people with disabilities including PWE. The GPG (2010:29) commits to ensuring the setting and achieving targets designed to expand the participation of people with disabilities and PWE in learnerships, business mentorships and apprenticeships. The GPG (2010:33) also undertakes that discrimination in the training and development of people with disabilities PWE shall be prohibited. PWE will be afforded an opportunity to improve their skills, increase their competence in the workplace and give them job satisfaction.

The International Labour Organisation (ILO, 2009a) explains that promoting more inclusive societies and employment opportunities for PWE requires improved access to basic education, vocational training relevant to labour markets needs and jobs suited to their skills, interests and abilities, with adaptations as needed. In agreement the European Social Fund (ESF, 2014-2020) suggests that investing in education, training and vocational training for skills and lifelong learning is critical for PWE. This will focus on enhancing access to lifelong learning, upgrading the skills and competencies of the workforce, and increasing the labour market relevance of education and training systems (ESF, 2014-2020). This programme is linked to the objectives of the Skills Development Act (1998) subject to appropriate funding for skills training programmes for getting PWE into jobs. It requires a strong political will from the government and cooperation by the private sector for the practical implementation of socio-economic justice for PWE.

In agreement the ILO (2009b) notes that involving people with disabilities and PWE in training would help to achieve the envisaged positive results and inclusive economic development. Thus, PWE should also participate actively in self-representation and decision making structures to highlight the significance of social integration with specific reference to securing and retaining work in the open labour market. The impact of skills training programmes should be evaluated against PWE's acquired skills, capacity for improved productivity, economic growth and the ability of various employment sectors to

absorb them in the open labour market NSDS111 (DHET, 2011-2013). Therefore, the commitments of the National Skills Accord (EDD, 2011) will create increased employment opportunities for PWE in the open labour market in a fair and equitable manner. In addition, the National Development Plan (NDP) (2012) is a plan for the country to eliminate poverty and reduce inequality by 2030 through uniting South Africans, unleashing the energies of its citizens, growing and inclusive economy, building capabilities, enhancing the capability of the state and leaders working together for the betterment of all citizens. This implies that PWE will also benefit from the envisaged programme and participate in an inclusive economic environment without being discriminated. Furthermore the NSA (2011-2013) urges the representatives of business and organised labour to invest in partnerships in order to achieve the New Growth Path of five million jobs by 2020. In agreement, (Mulder, 2015:63) states that public-private partnerships are essential components of a strong economy and an empowered people.

The way forward is for all parties to collaborate through these established partnerships for PWE to create equal employment opportunities and to ensure that people with disabilities including PWE enjoy equal access as their basic right (Pretorius & Yates, 2014:13). The Twenty Year Review (RSA, 1994-2014) highlights that the right to live independently and to be included as an equal citizen in one's social and economic environment, requires partnerships between all sectors of society. It is argued that a skilled and capable workforce that includes PWE will contribute towards economic expansion, create additional employment opportunities and contribute to the achievement of developmental goals (DHET 2011-2013).

2.10 Conclusion

This chapter presented key concepts that demonstrated the researcher's awareness of the subject matter.

2.11 Summary

The chapter acknowledged the strides made in provision of services that protect and promote the rights of PWE. Despite all these efforts, it highlighted a gap or lack of

congruency between the development of legal instruments (Acts, Regulations, Conventions and Policies) and implementation for PWE.

The main impact of epilepsy on PWE was related to societal attitudes toward PWE rather than the condition per se. There was also emphasis on the effects of epilepsy on PWE and how it affected their active participation in all spheres of life for them to realise the common goal of better life for all in a democratic, non-discriminatory and inclusive society.

The chapter further explored the relevance of the developmental approach in line with socio-economic rights and social justice affecting PWE. Chapter 3 outlines the research methodology and presents the study findings.

CHAPTER 3

EMPIRICAL STUDY AND RESEARCH FINDINGS

3.1 INTRODUCTION

In this chapter, the research approach, type of research, the research design, methodology, ethical aspects related to the study and the empirical research findings of the study will be discussed.

The study was guided by the following research question: “What are the socio-economic experiences of PWE employed in the open labour market in the Ekurhuleni region?”

The goal of the study was to explore the socio-economic experiences of PWE employed in the open labour market in the Ekurhuleni region.

To obtain the goal and answer the stated research question, the following objectives were formulated:

- To explore and describe various types of epilepsy;
- To explore the influence of epilepsy on PWE’s social functioning and well-being;
- To explore and describe the socio-economic benefits enjoyed by PWE employed in the open labour market; and
- To explore and describe the challenges PWE experience in the workplace.
- Based on the research findings, the researcher made recommendations for improved employment conditions to the benefit of both the employer and PWE.

3.2 RESEARCH METHODOLOGY

Leedy and Ormrod (2005:95) describe the research methodology as a systematic process of collecting, analysing, and interpreting information in order to increase the understanding of the phenomenon about which researcher is interested or concerned. In agreement Brink (2010:2) states that the research methodology is as a philosophy of the research process. Further Brink (2010:22) articulates that research methodology enables the researcher to engage in processes and specific procedures to determine

the reality as perceived by participants. In this context, the researcher sought to explore the meaning and promote understanding of the experiences from participants' viewpoints regarding their socio-economic experiences of being employed in the open labour market in the Ekurhuleni region.

3.2.1 Research approach

In this study a qualitative approach was adopted. The choice of the qualitative approach was based on the premise that the researcher wanted to gain a first-hand and holistic understanding of the socio-economic experiences of PWE employed in the open labour market in the Ekurhuleni region

The researcher adopted a qualitative approach to answer questions of a complex nature related to the phenomenon with the purpose of describing and understanding the participant's point of view (Leedy & Ormrod 2005:94). Fouché and De Vos (2011:95) explain that the main focus of a qualitative approach was to answer the "what" questions pertaining to the study. In agreement Brink (2010:53) asserts that a qualitative approach sought to answer the research question with a view of achieving the objectives of the study.

The study was exploratory in nature. Bless, Higson-Smith and Kagee (2006:76) view exploratory research as "the study arising out of a lack of basic information on a new area of interest." In support, Terre' Blanche et al. (2006:43) state that the goal of exploratory research is to make a preliminary investigation into relatively unknown areas of research and attempt to gain new insight into the phenomenon under study. The participants were requested to describe their socioeconomic experience in the workplace. The exploratory research approach was relevant and assisted the researcher in understanding the socio-economic experiences of PWE employed in the open labour market in the Ekurhuleni region.

3.2.2 Type of research

The researcher utilised applied research for this study. Fouché and De Vos (2011:95) assert that applied research is designed to solve practical problems of society through a scientific planning process. This brings about desired outcomes to the presenting

problem in the community. The problem addressed in this study included lack of understanding of epilepsy despite its prevalence in various communities. Baillie (2011) asserts that it is important to close the gap where there is lack of further research about the field. The research gap was that employers were not informed about the psychosocial aspects of PWE, the tendency to exclude and discriminate against PWE. The researcher is of the view that the findings will provide a platform to raise awareness, sensitise employers and employees on epilepsy and gain insight on the socioeconomic experiences PWE encounter in the workplace.

3.2.3 Research design

This study utilised the phenomenological design. Brink (2010:113) states that the phenomenological design is intended to describe what participants experience and how they interpret their current situations. Creswell (2007:57) adds that the phenomenological design is a study that describes the meaning of the lived experiences, attitudes and perceptions of the research participants. Tavallaei and Talib (2010:575) agree that the purpose of the phenomenological design is to capture the experiences of individuals in a practical setting so that the description of the universal essence is created to depict the actual situation. In agreement, Creswell (2013:81) affirms that the researcher should create an enabling environment for participants to express their experiences in their natural setting. The flexibility of the design enabled the researcher to probe the emerging patterns in relation to new feelings and emotions expressed by participants for better understanding. The design was appropriate as it enabled the researcher to gain an in-depth understanding of the socio-economic experiences PWE in the open labour market in the Ekurhuleni region.

3.2.4 Research population, sampling method

3.2.4.1 Population

In the context of this study, a population refers to the total number of PWE employed on the open labour market in Ekurhuleni region (Bless et al., 2006:98). Strydom (2011:223) emphasises that a population sets boundaries on the study units or individuals in the universe, who possess specific characteristics such as living with epilepsy.

Epilepsy South Africa and recruitment agencies' databases indicated that there were 60 PWE employed in the open labour market in different regions. The researcher excluded PWE employed in other regions and the focus was on PWE employed in the Ekurhuleni region.

3.2.4.2 Sample and sampling method

The researcher used the non-probability sampling technique. According to Brink (2010:132) non-probability sampling involves a judgement by the researcher to select participants who are articulate about the phenomenon under study. The advantages of non-probability sampling are that it has a great potential to bring about quality data if the researcher is dealing with cooperative and able participants. Further Brink (2010:132) states that the major disadvantage of this type of sampling is that it does not contribute towards generalisation, thus the extent of sampling error cannot be estimated and bias may come into existence

The researcher used the purposive sampling technique in the study. Strydom (2011:232) articulates that a purposive sampling is a procedure which is based on the judgment of the researcher in determining the characteristics of a representative sample. The advantage of purposeful sampling is that it enables the researcher to select the sample based on knowledge of the phenomenon being studied (Brink, 2010:134). In this study the sample size consisted of 10 participants.

Further, Brink (2010:135) urges researchers to base his or her decision regarding the sample size on the scientific and practical consideration when conducting the study. The researcher selected and focused only on ten participants employed in the Ekurhuleni region. Creswell (2013:156) asserts that the researcher selects research participants with the intention to purposefully inform an understanding of the research problem and determine the core objective of the study. According to Rubin and Babbie (2008:247); Strydom and Delpont (2011:392), the researcher's judgement is significant in determining the selection criteria. This may contain the most characteristics representative or typical attributes of research participants. The following selection criteria were used:

- Must be a person with epilepsy;
- Must be of any racial group;
- Must be occupying any work position;
- Must have a minimum of 12 months being employed; and
- Must be employed in the open labour market in the Ekurhuleni region.

3.2.5 Data collection method

In line with the qualitative approach, data was collected by engaging participants using a semi-structured interview schedule. Brink (2010:152) states that a semi-structured interview schedule is a communication method with a specific purpose and questions for additional probing. Burnette, Sanders, Howard, Butcher and Salois (2011:282) affirm that the use of a semi-structured interview schedule helps to create an enabling environment for participants to express their experiences about the phenomenon under study. Greef (2011:351) explains that a semi-structured interview schedule enables the researcher to gain a detailed picture and in-depth information on the participant's beliefs and attitudes or accounts of the phenomenon. Participants were informed about the importance of using a voice recorder during the interviews and their written permission was secured.

The researcher conducted semi-structured interviews with ten participants in their respective workplaces. With the use of a semi-structured interview schedule, the researcher gained a first hand and detailed accounts of participants' socioeconomic experiences, challenges and benefits relating to their work in the open labour market. Brink (2010:152) highlights that the semi-structured interview schedule has the advantage to bring about more in-depth information on participants' attitudes, feelings and experiences. The semi-structured interview also allowed the researcher to obtain different viewpoints from the participants in relation to their socio-economic experiences in the open labour market in the Ekurhuleni region. The method also provided participants with an opportunity to give a fuller picture about their experiences and in turn, the researcher was able to probe and made follow-ups for better understanding.

3.2.6 Data analysis

According to Creswell (2013:179) data analysis involves categorisation, ordering, summarising, coding and organising themes, representing the data and presenting information in a meaningful manner. Brink (2010:170) states that qualitative data is presented non-numerically in the form of written words. In the context of this study the researcher chose the Creswell's data analysis spiral as articulated by Schurink, Fouché and De Vos (2011:404). The nine steps of data analysis as are follows:

- **Planning for recording of data**

Schurink et al. (2011:404) articulate the importance of the researcher's role to engage in a systemic planning process prior to the collection of data in the preparation and organising data. The researcher set up appointments with the selected participants. The researcher sourced a voice recorder to record data. The researcher used an examination pad for field notes. The researcher developed a system to record and to retrieve data in an organised and orderly manner.

- **Data collection and preliminary analysis**

This step entails a two-fold approach, namely the analysis of data through the collection phase on site and off site (Schurink et al., 2011:405). During the on-site stage the researcher used a semi-structured interview schedule and recorded participants' responses using an electronic voice recorder and wrote down notes on the exam pad.

After the interviews off-site, the researcher listened to the recording device in a repetitive manner and wrote the responses of participants on the examination pad to develop transcripts. Data collection and analysis were conducted in a coherent manner. The researcher transcribed the recorded interviews in order to capture every word said during the semi-structured interviews. The researcher also compiled field notes that enabled the researcher to capture linkages and emerging themes.

- **Management of data**

According to Schurink et al. (2011:408) this is the first step away from the site. During this phase the researcher organised data into file folders. The files were then converted to appropriate text units, for example, a word, a sentence, an entire story for analysis by hand. The researcher used the computer generated file. All participants' information from the voice recorder was downloaded and saved in the data storage computer file. The researcher also organised and managed the data into text in the format of transcripts. The researcher used the service of Information (IT) Technicians who activated a password for safekeeping and protection of the data. Schurink et al. (2011:409) highlight the importance of storing all transcripts and field notes on the researcher's personal computer's hard drive and a memory stick.

- **Reading and writing memos**

This step entails reading the data repetitively to familiarise the researcher with data contents (Schurink et al., 2011:409). The researcher also listened to the voice recorder and wrote notes. At this stage, the researcher highlighted the emerging key ideas and concepts from data analysis and these were recorded by writing memos in the margins of the transcripts and notes. This process enabled the researcher to use the data as a source of reference for data analysis.

- **Generate categories and coding the data**

According to Schurink et al. (2011:410) this step refers to the researcher's awareness and describing of the meaning of the data in relation to the recurring ideas and themes emerging from the participants' response statements. The researcher read the data continually to ascertain themes and their meaning. This process assisted to check similarities and differences on the data. Different colour coding was applied where naming of the main categories and themes were described to which the data were linked.

- **Testing the emergent understandings and searching for alternative explanations**

Schurink et al. (2011:415) highlight that in this step the researcher examines critically the data and challenges the emergent understandings and patterns to identify any negative aspects. The researcher determined the value of the data and the linkages to the study. This process enabled the researcher to evaluate the data obtained from participants and established the most likely alternative explanations for richness of the results.

- **Interpreting and developing typologies**

Schurink et al. (2011:416) state that the interpretation involves making meaning and sense of the data. It is further highlighted that a typology refers to a conceptual framework in which the phenomena are clustered together as a result of similarities (Schurink et al., 2011:416). The researcher noted similarities in the participants' responses and these were classified as themes and sub-themes which were then supported by quotations from participants. Schurink et al. (2011:417) state that the data collected is interpreted and given meaning, thus making linkages with participants' point of view.

- **Presenting the report**

This is the final stage of the spiral where the researcher presents the data in what was found in the text, either tabular or figure form (Schurink et al., 2011:419). Data was made accessible in a report format for this dissertation. Tables were added to illustrate the study findings in order to create better understanding of the narrated report. Relations and linkages among categories of information presented were reported as well. This step is viewed as the primary mode for reporting the results of research (Schurink et al., 2011:419).

3.2.7 Trustworthiness of data

Rubin and Babbie (2011:451) define trustworthiness as the main focus of evaluating the rigour of a qualitative study. The researcher used the following techniques to establish

trustworthiness of the findings, namely: credibility, member checks, reflexivity and audit trail. These techniques are presented as follows:

3.2.7.1 Credibility

Schurink et al. (2011:419) state that credibility in qualitative research refers to the correct and accurate identification and description of the participants' responses. The researcher determined linkages between research participants' views and the researcher understands. Hall (n.d.:1) describes credibility as a strategy to ensure that the qualitative research is believable and account to participants' point of view. Peer briefing was also done with fellow researchers to determine accuracy, thus ensuring credibility of the study.

Lietz and Mayas (2010:196) assert that the utilisation of peer briefing helps to improve the research process by generating new ideas and determining any potential pitfalls in relation to the study.

3.2.7.2 Member checking

Creswell (2013:252) explains that member checking involves taking data, analyses, interpretations, and conclusions back to the participants in order for them to make a judgement about the accuracy and the credibility. The researcher went back to all ten research participants and presented the findings and asked them to confirm the accuracy of the presented data. The participants confirmed that the findings were a true reflection of their responses. The purpose of this exercise was to eliminate any contradictions in existence in relation to the data obtained from the participants. Harper and Cole (2012:511) affirm that member checking entails taking data and tentative interpretations back to participants to determine and confirm whether what was recorded and transcribed accounted to the same meaning provided by the participants

3.2.7.3 Reflexivity

Creswell (2013:47) indicates that reflexivity enables the researcher to take a standpoint regarding his background for example, work experiences. Lietz and Zayas (2010:192) assert that reflexivity entails building self-awareness by the researcher throughout the research project. The researcher disclosed his background to the participants. This was

intended to solicit the confidence of participants in order for them to participate in the study. Creswell (2013:217) states that the researcher needs to be self-conscious about his/own biases, values and cultural background when conducting the study. The researcher was conscious about his values, beliefs and work experiences to avoid any biases in the execution of this study.

3.2.7.4 Audit trail

Schurink et al. (2011:422) state that an auditing trail is a carefully planned activity incorporating all decisions and actions implemented by the researcher throughout the research process. The audit trail involved the tracking of all the documentation regarding the interactions between the researcher and the participants of the study. This required the researcher to look into his own perspective and self-critique to exclude biases.

3.2.8 Pilot study

Bless et al. (2006:184) state that the pilot study is a preliminary study conducted to determine whether the research methodology and the instrument are appropriate. It incorporates all the elements of the main investigation and helps to assess the appropriateness for data collection. According to Brink (2010:54), a pilot study in a qualitative research project helps to obtain information aimed at improving and making adjustments of the research instrument. The researcher conducted interviews with two PWE who are employed in the open labour market in the Ekurhuleni region. A semi-structured interview schedule was used in conducting the pilot study.

These two sampled participants were excluded in the main investigation. The process was aimed at testing the designed instrument to assess whether the questions would elicit meaningful responses and achieve the goals and objectives of the study. The instrument was adjusted accordingly and used in the main investigation.

3.2.9 Ethical considerations

The study adhered to the ethical principles of research, which are defined by (Strydom, 2011:114) as “a set of moral principles which is proposed by an individual or group, is subsequently accepted, and offers rules and behavioural expectations to guide the

researcher in relation to his/her interaction with research participants”. The researcher utilised Epilepsy South Africa’s and recruitment agencies’ databases to select participants guided by the selection criteria. The second phase was to contact selected participants by telephone and the researcher also indicated the purpose of the study to the participants.

Brink (2010:30) and Creswell (2013:174) agree that it is the researcher’s responsibility to conduct research in an ethical manner such as, protecting the anonymity of participants, voluntary participation, informed consent, avoidance of harm, debriefing, actions and competence of the researcher and the publication of the findings. The following ethical aspects were central to this study to ensure compliance.

3.2.9.1 Voluntary participation

Brink (2010:37) states that voluntary participation refers to the formalised established relationship between the researcher and the participants. The researcher utilised Epilepsy South Africa’s database and engaged in telephonic conversations with identified participants and introduced the study. The researcher also indicated to the participants the purpose of the study.

The researcher requested participants to form part of the study if they wanted to do so. The researcher also emphasised that participants were not unduly influenced or coerced to participate. The researcher also informed participants that they had a right to decide for themselves whether to participate in the study or not and that they would not be penalised.

3.2.9.2 Informed consent

Strydom (2011:117) emphasises that it is important for the research participants to sign the informed consent form as an indication of their voluntary participation in the study. As argued by Bless et al. (2006:142) informed consent is the right to know the purpose, benefits and risks of the study. Creswell (2013:174) affirms that informed consent requires the researcher not to deceive the participants in order to achieve the study objectives. In order to comply with ethical aspects, the researcher developed written consent form which contained information such as the purpose of study, the procedure

to be followed during the investigation, and the advantages and disadvantages of their participation.

This form enabled the researcher to create an enabling environment to avoid deception and misleading of participants. The researcher highlighted to participants that the aim of the study was intended for academic purposes. After this explanation, participants who agreed to participate signed the forms.

3.2.9.3 Avoidance of harm

Brink (2010:33) states that avoidance of harm is described as an undertaking by the researcher to avoid distress to participants. The author further emphasises that it is important for the researcher to minimise all risks of harm.

Creswell (2013:34) articulates that the researcher must ensure that he does not further marginalise the participants, but respects the participants and the sites for research. The researcher designed questions in such a manner that potential harm to participants was minimised.

The researcher conducted interviews with participants in their familiar workplaces to secure their physical and emotional well-being and to protect them from discomfort. The participants were assured that their participation in the study would not put their jobs at risk and that the information collected would not be shared with their management. The researcher also made arrangements in the event anyone was harmed.

3.2.9.4 Violation of privacy or confidentiality/anonymity

Strydom (2011:119) defines privacy as “to keep to oneself that which is normally not intended for others to observe or to analyse”. He further asserts that every individual has a right to privacy and it is his or her right to decide when, where, to whom, and to what extent his or her attitudes, beliefs and behaviour will be revealed.

Confidentiality was included in the signed voluntary informed consent form. Strydom (2011:119) emphasises that confidentiality can be viewed as an extension of privacy, which entails the agreements between the researcher and participants in the sharing of private information. The researcher assured the participants that their identities would

be protected by using codes and all data gathered during the study would not be divulged or made available to any other person without their informed consent and that their names would not be revealed. The researcher used codes to replace the participants' respective identities.

According to Strydom (2011:120) anonymity means that “no one, including the researcher, should be able to identify the participants after the research has been concluded”. However, anonymity could not be safeguarded because the participants are known to the researcher.

3.2.9.5 Debriefing

Strydom (2011:122) states that debriefing refers to an aftermath of organised sessions to address negative experiences encountered by participants during the data collection process. The researcher enquired from the participants and asked if there were any issues that had a negative effect on their emotions or they needed clarification with. However, all the participants in the study indicated that they were fine and there was no observation or manifestation of both physical and emotional harm. The participants did not express the need for clarification of issues.

3.2.9.6 Actions and competence of researcher

Bless et al. (2006:145) state that researchers have an ethical obligation and responsibility to develop projects that are well constructed and implement them appropriately. The researcher successfully completed the research module (MWT864) at the University of Pretoria prior to the implementation of the reported study. This process enabled the researcher to prepare adequately to conduct the study. Bless et al. (2006:145) emphasise the importance of ensuring that ethical obligations and all research requirements are met. The researcher also developed a well-designed project and executed it with care under supervision. Strydom (2011:124) urges researchers to evaluate all possible risks and advantages of the investigation and to assume responsibility for conducting the investigation in a professional manner.

3.2.9.7 Publication of the findings

The findings of the study will be introduced to the reading public in a scientifically written form (Strydom 2011:126). Further, the research report will be submitted and made available to the University of Pretoria as well as Epilepsy South Africa in the Ekurhuleni region. The data will be stored for 15 years at the Department of Social Work and Criminology in line with the policy guidelines of the University of Pretoria.

3.3 RESEARCH FINDINGS

This section will entail the biographical data of participants, themes, sub-themes and a summary. Findings of the biographical information will be presented in figures with analysis. The findings of the interviews will be presented in the form of themes and sub-themes emerging from the analysis. The next section presents the participants' biographical information and the empirical research findings.

3.3.1 Biographical data

In this section, the research findings of the biographical data are presented. Table 1 presents a summary of the age profile of participants as follows:

3.3.1.1 Age of participants

AGE	No. of participants	%
23-35	5	50
35-45	1	10
45-55	4	40
55-65	0	0
Total=	10	100

Table 1: Age of participants

Table 1 indicates that five out of ten participants between the ages of 23-35 years were gainfully employed in the open labour market, whilst one was between 35-45 and the remaining four were falling between the 45-55 age categories.

The finding indicates that PWE in these prime ages were able to trade their skills and remained active in the open labour market. MerSETA (2008) supports the finding by stating that young people were targeted for learnerships as one of the skills development and training programmes to enable the youth to participate actively in the employment sector.

This finding also highlights that an insignificant number of PWE falling between 35-45 age categories was employed in the open labour market. Further it is important to note that four out ten participants aged 45-55 years had an opportunity to participate in the open labour which was a significant number compared to one out ten between the ages of 35-45 years. It is however interesting to note that no participants between 55-65 age category formed part of this study as a result lack of economic activities and retirement.

According to the study conducted by (Statistics South Africa, 2014:2), the working age population comprised of persons aged between 15-64 years. However, in the context of this study, participants started to engage in economic activities at an earlier stage from 23-55 age categories.

3.3.1.2 Gender of participants

GENDER	No. of participants	%
Male	7	70
Female	3	30
Total=	10	100

Table 2: Gender of participants

Table 2 indicates that seven out ten male participants were employed in the open labour market. This gender presentation highlights the challenges experienced by female PWE to participate in the open labour market. This is supported by the INDS (1997:4) which states that women are typically viewed as second class citizens, subservient to males and in need of protection. Further, Emmert (2006:207) argues that being a woman implies an increased set of barriers and obstacles to participating in various spheres of life. To take the argument further, the picture painted by the finding implies that female

PWE are significantly excluded from being economically active in the open labour market. This also indicates that females with epilepsy experience double discrimination, at first as females in general; and then as females with epilepsy when it comes to employment issues.

This finding further confirms that the South African society is still patriarchal and very discriminatory (INDS, 1997:4). In agreement, Majiet and Africa (2015:101) state that patriarchy continues to restrain full participation of women in leadership structures in African countries such as Zimbabwe. In support, Mompei (2015:32) states that while the lives of many women in South Africa have improved the majority still live under challenging social and economic circumstances. Olney (2015) asserts that when women are engaged in developmental projects there is a potential for enhancing sustainable livelihoods. This is an indication that there is a need to intensify gender transformation processes in South Africa to achieve sustainable developmental goals (SDG's) for PWE.

3.3.1.3 Race of participants

Race	No. of participants	%
African	5	50
White	5	50
Coloured	0	0
Indian	0	0
Total=	10	100

Table 3: Race of participants

Table 3 indicates that five participants were African and White respectively. There were no participants representing the Coloured and Indian races in the industries from which participants were sampled. The Commission for Employment Equity Annual Report 2012-2013 (Department of Labour, 2013:9) indicated that the Coloured and Indian social groups would be economically active in other work environments. According to Statistics South Africa (2015:3) the coloured community accounted for 8.8% of the total

population, whereas the Indian group was at the lowest level at 2.5% of the total population in South Africa. The non-participation of the Indian group in the study could be attributed to their low level of representation.

3.3.1.4 Educational level of participants

Educational Level	No. of participants	%
Grade 6-9	3	30
Grade 10-12	4	40
Certificate	1	10
Diploma	1	10
Degree	1	10
Total=	10	100

Table 4: Educational levels of participants

Table 4 indicates that three out of ten participants obtained Grades 6 - 9, while four have passed Grades 10-12. One participant obtained a certificate, the other participant obtained a diploma and the remaining participant obtained a degree as their highest educational qualifications. This finding highlights that PWE were able to obtain high school and tertiary qualifications. Sung, Muller, Jones and Chan (2014:469) state that higher levels of education and vocational rehabilitation services are enabling mechanisms to obtain successful employment. This is supported by Engelbrecht (2008:167) who states that education, knowledge and skills are essential job requirements for economic productivity. The Department of Women, Children and People with Disabilities (DWCPD) (2012:2) however, suggests that functional illiteracy result in low skills levels and a correspondingly limited access to employment opportunities for people with disabilities including PWE.

In support, the White Paper for Post School Education and Training (2013:57) highlights that low skill levels have consistently been identified as a serious impediment to economic development. The White Paper for Post School Education and Training (2013:3) further argues that. quality education is an important right, which plays a vital

role in relation to a person's health, quality of life, self-esteem, and the ability of citizens to be actively engaged and empowered. The Paper further highlighted that good quality education and training will allow more rapid economic, social and cultural development for society as a whole.

3.3.1.5 Type of employment

Type of employment	No. of participants	%
Manager/supervisor	1	10
Director/Assistant Director	0	0
Cleaner/Labourer	2	20
Admin clerk/Receptionist	2	20
Security Guard	0	0
Other	5	50
Total=	10	100

Table 5: Type of employment

Table 5 indicates that only one out of ten of participants occupied a managerial or supervisory position in the open labour market. The other three participants were employed in lower job categories. The remaining four participants' employment statuses were not described as they were classified under others, such as, a precision blaster, a driver, teacher and petrol attendant. Holland et al. (2009) argue that employment rates increase among highly educated professional workers with epilepsy, as employers may implement a different retention strategy compared to the one on low-skilled manual occupations. The next section will present themes and sub-themes that emerged from the research findings.

3.4 KEY THEMES

The research findings are presented narratively and direct quotes and literature are used to support the findings.

Table 6: A summary of the identified themes and sub-themes

Themes	Sub-Themes
Theme 1: The potential to work in the open labour market	1. Capacity to work in the open labour market. 2. Insight on personal ability.
Theme 2: Coping with epilepsy	1. Dealing with seizure occurrence 2. Understanding of epilepsy by colleagues.
Theme:3 Knowledge about the rights of workers	1. Equal pay for equal work 2. Disclosure versus non-disclosure 3. The right to decent work
Theme: 4 Support systems.	

Theme 1: The potential to work in the open labour market

All participants indicated that they have the ability to execute their duties as required by their respective employers. They also highlighted that sometimes epilepsy and limited resources can limit their ability to do work as prescribed in their job descriptions. Sub-themes emerge and participants' views are captured by the quotations.

Sub-theme 1: Capacity to work in the open labour market

The findings reveal that eight out of ten participants reported that having epilepsy did not compromise their ability, strengths and skills to perform their work activities as expected by their employers. The finding is supported by the following quotes from participants:

“My work responsibilities as a front desk receptionist entail welcoming clients into the slow lounge room of the British Airways.

‘My job involves capturing client’s information on the system, do rounds just to check cleanliness according to hygiene standards, check the food if it’s in a good order and sorting of magazines and newspapers.’

“My responsibilities involve supervising people...to ensure that they are doing their job properly and help where I can solve any existing problems”

“My work responsibilities as a warehouse controller involve preparing transport schedules, stocktaking, checking orders, deliveries and compiling weekly reports”.

“My responsibilities involve cleaning, sweeping, replacing roller tissues, cleaning substrates and liaison with stores for material supplies.”

“Although I am living with epilepsy, I am skilled and use my ability to perform my duties in the open labour market”.

“My physical and emotional strengths allow me to perform my tasks to the best of my ability according to my job specifications.’

‘In my work environment I have developed skills to clean basins and wall tiles, empty and wash dustbins. Again, I sweep passages, scrub, mop and polish floors. In addition, I dust and polish furniture... clean windows, doors and walls, vacuuming offices and stripping floors. My supervisor usually helps me with the work schedule.’

It also emerged from the findings that two out of ten participants reported the contribution of the employer skills development programme in the form of workshops, in-house and external trainings enhances their capacity to execute their duties effectively. The following direct quotes confirm the finding:

“We are exposed to work related training programmers in order to do our work effectively and improve our productivity.”

“Our employer provided skills training workshops with regard to health and safety issues in order to promote safety for PWE in the work environment.....”.

The above-mentioned statements endorse the view which states that PWE with necessary knowledge and skills are able to perform in a variety of jobs effectively and with success (Epilepsy Foundation (n.d.:1). The ILO (2009c) states that PWE who have had access to education and training have the opportunity to make a major contribution at all levels of the economy and society. The end result is that PWE will be enabled to improve their socioeconomic living conditions. Lee (2005:57) articulates that knowledge

and skills of PWE have a positive impact on (PWE) employability in the open labour market. Further, Lim et al. (2013:132) highlight that education plays an important in sourcing employment and creating opportunities for all people to participate in economic activities.

Sub-theme: 2 Insight on personal ability

All participants reported that they are aware of their strengths and weaknesses when carrying out their duties. The insight on personal ability of participants is reflected in the following statements:

“I know what my job entails and I am always conscious about safety issues at work because of my condition”

“Although I know my work, obviously... I cannot continue with any work after having had a seizure...because I am exhausted.....and my mind is battling to function and still recovering. However, I know my abilities in relation to my work and limitations because of epilepsy.’

“I am aware of my strengths and weaknesses in my work situation... and strive to do my best in performing my work activities.’

“I always try to perform tasks and adhere to my job specifications as required by my supervisor.”

One participant acknowledged that his job was a high risk but continued to work as driver and providing chauffer services to clients. The following statement confirms participant’s position:

“My job involves driving customers to different destinations. Although I know the risks involved, I do perform my tasks as required because my seizures only happen at night and not during the day.”

The findings confirm participants’ basic understanding of their personal abilities as aligned to their work activities. The National Policy of Social Development Services to People with Disabilities (DSD, 2013:13) articulates that the developmental approach

acknowledges people's capacities, skills and abilities which are best supported by an enabling social and economic environment.

Theme 2: Coping with epilepsy

All participants reported that they have sufficient knowledge with regard to epilepsy management in their workplaces. The following sub-themes emerged from the analysis:

Sub-theme 1: Dealing with seizure occurrence

The finding reveals that the majority eight out of ten do not experience frequent seizure occurrences as indicated by the following statements:

"I don't get seizures at work."

"In my case, I have never had a seizure at work."

"I have no seizures at work. I do my tasks and responsibilities as required by the company."

"I have no seizures at work or when I am not off work... my epilepsy is well controlled. I have been seizure free for five years now."

"I only work when I feel healthy but never had a seizure at work."

"I have no seizures...my epilepsy is controlled. I am now 32 years without a seizure working in the open labour market."

"I have no seizures at work but I cannot remember when last I had a seizure. It must be two years."

"In the six years working here I have had only two seizures. So I cannot remember being helped by my colleagues."

The findings confirm that participants who do not have seizures at work are able to continue with their work activities without any disruption. Three participants indicated that their seizures were well controlled and never had seizures at any given intervals. Although one participant PWE might not have experienced a seizure in the past 32

years it does not mean that his epilepsy has been resolved or cured. Further there are no guarantees that a person's epilepsy will not happen again (ILAE, 2014).

The findings also indicated that the remaining two participants experienced seizures, but in different ways. The following quotations illustrate different patterns of seizure onset experienced by participants:

"It's quite tough because sometimes I feel dizzy and become unfit to work when it happens. After a seizure I need a full rest."

"For me the seizure onset does not last long. My recovery is immediate and after having had a seizure, I can continue with my work."

The finding highlights that PWE have different seizure experiences. One participant was unable to proceed with work activities whilst another participant was able to continue with his or her activities after having had a seizure. Holland et al. (2009:1035) mention that a seizure onset is a determining factor in performing tasks and retaining employment, but this differs with individuals. Further Fisher et al. (2005) state that epileptic seizures occur at different intervals. This means that no PWE would experience the same type of seizure in their lives. Thompson (2013) asserts that living with epilepsy means coping with unpredictable seizure episodes for better management. The Epilepsy Talk (2012) highlights that anti-seizure medication plays a critical role in seizure control and helps to minimise the frequency of occurrence. However, this does not mean that medication will diminish the permanent occurrence of seizures to PWE. Epilepsy Society (2014) states that for some PWE seizures stop on their own accord and this situation is called spontaneous remission. However, the findings indicate that PWE complying with their medication will have less frequent seizures.

Sub-theme 2: Understanding of epilepsy by colleagues

The finding indicates that seven out of ten participants reported that their colleagues had basic information and understanding of epilepsy and treated them equally as colleagues.

The finding is supported by the following responses from the participants:

“Firstly... they treat me like any other person....should a seizure happen they get frightened but after some time they understand my condition.”

“All colleagues understand that I’ve got epilepsy.”

“My colleagues have a positive understanding of my condition.”

‘My colleagues do understand and know about my epileptic condition. They can also tell when a seizure is going to occur to me. ’

“My colleagues understand epilepsy as they have information around epilepsy.”

“My colleagues understand epilepsy as they have been trained how to deal with person when he is experiencing a seizure.”

“My colleagues understand that people with epilepsy are like any other person and that they should be given opportunities in the open labour market”.

Two participants reported that their epileptic condition provided challenges to their colleagues in the work environment. Two participants elaborated as follows:

“I wouldn’t say that my colleagues understand epilepsy...because in my understanding epilepsy is not out there. It’s not exposed like HIV/AIDS. A lot of people don’t still know about epilepsy....therefore, they are not so much exposed to this sickness.”

“My colleagues know about the disease... but when a seizure happens they become scarred and it appears they are not well sensitised about epilepsy.”

One participant reported that all of his counterparts did not know about his epileptic status with the exception of one colleague that he confided to. The following quotation demonstrates participant’s position:

“I have not disclosed my condition to my colleagues with the exception to one person closer to me”.

The findings indicate that participant’s other counterparts were not aware of the participant’s epilepsy status. Some participants are afraid to disclose their epilepsy condition. The Epilepsy Talk (2012) states that it is important for PWE to inform their

colleagues about their epileptic condition. The advantage of sharing this information will enable PWE's colleagues to provide necessary assistance should a seizure happen. PWE's colleagues need to be alert when their co-workers (PWE) have a seizure in order to know what to do before, during and after a seizure and what they should not do if a seizure occurs.

On the contrary, the disadvantage of withholding information about the condition will bring about fear and shock to PWE's colleagues when suddenly someone gets a seizure (The Epilepsy Talk, 2012). Counterparts might leave PWE on their own when a seizure occurs. Furthermore, this situation might lead to isolation of PWE and impact negatively on PWE's productivity at work (Epilepsy South Africa Employment Manual, n.d.:12).

Theme 3: Knowledge about the rights of workers

All participants reported that they have basic knowledge of their rights in the work environment.

The following sub-themes emerged from the analysis:

Sub-theme 1: Equal pay for equal work

The finding reveals that nine out of ten participants responded in the same manner and indicated that they are treated equally as their counterparts as they earned the same salary for equal work done as their colleagues. The finding further confirms that participants had knowledge about their rights to have access to the same opportunities as with their co-workers (RSA, Constitution 1996). Further the RSA (Constitution 1996) provides that all people have the right to fair treatment by their employer. Further this finding confirms meeting of different needs of vulnerable people including PWE as a developmental approach aspect (Twenty Year Review, South Africa, 1994-2014:31).

However, it also emerged from the findings that the remaining one participant reported that he does not earn the same salary as his colleagues because the employer uses the standard grading system from A – D. One participant said:

'My remuneration is based on the number of clients that I have transported on a daily basis to different destinations. However, my salary is also based on the job grading system between A-D categories.'

This means that no discrimination existed as the participant was remunerated according to his job grading system. The finding indicates that employers treated PWE equally, hence upholding the principle of equality in the work place in line with the Labour Relations Act (1998) and the Broad Based Black Economic Empowerment Act (2003). Further, the European Social Fund (2014-2020) states that employment and equal remuneration provide people with disabilities PWE with independence, financial security and a sense of belonging. In support, the Employment Equity Act (1998 as amended) promotes the elimination of unfair discrimination in respect of remuneration by applying the principle of equal remuneration for equal work.

The Constitution of Republic of South Africa, 1996 also stipulates that people with disabilities including PWE are entitled to enjoy equal rights in their respective workplaces without any form of discrimination by their employers.

Findings indicate that PWE enjoy economic rights similar to their counterparts. They are treated fairly and equally.

Sub-theme 2: Disclosure versus non-disclosure

During the interviews participants were asked about their position with regard to disclosure or non-disclosure of their epilepsy status to their employers and co-workers. The findings indicate that participants expressed different views regarding disclosure or non-disclosure. Some believe that it is necessary to disclose their epilepsy condition to employers and co-workers while others think differently. The following quotation articulates one participant's opinion:

"I have not disclosed my epilepsy to my other colleagues. It's only one person that I have confided in. I have told him about my condition and asked for advice from him as what to do. He said that if our employer could know about my epileptic condition, the employer might terminate my employment. So, I asked him what I should do. He

advised me that I should continue with my treatment. If it becomes worse, he suggested that I will have to disclose my condition.”

One participant highlighted the following:

“... I am not obliged to come out and tell the whole staff that I am suffering from epilepsy. I have a right to privacy”.

It also merged from the findings that eight out of ten participants believe that it is right to disclose their condition to their employers regardless of whether or not they support them. Participants expressed their views in the following manner:

“PWE need to inform their colleagues and management about their condition in case it happens while they are on duty”.

“PWE should disclose their condition in the workplace so that they can be assisted appropriately”.

“I have informed have my management and colleagues about my epileptic condition”.

“If your employer knows about your status I don’t think it affects one’s ability as long as you report to the people whom you work with and tell them that you have epilepsy so that everything will be OK”.

The Epilepsy Talk (2012) states that it is not always necessary to discuss epilepsy with the employer. This means that PWE have a right to disclose or not to disclose their condition to the employer as protected by The Labour Relations Act (1995) and the Employment Equity Act (1998).

However, it is further highlighted that if PWE have excellent seizure control and have a choice to discuss their epilepsy status with the employer then reasonable accommodation can be negotiated (Epilepsy Employment Manual, n.d.:57). The advantage of disclosure will enable PWE to benefit and secure workplace accommodation that meet their individual needs (The Epilepsy Talk 2012). This will enable the employer to make necessary adjustments and concessions to create an enabling work environment for PWE.

Sub-theme 3: Right to decent work

All participants are aware of their working conditions and right to decent work and believe that they are entitled to employee benefits in their respective workplaces like any other person who does not suffer from epilepsy. Participant stated that as employees, they are entitled to resting and intervals such as tea breaks and lunch and other related benefits. The participants said:

“I am medically covered by the company. I am contributing a quarter of my salary and the company provides its equal contribution. Other benefits include Unemployment Insurance Fund and access to the Employee Wellness Programme. If employees experience hard times in their lives, employees are assisted through this programme.”

‘I am entitled to resting and interval times such tea breaks and lunch on a daily basis.

“ I receive my basic monthly salary. I am also entitled to transport and sleep out allowances when working outside the province.”

‘I do get benefits in the same manner like my colleagues. My benefits include pension fund, Unemployment Insurance Fund, a funeral scheme, and study fund.’

‘My benefits involve education and training courses that are paid for by our employer.’

‘My company pays my basic salary, leave days, sick leave and the employer contribution towards my pension fund.’

‘I am entitled to leave days, sick leave and medical assistance as part of my benefits as an employee in my company.’

‘My benefits only entail the Unemployment Insurance Fund and the Provident Fund.’

The INDS (1997:43) states that people with disabilities including PWE must enjoy the same employment benefits like other employees in line with the Labour Relations Act (1995) and the Employment Equity Act (1998) for example, unemployment insurance, pension scheme and medical aid. The labour legislation and other international instruments such as the ILO promote decent work for PWE employed in the open labour market. Banerjee (2005:9) explains that people with disabilities including PWE deserve

decent working conditions that are inclusive of benefits in their respective workplaces. In agreement, Somavia (2009) affirms that the primary goal of decent work is to promote the fundamental rights and dignity of people with disabilities, including PWE in the work place, thus achieving sustainable developmental goals. The ILO (1996-2015) affirms that decent work involves opportunities for work that deliver a fair income; provide security in the workplace and social protection for workers.

Theme 4: Support systems

Participants were further asked about the existence of support systems in their workplaces. Seven out of ten participants reported that they received support from their management.

Participants' statements on support systems are as follows:

"The in-house medical team members and my colleagues are part of my support system."

"I must say that structures such as the Employee Wellness Programme, and psychological counseling services provide crucial network support system at work".

"Supervisors/managers play an important role in providing their support to PWE.

"My supervisor/manager displays a positive attitude towards me and this shows acceptance and understanding of my condition.'

However, some participants had a different experience. Three participants reported that they do not get support from their employer, only from colleagues. The following remarks confirm this finding:

"It's only my colleagues have always shown their willingness to assist should it happen that I have seizure.'

'There is a definite lack of management support systems within the company but colleagues do come together to assist when someone is having a problem."

"I know that my only colleagues always play a supportive role whenever I have seizures in my work environment.'

Blaauw, Pretorius, Louw and Schenk (2007:231) indicate that several studies affirm that social networks for support are vital in coping with various negative aspects of a given environment. In support, Schneider (2006:8) contends that environmental factors in the individual's level of functioning, such as a positive attitude of the employer and co-workers and structural arrangements will enable people with disabilities including PWE to feel accepted and being part of the team in their respective workplaces. Furthermore, contradictions were observed with the findings. One participant had a different view and said that:

"I do not need any support system because I have a mild type of epilepsy and my recovery is immediate. Therefore... I do not need any support from my colleagues or management".

In extreme cases some participants reported that employers can dismiss an employee in instances where support systems do not exist. One participant said:

"If one has a problem with the employer, the employer will go the Agency/Labour Broker and inform him that he can no longer work with you (PWE). In that case, one gets retrenched from work or his employment is terminated with immediate effect without any benefits."

Participants acknowledged that support was mostly obtained from their colleagues whereas one participant indicated dual support coming from the in-house medical team and colleagues at work. One participant cited the provision of the Employee Wellness Programme which involves psychological counseling and it is a management supported programme.

3.5 SUMMARY

This chapter presented the research methodology and served as a foundation and guideline for the entire study. Further it discussed and detailed the research findings that emanated from the empirical study. Four themes emerged from the data, of which three themes included sub-themes. The empirical findings were presented in a table forms; and narratively with its analysis supported by participants' responses.

Chapter 4 presents a summary of the key findings of the study, followed by conclusions and recommendations based on the research result.

CHAPTER 4

KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

This chapter presents the key findings. Conclusions are drawn from the literature review and empirical findings on the socio-economic experiences of PWE employed in the open labour market. It also provides recommendations based on the key findings and conclusion.

4.2 GOAL AND OBJECTIVES OF THE STUDY

The research goal was to explore the socio-economic experiences of PWE employed in the open labour market in the Ekurhuleni region.

The goal of the study was achieved; supported by the objectives:

Objective 1: To explore and describe various types of epilepsy.

This objective was achieved and described at length through a literature review in Chapter 2. Types of epilepsy and different behavioural patterns experienced by PWE were also discussed. An alignment was made with regard to seizure onset and PWE's work activities.

Objective 2: To explore the influence epilepsy has on people's social functioning and well-being.

This objective was achieved as participants reflected on their overall social functioning and well-being in the work environment.

The findings indicated that epilepsy did not prevent PWE to work in the open labour market. Furthermore the findings revealed that PWE developed effective coping mechanisms through compliance to their epilepsy medication.

Objective 3: To explore the socio-economic benefits enjoyed by PWE employed in the open labour market.

This objective was achieved as the findings highlighted the socio-economic benefits obtained by PWE.

The empirical findings revealed that PWE are entitled to the same employment benefits such as the provident fund, Unemployment Insurance Fund, resting times and sick leave as their colleagues within their respective work places. The findings also indicated that PWE received equal economic benefits as with their able-bodied counterparts.

Objective 4: To explore and describe the challenges PWE experience in the workplace.

The objective was achieved as the participants (PWE) expressed the challenges they experience in their work environment.

The findings revealed that some employees (PWE) were afraid to disclose their condition to the employer. Further, findings reveal that some PWE are not well informed about their rights. The findings also indicated that some PWE experienced challenges after having had seizures in the workplace such feelings of dizziness and inability to continue with work tasks.

4.3 KEY FINDINGS AND CONCLUSIONS

The conclusions drawn from the findings are presented holistically to highlight critical aspects that emerged from the analysis of the study. The conclusions are:

4.3.1 Employability of PWE in the open labour market

The findings revealed that living with epilepsy is not a barrier to employment of PWE in the open labour market. The findings also revealed that PWE are like any able-bodied people and have the capacity to work in different job categories in line with their work skills. The findings also confirmed that PWE are able to perform various tasks as expected by their respective employers in accordance with their job descriptions. Furthermore the findings indicate that PWE are like any other able - bodied people, they have the potential to be employed in different positions in the open labour market.

4.3.2 Coping with epilepsy management

The findings revealed that PWE with less frequent or no seizures at work are able to function effectively with minimal disruptions in the execution of their work activities.

The findings revealed that PWE are coping well at work, do not experience frequent seizures and that they are able to function effectively with minimal disruptions whilst performing their work tasks. The findings also indicated that PWE benefitted from the Employee Wellness Programme which promotes improved quality of life, productivity and compliance to medication. The findings also revealed that PWE experiencing less frequent seizures can participate in mainstream economic activities

4.3.3 Knowledge about the rights of workers

The findings reveal that PWE enjoy the same economic benefits like their able-bodied counterparts and do not experience any discrimination. However, the findings also indicated that PWE are not well informed about their rights with regard to disclosure or non-disclosure to the employer in relation to their epilepsy status. The decision whether or not to disclose epilepsy is dependent on PWE as it would have positive or unintended consequences such as immediate dismissal by an employer. Reasonable accommodation is partially implemented, some employees disclosed their condition, but others were reluctant to do so.

The findings also reveal that although PWE are conscious about their right to equal pay for equal work as with their able-bodied counterparts. However, they are not knowledgeable about the protection of their socioeconomic rights as provided in the Labour Relations Act (1995) and the Basic Conditions of Employment Act (1998).

4.3.4 Support networks

The findings reveal that PWE's received support from colleagues. It also emerged from these findings that PWE benefitted from existing support networks such as the Employee Wellness Programme in terms of psychological counseling services. The findings also indicated that PWE's condition was well understood by their colleagues and accepted PWE as part of the team.

Based on the above findings, it can be concluded that support systems for PWE exist in other work environment and that PWE are understood by their colleagues. However the findings also revealed that there is lack of support from management in other workplaces.

4.4 RECOMMENDATIONS

The following recommendations are presented based on the key findings and conclusions:

- A strategy is needed to increase the employability of PWE the open labour market. Employers should establish Workplace Skills Committees where they are non-existent to ensure that PWE placed in jobs that match their skills levels
- PWE whose seizures are controlled should be encouraged by employers and colleagues to comply with their medication as this would yield long-term work retention.
- Epilepsy South Africa as an expert leader on epilepsy has an important role to strengthen its advocacy programme and partner with labour to monitor the legislation pertaining to the rights of PWE in the open labour for example, the right to disclose or non-disclosure and non-discriminatory practices in the workplace. The monitoring process should be done on a quarterly basis to track compliance to the legislation by employers.
- To empower employers and employees with correct information on epilepsy and its management to employers and colleagues of PWE. This support service will complement existing Employee Wellness Programmes where these are non-existent. This should be done through education and training of employers and colleagues.
- Promotion of inclusion of PWE in the open labour market will strengthen the Code of Good Practice with regard to the employment of PWE in the open labour market. This could be done by conducting workshops on the labour legislation and the rights of PWE.

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APPENDIX A

PERMISSION LETTER FROM EPILEPSY SOUTH AFRICA


EPILEPSY
SOUTH AFRICA
GAUTENG BRANCH

NPO: 001-912 / PBO: 930007586

17 October 2013

Mr DA Kandawire

No 11 Napier Street

Crystal Park

Benoni 1515

Dear Mr Kandawire

PERMISSION TO CONDUCT A RESEARCH STUDY IN RESPECT OF PEOPLE WITH EPILEPSY EMPLOYED IN THE OPEN LABOUR MARKET IN THE EKURHULENI REGION.

On behalf of the Board of the Epilepsy South Africa Gauteng Branch's Board of Management, I hereby grant permission to DA Kandawire who is currently enrolled for a Masters' degree in Social Work at the University of Pretoria to conduct a research study.

Title of study: The socio-economic experiences of people with epilepsy employed in the open labour market in the Ekurhuleni Region.

Purpose of the study: To explore the socio-economic experiences of people with epilepsy employed in the Ekurhuleni Region.

It is envisaged that the study will contribute to the body of knowledge regarding the working conditions of people with epilepsy.

Yours faithfully



MJ Kruger

Director



Share Call Number: 0860 EPILEPSY (0860 374537) • www.epilepsy.org.za

East Rand Workshop: Tel: 011 8111591 • Johannesburg Workshop: Tel: 0826957405

Gauteng Branch:
Tel: +27 11 816 2040 • Fax: +27 11 816 1501
Postal: PO Box 1070, Springs, 1560
South Africa

Geduld Residential Care Centre:
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Daggafontein Residential Care Centre:
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South Africa

APPENDIX B
ETHICAL CLEARANCE LETTER FROM THE UNIVERSITY OF PRETORIA



F

19 December 2013

Dear Prof Lombard

**Faculty of Humanities
Department of Social Work & Criminology**

Project: The socio-economic experiences of employed in the open labour market
Researcher: DA Kandawire
Supervisor: Ms KP Mashego
Department: Social Work and Criminology
Reference number: 10590120

Thank you for your response to the Committee's correspondence.

I have pleasure in informing you that the Research Ethics Committee has approved the above study at an *ad hoc* meeting held on 18 December 2013. Data collection may now commence.

Please note that this approval is based on the assumption that the research will proceed along the lines laid out in the proposal. Should your actual research differ from the proposed research, it will be necessary to apply for a new ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. Norman Duncan
Dean: Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: tracey.andrew@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Panebianco-Warrens; Prof GM Spies; Prof E Tajard; Dr FG Wolmarans; Dr P Wood

APPENDIX C LETTER OF INFORMED CONSENT FOR PARTICIPANTS (PWE)



Researcher: Dominic Alpheus Kandawire (Kandas)

Address: 11 Napier Street

Crystal Park, Benoni

1515

Name of institution: University of Pretoria

INFORMED CONSENT FORM

Title of study: The socio-economic experiences of people with epilepsy employed in the open labour market in the Ekurhuleni Region.

Purpose of the study: To explore the socio-economic experiences of people with epilepsy employed in the Ekurhuleni Region.

Procedures: As a participant I will be required to participate in an unstructured interview that will require 60 minutes of my time. Afterwards I will be requested to complete a questionnaire which also forms part of the study (deleted).

Risks and Discomfort: I understand that there are no risks and discomfort that I may be exposed to in participating in this study. If I experience any psychological distress at any time during the research study, I will inform the researcher. I expect the researcher to then arrange counselling with a suitably qualified counsellor.

Benefits: I understand that there is no direct financial benefit to me for participating in this study. However, my participation in this study will help in promoting socio-economic rights of PWE rights in the workplace.

Participant's Rights: My participation in this study is voluntary and I may withdraw my participation at any time without negative consequences.

Confidentiality and anonymity: In order to record accurately the participant will say during the interview, a tape recorder/voice recorder will be used. The tapes will only be listened to by the researcher and authorized members of the research team. The information received from me will be treated confidentially and my identity will not be revealed.

Should I withdraw from the study, my data will be destroyed. The results of this study may be published in the researcher's thesis, professional journals or presented at professional conferences, but my identity will not be revealed unless required by law. I am aware that the data will be stored for 15 years

at the Department of Social Work and Criminology, University of Pretoria, according to the policies of the University.

Person to contact: If I have any queries or concerns, I can contact Mr Dominic Alpheus Kandawire (Kandas) on 082 932 0305 at any time. I understand my rights as a research participant and I voluntarily give consent for him/her to participate in this study. I understand what the study is about and how and why it is being done. I have received a copy of this consent form.

Declaration

I,....., understand my rights as a research participant, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being conducted.

-----	-----	-----
Date	Place	Participant's signature
-----	-----	-----
Date	Place	Researcher's signature

APPENDIX D
SEMI-STRUCTURED INTERVIEW SCHEDULE

THE SOCIO-ECONOMIC EXPERIENCES OF PEOPLE WITH EPILEPSY EMPLOYED IN THE OPEN LABOUR MARKET

SECTION: DEMOGRAPHIC INFORMATION

Please answer ALL the questions in this section by placing an X in the appropriate box

1. Age:	25-35		35-45		45-55		55-65	
2. Gender:	Male		Female					
3. Education:	Grade 6-9		Grade 10-12		Certificate		Diploma	
	Degree							
4. Type of employment:	Manager / Supervisor		Director / Assistant Director		Other			
	Cleaner / Labourer		Admin Clerk / Receptionist		Security Guard			

SECTION: B INTERVIEW QUESTIONS

1. THE INFLUENCE OF EPILEPSY ON THE SOCIAL FUNCTIONING AND WELL- BEING OF PWE.

- 1.1 Do you think epilepsy serves as a barrier to employment for PWE in the open labour market? If yes, please elaborate
- 1.2 How does living with epilepsy affect your ability to work in the open labour market?
- 1.3 Do you think the co-workers' attitude towards you impacts on your social functioning in the work environment?
- 1.4 How does the stigma attached to epilepsy affect your work activities?

2. SOCIO-ECONOMIC BENEFITS/RIGHTS ENJOYED BY PWE IN THE OPEN LABOUR MARKET?

- 2.1 What is your view regarding the rights of people with epilepsy to work in the open labour market?
- 2.2 Do you know your rights as an employed PWE in the workplace? Yes or no
Please elaborate.
- 2.3 Do you think PWE have the right to employment in the open labour market?
- 2.4 How are your rights violated in the work environment?
- 2.5 What benefits do you receive in your workplace?
- 2.6 Does your employer treat you equally as with your co-workers?

3. CHALLENGES EXPERIENCED BY PWE IN THE OPEN LABOUR MARKET

- 3.1 What do your colleagues do during and after a seizure?
- 3.2 What are your work responsibilities?
- 3.3 How do you deal with your work responsibilities after having had a seizure?
- 3.4 What support services are available to you in your work environment?
- 3.5 Does epilepsy affect your work performance?

4. What suggestions do you have for the employment of PWE in the open labour market?

APPENDIX E EDITORIAL LETTER

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Box 84664
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2034

0116463471 / 0824081917
janetwil@tafrica.com

Janet Wilhelm

March 16, 2015

I hereby declare that I have edited this document by Dominic Alpheur Kandawire (Kandas) entitled "The Socio-Economic Experiences of People with Epilepsy Employed in the Open Labour market in the Ekurhuleni Region". The edit entailed reviewing spelling and grammar, and checking for consistencies in style and reference method. I have not helped to write this document or altered the student's work in any significant way.

I did not check the validity of student's statements/research/arguments but undertook a basic copy edit. I cannot be held accountable for other errors or where the student has not accepted my editing. It was not my responsibility to check for any plagiarism and I cannot be held accountable should the student commit plagiarism.



Janet Wilhelm

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