

**PERSPECTIVES ON EPILEPSY ON THE PART OF PATIENTS AND CARERS IN  
A SOUTH AFRICAN URBAN TOWNSHIP**

by

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## DECLARATION

By submitting this thesis electronically, I MPOE JOHANNAH KEIKELAME declare that the entirety of the work contained therein is my own original work, that I am the authorship owner thereof (unless to the extent explicitly otherwise stated), and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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## DEDICATION

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## ABSTRACT

In a setting where epilepsy support services are available but are inaccessible and where the population is of low-socio economic background and where there are experiences of marginalization and oppression, people with epilepsy and their carers may have difficulties in accessing appropriate treatment and care. This qualitative study provides rich description of perspectives and subjective experiences of adults who have epilepsy and their carers in an urban Xhosa-speaking Black township in Cape Town, South Africa. The study sought to gain an understanding of how adults who have epilepsy and their carers understand the illness (epilepsy). Its aim was to explore their perspectives and subjective experiences and the objectives were to describe and analyse these aspects and to provide information that can be used to guide policy and future research.

The study used Kleinman's (1980) Explanatory Model Framework and his theoretical framework of understanding systems of health care and healing and the Socio-ecological theory of Bronfenbrenner (1994, 2005) to guide the inquiry process. A total of sixty one adults who had epilepsy and were on seizure medication and their carers such as medical doctors, home-based carers, traditional healers, family members who included wives, partners, siblings and parents and other carers such as friends and neighbours volunteered to take part in the study. Individual in-depth interviews, focus group discussions and direct observations of interactions between health care professionals and adult patients with epilepsy in a health care setting from which they received their treatment and care were conducted to gain insight into the problem. The findings point to differences in the way epilepsy is understood and experienced by people living with the illness and their carers from different sectors of health care. They show how lack of appropriate, empathetic, collaborative and integrated care can affect the health and well-being of adults who have epilepsy and their carers in the setting in which the study was conducted. The study concludes by providing a tentative conceptual model for future research and recommendations for actions that can inform and influence local policy and enable adults who have epilepsy and their carers to attain a good quality of life.

## Opsomming

In 'n omgewing waar epilepsie ondersteuningsdienste beskikbaar, maar nogtans ontoeganklik is, en waar die bevolking van 'n lae sosio-ekonomiese agtergrond met ervarings van marginalisering en onderdrukking bestaan, kan mense met epilepsie en hul versorgers probleme met toegang tot behoorlike behandeling en sorg ervaar. Hierdie kwalitatiewe studie bied 'n ryk beskrywing van die perspektiewe asook die subjektiewe ervarings van volwassenes met epilepsie en hul versorgers in 'n stedelike Xhosa-sprekende swart woonbuurt in Kaapstad, Suid-Afrika. Die studie het gesoek om 'n begrip van hoe volwassenes wat met epilepsie lewe en hul versorgers die siekte (epilepsie) verstaan. Die hoofdoel was om hulle perspektiewe en subjektiewe ervarings te verken, terwyl die hoofdoelwitte die beskrywing en ontleding van sodanige aspekte om inligting wat gebruik kan word om die gids beleid en toekomstige navorsingsondernemings te voorsien.

Hierdie studie gebruik Kleinman (1980) se verduidelikende model met sy teoretiese raamwerk oor die begrip van gesondheidsorg en genesings stelsels asook Bronfenbrenner (1994, 2005) se sosiologiese teorie om die ondersoek uittevoer. 'n Totaal van een en sestig volwassenes met epilepsie wat medikasie ontvang en hul versorgers soos mediese dokters, tuisversorgers, tradisionele genesers, familieledes soos vrouens, broers, susters, eggenote, maats en ouers tot vriende en bure het aangebied om in hierdie studie deel te neem. Individu in-diepte onderhoude, fokusgroepbesprekings en direkte waarnemings van interaksies tussen wespogeliede gesondheidswerkers en volwassenes pasiënte met epilepsie in die gesondheidsorg instelling waar hulle hul behandeling en versorging ontvang, is gedoen om insig in die probleem te kry. Die bevindings dui op die verskillende maniere hoe epilepsie verstaan en ervaar word deur volwassenes wat met epilepsie lewe en hul versorgers in die verskillende sektore van gesondheid. Dit wys hoe 'n gebrek aan geskikte, empatiese, saamwerkende en geïntegreerde sorg die gesondheid en welstand van volwassenes met epilepsie en hul versorgers in die omgewing waar die studie uitgevoer is kan bewerkstillig. Die studie sluit deur om 'n voorlopige konseptuele model vir toekomstige navorsing, aanbevelings vir optredes wat kan inlig en plaaslike beleid kan beïnvloed om vir volwassenes met epilepsie en hul versorgers te verskaf en in sodoene in staat stel om 'n goeie lewensgehalte vir hulle te behaal.



## **CHAPTER ONE**

### **Introduction and background to the study**

#### **1.1. INTRODUCTION**

This manuscript-style dissertation consists of and draws together seven co-authored published articles of which I am the first author. The dissertation is about perspectives and subjective experiences of adult people who have epilepsy; about carers from different sectors of health care such as health care professionals (HCPs), traditional healers (THs), home-based carers (HBCs), parents, wives, partners, siblings, friends and neighbours who provide support, treatment and care for people with epilepsy (PWE). The study seeks to understand how adults who have epilepsy and their carers who live in a predominantly Xhosa-speaking urban township in Cape Town, South Africa understand the illness (epilepsy). The main purpose of understanding perspectives on and subjective experiences of epilepsy from adults who live with the illness (epilepsy) and those who care them is that individuals have different understandings of illness in terms of its cause, treatment and care. There are social factors that have a great influence on individuals' health seeking behaviours. In addition, illness experience is also shaped by culture, which is a crucial part of the social system of meaning and norms that govern behaviour (Kleinman, Eisenberg & Good, 1978, p. 252). Therefore, the most appropriate way of understanding individuals' perspectives and subjective illness experiences is through exploring their personal stories (Fadiman, 1997; Schachter & Andermann, 2008). This dissertation therefore used the well-established Explanatory Models (EMs) Framework of Kleinman (1980) to provide in-depth descriptions of perspectives and subjective experiences of the study participants.

Swartz (1998) highlights the work of Kleinman (1980) who emphasized the importance of not just focussing on understanding the physical aspects of the illness, but also on individuals' experience of the illness. This is crucial because illness experience is characterized by concerns and questioning and a quest for meaning – “Why me? Why now?”. Therefore, exploring illness experiences enables shedding light on difficult issues with regard to the physical and social consequences for the individual and the carer, especially when the patient's condition worsens and the body bears more and more marks and is harmed or destroyed (Pierett, 2003, p.7). In epilepsy per se, illness experiences and illness stories are crucial because the illness itself is characterized by multiple factors which are responsible for its cause (Schachter & Andermann, 2008, pp. 9-11). Illness stories provide a good avenue to understanding individuals' lived experiences at different levels of the social and health systems. This further implies that studying illness stories is crucial because the illness can change or disrupt a person's life and can also create new and qualitatively different life conditions for the individual (Hyden, 1997, p. 52) and for those caring for them. This may be especially so in epilepsy because of the nature of its course and symptoms (Schachter & Andermann, 2008). This study therefore views the experience of epilepsy as part of a life story. It seeks to understand perspectives and subjective experiences of adults who have epilepsy and those who care for them. It is hoped that the study will be able to provide in-depth descriptions of perspectives and subjective experiences on epilepsy within the theoretical framework on which the study is based.

The seven peer reviewed journal articles included in this dissertation differ in focus and content and will each be presented in a separate chapter with an introductory note on what each chapter is about and on how each article links to the dissertation as a whole. An outline of the layout structure of the chapters of this dissertation and the publication status of each article is provided at the end of this introductory chapter in Table 1.1 (see page 9).



### 1.1.1. Motivation for doing the study

This study follows on from my work as a project manager in a community-based project that rendered community-based primary care services through home visits in a peri-urban Xhosa speaking township in Cape Town. CHWs raised concerns that during their home visits, there were some parents of CWE who did not understand epilepsy and its cause and treatment. They further reported that some of these parents informed them that they had removed their children from school because they were of the view that the condition would affect their learning. These workers further noted that other parents were reluctant to disclose their children's condition and this resulted in some leaving their work and some restricting their children from playing with others. In addition, they also stated that there were some parents whose children indulged in alcohol and drugs (Keikelame, 1998).

On the basis of these CHWs' concerns, I conducted a small qualitative study in 1998 among twelve parents whose children had epilepsy. The study explored what parents understood as the cause of their children's epilepsy and how they managed the illness. The study found that only four parents knew the medical cause of their children's epilepsy while eight did not know the cause. They lacked knowledge about management of seizure treatment as well as first aid care for seizures. There were some parents who believed that evil spirits and bewitchment triggered or caused their children's epilepsy and some reported that they were combining western and traditional treatment for their children's illness. In addition, parents lacked knowledge about a seizure diary, the kind of information to record in it and reasons for keeping a record of seizures. There were those who were willing to disclose their children's condition and some who were not in favour of the idea. Others reported that their children had some behavioural difficulties which they were unable to deal with. Part of the findings from my masters' project were published in a co-authored peer reviewed journal article entitled: 'Parents' understanding of the causes and management of their children's epilepsy in Khayelitsha, Cape Town' which was published by Keikelame and Swartz (2007) in the *South African Journal of Psychology*.

Reflecting back on these findings, there were some limitations. *First*, my sample consisted only of twelve parents whose children had epilepsy. *Second*, the findings could not be generalized because the study was specifically done among a group of Xhosa-speaking parents who were receiving community health care services from the project in which I worked. *Third*, I only interviewed parents who were known by these CHWs through their home visits. Therefore, I could have missed others who were residing in the study setting, who may have been receiving health care elsewhere. *Fourth*, PWE and other carers from other sectors of health care were not included in the study. Kleinman (1980) identifies three sectors of health care: the popular sector which comprises family members, neighbours and friends; the folk sector which constitutes carers such as THs and the professional sector which is made up of western trained health care professionals. Therefore, on the basis of my personal reflections, it was imperative to conduct this exploratory study into perspectives and subjective experiences of people who live with epilepsy and their carers in a context in which they live and receive health care. I was also interested in the current study to shift the focus of attention from children to adults with epilepsy because some of the CWE who had dropped out of school informed me that I could have also interviewed them after interviewing their parents.

### 1.1.2. Rationale for the study

Globally, epilepsy is regarded as an important public health problem (Ba-Diop et al., 2014; Bruno et al., 2015; Riasi, Sanati, & Ghaemi, 2015) and also one of the major causes of disability and mortality (Ngugi, Bottomley, Scott et al., 2013). It is also reported as one of the most stigmatized conditions (Baskind & Birbeck, 2005; Elafros, Bowles, Atadzhanov, Mbewe, Haworth et al., 2015; ILAE, 2003; Mula & Sander, 2016), and that epilepsy associated stigma is also one of the factors that affect quality of life (QoL) of PWE (Baskind & Birbeck, 2005; Mula & Sander, 2016). The problem is found to be worse in sub-Saharan Africa (SSA) (Baskind & Birbeck, 2005). Current estimates are that epilepsy affects about 70 million people world-wide (Abubakar et al., 2015; Sebera et al., 2015) – with 80% of PWE living in developing countries (Sebera et al., 2015; Sawant & Kinra, 2015). In the Global Burden of Disease 2010 study, in multinational surveys aimed at quantifying the burden of epilepsy in disability-adjusted life years relative to over 200 conditions and diseases, uncontrolled epilepsy ranked second. (Murray et al., 2012). In addition, the epilepsy burden is reported to pose some serious psychological and social challenges to PWE and their families (Fawale, Owolabi, Mustapha, Komolafe, & Adesola, 2015; Mula & Sander, 2016; Saada, Wang, & Batuista, 2015). PWE and their families must contend with the stigma due to sociocultural beliefs about contagion, probably especially in Africa (Ekeh & Ekrikpo, 2015). These challenges have a negative impact on the lives of PWE and their family members (Wolf, 2010). Efforts to address these challenges have been undertaken via the World Health Organization (WHO) Global Campaign against Epilepsy (GCAE) which aims to increase the public's understanding of epilepsy and to destigmatize the illness (De Boer, 2010; Dua, De Boer, Prilipko, & Saxena, 2006; WHO, 2004).

In South Africa (SA), about 84% of the population receives health care from the public health sector which is most rendered by clinical nurse practitioners (CNPs) with the support from medical doctors (Mash et al., 2012). Most of the patients with chronic illnesses are being seen by CNPs (Brand et al., 2013; Mash, Levitt, Van Vuuren, & Martell, 2008) and the majority are from lower socio-economic population groups (Mash et al., 2008). In addition, management of epilepsy in the public health sector is affected by a number of factors such as lack of trained HCPs in epilepsy, irregular supplies of anti-epileptic drugs (AEDs), language barriers, poverty and diverse cultural beliefs about epilepsy (Eastman, 2005; Williams, Nefdt, & Wilmshurst, 2015). Other factors affecting management of epilepsy and other chronic illnesses are comorbidities between mental, neurological and substance use (MNS) disorders (Jack et al., 2014).

Although current evidence shows that there are epilepsy studies that have been conducted in SA, they have tended to focus on examining the prevalence and risk factors related to active convulsive epilepsy (Wagner et al., 2014). Recent cross-sectional studies leaned towards the biomedical aspects of epilepsy such as those determining the types of investigations undertaken for adult PWE who were presenting with first onset of seizures in emergency care (EC) in the Western Cape (Smith, van Hoving, & Wallis, 2013). Another study by Gilani, Naidoo and Ross (2015) in Kwa-Zulu Natal assessed medical knowledge about epilepsy among PWE using the validated Epilepsy Knowledge Profile-General (EKPG) questionnaire. Those studies focussing on indigenous health practices for epilepsy were inclined to examine conditions where patients use herbal treatments (Marais, Steenkamp, & Du Plooy, 2015) while others investigated traditional treatments that are used to treat epilepsy (Marchetti, Gavazzo,

Stafford, & Van Staden, 2011). The recent 2015 Provincial Integrated Non-Communicable Disease (NCD) audit report of the Western Cape Provincial Government stresses some important strategies for improving the treatment and care of PWE – such as the patient centred approach which is emphasized in the Health Care 2030 document, facilitating empowerment, increased compliance and treating PWE with dignity and respect (Cloete, 2015). However, it does not emphasise the socio-cultural factors which are reported to pose some difficulties in understanding the illness (Bruno et al., 2011; Wolf, 2010).

Literature shows that epilepsy is an illness that is associated with many names which may have different meanings and interpretations. In one of the WHO International League Against Epilepsy (ILAE) anthropological studies conducted by Bruno et al. (2011, p. 347) among the Guarani people, the authors found that epilepsy was known as “*mano*” or “*die*” and that the terms meant that a PWE dies several times. In South Africa in Limpopo province, epilepsy names such as “*tshiiva*”, “*tshifakhole*”, “*tshirivha*” were reported by (Mangena-Netshikweta, 2003), but the author does not explain the meanings of the terms used. It is important to gain an understanding of these lay explanations since they may differ from how epilepsy is explained from the medical point of view (Kleinman, 1980). Even where medicalized terms such as “turns”, “fits” and “faints” are used by patients in their clinical encounters, the terms may be understood in myriad ways – which according to Ntusi (2015) often poses some challenges for proper investigation and management. Differences in understandings may have a negative influence on the health-seeking behaviour of patients with epilepsy and their carers. For example, in a South African rural study that explored patients’ experiences about their illness, Mc Queen and Swartz (1995) found that the word “mal” in grand mal and petit mal epilepsies was interpreted as “mad”, as the Afrikaans word for “mad” is “mal”. This interpretation resulted in labelling PWE in that community as “a little mad” (petit-mal) or “very mad” (grand-mal). For Kleinman (1980), the complexity of the difference between the explanations of illness between the lay and western trained professionals’ poses challenges for understanding of the illness. This study hopes to contribute to a better understanding of the way adult PWE and their carers understand and experience the illness (epilepsy).

### **1.1.3. Problem statement**

In South Africa, PWE may seek care from different health care sectors and may struggle to understand and manage the illness because of different understandings and explanations about its cause and treatment (cf. Kleinman, 1980). This could be due to some contextual factors that may have a direct or indirect influence on the treatment and care of adults who have epilepsy and their carers and these factors may be at different levels of the health system.

### **1.1.4. Research question**

The main research question for this study is: “How do people with epilepsy and their carers in an urban township in Cape Town understand epilepsy?”

*The sub-questions were:*

- What factors affect the understanding of epilepsy at the levels of individual, family, community and society and in what way?
- In the opinion of people with epilepsy and those who care for them, what kind of actions should be taken to address the factors mentioned? Who should take action?

- What are the likely challenges or barriers to taking such action?

### 1.1.5. The study aim

The main aim of this study was to explore perspectives on epilepsy and subjective experiences of adult PWE and their carers in an urban township in Cape Town, South Africa. The objectives were to describe and analyse these perspectives and subjective experiences in order to provide first-hand information which can be used to inform policy and to provide recommendations for appropriate interventions for improved treatment and care of adult PWE and their carers in this Black urban township in Cape Town.

## 1.2. THEORETICAL FRAMEWORK

The interest in making epilepsy understandable to the lay general public has been noted in the recent review of the medical definition of epilepsy by the ILAE and International Bureau for Epilepsy (IBE) (Fisher et al., 2014). This was in view of concerns that the word *disorder* that is used in the epilepsy definition could be contributing to the confusion and poor understanding of the illness by the general public (Fisher et al., 2014, p. 476). This led to the replacement of the word “*disorder*” with the word “*disease*” in order to align with other chronic conditions such as hypertension which are referred to as *diseases* – and also to promote acceptability of epilepsy as a disease like other diseases. According to Fisher et al. (2014, p. 477), the currently revised practical clinical definition of epilepsy which has been released is as follows:

*Epilepsy is a disease of the brain defined by any of the following conditions: (i) At least two unprovoked (or reflex) seizures occurring >24 hours apart, (ii) One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years, (iii) Diagnosis of an epilepsy syndrome.*

However, medical anthropologists such as Kleinman (1980) highlight that the word *disease* is a word that is used by western trained biomedical professionals, while lay people are orientated towards what he terms *illness* explanations. He explains illness and disease as follows:

*Illness refers to the psychosocial experience and meaning of perceived disease and involves different processes such as attention, cognition, perception, feelings, valuation of a disease and its manifestations, communication and interpersonal interactions within the family and social networks – while disease is about the malfunctioning of biological and or psychological processes.* (Kleinman, 1980, pp. 72-73)

The two conceptual frameworks that I used to inform my inquiry are described below:

### 1.2.1. Kleinman’s Explanatory Model approach

To conceptualize how PWE and their carers understand the illness (epilepsy), I used Kleinman’s (1978, pp. 87-90) EMs to guide my inquiry. For Kleinman (1978), EMs constitute a way of understanding how people recognize an illness, explain it and respond to it. These EMs are shaped and influenced by culture and are held by patients and their carers and can provide personal and social meaning with regard to the way illness is experienced by patients and carers in different sectors of the health system. In particular, Kleinman (1978) states that EMs provide explanations on any of

the five key aspects of the illness: (i) the illness aetiology; (ii) onset of symptoms; (iii) pathophysiology; (iv) course of sickness (severity and type of sick role); and (v) treatment. Kleinman (1978) further points out that EMs are of particular importance because they are also influenced by historical and socio-political factors and that they quite often conflict with each other and can influence health-seeking behaviours.

In her book entitled: *The spirit catches you and you fall down: A Hmong child, her American doctors and the collision of two cultures*, Anne Fadiman (1997, pp. 260-261) shows the health consequences for patients and carers when there are conflicting EMs between western trained medical doctors and lay people. The author echoed the importance of using Kleinman's (1980) eight key questions (covering the five aspects mentioned above) as a framework which can elicit lay cultural explanations of epilepsy and its treatment and care for improved health outcomes.

### **1.2.2. Kleinman's typology of systems of health care and healing**

According to Kleinman (2010), experiences of illness encompass the flow of words, movements and emotions – and are also about interpersonal actions in people's local settings such as networks, families, institutions and communities. He points out that health care is provided not only by western trained health care professionals. For him, there are three types of sectors of health care which have their own ways of explaining and treating illness and their own rules which govern the patients' treatment and interactions in the care giving process.

Kleinman (1980) identified three sectors of health care: the folk, popular and professional sectors from which people seek health care. In selecting my sample for this study, I used Kleinman's (1980) classification of types of sectors of health care to guide the selection of my study sample in order to gain a deeper insight on perspectives and subjective experiences of epilepsy from a broader network of carers who provide care for people with epilepsy in the study setting.

Using Kleinman's (1980) typology of health care sectors, my sample included the following carers: (i) folk carers who comprised THs; (ii) popular carers such as family members (wives, partners, neighbours, friends); and (iii) professional carers such as trained medical doctors (from the public and private health sector). In addition, my sample consisted of other types of carers such as HBCs from a local non-governmental organisation (NGO) who provided outreach health care services at community-based level (Nxumalo, Goudge, & Thomas, 2013). These carers have minimal training and straddle a space somewhere between the folk, professional and popular sectors and represent a group of carers not fully anticipated by Kleinman's typology. In terms of PWE, my sample consisted of adult males and females.

### **1.2.3. Bronfenbrenner's socio-ecological theory**

In order to gain a layered picture of these experiences from people who have epilepsy and their carers from different sectors of health care, I used Bronfenbrenner's (1994, 2005) socio-ecological model as a conceptual framework to organize my inquiry. Based on this conceptual framework, I assumed that PWE and their carers may have positive or negative experiences of the illness and its treatment and care through their continuous interactions within the different levels of the health system and that these experiences may vary between them.

According to Bronfenbrenner (1994, 2005), individuals have continuous interactions



at different levels of the social context. The author further states that individuals can be influenced or can influence the environments in which they live and grow through their continuous interactions within the system. I therefore thought that subjective experiences of PWE and their carers may be different for each individual as each individual can influence the environment and that the environment can also influence the individual. For Bronfenbrenner (1994, 2005), the social context is characterized by five dynamic interdependent and interrelated systems, each of which is briefly discussed in relation to the current study:

- (i) the micro-system, which is the level that is closest to the individual and in which the person has direct interaction and relationships in the person's closest physical and social environment such as the direct interactions of a person with epilepsy with the spouse or partner, with children and grandchildren, siblings and parents;
- (ii) the meso-system, where PWE and their carers may have interrelationships or connections within the micro-system – such as friends, neighbours, social networks or interactions in different community settings, and peers in other environments such the school;
- (iii) the exo-system, which refers to the level at which there are interconnections between the other systems where a person with epilepsy does not have direct interaction – but can have an indirect influence on the individual and the family such as the media, the church, home-based care, epilepsy support services and THs;
- (iv) the macro-system, which encompasses a broader level of the social context which can have a great influence on the individual and the family – for example in the study setting, factors such as language, political/policy, poverty, crime, migration and lack of integrated community-based health care services and societal attitudes towards epilepsy can have a negative or positive impact on the individual and the family; and
- (v) the chrono-system, which encompasses transitions and changes over time – for example the impact of the course of epilepsy and its treatment and care and difficulties posed by the illness over time to the PWE and those caring for them.

### 1.3. DEFINITION OF KEY TERMS

- **Perspectives:** On searching literature I found two definitions that I used for this study: (i) Perspectives are aspects of a persons' being that include attitudes, cultural beliefs, knowledge, future aspirations, past or present experiences and values about living with the illness (Auduluv, Asplund, & Norbergh, 2011); (ii) Self-perceived impact of the health condition on the lives of people living with epilepsy and their carers as well as the most important aspects of the outcomes of treatment and care (Zanini, Sarzi-Puttini, Atzeni, Di Franco, & Rubinelli, 2014, pp.1-2).
- **Folk carers** were defined as carers from the folk sector of health care who practice indigenous knowledge who also provide support and care to people living with epilepsy (Kleinman, 1980). In South Africa, THs are divided into the following types: isangoma (diviner); inyanga (herbalist) (Pretorius, 2004, pp. 536-541; Truter, 2007, pp. 57-58).

- **Popular carers** were defined as carers from the popular sector of health care who included friends and neighbours and close relatives of people with epilepsy such as wives, partners, siblings and parents who provided care and support to people living with the illness (Kleinman, 1980).
- **Home-based carers** were defined as carers who lie between the popular and professional carers who have received some minimal training in some aspects of health care but are not health care professionals.
- **Professional carers** were defined as western trained health care practitioners such as professional nurses, pharmacists and doctors (Kleinman, 1980).
- **People with epilepsy** were defined as any adult person who had been diagnosed with epilepsy and was taking seizure medication.

#### 1.4. STRUCTURE AND LAYOUT OF CHAPTERS

In this manuscript style dissertation, the traditional sections such as the Methods, Results and Discussion are replaced because each published paper comprises each of these components including related literature reviewed. All seven articles in this thesis have been peer-reviewed and have already been published in international journals. Each article will be presented in individual chapters and a summary for each article will be provided. This dissertation links these contributions and aims to present a unified body of work in a coherent whole. In addition to the seven published articles, this dissertation has two manuscripts (in Chapter Two and Chapter Ten) which have been formatted according to the specific journal requirements for submission for peer review. A summary of each chapter is given below:

**Chapter One** provides the general introduction to this dissertation and my motivation for doing the study and the theoretical framework on which this study is based.

**Chapter Two** is presented in a manuscript format with the aim of submitting it for peer-review to a suitable journal. It covers evidence of existing knowledge from a review of literature on published studies which examined the psychosocial and cultural issues affecting adults with epilepsy and their carers in Africa between 1994 and 2014. It asks the following questions: What are the psychosocial and cultural issues that affect adults with epilepsy and their carers in Africa? What are the gaps in current knowledge?

**Chapter Three to Chapter Nine** present peer-reviewed published journal articles on data collected for this dissertation. I was first author for all of the articles; details of authorship contributions and copyright permission to include the articles in the dissertation appear as appendices as follows: Copyright permission from the publishers (Appendices A1 – A4); Co-authors' approval for inclusion of co-authored published articles in this dissertation (Appendices B1 – B4); declaration of the first author's contributions (Appendix C) and declaration of illustrations (Appendix C1). Each of the seven peer-reviewed journal articles will be presented in individual chapters. In each case, the articles are free-standing and highlight the key themes that emerged but report only on the main key theme which provided rich descriptions of perspectives and subjective experiences of epilepsy from the point of view of adults

who have epilepsy and their carers from different sectors of health care. These will be given at the beginning of each chapter to show how they fit into the aim of dissertation as a whole. As the next step, these unreported themes will be pursued with co-authors with the aim of submitting manuscripts for peer-review to suitable journals. This step is one of the recommended actions in Chapter Eleven, section 11.3 (see page 99).

**Chapter Ten** discusses my personal reflections on my emotions, identity, position and ethical and cultural challenges that I faced in the field and my choices, decisions and actions in the process of my inquiry. The chapter is presented in a manuscript format with the aim of submitting it for publication in the *International Journal of Social Research Methodology*.

**Chapter Eleven** is a concluding section of the thesis and will show how all different articles cohere to form a whole. As a basis for this concluding chapter, I will provide the recommendations for future actions based on what I have learnt in the process. A summary of the layout of chapters and status of published peer-reviewed articles and manuscripts is provided below in Table 1.1.

Table 1.1.

*Layout of chapters and publication status*

Chapter	Topic	Publication status	Authors and Title
1	General introduction and motivation		
2	What psychosocial and cultural issues affect adults with epilepsy and their carers in Africa? What are the gaps in current knowledge?	Manuscript to be submitted to a suitable journal.	Keikelame, M. J., & Swartz, L. Psychosocial and cultural issues affecting adult people who have epilepsy and their carers in Africa: A review of literature
3	Interviews with carers from the professional sector of health care.	Published in the international journal, <i>Epilepsy &amp; Behavior</i> , 25, 105-109.	Keikelame, M. J., Hills, R. M., Naidu, C., de Sá, A., & Zweigenthal, V. (2012). General practitioners' perceptions on management of epilepsy in primary care settings in Cape Town, South Africa: An exploratory pilot study.
4	Observations of health care provider and patient interactions.	Published in the international journal, <i>Epilepsy &amp; Behavior</i> , 26, 36-41.	Keikelame, M. J., & Swartz, L. (2013). Lost opportunities to improve health literacy: Observations in a chronic illness clinic providing care for



			patients with epilepsy in Cape Town, South Africa.
5	Focus group discussion with home-based carers.	Published in the <i>International Journal of Qualitative Studies on Health and Well-Being</i> , 11, 30213	Keikelame, M. J., & Swartz, L. "It's always HIV/AIDS and TB": Home-based carers' perspectives on epilepsy in Cape Town, South Africa. (2016)
6	Individual interviews and focus group discussion with carers from the folk sector – "traditional healers".	Published in the international journal, <i>Transcultural Psychiatry</i> , 52(5), 659-680.	Keikelame, M. J., & Swartz, L. (2015). 'A thing full of stories' Traditional healers' explanations of epilepsy and perspectives on collaboration with biomedical health care in Cape Town.
7	Individual interview with a male popular carer from the popular health sector.	Published in the international journal, <i>Epilepsy &amp; Behavior</i> , 28, 512-518.	Keikelame, M. J., & Swartz, L. (2013). A lay carer's story about epilepsy in an urban South African context: They call it an illness of falling or an illness of fitting because a person shakes and eventually falls.
8	Individual interviews with nine female popular carers from the popular health sector	Published in the international <i>Journal of Health Psychology</i> , 1-12.	Keikelame, M. J., & Swartz, L. (2015). 'Whom will I give him to? The difficulty is mine': Psychosocial difficulties experienced by care givers of patients with epilepsy in Cape Town, South Africa.
9	Individual, interviews with patients with epilepsy.	Published in the <i>BMC International Health and Human Rights Journal</i> , 16, 9.	Keikelame, M. J., & Swartz, L. (2016). "The others look at you as if you are a grave": A qualitative study of subjective experiences of patients with epilepsy regarding their treatment and care in

			Cape Town, South Africa.
10	My personal reflections in the field and ethical challenges in the process.	Submitted to the <i>International Journal of Social Research Methodology</i> .	Keikelame, M. J. “ <i>The tortoise under the couch</i> ”: An African Woman’s Reflections on Critical Moments, Culture and Ethics on Conducting a Qualitative Research Project.
11	Concluding thoughts.		

#### **1.4.1. Chapter Two: Psychosocial and cultural issues affecting adults with epilepsy and their carers in Africa: A review of literature.**

This chapter is presented in manuscript style with the aim of submitting the manuscript to a suitable peer reviewed journal. The chapter focuses on studies conducted in Africa between 1994 and 2014 that examined the psychosocial and cultural issues affecting adult PWE and their carers from different sectors of health care – popular, folk and professional, and those that lie between the lay and professional such as HBCs. It starts by highlighting the significance of the psychosocial and cultural issues and their impact on the treatment and care of adult PWE and their carers from published literature. Thereafter it provides the review questions, the methodology, search engines and key terms used, the inclusion and exclusion criteria and a discussion of the gaps in research and limitations of the review.

#### **1.4.2. Chapter Three: General practitioners' perceptions on management of epilepsy in primary care settings in Cape Town: An exploratory pilot study**

This chapter provides a glimpse of perceived health system factors affecting management of epilepsy in the public health sector in Cape Town. It presents a summary of findings from individual interviews with ten medical doctors who worked in the public and private health sectors in Cape Town. It sheds light on factors that affect the treatment and care of patients with epilepsy in the public health sector. It postulates that seizure freedom and a good quality of life cannot be attained when PWE are put on incorrect treatment regimens; when PWE have breakthrough seizures; when prescriptions of patients’ seizure medication are repeated without evaluation of their effectiveness; and when patients are not counselled on life style factors and on side effects of seizure medication. The chapter asserts that these perceptions suggest that there could be some violation of patients’ health rights in the process.

The view that patients do not complain about side effects of seizure medication highlights a lack of care, especially of patients with epilepsy who are most vulnerable to marginalization and poor treatment because of their illness as well as their socio-economic background. Where these issues are not attended to, there will be implications for the health system which is reported to be weak (Levitt, Steyn, Dave, & Bradshaw, 2011) as well as for people with epilepsy and their carers. The chapter highlights that a proactive approach to care is needed for improved health outcomes of this vulnerable group of patients (Fitzsimons, Normand, Varley, & Delanty, 2012).

### **1.4.3. Chapter Four: Lost opportunities to improve health literacy: Observations in a chronic illness clinic providing care for patients with epilepsy in Cape Town, South Africa**

This chapter highlights to the reader a clear picture of the health systems factors that were captured from observing behaviours and events during routine clinical encounters between HCPs and adult PWE in the setting in which they receive their treatment and care. It argues that routine clinical tasks which lack promotion of active participation of patients in their treatment and care are disempowering not only to patients but to the health care professionals as well. Examples of observed events include patients being asked about the number of seizures that they had and whether they were taking seizure medication; patients not knowing reasons for blood investigations and the type of test done; health education talks given in a non-conducive environment, language barriers and lack of epilepsy support group.

The chapter further brings to the fore the importance of carer education and counselling on the care-recipients' illness and treatment. It shows some real examples of events such as a carer not understanding the correct dosage of the partner's seizure medication. It highlights that pharmacist's role should not just be limited to dispensing medications – but that they can play a role in reinforcing patients' understanding of their seizure medication. It further shows that non-pre-tested epilepsy poster messages can lead to confusion and misinterpretation.

### **1.4.4. Chapter Five: “It is always HIV/AIDS and TB”: Home-based carers' perspectives on epilepsy in Cape Town, South Africa**

This chapter provides a summary of the findings from two focus group discussions (FGD) conducted with eighteen HBCs who worked for a faith-based NGO that provided home-based care services in the study setting. The chapter addresses subjective experiences of these carers and their perspectives on epilepsy. In particular, the chapter argues that the lack of inclusion of epilepsy in home-based care services is one of the factors that affects community-based treatment and care of people with epilepsy in the study setting. It further expresses the importance of examining religious beliefs of health care workers as these may have an influence on care giving of PWE and their families. Among these eighteen HBCs, there was only one male – highlighting that very few males engage in this type of work.

The chapter highlights three main key findings from the two FGDs with HBCs: HBCs' cultural explanations of the names of epilepsy; their perspectives and experiences about religious factors and their perceived role in epilepsy treatment and care. The most interesting discussion was about a metaphor for epilepsy which was explained as *ukuhlutha inkuku* (plucking the chicken) which was identified by one of the HBCs in the second FGD. What can be learned about these African metaphors is that they could be subjected to misinterpretation which may lead to stigma. On the other hand, these metaphors may probably enable witnesses to describe the symptoms that present during a seizure attack to enable history taking and appropriate investigations.

The second finding of this chapter is about religious factors. This was one of the topics that was raised in the two FGDs, which was discussed at length and focussed on three critical issues. The first issue was that some HBCs were of the view that there are some powerful faith leaders who encourage PWE to stop their medication and to use religious treatments. The second issue was that changing behaviours of PWE and carers who hold such beliefs about the cause and treatment for epilepsy can be

difficult. The third issue was that HBCs who hold such beliefs may also impose their cultural religious values on PWE for whom they are caring.

The third finding was that although these HBCs' main tasks did not focus on epilepsy, it was evident that they had witnessed PWE whose seizures were poorly controlled during their home visiting and that they had knowledge about community strategies that would enable support for PWE - such as an integrated home-based care approach for NCDs in general and collaborative partnerships between the NGOs and community structures and local CHC by shifting tasks to HBCs so that HCPs can focus on better patient care. This aspect of task shifting has been reported by de Wet, Wouters and Engelbrecht (2011) in an HIV/AIDS programme as well as in Botswana (Ledikwe et al., 2013) – highlighting a need for research that focusses on religious beliefs of this group of workers.

#### **1.4.5. Chapter Six: “A thing full of stories”: Traditional healers’ explanations of epilepsy and perspectives on collaboration with biomedical health care in Cape Town**

The chapter advances current knowledge on the importance of understanding cultural factors in epilepsy from the THs point of view. The THs had the experience of caring for people who had epilepsy and some also had family members living with the illness. From the FGD with THs, it was evident that these healers held biomedical explanations of the cause of epilepsy and cultural explanations of the cause and treatment of epilepsy. They explained that epilepsy is known as “the illness of falling” (*isifo sokuwa*); “illness of fitting” (*isifo sokuxhuzula*) and “fits” (*ukuxhuzula*), consistent with Keikelame and Swartz (2007). There was only one additional name, “sickness of fainting” – but as the discussion progressed, the healers distinguished between the words “fainting” and “fitting”. They then came to a consensus that the word “fainting” is not a Xhosa word – thereby showing some linguistic issues which would be crucial in cross cultural communication.

Although the healers did not suggest how these linguistic issues could be addressed, the findings suggest a need for documentation of these terminologies since they can be used by witnesses to describe the symptoms that they witnessed in order to enhance appropriate clinical investigations. In addition, the healers stated that epilepsy was difficult to understand and diagnose because of the different ways in which it presents itself. They also provided some symptoms which were suggestive of psychogenic non-epileptic seizures. The THs' beliefs about the “thing inside the body” was also reported in the focus group discussion with home-based carers in Chapter Five – but the HBCs thought that it was a “demon inside the body” while the healers were not specific – but aligned the belief about the ‘thing inside the body’ with the symptoms of general tonic-clonic seizures – showing that cultural explanations of the cause of epilepsy may influence the kind of treatment that will be sought.

In their discussion about their approach to treatment, their emphasis was on the importance of thorough investigations – “we first search on how did it enter” certainly because of their belief that epilepsy is a “thing that is inside the body” and also to establish bewitchment or witchcraft-related causes in terms of “how the person got it”. As they talked, they emphasized the importance of explaining the benefits of treatment, for example, that the medicine will give the person “power”. In Chapters Three and Four of this thesis, there was evidence of lack of patient education and counselling on the illness and its treatment. In this chapter, THs stress the importance

of informing patients about the benefits of treatment. Therefore, when a PWE experiences fatigue or dizziness from taking seizure medication and the healer informs the person that his or her medicine will give the person “power” – certainly any person with such experiences will opt for treatment that can provide better health outcomes when informed by a trustworthy source.

When THs talked about collaboration with western trained health care professionals, they were quite wary about collaboration because they felt that their attempts and efforts to foster relationships with biomedical practitioners had been unsuccessful. Although this was their concern, there are successful models of collaboration with THs in Zambia (Baskind & Birbeck, 2005) and in Kwa-Zulu Natal in South Africa (Shizha & Charema, 2011; Van Niekerk, 2012) to learn from. Even though THs healers were willing to collaborate, they expressed that there must be a memorandum of understanding to ensure respect, freedom of expression and protection of their intellectual property because of their experience of the past oppressive laws in South Africa.

#### **1.4.6. Chapter Seven: A lay carer’s story about epilepsy in an urban South African context: They call it an illness of falling or an illness of fitting because a person shakes and eventually falls**

This chapter focuses on research with a carer from the second type of Kleinman’s (1980) sectors of health care – referred to as the popular sector of health care. It advances the importance of using Kleinman’s (1980) EMs framework to elicit individual stories about the cultural understandings and explanations of the illness, experiences of living with the illness and of caring for a relative or friend who has the illness. The chapter postulates that these popular carers play a crucial role in care giving and that they can also influence health seeking behaviours of patients in their care (Kleinman, 1980).

The chapter aims to show the importance of listening to individual stories. It further extends current knowledge of the cultural understandings and explanations of epilepsy and care-giving in an urban context which is characterized by poverty, unemployment and marginalization – especially as a migrant. This story also affirms some of the health system factors affecting management of epilepsy at different levels: community, public health sector and policy levels. It stresses important health system factors such as a need for HCPs to undertake proper investigations as to the cause of epilepsy and to ensure that people receive appropriate treatment to enable them to get seizure freedom and a good quality of life. In my interview with this carer, he was overly concerned about the mortality of PWE and was convinced that from his experience, there are people who die from epilepsy – indicating a need for research in this area.

The chapter predicates that the negative influence of aspects of western ideologies has made some Black people disregard their own cultural values and view these knowledge systems as barbaric. This view is also echoed by Owusu-Ansah and Mji (2013) who state that this problem exists even among some African scholars who do not cherish the benefits and role of African knowledge. Therefore, when such a carer holds these cultural values in a social context that may not embrace them, he or she may suffer exclusion – and may be viewed as someone who does not fit in the setting in which he or she resides. This notion of “good fit and poor fit” has been raised by Kirmayer and Swartz (2013, p. 46) in their article on culture and global health in mental health care. The authors state that a poor fit in terms of worldview and beliefs may



lead to suffering of people who hold cultural values that are not supported by the community in which they live.

#### **1.4.7. Chapter Eight: “Whom will I give him to? The difficulty is mine”: Psychosocial difficulties experienced by care givers of patients with epilepsy in Cape Town, South Africa**

This chapter provides insights on subjective experiences of providing care in a context that is characterized by marginalization, poverty and poor access to available epilepsy support services. It argues that the issue of equity becomes a cause for concern especially under conditions such as the ones in this urban Black township in which this study is conducted. While there are other contextual constraints that affect health in South Africa that include issues such as lack of access to water, sanitation, nutrition and housing (Mayosi & Benatar, 2014) – this can make care giving difficult under these circumstances – and this could be worse for disabled care givers.

The chapter provides additional insights into psychological and social issues affecting popular carers of PWE such as bewitchment-related fears where a person may present with psychological symptoms such as catatonia and hysteria as a result of these fears (Ivey & Myers, 2008). It provides additional insights with regard to psychological fears related to bewitchment; the reasons for worries about the difficulties posed by the long course of the illness and loss of hope due to lack of seizure freedom. It also shows the importance of attending to siblings who may also provide care for their family members who have epilepsy. It further highlights the importance of carer and patient counselling about sexual health matters, especially among carers who are married or who live with their partners, as well as relationship issues, since these can lead to domestic violence. The chapter also shows a need for involving police in epilepsy treatment and care since some of the caregivers revert to them for support. In literature reviewed on studies done in Africa, there was only one study in Zambia that investigated police officers’ knowledge, attitudes and practices about epilepsy (Mbewe, Haworth, Atadzhanov, Chomba, & Birbeck, 2007) – highlighting a need for research in this area.

In addition, the chapter informs us that some popular carers used religious strategies such as “we leave it to God” with the hope that God would provide them with some means to overcome their difficulties of caring for their close relatives who had epilepsy for, in some cases, approximately twenty years. These strategies were mentioned by older married women who, despite these difficulties, remained in the relationship. The chapter highlights a need for a multi-disciplinary team approach to address the psychosocial difficulties experienced by these care givers in order to enable them to enjoy a good quality of life on their part as well as on the part of their family members and friends who have epilepsy.

#### **1.4.8. Chapter Nine: “The others look at you as if you are a grave”: A qualitative study of subjective experiences of patients with epilepsy regarding their treatment and care in Cape Town, South Africa**

This chapter presents Article 7 which aimed to explore perspectives and subjective experiences of patients with epilepsy about their illness in an urban township in Cape Town. The twelve adult Xhosa speaking PWE were individually interviewed at their homes. These patients had epilepsy for more than twenty years and their ages ranged between 26 and 65 years and the sample comprised of eight males and four females. Some had other chronic illnesses such as asthma and hypertension and only one female

PWE was on anti-retroviral therapy (ARVs). Among these patients, only one had participated in the observations that were conducted during routine follow up clinic (Chapter Four, Article 2). The patients' background information on the study setting is similar to the one provided in Chapters Four to Eight. Six of these patients were receiving a government disability grant and only one was receiving an old age pension grant. Three had applied for a disability grant but their applications were unsuccessful and only two were working part-time.

The chapter extends our understanding of some of the health systems and patient related factors that pose some difficulties for accessing appropriate treatment and care. Their verbatim accounts show lack of counselling on their individual needs such as pregnancy-related matters, sexual health issues, side effects of seizure medication and their understanding of medical instructions and health information. For example, one PWE reported that he/she did not understand whether the doctor recommended an operation or not, but the patient could not follow up on this issue because of his/her inability to comprehend what the doctor had said. This finding alerts us to the powerful nature of medical language (Henderson, 2006), which can prevent patients who do not speak English and who lack health literacy such as the ones in this study from asking questions during their interaction with health care professionals.

The chapter expands the findings reported in Chapters Three and Four and enables us to gain a deeper understanding of the complex nature of the routine task system and its lack of focus on the psychological and social aspects of the individual – only recording the number of seizures and whether the person has taken seizure medication or not – a notion referred to by Henderson (1994) as “the recorded bodies” (p. 937-938). The verbatim account on this aspect is expressed by one PWE who was angry about having to repeat his blood sample investigations – which disregards how the person feels about his or her body being subjected to repeated pain because of loss of his blood results. I personally do not know how I would react if I had the same experience as articulated from the verbatim account of the respective patient. I also wondered whether this patient would ever come back for treatment having had this type of experience and also wondered how it would impact on his trust in the health system. This issue of the importance of building trust and a trusted health system for improved health care has been raised by Gilson (2003). The individual stories about the subjective experiences of living with epilepsy for a long time with no better health outcomes were very difficult to comprehend – and most of them showed issues related to lack of care in general.

These findings complement findings from individual interviews with medical doctors who were of the view that epilepsy is poorly managed in primary care settings in Cape Town and identified the factors that they thought promoted the problem. They also complement the findings from observations conducted during clinical encounters between PWE and HCPs in a chronic illness during routine follow up visits in Article 2 in Chapter Four of this dissertation. The main theme that emerged in Chapters Two to Eight was primarily about quality of care. This chapter broadens our understanding thereof from the point of view of adults who have epilepsy and calls for a need for empowerment of these patients and their carers. Collaborative advocacy actions for their improved health care in this urban Black township is also needed.

#### **1.4.9. Chapter Ten: “*The tortoise under the couch*”: An African Woman’s Reflections on Critical Moments, Culture and Ethics on Conducting a Qualitative Research Project**

This chapter presents reflections on my personal journey in conducting a qualitative inquiry into perspectives and subjective experiences of patients with epilepsy and their carers. It offers personal experiences and challenges in the field as a researcher and as an older African woman who has had the experience of working among marginalized Xhosa-speaking communities in one of the peri-urban townships in Cape Town. The chapter uses an analogy of the tortoise to shed light on some critical moments, surprises and the decisions, actions, cultural and ethical issues that posed some challenges in the inquiry process. It maintains that researchers who use a qualitative research design to conduct studies among marginalized population groups have an opportunity to hear the painful struggles and frustrations of participants in their natural settings and that they also bear witness to contextual factors affecting the health of their studied population groups. The manuscript argues that researchers need to find the best strategies that can help them to engage in advocacy and activism roles in order to address the issues they have heard, seen and felt in the process of their inquiry, especially of those groups who have suffered marginalization and oppression (Traianou, 2014 in Leavy, 2014, pp. 62-77) such as the ones in the study.

#### **1.4.10. Chapter Eleven: Concluding thoughts**

The concluding section of this dissertation will show how all the different articles cohere to form a whole. As a basis for this conclusion I will rely substantially on my reflective manuscript which is presented in Chapter Ten of this dissertation. I will also show how the different voices that I have heard during the process of this inquiry link together to give a broader picture outlining the landscape of the experience of epilepsy in the setting in which I conducted the study. In my introduction to the dissertation, I have introduced the key work of Arthur Kleinman, who provides a framework for understanding systems of care and healing, as well as Bronfenbrenner’s (1994, 2005) socio-ecological framework, to show the levels of the system in which the difficulties regarding treatment and care of PWE were experienced and I will draw together the various strands to form a whole picture. I will highlight both the consistencies across the chapters and the ways in which there may be inconsistencies. I am hopeful that this piece of work will contribute to our understanding of what it means to live with epilepsy and to care for adults who have epilepsy with no hope of seizure freedom and enjoyment of a good quality of life.

### **1.5. METHODOLOGY**

#### **1.5.1. Why I chose a qualitative research design**

This dissertation uses qualitative research because the design employs a naturalistic approach and allows the researcher to use a range of worldviews and approaches in order to understand, interpret and explain the studied phenomena (Leavy, 2014, pp. 1-5). This was particularly relevant for my study since it involved exploring sensitive issues on participants’ subjective experiences and perspectives about epilepsy in privacy in order to gain an insider perspective about the studied phenomenon through direct interaction with participants in their natural settings (Ulin et al., 2002). In addition, my choice of this design was based on my research question and the aims and objectives of my study (Leavy, 2014, pp.1-5). Thus an important principle of the qualitative design is that participants are viewed as people who have knowledge and who also share in the creation of knowledge derived from research.



Furthermore, the design enables the use of a combination of data collection methods such as field notes, reflective journals, informal conversations, interviews and audio-recordings in order to provide an in-depth understanding of the problem and its context (Leavy, 2014, pp. 1-5). It can also enable the researcher to gain information on the cultural values, opinions, behaviours and social contexts of the population groups that are being studied (Mack, Woodsong, MacQueen, Guest, & Namey, 2005).

### **1.5.2. My background and beliefs**

The importance of reflexivity has been emphasized in qualitative research because of the direct and close relationships that become established between the researcher and the study participants during the research process (Mc Hugh, 2014 in Leavy, 2014, pp. 137-164). I have had direct interaction with different adults who have epilepsy and those who care for them. I have listened to their personal stories and have seen their individual struggles as a result of marginalization and displacement due to unjust policies of the past. These factors could have affected my approach to interview questions, analysis and interpretation of participants' responses as it would have been difficult to hide.

As reflexivity is an important strategy in qualitative research, I also took note of my own ethnicity, age and my position as a health promotion lecturer and previous board member of the local branch of the epilepsy NGO. I was aware of the importance of reflexivity in qualitative research because of the direct and close relationships that become established between the researcher and the study participants during the research process. I have listened to personal stories of PWE at the international and local epilepsy conferences that I attended. It was therefore important for me to use this strategy in order to reflect on my actions, decisions and choices in the process to ensure accountability, transparency and truthfulness of the findings by keeping a personal journal which I used for ongoing reflection (Watt, 2007).

### **1.5.3. Recruitment**

The qualitative research design recognizes field entry as an important strategy for gaining access to participants and making data collection possible (Patton, 2002). My field entry, recruitment and access to participants was made possible by the three local field workers who introduced me to the executive members of the local health committee and the traditional healers' organization (THO). These fieldworkers were also volunteer health care workers and knew some families who had family members who had epilepsy. Through their assistance, I was able to present my study aim and purpose, inclusion and exclusion criteria, methods of data collection, the kind of instruments that I would use and participant information leaflets about informed consent, benefits and their right to participate in the study. These information leaflets were translated and presented in isiXhosa (predominant spoken language) in the setting. Although I can speak isiXhosa, it is not my first language. I was assisted by local field workers in the interpretation of the study aims and consent information leaflets. This process enabled me to ensure that recruited participants gained an understanding of the study purpose and enabled them to make informed decisions and choices regarding their rights to participate or to decline participation in the study.

These local field workers also assisted me in locating the homes of the participants since it would have been difficult for me to do so without knowledge of the area. Because of the flexibility of the study design (Al-Busaidi, 2008, pp. 12-13; Gray, 2009),

I was able to approach and recruit HBCs about whom I came to know during the fieldwork process, their inclusion being crucial to the study.

#### **1.5.4. Participants**

All participants who gave informed consent to participate in the study were informed of their rights and responsibilities in the process as well as their ability to withdraw from the study at any point in time. They were also informed that the information would be disseminated to various audiences; that it would be published in scientific journals; that they would receive feedback in the process to validate their information and that their identity would be protected via the use of pseudonyms. My sample consisted of 10 professional carers (medical doctors), 11 folk carers (traditional healers); 18 home-based carers (carers who are either lay or professional); 10 popular carers (close relatives, friends and neighbours); and 12 PWE. All study participants, namely, PWE, popular carers, HBCs and THs were Xhosa-speaking and their ages ranged from 18 years to 65 years. Some spoke English and other African languages such as Xitsonga, Sesotho and Setswana. From the professional health sector, all participants were proficient in English with very of the doctors not speaking isiXhosa.

#### **1.5.5. Why I chose the study setting**

Social conditions in which people are born, live and work are crucial determinants on an individual's health status (Satcher, 2010, p. 6). Therefore, in this study setting where residents are of low socio-economic background and have experiences of marginalization and oppression, and where the situation has remained substantially unchanged even after democracy, epilepsy may be experienced differently from both the biomedical and psychosocial perspective. It was therefore important for me to do the study in this setting for the following reasons: First, inequalities between the rich and the poor due to discriminatory policies related to employment and education still prevails in Cape Town (Scott, Stern, Sanders, Reagon, & Matthews, 2008) – and the setting in which this study is conducted is an example thereof. Although initiatives such as the Cape Town Equity Gauge (CTEG) are in place (Scott et al., 2008; Sanders & Chopra, 2006), these inequalities still exist (De Swardt, Puoane, Chopra, & du Toit, 2005; Sanders & Chopra, 2006). Second, epilepsy is also not reported in the situational analysis conducted in the setting (Naidoo & Irlam, 2005). Third, local epilepsy support services are available but are inaccessible to the study population. Fourth, literature shows that most of the South African communities of low socio-economic background access health care from THs (Petersen, Bhana, & Swartz, 2012). In addition, there were a number of practising THs in the study setting who I wanted to recruit to participate in the study. Fifth, there is no study that I know of that has investigated perspectives and subjective experiences on epilepsy among PWE and carers from the popular, folk and professional sectors of health care in this urban township in Cape Town.

#### **1.5.6. Data collection**

In this dissertation, I used Kleinman's (1980) EMs framework to guide the design of the data collection instruments that I used for individual in-depth interviews and focus group discussions. My aim was to elicit lay explanations of epilepsy and subjective experiences of the illness from PWE and those who cared for them.

##### **1.5.6.1. Observations**

According to Punch (2009), qualitative interviewing which is informed by observational data can lead to rich, high-quality data (p. 156). Based on my research question, "How

do PWE and their carers understand epilepsy?” I first conducted preliminary observations with permission gained from the facility manager of the local CHC from where my study participants received their health care. The aim was to orientate myself to the setting and routine tasks in order to determine the length, number and days on which observations could be made, the kind of behaviours to observe and questions to ask.

Thereafter, I designed a semi-structured observation guide which consisted of a list of items to observe during interactions of PWE and HCPs in their routine clinical follow-up visits (Appendix D1) and events such as the delivery of the health education talk (Appendix D2). This I used to document data in order to provide descriptions of the date, time and duration of the observation, the type of observations, characteristics of those who were observed, types of questions asked and responses to questions and the physical set up of the venues (Hellesø, Melby, & Hauge, 2015; Mulhall, 2003). I played the role of an “observer as participant” (Mulhall, 2003, p. 308) because my observations were of short duration and I had openly divulged my role when seeking permission and when recruiting participants. Observed events are explained in detail in Chapter Four, Article Two of this dissertation. During the observations, I did more listening and observing and took notes on observed aspects related to my research question, what Flick (2006, p. 220) refers to as ‘focused observation’. A total of five observations were conducted among Xhosa speaking PWE and HCPs in a local community health clinic (CHC) that provides care to predominantly Afrikaans and Xhosa-speaking communities. During observations, confidentiality of the participants’ information and anonymity of the observed participants and the setting was protected. An example of the diagram of the physical setting of the venue in which the epilepsy health talk was observed is provided in Appendix E.

#### **1.5.6.2. Individual interviews**

A total of 38 individual interviews (12 PWE; 10 popular carers; 6 THs and 10 medical doctors) were conducted through participants’ permission to record and transcribe the audio recorded data. A semi-structured interview guide for PWE and carers, adapted from Kleinman (1980) EMs framework interview questions, was designed in English and translated into the participants’ spoken language (isiXhosa) and was used to collect the data from individual interviews with PWE (Appendix F1) and lay carers (Appendix F2). The duration of interviews ranged between 30 and 90 minutes and they were conducted at venues which were chosen and preferred by participants. I also kept a personal reflective journal to compile notes that were later used in the data analysis and interpretation of the data (McHugh, 2014 in Leavy, 2014, pp. 145-146). Gift vouchers were only given to PWE and lay carers after each individual interview as a token of appreciation for their time and for sharing their stories.

#### **1.5.6.3 Focus group discussions**

In all three FGDs that I conducted, a focus group interview guide (Appendix G) adapted from Kleinman (1980) EMs framework was designed and was used to collect the data. All three FGDs were held at participants’ venue of choice and on the date and time that suited them. All participants gave permission to audio-record the interviews and to disseminate the findings to various audiences and for publishing and were assured of anonymity and confidentiality. They were all informed of the purpose of the FGD, difficulties in maintaining confidentiality with larger groups and the importance of not divulging information (Powell & Single, 1996; Ulin et al., 2002). Regarding the ethical considerations in FGD, there were some personal stories and experiences shared by

some individuals in the FGD. Allowing each participant to reflect on the FGD process helped me to gauge whether there were any issues that might warrant referral. However, most said that the FGD was a learning exercise and that the nature of the questions, the good rapport that was established and the facilitated process allowed them to reflect and to freely ask each other questions and to respond comfortably to issues under discussion. All participants were reimbursed for their transport costs and refreshments were served after each discussion.

### ***Focus group discussion with traditional healers***

One FGD was conducted with nine Xhosa-speaking THs of whom two were male isangomas and herbalists and seven female isangomas with one of them being a trainee “mkwetha”. Among these nine FGD participants, only four had been interviewed in individual interviews. The aim was to explore their perspectives on epilepsy and their views about collaboration with western trained health care professionals. These THs had experience of caring for people with epilepsy and some had family members who had epilepsy. These THs knew each other and some were registered members of the local THO.

### ***Focus group discussion with home-based carers***

I conducted two FGDs with 18 Xhosa speaking HBCs who worked for a faith-based NGO in Cape Town, with only one of them being male. These HBCs were all residing in the study setting and were providing home care services which did not focus on epilepsy, but on HIV/AIDS and TB and other chronic illnesses. Each FGD had nine participants and the FGDs were held in one of their offices at their work place. My aim was to explore their perspectives on epilepsy and the kind of role that they could play in caring for PWE in their community.

## **1.5.7. Data analysis**

### **1.5.7.1. Data analysis of observation data**

The observed data and field notes were typed and analysed using an inductive approach (Mays & Pope, 1995). Article Two provided in Chapter Four supplies examples that capture the described elements of the observations conducted in the chronic illness clinic. Article Two also enables us to gain insights on the kind of health system factors that affect the understanding of epilepsy and its treatment and care in the public health care sector. The findings from these observations were presented to the local CHC, the health committee in the study setting and the local epilepsy organisation as a way of initiating advocacy actions which according to Birbeck (2000) are crucial strategies that can help to improve the treatment and care of PWE. In the process, I reflected upon my feelings, experiences and thoughts as these can have a great influence on the researchers’ analysis and interpretation of the data (Watson, Booth, & Whyte, 2010, in Gerrish & Lacey, 2010, pp. 382-394).

### **1.5.7.2. Data analysis of individual interviews**

All audio-recorded data were transcribed and analysed using Braun and Clarke’s (2006) thematic analysis method in order to identify emerging themes which best explained the phenomena under investigation (Joffe, 2011). The details of identified themes from individual interviews with professional carers, popular carers and PWE are described in detail in individual published Articles presented in Chapters Three, Seven, Eight and Nine of this dissertation.

### **1.5.7.3. Data analysis of focus group discussions**

I employed Braun and Clarke's (2006) thematic analysis method as described in individual interviews and which has been explained fully in individual published Articles presented in Chapters Five and Six which report on focus group discussion data of HBCs and THs.

## **1.6. ETHICAL CONSIDERATIONS**

The ethical approval for this dissertation was obtained from the four local Health Research Ethics Committees of University of Cape Town's Health Sciences Faculty (Appendix H1 and H2: HREC REF: 440/2011 and REC REF: 447/2009); Stellenbosch University's Faculty of Health Sciences (Appendix H3: HS739.2011); Provincial Administration of the Western Cape Government (Appendix H4: RP 163/2011) and City Health (Appendix H5: ID 10272). In addition, although I had gained ethics approval from City Health, I have not been at the local City Health Clinic in the study setting throughout the duration of this study due to PWE not receiving health care from any City Health Clinic. In all my visits to the local CHC where I conducted observations, I sought permission as per ethics approval from the Provincial Administration of the Western Cape Government. I did not disrupt any clinic services or routines as I made appointments timeously and agreed upon times and dates.

According to Traianou (2014, in Leavy, 2014, pp. 62-77), the emergent and flexible nature of qualitative research and its emphasis on studying phenomena in natural settings poses some ethical challenges. These challenges have been raised as issues of concern since the 20th century. For example, issues such as using open-ended questions for in-depth interviewing was viewed by feminists as a way of encouraging people to disclose aspects of their personal experiences which can be done under false rapport established by interviewers. The author further points out that the notion of power and authoritative relationships of interviewers was deemed to be exploitative and that qualitative research seemed to have no power to change the concerns raised.

Subsequent to these concerns and others, in the 1970s and 1980s, there was a call for qualitative research to challenge issues of oppression, social inequality and human rights abuses. Therefore, these developments and challenges meant that ethical issues in qualitative research should consider the goals of research and the methods for carrying out the study. The following considerations were therefore crucial in my study because of the sensitivity of my topic and because my study involved a marginalized and displaced population group that was affected by discriminatory laws of the past. These considerations were therefore important ethical issues to reflect upon. I also wanted to disclose the challenges that I encountered in the field which I describe in detail in Manuscript Two in Chapter Ten of this dissertation.

Gilgun (2014, in Leavy 2014, pp. 658-676) stresses the importance of researchers divulging the recruitment strategies and gifts given to participants as it is ethical to do so. I disclosed the reasons for giving my participants gift vouchers in the process. The ethical issues considered were:

1. Regarding gaining informed consent from all participants, the following actions were taken: using a language practitioner who is fluent in isiXhosa and English to translate the informed consent forms and participants' information leaflets; using local Xhosa- speaking field assistants to interpret the documents; giving participants time, for example: between two weeks to a month to read the information leaflets and to consult with others should they wish to do so; informing them how



confidentiality and anonymity would be ensured, and of their rights and responsibilities should they change their minds having given consent to participate in the study. The participant information leaflets (Appendix I-1) and the informed consent forms (Appendix 1-2) explained all information regarding ethical issues concerning the study and participants' rights and responsibilities in the study as well as contact details of the researcher, the names of the local research ethics committee members of Stellenbosch University (SU) where I am registered and of my supervisor, should participants wish to contact them.

2. Participants were informed of the gifts that they would receive after the interview and that this was not payment but a token of appreciation for their contributions to the study and for their time.
3. Consent to take pictures of personal information materials that participants wanted to give to the researcher was also sought (Appendix J).

## **CHAPTER TWO**

### **MANUSCRIPT ONE**

#### **Psychosocial and cultural issues affecting adult people with epilepsy and their carers in Africa: A review of literature**

##### **2.1. INTRODUCING MANUSCRIPT ONE**

This chapter is presented in manuscript form for submission to a suitable journal. It provides an analysis of published studies conducted in Africa between 1994 and 2014 which examined psychosocial and cultural issues affecting adult PWE and their carers. The selection of carers was based on Kleinman's (1980) typology of sectors of health care, which is a framework on which this study is based. Although the chapter does not provide a systematic review of literature, it provides a detailed methodology involved in conducting a literature review (Ross & Mash, 2014).

## MANUSCRIPT ONE

### Psychosocial and cultural issues affecting adults with epilepsy and their carers in Africa: A review of literature

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#### Abstract

##### Objective

This literature review aimed to examine literature on published studies conducted in Africa between 1994 and 2014 which examined psychosocial and cultural issues among adult people with epilepsy and their carers such as popular, folk, professional and others like community health workers who fall between the lay and professional. The objective was to describe these issues and to identify gaps in current knowledge and to suggest actions for future research.

##### Methods

Data were searched from MEDLINE, Pub Med, ERIC, Web of Science, Scopus, Cochrane Library, Africa Wide, PsycINFO, EMBASE, PASCAL, SABINET, and Google Scholar data bases. In addition, hand searches of journals such as Epilepsy & Behavior, Epilepsia, South African Medical Journal, African Journal of Disability and African Journal of Primary Health Care and Family Medicine were done.

##### Results

The findings from the analysis of forty three articles which we reviewed included quantitative and qualitative studies examining these issues in Africa. Among these articles, we found very few that used qualitative designs and those that focused on special groups such as adult women with epilepsy. In addition, there were also very few studies that examined these issues among carers from different sectors of health care as well as adults who have epilepsy, using validated instruments. Nevertheless, there were psychosocial and cultural difficulties that emerged from our review and these differed due to different types of designs used, sample population and parameters examined. Amidst these issues, there were some cultural metaphors and a range of lay terminologies for epilepsy and seizures and meanings thereof, including stigma and some medical labels such as 'epileptics' which referred to people with epilepsy.

##### Significance

Current evidence shows that little attention has been paid to the psychosocial and cultural issues affecting PWE and their carers in Africa, yet these have been reported



to have a major impact on the treatment and care of people living with the illness and those that provide care for them.

**Key Words:** Literature review on epilepsy in Africa, Adult patients and carers, Psychosocial and cultural issues.

## 1. Introduction

*To suffer from epilepsy in Africa often means to also suffer from a very specific psychological and social trauma (Jilek-Aall et al., 1997, p. 784)*

The psychosocial and cultural issues have been endorsed by the International League against Epilepsy (ILAE) as the most significant issues that have a huge impact on the quality of life of people with epilepsy and their family members (Wolf, 2010; WHO, 2004). Literature shows that issues such as anxiety, depression, low self-esteem, stigma, discrimination and misperceptions about the cause and treatment of epilepsy are the main factors affecting the treatment and care of PWE (Baker, 2002, Diop et al., 2003; Quintas et al. 2012). In her review article on epilepsy stigma, de Boer (2010) highlighted that the names referring to epilepsy as a 'burning disease, drowning disease, shameful disease or it' have also fueled the stigmatization of the illness. There are also concerns that little attention has been paid to investigate these issues from the point of view of people living with the illness (Bhalla et al., 2013). In recognition of the significance of these issues and their impact on the health outcomes of PWE and their families, the ILAE and the International Bureau of Epilepsy (IBE) initiated global actions such as the Out of the Shadows Campaign to address these issues (Diop et al., 2003; WHO, 2004). In addition, the World Health Assembly has also called for a universal commitment to address these issues (Covanis et al., 2015; Mula & Sander, 2016).

In a systematic review conducted by Quintas et al. (2012) which examined these aspects between 2005 and 2010, focusing on studies that reported longitudinal data, the authors found that there was evidence of the psychosocial difficulties. However, the authors cautioned that there was uncertainty with regard to whether there was any change over time and suggested a need for research in this area. Another review of published evidence on the epidemiology, anthropological and sociological issues affecting PWE in sub-Saharan Africa (SSA) revealed that epilepsy associated stigma causes severe burden on PWE and that appropriate interventions are needed to address the problem (Baskind & Birbeck, 2005).

This literature review outlines findings from published studies in Africa between 1994 and 2014 that examined the psychosocial and cultural issues among adult PWE and their carers such as the popular, folk, and professional and those that fall between the lay and professional. The review questions were:

- What are the psychosocial and cultural issues that affect adult PWE and their carers in Africa?
- What are the gaps in current knowledge?

## 2. Methods

This review of literature was conducted between July 2013 and July 2015 using a search strategy that was developed in consultation with information science professionals (TS and MVW) using the following data bases: MEDLINE, PubMed,

ERIC, Web of Science, Scopus, Cochrane Library, Africa Wide, PsycINFO, EMBASE and PASCAL. The electronic search was supplemented by hand searches of articles that had been cited in reference lists of included screened articles, published brief communications, letters to the editor, journals such as *Epilepsy & Behavior*, *Epilepsia* (the ILAE journal), *Gray Matters* from *Epilepsia*, and relevant African journals such as the *South African Medical Journal*, *African Journal of Disability*, and *African Journal of Primary Health Care and Family Medicine*, and via other sources such as SABINET and Google Scholar to avoid missing other important articles (Ross & Mash, 2014). The search terms that depicted epilepsy, psychosocial, social, psychological, culture, indigenous, traditional, lay, perspectives, patient experiences, subjective explanatory and African countries were used. A description of the search terms is provided below in Text Box 1.

### Text Box 1: key terms used in the search strategy

'Epilepsy' AND psychosocial OR social OR psychological OR culture OR indigenous OR traditional OR floor lay OR perspectives OR patient experienter subjective, explanatory AND African countries. The following country names were used: 'Africa\*' or sub-Sahara\* OR Angola OR Benin OR Botswana OR "Burkina Faso" OR Burundi OR Cameroon OR "Cape Verde" OR "Central African Republic" OR Chad OR Comoros OR "Republic of the Congo" OR DRC OR "Congo" OR "Cote d'Ivoire" OR "Djibouti OR "Equatorial Guinea" OR Eritrea OR Ethiopia OR Gabon OR "Gambia" OR Ghana OR Guinea OR Guinea-Bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR "Sao Tome and Principe" OR Senegal OR Seychelles OR "Sierra Leone" OR "South Africa" OR "South Sudan" OR Sudan OR Swaziland OR Tanzania OR Togo OR Uganda OR Zambia OR Zimbabwe AND NOT "African American".

#### 2.1. Inclusion and exclusion criteria

Peer reviewed published articles of studies conducted in Africa between 1994 and 2014, which were written in English, were included. All articles which involved adult PWE and carers such as parents, siblings, community health care workers, traditional healers and western trained health care professionals were included. Studies which reported on children's issues, and where the informants were adults, were also included. All titles and abstracts of retrieved articles were screened to check if they fitted the inclusion criteria and where these were unclear, full articles were retrieved and were read and fully evaluated. A record of articles considered and reasons for exclusion is described in Table 2.1 (see page 42).

Articles were excluded if: (i) children with epilepsy were participants and were aged below 18 years of age; (ii) participants were drawn from the general community without roles either as PWE or as popular, folk, professional or CHWs; (iii) they reported on studies that were not conducted in Africa and articles were not written in English; (iv) they focused solely on prevalence, incidence or medical aspects; (v) they focused solely on evaluation of medical treatment and care, costs, compliance and prevalence without any exploration of psychosocial and cultural issues among adult PWE and carers from different types of sectors of health care; (vi) they had major methodological issues which would affect analysis and interpretation.

## **2.2. Data management, extraction and analysis**

Articles reporting on studies done in Africa between 1994 and 2014 were reviewed using the preview, question, read and summarize method (PQRS) (Ramdhani, Ramdhani & Amin, 2014). Our analysis of the data involved extracting key studies that examined different parameters of the psychosocial and cultural issues related to epilepsy that focused on adult PWE and their carers such as THs, CHWs, close relatives of PWE and western trained health care professionals. The sources were extracted into a synthesis matrix for analysis, synthesis and interpretation (Ramdhani, Ramdhani & Amin, 2014). The matrix consisted of a descriptive summary of information required in review such as: study title, authors and year, full journal details, study purpose, study design, participants, setting, the period in which the study was done, sampling methods, types of instruments, data analysis methods and summary of findings, recommendations, methodological limitations and reviewers' personal reflections (Ramdhani, Rhamdhani & Amin, 2014).

## **3. Results**

A total of 74 articles reporting on studies done in Africa between 1994 and 2014 which employed cross sectional surveys with and without matched groups; qualitative studies, exploratory and descriptive surveys, ethnographic studies and those that employed quantitative and qualitative components and reviews were reviewed and analyzed. Data were extracted into a matrix which consisted of descriptive characteristics of the studies such as: the study title, authors, journal in which the study was published, type of study design, the study participants and setting, aims of the study and the period in which the study was done, sampling methods, types of instruments, data analysis methods and summary of findings and methodological limitations. 43 of the 74 articles reviewed addressed issues directly pertinent to the current study and the analysis which follow focuses on these articles. However, as it will be seen from the publications which form part of this dissertation, broader reading was used where appropriate to a particular sub-study.

### **3.1. Studies reporting on cultural explanations of epilepsy**

The importance of understanding cultural explanations of epilepsy has been well demonstrated by Fadiman (1997) in her book entitled, 'The spirit catches you and you fall down: A Hmong child, her American doctors and the collision of two cultures'. The author provides an in-depth understanding of how the lack of attention to lay cultural explanations of epilepsy can affect the treatment process of those receiving it and those providing it, partly because explanatory models of illness are held by both the lay and western trained health care professionals and are also different (Kleinman, 1980). In reviewed articles, there was evidence of different lay terms and metaphors that are used to explain epilepsy and seizures and meanings thereof were provided in some of the studies. These lay terminologies and metaphors differed in different areas of the same country and between countries and had different interpretations and meanings. There was also evidence that PWE are also referred to as 'epileptics' (Allotey & Reidpath, 2007). This medical labelling of PWE may predispose them to be viewed as 'illnesses' and not as human beings, but research is needed in this area. Examples of the lay terms for epilepsy and seizures and some epilepsy-related metaphors are described in Table 2.2 (see page 52).

### **3.2. Studies reporting on psychosocial and cultural issues of professional carers**

The importance of examining these issue among health care professionals cannot be over emphasized. A recent study conducted by Ekeh and Ekrikpko (2015) in Nigeria showed the importance of examining these issues among western trained health care professionals. In their study, which examined the knowledge, attitudes and perceptions towards epilepsy among medical students in Uyo, they found that these issues were evident despite the educational background of their participants. In the reviewed literature, there were very few studies that examined these aspects among professional carers, thereby highlighting a need for research in this area. The different types of these aspects that were evident from the review are described below under the following headings:

#### *Attitudes and perceptions*

Five articles on studies conducted in Cameroon, (Njamnshi et al., 2010) Ghana (Adjei et al., 2013), Nigeria (Ekenze & Ndukuba, 2013), Zambia (Chomba et al., 2007) and Zimbabwe (Adamolekun et al., 2000). The authors examined different parameters which included knowledge, attitudes, beliefs, perceptions and practices on epilepsy among a variety of health care workers. However, our review shows that the studies were very few and used quantitative and qualitative designs and tended to examine issues related to medical management of epilepsy with little focus on psychosocial and cultural issues. Despite this, there was evidence of negative attitudes towards epilepsy within the reviewed studies, with some authors further stating that there could also be a possibility of hidden cultural beliefs among HCWs.

On the other hand, Adjei et al. (2013) in Northern Ghana reported on some perceptions of these issues which HCWs thought existed in their communities. Although these were not examined from the HCWs themselves, the authors' findings extend our knowledge of the importance of understanding these cultural issues from communities' point of view as well as from HCPs' point of view. For example, there was evidence of perceptions that epilepsy is not a medical condition but a spiritual illness and that it can be invoked by spiritualists on wrong doers; that a new-born baby can get epilepsy when the mother disobeys traditional norms which prohibit mothers delivering at hospital and that women who commit adultery and are unfaithful will get epilepsy as punishment from the gods. However it was surprising that this view about adultery was only related to women. In addition, there were views that women with epilepsy (WWE) were perceived to be married to spirits called 'jinn', which could be another way of stigma against WWE. In addition, there were also perceptions that men who have epilepsy have worms in the anus. However, the authors report that this perception could be due to onchocerciasis which is endemic in Northern Ghana. Of concern were perceptions that death of a PWE is regarded a relief from the hardships of living with epilepsy. According to the authors, the death of a PWE was perceived as 'gaining freedom' or a state of reaching emotional relief from either living with the illness or caring for a PWE.

Adjei et al.'s (2013) study further highlighted some social issues related to social exclusion, marriage and employment. In their participants' verbatim quotations, there was evidence of examples of actions of persecution such as that of a woman who had

to leave the village because of witchcraft-related accusations that she inflicted epilepsy on her son to gain evil wealth. Another example was of a key leader who had epilepsy who suffered social exclusion and neglect.

With regard to marriage and employment, there were negative attitudes towards marriage rather than employment in Njamnshi et al.'s (2010) study, while Chomba et al.'s (2007) study reported on negative attitudes towards marriage and employment. Authors suggested a need for qualitative studies to explore these issues further as they have a great impact on the treatment and care of PWE. What was intriguing in Adjei et al.'s (2013) study was the perceptions that employing a PWE can bring bad luck to the work place and that productivity could be affected.

### *Religious beliefs*

Taking an historical approach on religious aspects of epilepsy, Jilek-Aall (1999) described terminologies such as 'morbus sacer'; 'morbus daemonicus', 'lues deifica', 'the holy sickness', 'the divine disease', 'the falling evil' and the 'Rod of Christ' which were deemed as possession by supernatural demonic powers of gods and these beliefs have been evident worldwide. We reviewed one article reporting on survey findings and observations conducted in three religious camps (Catholic/Protestant) in Madagascar which offered care for patients with epilepsy (Ratsimbazafy et al., 2012). The authors found that shackling treatment was used on PWE whose behaviours were deemed to be dangerous after a seizure attack, but authors were of the view that this could be due to beliefs about spirit possession and that the shackling treatment was used to control the power of the spirit. The authors further report that the shackling treatment has been reported in some studies in Uganda with a child who had nodding syndrome. However, the difference was that this treatment was given by the family in order to protect the child from injuries, drowning or burns. The authors suggest that there should be education about epilepsy geared at the public as well as health care professionals and that appropriate actions are needed to stop these harmful actions.

### **3.3. Studies reporting on psychosocial and cultural issues of folk carers**

We reviewed four studies which investigated different parameters of the psychosocial and cultural issues affecting epilepsy among the folk carers which used different research designs. Two were survey studies conducted in Cameroon (Njamnshi et al., 2010) and Burkina Faso (Millogo et al., 2004). The other two used multi-methods qualitative designs in Kenya (Kendall-Taylor et al., 2009) and the other one was in Zambia (Baskind & Birbeck, 2005). The different types of these aspects that were evident from the review are described below under the following headings:

#### *Beliefs about the cause, contracting and treatment of epilepsy*

There were beliefs about contracting epilepsy via saliva, blood and sexual intercourse which were reported by Njamnshi et al. (2010) in Cameroon, but did not elaborate on saliva and blood as did Millogo et al. (2004). For example, in Millogo et al.'s study (2004), most THs thought that epilepsy was contagious and that it could be transmitted via saliva of cats, of lizards and of patients, and that urine, blood and raw meat of cats and lizards would spread the illness. An interesting finding from Kendall-Taylor et al.'s (2009) study was about beliefs about blood which were that people who have sweet blood can be predisposed to epilepsy. These beliefs that epilepsy can be passed via



sexual intercourse are of concern and needs to be explored further with regard to the impact they may have on quality of life of PWE and their carers. On the other hand, beliefs that epilepsy is contagious and that it is a form of insanity were deemed as predictors of negative attitudes towards PWE (Njamnshi et al., 2010).

The Kendall-Taylor et al.'s study (2009) in Kenya highlighted the different types of spirits that are believed to cause epilepsy, their names, kind of symptoms, and methods of treating spirits such as removal and deflection, and reading the Koran, if the healer is a Muslim. In addition, Kendall-Taylor et al. (2009) reported on beliefs about spirits that live in the environment, and visual signs associated with seeing a hawk which may be associated with environmental factors that may trigger epileptic seizures, showing a need for research focusing on beliefs about trigger factors for epilepsy. There was also evidence of different treatment approaches to epilepsy which could be related to THs beliefs about the cause of epilepsy. For example, in Burkina Faso, treatments such as herbs and root concoctions, infusions, baths, incantations and fumigation were reported by Millogo et al. (2004), while Baskind and Birbeck (2005) reported on blowing smoke in the nostrils and immunizing family members against epilepsy. However Millogo et al. (2004) stated that the treatment outcome depended on diet especially when PWE do not consume fresh fish, chicken, goat, meat, shea-butter, okra and alcohol. Similarly, in Kendall-Taylor et al.'s (2009) study, there was evidence that foods such as coconut and eggs were forbidden as healers believed that they could trigger seizures. The findings on beliefs about foods are crucial as these beliefs may have a great impact on the health and well-being of PWE.

#### *Marriage and employment*

With regard to marriage and employment, there were varied perceptions in studies that examined epilepsy among THs. For example, Millogo et al. (2004) found that males who have epilepsy can only marry when their epilepsy is treated, but nothing was reported on whether this would be the case for women with epilepsy. In Njamnshi et al. (2010), there was evidence that most THs had negative attitudes in terms of their children befriending or marrying a PWE. Surprisingly, this appeared not to be the case with middle-aged THs. The authors further found that there were positive attitudes towards employment of PWE and this was mostly favoured by female THs. It would therefore be important to further explore these issues among male THs.

### **3.4. Studies reporting on psychosocial and cultural issues of carers that fall between the lay and professional sectors**

Only one cross sectional study with qualitative and quantitative components which was done by Otte et al. (2013) in Guinea Bissau. The study explored community rehabilitation volunteers' familiarity with, understanding of and attitudes towards epilepsy. The authors found that most community volunteers did not hold myths that epilepsy is contagious; it is a disease of the blood and did not relate it to mental illness or disability. An interesting finding though was that these volunteers were also Christians. How their religious values would influence the treatment and care of PWE was not reported, showing a research gap in this area. We also noted that despite that these volunteers did not view epilepsy as mental retardation or learning disability. It was of concern to find out that they were of the view that PWE should be educated in special schools, but the reason for this view was not explored. There was also evidence of some beliefs about diet which related to high consumption of eggs.

Although this view was not held by the majority of the volunteers, it highlights a need for research on these aspects.

### **3.5. Studies reporting on psychosocial and cultural issues of popular carers**

The nine reviewed studies reported on psychosocial and sociocultural issues that affect adult popular carers of PWE. These studies, although few, reported on different parameters of these issues focusing specifically on different types of adult popular carers. These are described below:

#### *Socio-cultural issues*

There were a range of cultural beliefs about the cause and treatment of epilepsy which were mainly about supernatural causes, and these were evident in studies reviewed (Keikelame & Swartz, 2007; Maiga et al., 2014; Mohammed & Babikir, 2013; Sidig et al., 2009). An interesting finding reported by Shehata and Mahran (2014) in Egypt was that these supernatural beliefs were not held by parents whose children had epilepsy, but by those who did not have CWE. Other beliefs that epilepsy is caused by an insect in the stomach was reported by Munthali et al. (2013) in Malawi. In addition, Mohammed and Babikir (2013) in Sudan, reported on findings from a cross-sectional study which explored the influences of religious and cultural beliefs on explanations of the cause of epilepsy and choice and methods of religious and traditional medicine used by carers in management of epilepsy. There were a range of different types of treatments such as wet or dry cupping to let the blood out, sitting by the grave and reading Quranic verses. These beliefs are important to consider because they can influence the treatment and care of PWE.

#### *Psychological issues*

Three studies reported on psychological issues affecting popular carers of PWE which involved issues such as the emotional burden of care and emotional stress. One descriptive cross sectional study was done by Saburi (2011) in Zimbabwe to identify stressors of caregivers of school-aged CWE and to assess whether the use of community resources alleviated or contributed to care giver stress using a three part interview schedule. Reported care giver stressors included worries about the child's future, life time dependency, fears of seizure-related injuries and school-related stressors such as CWE being deemed to be faking seizures and given simple tasks. Other stressors that were reported by Saburi (2011) were negative attitudes of siblings towards siblings who have epilepsy, lack of knowledge about the illness and lack of spousal support.

The other two studies reporting on psychological issues were conducted in Nigeria. One study done by Nuhu et al. (2010) used the Zarit Burden Interview (ZBI) instrument to assess the burden of care among care givers of PWE. They found that the carers' worries about uncertainty of the future of a PWE, polygamous marriages and unemployment affected their psychological well-being. Their findings show that the ZBI score for most carers was above 25 which indicated a high burden of care. The other study by Yusuf et al (2013) was a quantitative cross sectional study which aimed to identify the magnitude of and factors associated with emotional distress among care givers of PWE, using the Hospital Anxiety Depression Scale (HADS). There was evidence that most carers experienced anxiety, depression and co-morbid depression and anxiety. There was also evidence of emotional burden among siblings who

provided care, who were young and who lacked care-giving and coping skills. The majority of caregivers had more than five members in their households with no means of regular income and lived in rural areas. The findings show a need for psychological interventions and assessment of these aspects among carers of PWE.

### **3.6. Studies reporting on psychosocial issues of PWE**

Within the review, we found few review articles and articles reporting on different parameters of these aspects using different research designs.

#### *Psychosocial issues*

These issues were reported in reviewed studies conducted in Nigeria (Akinsulore & Adewuya, 2010) and in South Africa (SA) (Spangenberg & Lalkhen 2006). We found that Akinsulore and Adewuya's (2010) systematic review of 242 articles of studies conducted in Nigeria between 1966 and 2009 provided deeper insights with regard to the psychosocial and socio-cultural challenges affecting PWE in Nigeria. There was evidence of psychological issues such as anxiety, low self-esteem and depression, and fears of experiencing seizures, fear of work and fear of social participation as well as challenges related to psychiatric comorbidities. Social issues related to stigma, discrimination in terms of education, employment and marriage and myths about contagion and contracting the illness. Interestingly, there were more positive attitudes towards male people who have epilepsy than females. However, the reason for this was not reported. On the other hand, Spangenberg and Lalkhen's (2006) review article in SA reported on factors affecting CWE and their carers and the authors recommended a patient-centered approach and empowerment of carers.

In Nigeria, Komolafe et al. (2011) reported on psychological fears which were related to fears of drowning and fears of suffering burns. Many of these fears were also reported by Birbeck et al.'s (2008) in Zambia. However, unlike Komolafe et al. (2011), Birbeck et al.'s (2008) study reported that WVE had fears of being killed and of their body parts being sold. In addition, the authors reported that WVE worried about financial difficulties; about being subjected to shame; about breaking cultural norms and how they would be responded to during a seizure attack by strangers who might, through their actions, subject them to shame by exposing their sacred body parts; subject them to shame by exposing their underwear which was viewed as a determining factor of the kind of relationship the woman has with her husband. Meaning that those whose quality of underwear was poor might be viewed as women who were not loved by their spouses or it might suggest that men could also be viewed as poor men who were unable to support their wives.

From studies using instruments to assess these aspects, Olley and Osinowo (2001) in Nigeria used the Washington Psychosocial Seizure Inventory (WPSI) to assess these aspects and found that psychosocial maladjustment was significant among the unemployed and in those whose seizures were poorly controlled and that male PWE showed higher psychosocial difficulties than female PWE on interpersonal and financial adjustments. The authors also highlighted a need for appropriate instruments to measure these aspect. Similarly, the study of Nubupko et al. (2004), which used the Goldberg's Anxiety and Depression scale (GADs), stated that psychological difficulties were related to employment (types of jobs), marriage, urbanization, lack of



care and support and that rural WWE were more anxious and depressed than their controls.

### *Stigma*

We reviewed three published studies that specifically examined epilepsy associated stigma among adult PWE and carers. One was conducted by Atadzhanov et al. (2010) and assessed determinants of felt stigma in Zambia. They found that felt stigma was due to forced disclosure, beliefs and misperceptions about contagion. Another study was conducted by Shibre et al. (2006) in Ethiopia using a Family Interview Schedule (FIS) and found that felt stigma was due to local beliefs and myths about epilepsy. The third study was done by Rafael et al. (2010) in Benin who used mixed instruments such as the Explanatory Model Interview Catalogue (EMIC), GADs and Jacoby Stigma scale. The authors found high scores of stigma and that these were associated with anxiety and depression and were also due to the long course of the illness. The authors also found that PWE did not extend their stigma to their families. They suggested a need for research on 'transferred stigma'. The issue of perceived stigma was deemed to need full attention since it affects treatment outcomes of PWE, especially in Africa.

### *Socio-economic and socio-cultural issues*

We reviewed one article by Allotey & Reidpath (2007) which examined the social, cultural and environmental context of epilepsy in Cameroon using mixed quantitative and qualitative methods among adult PWE. The review showed that PWE had a sick role identity, relationship difficulties, viewed themselves as disabled and chronically ill. In addition, their data showed the use of the medical diagnosis of epilepsy as a potentially stigmatizing label for PWE. For example, authors reported that participants were identified as 'epileptics' via the local health care sources in the rural and urban areas. This 'medical labelling' may reduce PWE to 'things' or 'bearers of things'. However, whether PWE also accepted to be referred to as epileptics was not reported.

We also found that there were some studies that examined factors affecting nutrition of PWE. These were done in rural Benin (Crepin et al., 2007) and in rural Ethiopia (Vaid et al., 2012). The authors reported that malnutrition was due to socio-economic factors and poverty. In addition, we also note that there are cultural beliefs that could also lead to malnutrition. Beliefs about foods and reasons for restricting PWE to consume such foods were highlighted by Jilek-Aall et al. (1997) in Tanzania, showing a need for research in this area.

### *Social issues of WWE*

Two reviewed studies done in Zambia (Birbeck et al., 2008) and in Nigeria (Komolafe et al., 2012) reported on issues of abuse of WWE. Komolafe et al. (2012) found that in cases where some WWE consulted with THs and remained under their care, they were often abandoned by their families with some being sexually abused by some healers. There was evidence of lack of just laws to protect WWE from these abusive actions (Birbeck et al., 2008). In addition, there was also evidence that less attention has been paid to investigating abuse of men with epilepsy (Birbeck et al. 2008). While advocacy actions for just laws were reported (Birbeck et al., 2008), the findings suggest a need for educational interventions on abuse, recognition thereof and interventions to empower WWE and their carers with skills and support systems to deal with the problem.

There were other social issues such as transactional sex that were reported among WWE in two reviewed studies conducted in Nigeria (Komolafe et al., 2012) and in Zambia (Birbeck et al., 2008). This issue was related to limited financial support, social exclusion, abandonment and marginalization. However, Komolafe et al. (2012) caution that even though this sexual activity may be viewed as different from commercial sex, it may lead to promiscuity and unintended sexual risk in WWE. The authors reported that WWE denied this view because they reported having other means of income, details of which authors did not provide.

### *Marriage*

An interesting finding was that marriage difficulties can be perpetuated by significant others such as mothers-in-law. Komolafe et al. (2012) in Nigeria reported on this issue where daughters-in-law who present with epilepsy after marriage are often abandoned and rejected, the main perpetrators being the mothers-in-law.

This powerful role of the mother-in-law has been portrayed in a number of African movies and television shows aired on the continent (see, for example, 'Africa Magic' <http://africamagic.dstv.com/africa-magic-movies>). This finding suggests a need for research on how television movies may possibly be used to promote norms that are enabling rather than those that inhibit the health and well-being of WWE. Other marriage-related factors such as sexual dysfunction and polygamous relationships were reported to pose challenges for WWE (Birbeck et al., 2008), but these were not fully discussed.

### *Employment and driving*

Our review findings showed marginalization of PWE in terms of employment and driving. In SA, McQueen and Swartz (1995) found that there were some PWE who were unable to access disability grants (a governmental form of financial support) and were also unable to get employment in protective workshops of the local epilepsy organization. In another SA study, Segar (1994) found that despite the availability of these grants, PWE have difficulty in accessing them because access depended on compliance and on medical doctors' decisions to motivate for or against getting a grant. On the other hand, PWE whose seizures were poorly controlled and who may request a written motivation to access these grants would either be viewed as beggars for an income or beggars for a free meal ticket or faking seizures with no proper evaluation of their social circumstances. With regard to driving, one of the most troublesome issues that was reported by Sunmonu et al. (2011) in Nigeria was that some PWE were of the view that they could 'double' the seizure medication dose in order to drive. This finding further highlights social issues on which PWE should receive counselling and those that need to be considered when designing the content for educational interventions.

## **4. Discussion**

Our review of available literature on studies that examined the psychosocial and cultural issues among adult PWE and their carers in Africa between 1994 and 2014 has contributed to the existing body of knowledge by providing an overview of the kinds of psychosocial and cultural issues affecting adult PWE and their carers in different countries and settings in Africa. In this review, we included a range of relevant articles which used quantitative and qualitative research designs which examined variable parameters of these issues among adult PWE and carers from different sectors of health care. Through our synthesis of the results of the included studies that

we accessed and reviewed, we provided an overview of the different types of psychosocial and cultural issues which affect adult PWE and their carers in Africa.

The socio-cultural issues depicted from this review included negative attitudes toward the illness, discrimination towards marriage and employment, cultural beliefs about foods, different lay terminologies used for epilepsy and seizures and meanings thereof including cultural metaphors such 'death after death' (Adjei et al. (2013) and reference to PWE as 'epileptics'(Allotey & Reidpath, 2007). Across all studies, there was evidence of stigma. This was also reported in a recent cross-sectional study by Biffittu, Dachew and Tiruneh (2015) in Ethiopia which assessed the prevalence of stigma and associated factors among PWE. Although in our review there were concerns about the lack of appropriate instruments to assess these issues in Africa (Birbeck & Kalichi, 2003), we note that there is now a newly developed Kilifi Stigma Scale for Epilepsy in Kenya which would be a culturally appropriate instrument to measure these aspects in Africa (Mbuba et al., 2012). Other epilepsy researchers have suggested that peer support groups would be a beneficial intervention to address epilepsy associated stigma (Elafros et al., 2013).

The studies included in this review show that WVE face different psychosocial challenges such as physical and sexual abuse, abandonment and neglect and that some even resort to transactional sex. However, some authors are of the view that this could be a form of prostitution (Komolafe et al., 2012). There was also evidence that divorce subjects WVE to abject poverty and that absence of just laws to protect these women from financial abuse are lacking (Birbeck et al. 2008). Our review findings further show some gaps in research on studies that examine the psychosocial and cultural issues among adults with epilepsy carers from different sectors of health care such as professional, popular, folk and those that fall between the lay and professional such as CHWs. There were also very few studies that focus on religious and cultural issues of PWE and their carers and the findings suggest a need for research focusing on these aspects.

Our review was not a systematic review. Its aim was more to gain insight into existing knowledge and to identify research gaps in the evidence from published studies that reported on psychosocial and cultural issues affecting adult PWE and their carers in Africa. We relied on published articles that fitted our inclusion criteria of PWE, the review question and aims of the review. Therefore articles that examined issues such as compliance, prevalence and some that assessed these issues but were not written in English were not reviewed. This review was also limited to studies conducted in Africa and did not include studies in African American countries that might have examined these issues which we acknowledge as a limitation of our review process. We have also chosen to focus on themes of particular prominence in the literature and further work would be necessary in order to examine the information exhaustively.

In conclusion, our current review provides an overview of the psychosocial and cultural issues affecting adult PWE and their carers in Africa. It has also identified some gaps in research focussing on these issues. The findings from this review urge researchers to engage in interdisciplinary research to address gaps in current knowledge and to engage in advocacy actions that can help to alleviate these problems among adults with epilepsy and their carers in Africa.

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## Competing interests

None declared.

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## 2.2. EXCLUSION TABLE

The articles included in this table were selected for review after reading the abstracts of all retrieved sources after the search. The full articles were retrieved and read and were later excluded since they did not fit the criteria for inclusion and the review question. However, some were used in the discussion of this dissertation where relevant.

Table 2.1.  
Exclusion table

NO	Authors	Title of paper	Reason for exclusion
1	Babikar, H. E., & Abbas, I. M. (2011).	Knowledge, practice and attitude towards epilepsy among primary and secondary school teachers in South Gezira locality, Gezira State, Sudan. <i>Journal of Family and Community Medicine</i> , 18 (1), 17-21.	The study (type not stated) examined perceptions of teachers and did not fit inclusion criteria for carers and did not state if there were teachers who had epilepsy.
2	Millogo, A., & Siranyan, A. S. (2004)	Knowledge of epilepsy and attitudes towards the condition among school teachers in Bobo-Dioulasso (Burkina Faso). <i>Epileptic Disorders</i> , 6(1), 21-26.	Study did not state if there were teachers who had epilepsy or who had adult family members who had epilepsy.
3	Gedefa, M., Wolde, T., & Solomon, G. (2012).	Knowledge, attitudes and practices with respect to epilepsy among preparatory school students in Mekelle city, Ethiopia. <i>International Journal of Collaborative Research on Internal Medicine &amp; Public Health</i> , 4(3), 203-215.	The study (type not stated) examined perceptions of teachers but did not state if there were teachers who had epilepsy or who had had adult family members who had epilepsy.
4	Ali, D. B., Tomek, M., & Lisk, D. R. (2014).	The effects of epilepsy on child education in Sierra Leone. <i>Epilepsy &amp; Behavior</i> , 37(20), 236 - 240.	The cross sectional descriptive study sample focussed on children aged below 18 years and did not fit the inclusion criteria.
5	Chilopora, G. C., Kayange, N. M., Nyirenda, M., &	Attitudes to epilepsy in Malawi. <i>Malawi Medical Journal</i> , 13(2), 6-8.	The study sample was unclear as the authors only report on employment details of

	Newman, P. K. (2001).		participants such as bank managers, watchmen and labourers – and did not fit inclusion criteria for carers.
6	Frank-Briggs, A. J. (2013).	Perceptions of epilepsy among school teachers in Port Harcourt, Nigeria. <i>Highland Medical Research Journal</i> , 13(2).	Only the abstract was read – we experienced difficulty in accessing the full text – but the study investigated knowledge and attitudes about epilepsy among school teachers.
7	Ojinnaka, N. C. (2002).	Teachers' perceptions of epilepsy in Nigeria: a community-based study. <i>Seizure</i> , 11, 386-391.	This cross sectional survey determined the knowledge, attitudes and beliefs of teachers in rural areas towards epilepsy and did not state if the sample included teachers who had epilepsy or had adult family members who had epilepsy.
8	Ezeala-Adikaibe, B. A., Achor, J. U., Nwabueze, A. C., et al. (2014).	Knowledge, attitude and practice of epilepsy among community residents in Enugu, South East Nigeria. <i>Seizure</i> , 23(10), 882-888.	This cross sectional descriptive study determined the knowledge and attitudes of secondary school students towards epilepsy and did not specify if the sample had students who had epilepsy
9	Kabir, M., Iliyasu, Z., Abubakar, I. S., et al. (2005).	Knowledge, attitude and beliefs about epilepsy among adults in a Northern Nigerian urban community. <i>Annals of African Medicine</i> , 4(3), 882-888.	This cross sectional study determined perceptions, attitudes and beliefs about the causes, treatment and manifestations of epilepsy among adults in a traditional community but did not specify if there were adults who had epilepsy or who had family members who had epilepsy or

			whether there were carers of PWE.
10	Obiako, O. R., Sheikh, T. L., Kehinde, J. A., et al. (2014).	Factors affecting epilepsy treatment outcomes in Nigeria. <i>Acta Neurol. Scand</i> , 130, 360-367.	The study examined prognostic factors among PWE and was not the focus of the review question which was on psychosocial aspects.
11	Mustapha, A. F., Odu, O. O., & Akande, O. (2013).	Knowledge, attitudes and perceptions of epilepsy among secondary school teachers in Osogbo South-West Nigeria: a community based study. <i>Nigerian Journal of Clinical Practice</i> , 16(1), 12-18.	This cross sectional survey determined the knowledge, attitudes and perceptions of teachers on epilepsy and their attitudes towards PWE – it did not state if teachers had epilepsy or had adult family members who had epilepsy.
12	Matuja, W. B., & Rwiza, H. T. (1994).	Knowledge, attitude and practice (KAP) towards epilepsy in secondary school students in Tanzania. <i>The Central African Journal of Medicine</i> , Jan 40(1), 13-18.	Only the abstract was read. The full article could not be accessed – but the study focused on KAP of school students and did not specify if there were students who had epilepsy.
13	Burton, K., Rogathe, J., Hunter, E., et al. (2011).	Behavioural comorbidity in Tanzanian children with epilepsy: a community-based case-control study. <i>Developmental Medicine &amp; Child Neurology</i> , 53(12), 1135-1142.	This was a cross sectional study of behavioural disorders of CWE aged 6-14 years – it was excluded because of age of the sample age.
14	Mielke, J., Adamolekun, B., Ball, D., et al. (1997).	Knowledge and attitudes of teachers towards epilepsy in Zimbabwe. <i>Acta Neurologica Scandinavica</i> , 96(3), 133-137.	The study evaluated the knowledge and attitudes of teachers towards epilepsy but did not state if the sample included teachers who had epilepsy or had adult family members who had epilepsy.

15	Chomba, E., Haworth, A., Atadzhanov, M., et al. (2008).	The socioeconomic status of children with epilepsy in Zambia: implications for long-term health and well-being. <i>Epilepsy &amp; Behavior</i> , 3(4), 620-623.	This case control study on SES was excluded because the age of CWE was below 18 years.
16	Birbeck, G. L., & Munsat, T. (2002).	Neurologic services in Sub-Saharan Africa: a case study among Zambian primary healthcare workers. <i>Journal of the Neurological Sciences</i> , August 15; 200(1), 75-78.	The study assessed neurological services among PHC workers and was excluded as it did not focus exclusively on epilepsy.
17	Mbewe, E., Haworth, A., Atadzhanov, M., et al. (2007).	Epilepsy-related knowledge, attitudes, and practices among Zambian police officers. <i>Epilepsy &amp; Behavior</i> , 10(3), 456-462.	The study assessed the KAP of epilepsy among police officers and did not state if the sample included police officers who had epilepsy or had adult family members who had epilepsy. The article offered a list of names for epilepsy which were included in the Table 2.2.
18	Birbeck, G. L., Chomba, E., & Atadzhanov, M. (2006).	Zambian teachers: what do they know about epilepsy and how can we work with them to decrease stigma? <i>Epilepsy &amp; Behavior</i> , 9(2), 275-280.	The study assessed the KAP of epilepsy among teachers in urban and rural areas and did not state if there were teachers who had epilepsy or who had adult family members who had epilepsy.
19	Nyame, P. K., & Biritwum, R. B. (1996).	Epilepsy: knowledge, attitude and practice in literate urban population, Accra, Ghana. <i>West African Journal of Medicine</i> , 16(3), 139-145.	The full article could not be accessed. The abstract stated that the study was a cross sectional survey of government workers and general public.
20	Dugbartey, A. T., & Barimah, K. B. (2012).	Traditional beliefs and knowledge base about epilepsy among university students in	The full article could not be accessed. The abstract stated that the study determined the



		Ghana. <i>Ethnicity &amp; Disease</i> , 23(1), 1-5.	psychosocial beliefs and knowledge about epilepsy among university students in Ghana.
21	Afranie, S., Boafo, I. M., & Asante, K. O. (2009).	"Epileptic patient may be pardoned... but for AIDS you should know": HIV/AIDS, Stigma, discrimination and biographical disruption. <i>Gender &amp; Behaviour</i> , June 1, 10(1), 4585.	The study was excluded because it determined the prevalence of HIV/AIDS related stigma.
22	Berhanu, S., Alemu, S., Prevett, M., et al. (2009).	Primary care treatment of epilepsy in rural Ethiopia: causes of default from follow-up. <i>Seizure</i> , 8(2), 100-103.	The study was excluded because it determined the causes of default and traced PWE who defaulted on seizure treatments.
23	Shibre, T., Alem, A., Tekle-Haimanot, R., et al. (2008).	Community attitudes towards epilepsy in a rural Ethiopian setting: a re-visit after 15 years. <i>Ethiopian Medical Journal</i> , 46(3), 251-259.	The full article could not be accessed – however the study was excluded because the abstract stated that it was a cross sectional study that assessed the impact of seizure treatment among a rural community in Ethiopia. It did not clearly state if the sample included PWE or their carers.
24	Kariuki, S. M., Abubakar, A., Holding, P. A., et al. (2012).	Behavioral problems in children with epilepsy in rural Kenya. <i>Epilepsy &amp; Behavior</i> , 23(1), 41-46.	The study was excluded because it investigated behavioural problems of CWE aged below 18 years.
25	Ibinda, F., Wagner, R. G., Bertram, M. Y., et al. (2014).	Burden of epilepsy in rural Kenya measured in disability-adjusted life years. <i>Epilepsia</i> , 55(10), 1626-1633.	The study was excluded because it assessed the prevalence, incidence and mortality of epilepsy.
26	Bain, L. E., Awah, P. K., Takougang, I., et al. (2013).	Public awareness, knowledge and practice relating to epilepsy amongst	The study was a cross sectional community survey which investigated the KAP of

		adult residents in rural Cameroon – case study of the Fundong health district. <i>Pan African Medical Journal</i> , January 22, 14(1).	adults towards epilepsy – but it unclear if the sample included adults who had epilepsy or who had family members who had epilepsy.
27	Njamnshi, A. K., Tabah, E. N., Bissek, A. C. Z. K., et al. (2010).	Knowledge, attitudes and practice with respect to epilepsy among secondary school students in the Kumbo West Health District-North West Region-Cameroon. <i>Epilepsy &amp; Behavior</i> , 8(3), 247-253.	This survey study of students did not state if there were students who had epilepsy.
28	Njamnshi, A. K., Angwafor, S. A., Jallon, P., et al. (2009).	Secondary school students' knowledge, attitudes, and practice toward epilepsy in the Batibo Health District—Cameroon. <i>Epilepsia</i> , 50(5), 1262-1265.	This survey study of students did not state if the sample included adult students who had epilepsy.
29	Njamnshi, A. K., Tabah, E. N., Bissek, A. C. Z. K., et al. (2010).	General public knowledge, attitudes and practices with respect to epilepsy in the Batibo Health District, Cameroon. <i>Epilepsy &amp; Behavior</i> , 14, 83-88.	This hospital survey did not state if the sample included adult PWE and their care givers.
30	Peltzer, K. (2001).	Perceptions of epilepsy among black students at a university in South Africa. <i>Curationis</i> . 24(2), 62-67	This study (type not mentioned) investigated the relationship between knowledge, attitudes, causes, treatment and beliefs about epilepsy among university students – but did not state if there were students who had epilepsy.
31	Christianson, A. L., Zwane, M. E., Manga, P., et al. (2000).	Epilepsy in rural South African children – prevalence, associated disability	This study assessed the prevalence of epilepsy and associated disabilities

		and management. <i>South African Medical Journal</i> = Suid-Afrikaanse Tydskrif vir Geneeskunde, 90(3), 262-266.	and management therefore among CWE aged between 2-5 years and was therefore excluded
32	Van Niekerk, M., Dladla, A., Gumbi, N., et al. (2014).	Perceptions of the Traditional Health Practitioner's role in the management of mental health care users and occupation: a pilot study. <i>South African Journal of Occupational Therapy</i> , 44(1), 20-24.	This descriptive cross sectional survey did not focus on epilepsy nor include carers of PWE.
33	Smith, A. B., van Hoving, D. J., & Wallis, L. A. (2013).	Emergency centre investigation of first-onset seizures in adults in the Western Cape, South Africa. <i>SAMJ: South African Medical Journal</i> , 103(10), 723-727.	This study was excluded because it was a folder review of records of medical investigations on adult PWE who presented with history of first onset of seizures.
34	Ocana, G. S., Sablon, J. C. O., Tamayo, I. O., et al. (2009).	Neurocysticercosis in patients presenting with epilepsy at St Elizabeth's Hospital, Lusikisiki. <i>SAMJ: South African Medical Journal</i> , 99(8), 588-591.	The study was excluded because it examined the prevalence of neurocysticercosis among PWE and focused on assessment of blood results and CT scan findings.
35	Veary, C. M., & Manoto, S. N. (2008).	Neurocysticercosis: a possible cause of epileptiform seizures in people residing in villages served by the Bethanie clinic in the North West Province of South Africa. <i>Journal of the South African Veterinary Medical Association</i> , 79(2), 84.	The cross sectional study was excluded because it examined the prevalence of neurocysticercosis among households in Bethanie village.
36	Mathews, M., Mammen, K. J., & Mammen, M. (2012).	Myths and beliefs about the acquisition of taeniasis and cysticercosis amongst the Xhosa University students in South	This cross sectional study investigated beliefs regarding contracting neurocysticercosis and causes of epilepsy

		Africa. <i>Ethno-Med</i> , 6(3), 197-206.	among first year Xhosa speaking university students – and did not state if the sample included adult students who had epilepsy.
37	Leary, P. M., Riordan, G., Schlegel, B., et al. (1999).	Childhood secondary (symptomatic) epilepsy, seizure control, and intellectual handicap in a nontropical region of South Africa. <i>Epilepsia</i> , 40(8), 1110-1113.	The study was excluded because it was a prevalence study and did not focus on psychosocial aspects of epilepsy and adults PWE.
38	Osungbade, K. O., & Siyanbade, S. L. (2011).	Myths, misconceptions, and misunderstandings about epilepsy in a Nigerian rural community: implications for community health interventions. <i>Epilepsy &amp; Behavior</i> , 21(4), 425-429.	This cross sectional study investigated beliefs and perceptions about epilepsy among adults who did not have epilepsy – and authors did not state whether they were carers of PWE.
39	François, A. A., Elisée, B. K., Christian, T. A., et al. (2014).	Traditional health practitioners and epilepsies in Ivory Coast. <i>Rev Neurol (Paris)</i> , 4 Aug-Sep, 170(8-9): 508-11. doi: 10.1016/j.neurol.2014.05.006. Epub 2014 Sep 2. French.	The article was received from corresponding author – but was excluded for being written in French.
40	Ventevogel, P., Ndayisaba, H., & van de Put, W. (2011).	Psychosocial assistance and decentralised mental health care in post conflict Burundi 2000–2008. <i>Intervention</i> , Nov 1;9(3), 315-331.	The article was excluded – it reported on post-conflict Burundi issues affecting mental health– with very little focus on epilepsy – but lay name for epilepsy was noted.
41	Guinhouya, K. M., Beloa, M., Kombate, D., et al. (2014).	Epilepsy related costs in Togo. <i>Schweizer Archiv fur Neurologie und Psychiatrie</i> , 165, (6)	The abstract showed that this was a longitudinal quantitative study which included PWE and examined epilepsy related costs in Togo but the full

			article could not be accessed.
42	Owolabi, L. F., Shehu, N. M., & Owolabi, S. D. (2014).	Epilepsy and education in developing countries: a survey of school teachers' knowledge about epilepsy and their attitude towards students with epilepsy in Northwestern Nigeria. <i>The Pan African Medical Journal</i> , 18.	This KAP survey of school teachers did not fit carers' inclusion criteria.
43	Shehata, G. A., & Mahran, D. G. (2010).	Knowledge, attitude and practice with respect to epilepsy among school teachers in Assiut city, Egypt. <i>Epilepsy Research</i> , 92(2), 191-200.	This cross sectional study was a KAP survey of school teachers did not fit carers' inclusion criteria.
44	Frank-Briggs, A. I., & Alikor, E. A. D. (2011).	Knowledge and attitudes of parents toward children with epilepsy. <i>Annals of African Medicine</i> , 10(3).	This study (type not mentioned) was excluded because it examined KAP among parents, but did not specify whether parents had CWE.
45	Ogboi-Sonny, J., Babajide, F., Ademola, O. A., et al. (2011).	Evaluation of factors influencing medication adherence in patients with epilepsy in rural communities of Kaduna State, Nigeria. <i>Neuroscience &amp; Medicine</i> , 2, 299-305.	This cross-sectional study examined adherence factors among PWE, but did not focus on psychosocial aspects.
46	Ogunrin, O. A., Adeyekun, A., & Adudu, P. (2011).	Etiologies of epilepsy and health-seeking itinerary of patients with epilepsy in a resource poor setting: analysis of 342 Nigerian Africans. <i>Seizure</i> , Sep 30; 22, 572-576.	This observational cross-sectional descriptive study examined the medical causes of epilepsy and health seeking behaviours of PWE.
47	Pupillo, E., Vitelli, E., Messina, P., et al. (2014).	Knowledge and attitude towards epilepsy in Zambia: a questionnaire survey.	This survey was conducted among urban and rural communities and did

		<i>Epilepsy &amp; Behavior</i> , 34, 42-46.	not state if the sample included adult carers of PWE or PWE.
48	Kendall-Taylor, N., Kathomi, C., Rimba, K., et al. (2009).	Family well-being and children with epilepsy in Kilifi, Kenya: 'When a child convulses his family is affected'. <i>The Open Family Studies Journal</i> , 2, 54-65.	This study used an anthropological method to examine the concept of family well-being in order to gain an understanding of the effects if childhood epilepsy on the goals, values activities and social relationships of care givers.



### 2.3. LAY NAMES FOR EPILEPSY AND SEIZURES

The reviewed articles revealed evidence of a wide range of lay terms that are used to explain epilepsy and seizures. These terms differed in different areas in the same country and between countries and had different interpretations and meanings, as reflected in Table 2.2.

Table 2.2.

*Examples of lay names for epilepsy and seizures in some countries in Africa*

Author/Year	Country	Epilepsy/seizure names	Meanings
Adjei, et al., (2014)	Ghana	Death after death Fetish	PWE dies and wakes up and dies again repeatedly. Epilepsy inflicted for bad behaviour such as stealing.
Osakwe, et al., (2014)	Nigeria	Ndaafu; Ejighano	
Otte, et al., (2013)	Guinea Bissau	Durkabesa	Falling down sickness, knocking down the head; demonic possession.
Munthali, et al., (2013)	Malawi	Khunyu	Illness caused by the will of God.
Eisigbe, et al., (2013)	Nigeria	Itohu	A mysterious disease; an affliction caused by witchcraft and evil spirits which can be contracted via direct contact.
Deo, (2013).	Rwanda	Crisis Spectacle eyes	Seizure attack.
Mugumbate, J., & Nyanguru A. (2013)	Zimbabwe	Zvipusha Pfari Kugwinha	An infectious condition. Jerking. Fitting.
Mushi, et al., (2012)	Tanzania	Bad illness	Falling down disease; fainting disease.
Komolafe, et al., (2011)	Nigeria	Giri Ogun oru or nocturnal warfare  Warapa	Seizures Seizures caused by demonic spirits attacking a person during sleep Epilepsy (an illness that has poor health outcomes)
Mushi, et al., (2011)	Tanzania	Kifafa; degedege Ukugonjwa wa kuanguka Ukugonjwa wa kuzimia	Falling down sickness  Fainting illness or an illness with loss of memory or convulsions
Rafael, et al., (2010)	Benin	Gods disease Simple disease	
Birbeck, (2009)	Zambia	Fits, spells or fainting Kuyamamina	Names for seizures; To fit or to have a seizure; Having had a seizure attack;

		Kugamanyama mafwafwa	Evil spirits.
Jilek- Aall, et al., (1997)	Tanzania	Kifafa	African illness, clan affliction, dangerous affliction.
McQueen, A. H., & Swartz, L. (1995)	South Africa	Die siekte; aanvallende siekte or stuipe get sick being sick	Epilepsy.  Getting a seizure attack. Having a seizure attack.
Mbewe, et al., (2009)	Zambia	akakosh, cabana, chikonikoni, chikonya, chipumputu, chituwani, kaganyuka, kakoshi, kanono, kashita, kasuntu, kifwafwa, kikonyi, kishimo, kuganyuka, kunyu, kuwa, makwa, musamfu, nafwa, njilinjili. Njinjili, umusamfu, and vizilisi.	
Ventevogel, et al. (2011)	Burundi	Intandara	Epilepsy
Keikelame, M.J., & Swartz, L. (2007)	South Africa	Ukuxhuzula	Epilepsy
Mangena-Netshikweta, (2003)	South Africa	<i>tshiiva</i> , <i>tshifakhole</i> , <i>tshirivha</i>	Epilepsy

## CHAPTER THREE: COMMENTARY



**Dr Panana: “We think epilepsy is probably managed poorly because from my experience what we see is that lots of patients are having breakthrough seizures...lots of patients are probably put on wrong regimes.”**

## **CHAPTER THREE**

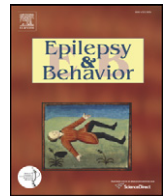
### **ARTICLE 1**

#### **General practitioners' perceptions on management of epilepsy in primary care settings in Cape Town: An exploratory pilot study**

##### **3.1. INTRODUCING ARTICLE 1**

This chapter presents the first article of the seven peer-reviewed journal articles that are products of this dissertation. It examines perceptions of medical doctors on management of epilepsy in primary care settings in Cape Town. As explained in the introductory chapter to this thesis, I used Kleinman's (1980) typology of the three sectors of health care – which are the professional, popular and the folk health care sectors – as my theoretical framework. This chapter deals with professional health care practitioners in Cape Town who had the experience of working in the public and private health care sectors and who also knew how chronic illnesses, including epilepsy, are managed in the public health sector. It shows some perceived health systems factors that affect management of epilepsy in the public health sector in Cape Town.

Preliminary findings from this part of the study were reported to various audiences in Cape Town, such as the Family Physician Forum, the local Epilepsy NGO, the Family Medicine Journal Club in the UCT School of Public Health and Family Medicine and at the clinical health care practitioners' meeting at the Community Health Centre (CHC) from which the study population received care in order to promote awareness about the problem.



## General practitioners' perceptions on management of epilepsy in primary care settings in Cape Town, South Africa: An exploratory pilot study

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### ABSTRACT

In a context where there are few neurologists, excellent management of patients with epilepsy at a primary care level is imperative. In South Africa, most uninsured patients suffering from epilepsy and other chronic illnesses are managed by general practitioners in state-provided primary care settings. We conducted a qualitative pilot study to explore perceptions of doctors working in primary care settings in Cape Town regarding the quality of epilepsy management. Our analysis revealed that these clinicians believe that epilepsy is poorly managed. Attributing factors were consistent with those found in literature. Although study findings cannot be generalized, we conclude that lack of attention to factors impacting on management of epilepsy is a serious concern and may lead to violations of health rights. Urgent prioritization, advocacy, collaboration, and empowerment of healthcare professionals, patients, lay carers, and the general public are needed to improve the management and quality of care of PWE.

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### 1. Introduction

Epilepsy is reported to be a serious public health problem [1,2] affecting about 50 million people worldwide [3,4]. Approximately 70% of patients with epilepsy (PWE) can successfully achieve seizure freedom with western medical treatment [3,5–7]. In resource poor countries, however, many PWE remain untreated due to factors such as a lack of trained health care workers, poverty, illiteracy, socio-economic factors, inaccessible health facilities, inadequate supply of epilepsy medication, cultural beliefs, stigma, and myths about epilepsy [1,2,5,8]. In South Africa, the burden of non-communicable diseases is reportedly growing [9]. With regard to epilepsy, it is thought that about 1 in every 100 South Africans suffers from the condition [10,11], but more accurate figures are unknown [12]. This could partly be that epilepsy statistics are combined with those of psychiatric illnesses such as schizophrenia, bipolar depression,

and dementia, which together accounts for 6% of the total burden of non-communicable diseases [13]. Neurocysticercosis, a cause of epilepsy, is reported as the “*silent epidemic*”, with a prevalence rate of 20% in the predominantly rural Eastern Cape province of SA [14,15]. Epilepsy management is not routinely assessed through clinical governance processes and a recent audit report of chronic illnesses (hypertension, diabetes, COPD, epilepsy, and asthma) by the Western Cape Provincial Health Department reported epilepsy as “*a relatively new area for audit*” [16].

South Africa delivers health care through sectors: private and public [17], and most people access health care through the public sector [18]. Access to the private sector, on the other hand, depends on the ability to pay for services, while care is free at state primary care service points. Nationally, there are 111 neurologists [19] and most of them work in the private sector [20]. There is also an informal health sector which comprises more than a hundred thousand traditional healers [21], from whom approximately 80%–85% of South Africans seek health care [22]. We conducted a qualitative study to explore experienced doctors' perceptions regarding management of epilepsy in primary care settings in Cape Town. Our objective was to gather information for future policy and planning, research and development of appropriate interventions for improved management of epilepsy.

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## 2. Methods

We used a qualitative research design to explore perceptions of general practitioners about management of epilepsy in primary care settings in Cape Town.

### 2.1. Sample and sampling strategy

Our respondents were purposively selected from a list of doctors who facilitate student teaching in the University of Cape Town's undergraduate medical curriculum and who work in public and private health sectors. Half were volunteer doctors who host students in their practices and are not remunerated for teaching. The respondents were approached following a non-systematic convenience method, based on what has been known collegially by the researchers. Doctors were recruited to ensure a good representation of doctors working in both the private sector and at various Community Health Centers rendering care to disadvantaged population groups in Cape Town. Public health doctors generally serve patients from a lower socio-economic background, while doctors from the private sector may see a wider variation of patients from differing socio-economic backgrounds.

As this was a pilot study and due to time and cost factors, we initially aimed to limit the sample size to 15 participants. Only nine doctors expressed an interest in participating; however, the possibility of needing to recruit further respondents for an expanded study was acknowledged. After recruitment, the respondents were emailed formal letters of invitation explaining the purpose, aim and objectives of the study, methodology, their rights to participation, and informed consent. Appointments for interviews were then set. After the final interview had been conducted, it was decided to include a neurologist who had an experience of working in both private and public sectors (tertiary care level) into the study. We expected that the neurologist may offer valuable insight into some of the issues raised by the primary care doctors already interviewed.

Our total sample, therefore, consisted of ten doctors. Three males and two females were from the private sector and included one neurologist. The remaining five respondents were from the public sector and comprised three females and two males.

### 2.2. Data collection

A semi-structured interview guide was constructed in English and was used by two researchers (MJK and RMH) to collect qualitative data from the respondents about their perceptions about management of epilepsy in primary care settings in Cape Town. Ten individual face-to-face interviews were conducted. Reliability and consistency in data collection were ensured by two researchers agreeing on the interview guide and the data collection method prior to administration. Interviews lasted between 30 and 60 min. Interviews were recorded with the respondents' consent and were conducted at the subjects' preferred venue and time. During data collection, the two interviewers reflected upon what they had heard from each completed interview and both felt reasonably confident that they had reached a point of data saturation as no new perceptions were emerging and that there was no need to recruit further participants. Pseudonyms were used to protect the identity of subjects. Approval to conduct the study was obtained from the Human Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town.

### 2.3. Data analysis

Transcriptions were completed immediately after the data collection concluded and were emailed to all researchers to familiarize themselves with the data. Data analysis followed, using thematic analysis. We used an inductive approach to identify themes from the data through reading and re-reading of transcripts to familiarize

ourselves with the data, to reflect, compare and contrast themes, and to interpret the data and gain consensus on the emerging themes [23–26]. Throughout the data analysis process, codes were modified, re-defined, grouped, and re-grouped as ideas were developed and data were recontextualized. NVivo qualitative analysis data software was used by the research assistant (CN) to manage and organize the data for coding. Broad main categories (themes) were coded as tree nodes while sub-themes as free nodes. Node models were developed to link and relate the free nodes to the broader tree nodes (see Fig. 1).

Four main themes emerged from the data: (i) 'management of epilepsy', which included management guidelines, poor seizure control, adverse reactions to antiepileptic drugs (AEDs), successful treatment outcomes, and factors impacting on epilepsy; (ii) 'psychosocial issues', which included cultural beliefs and practices, disability grants, employment, and alcohol and driving; (iii) 'women with epilepsy', which included pregnancy and contraception; and (iv) 'challenges facing management of epilepsy in South Africa'. Each main theme was reviewed and organized into sub-themes which had emerged from each of the four identified themes. Specific quotes of each respondent were further organized into tables. This paper reports on the findings specific to the first theme on 'management of epilepsy'.

## 3. Results

We interviewed ten general practitioners about their perceptions about management of epilepsy in primary care settings. The main theme that emerged from our study findings was that epilepsy is poorly managed. This finding is consistent with other South African studies on epilepsy [27,28].

*"Well I think it's probably managed quite poorly, because from my sort of experience what we see is that a lot of the patients are having breakthrough seizures, a lot of patients are probably being put on wrong regimes."*

One respondent thought that doctors do not receive sufficient training in management of epilepsy.

*"I think epilepsy is poorly managed mostly because there isn't as much proper training on part of primary care doctors particularly in the clinics."*

According to Iyer et al. [29], doctors need to have requisite skills in epilepsy care and management to be able to give an accurate clinical diagnosis and to get detailed history from a witness.

Views with regard to poor management of epilepsy are examined under the following sub-themes below.

### 3.1. Management guidelines

Most respondents perceived that epilepsy management guidelines were inaccessible, too detailed, and impractical to use on a daily basis. This echoes Eastman's [12] findings from a study in Gauteng, South Africa, where epilepsy guidelines were only used by some doctors in certain hospitals. In this line, Frost et al. [30] argue that while evidence exists that management guidelines can improve quality of care, it has not been established how this can be achieved in real practice. According to Pakenham-Walsh and Bukachi [31], there is a need to assess the availability, quality, and use of guidelines.

*"It's [guidelines] too detailed you see, it's not something you can use on a daily basis."*

### 3.2. Poor seizure control

When asked about their perceptions about poor seizure control, respondents reported some contributing factors such as poor adherence, alcohol, and cannabis use.



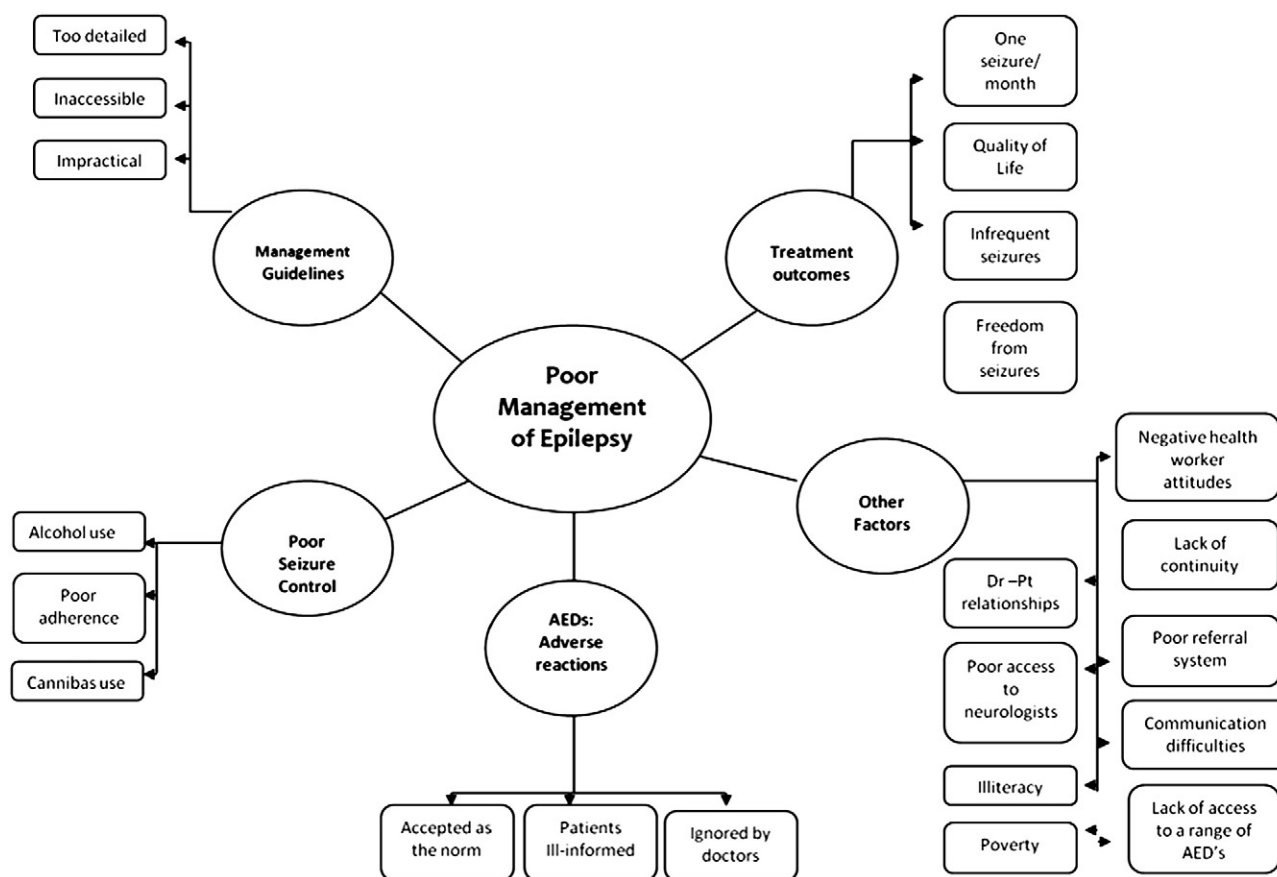


Fig. 1. Schematic of the theme 'Poor management of epilepsy', including sub-themes and important factors reported by the respondents.

"Poor seizure control in our situation, you have to look at lack of compliance and then you have to look at drinking alcohol and things like dagga which they are not very willing to tell you.... And then its maybe that the patient is compliant, but the medicine is not working. Then you may have to change the treatment, to either increase the dose or to change the drug."

One respondent believed that poor seizure control and adherence need to be explored in the South African context. Radhakrishnan [32] reported that many PWE in resource poor countries discontinue treatment because of poor access to treatment and lack of information about the effects of not adhering to prescribed AEDs, and most experience breakthrough seizures. Breakthrough seizures, according to Ettinger and Adigha [33], are seizures that can occur as a result of non-adherence to AEDs and other factors, which, among others, include emotional stress, sleep deprivation, infections, changes in blood sugar levels, flashing lights, and use of certain medications. However, Liow [34] reports that breakthrough seizures can occur due to changing from branded to generic agents and also acknowledges that this finding has not been reflected in scientific literature.

### 3.3. Adverse reactions to AEDs

One particularly interesting finding was that the respondents in the public sector thought that health care providers do not ask questions about side effects of AEDs and that patients are not well informed about them, resulting in patients ignoring them and accepting adverse effects as a part of life.

"I don't think that the question is asked often enough to patients if they do get any side effects, actually. And also maybe, okay there's not that many options so we just ignore the question...few patients

complain. Again, I think that patients possibly, in the state sector are not very informed and they are accepting them as the norm."

Lack of time to educate patients, poor counseling skills, and lack of appropriate information on the effects of non-adherence to AEDs exacerbate the problem [35]. Liu et al. [36] report that a reduction of the adverse side effects of AEDs can be achieved through patient education about their medication which will in turn reduce misinterpretation of how to take the medication and non-compliance.

### 3.4. Successful treatment outcomes

We were interested to hear what the respondents' viewed as successful treatment outcomes and found that there were a variety of perspectives. Some based this on the frequency of seizures. For some doctors, one seizure a month was acceptable, while for others, freedom from seizures was the ideal. Some respondents felt that quality of life was an important indicator of successful treatment outcomes, as described in the following quote.

"... They [PWE] want to drive and to have kids. They don't want to worry about side effects and fear of seizures. They want jobs. They don't want to be discriminated. They don't want to be tired all the time.... So good quality of life, I think those are good outcomes."

According to Moffat et al. [37], quality-of-life measures are crucial in epilepsy because it is such a chronic and debilitating condition. To improve quality of life, there is a need to shift from putting more emphasis on compliance to paying more attention to the psychosocial aspects of epilepsy [38].

Other factors the respondents perceived to perpetuate the poor management of epilepsy were: illiteracy, poverty, negative attitudes

of health workers, lack of continuity of care, poor referral systems, lack of access to neurologists, paternalistic doctor–patient relationships, and language difficulties. These findings are consistent with treatment gap-related factors which have been reported from studies done in Sub-Saharan Africa [39,3–7]. The finding about the lack of access to a range of AEDs in SA is of great concern since old and new antiepileptic drugs are in fact available [19]. Birbeck [39] reports that when there is limited access to ranges of AEDs, patients and health care providers tend to accept or ignore side effects more than patients and health care providers who have access to second- and third- line AEDs.

#### 4. Discussion

We used a qualitative exploratory design to explore perceptions of general practitioners about the management of epilepsy in primary care settings in Cape Town. Our sample was small and reflects the opinions of a few clinicians who were interested to participate in the study. The study did not intend to canvass the opinion of all practitioners in primary care settings in Cape Town. Rather, it sought to forefront issues regarding quality of care through selection of respondents who were keen to participate. The study was conducted in a rigorous way and the approach of the researchers and the way participants responded demonstrate trustworthiness. This is evident as the themes elicited recurred through the interviews. Our findings support the principle that management of epilepsy in SA should take into account factors such as stigma, illiteracy, poverty, and the effect of HIV/AIDS. Patients with low literacy levels have poor knowledge about their illness and experience difficulties in accessing care and self-management [40]. Human immunodeficiency virus is a risk factor for epilepsy [12,41], and the high HIV prevalence in many developing countries, especially in sub-Saharan Africa, is posing serious challenges with regard to managing the effects of the combined use of AEDs and antiretrovirals [42]. With the high HIV prevalence rates in SA, these findings emphasize that epilepsy needs urgent prioritization by the health services.

Since the majority of the African people seek care from traditional healers, collaboration between western and informal traditional healthcare services is also needed. A South African study found that some PWE combined western and traditional treatments for their condition [27]. Similarly, Bartolini et al. [41] found that in China, patients accessed both western and traditional medicines for the treatment of their epilepsy.

Our findings highlight a need for empowerment of patients and doctors [43]. Snape et al. [44] emphasize the importance of good communication between patients, doctors, and carers and counseling on beliefs about the cause and treatment of epilepsy, its triggering factors, and those that may reduce seizure frequency. The approach to treatment of seizures has greatly changed over the past two decades [29], and inclusion of epilepsy training in the medical curricula is crucial [45]. A more effective management of epilepsy requires a move from the “episodic reactive model of care” to a “proactive model of care”, which includes active patient participation and empowerment of clients and health care professionals [46].

#### 5. Conclusion

In our exploratory pilot study, epilepsy was perceived to be poorly managed in primary care settings in Cape Town. There is an urgent need for collaborative and integrated approaches to improve the quality of care for PWE. We identified themes that could be addressed accounting for current medical and financial capacity, and our study subjects would welcome this. Further research is needed to investigate the impact of these factors on patients and health care providers.

#### Acknowledgments and declaration

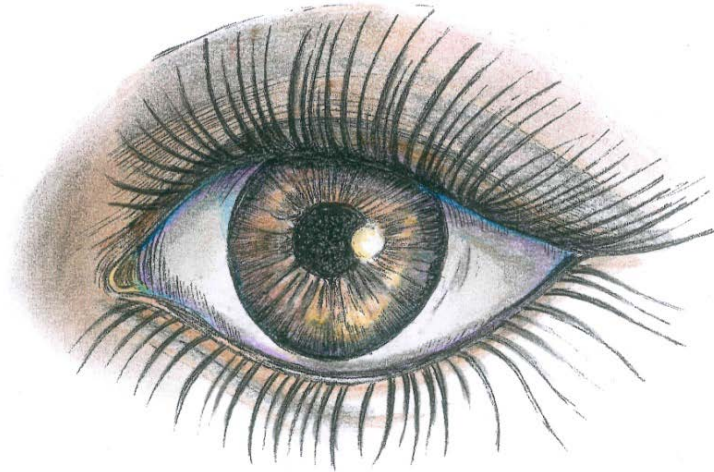
We thank the study participants for their invaluable input and time. Special thanks to Mrs. Hanneke de Boer and to the reviewers for their insightful comments that helped to improve this paper, the UCT Directorate of Primary Health Care and the Emerging Researchers' Carnegie grant.

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## CHAPTER FOUR: COMMENTARY



***It is sometimes important that we use our eyes and ears to gain an understanding of how social settings in which health care is provided are constructed. (Mulhall, 2003, p. 307)***

## **CHAPTER FOUR**

### **ARTICLE 2**

#### **Lost opportunities to improve health literacy: Observations in a chronic illness clinic providing care for patients with epilepsy in Cape Town, South Africa**

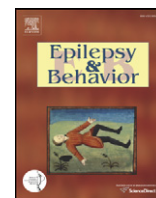
##### **4.1. INTRODUCING ARTICLE 2**

In Chapter Three, I described the health systems' factors that doctors reported which affected management of epilepsy in primary care settings in Cape Town. In order to understand the actual routine tasks and activities of the professional health sector, the next stage of my research involved observing practices concerning epilepsy in a chronic illness clinic in my catchment area. The article forms the bulk of this chapter and provides an examination of health systems factors that affect access to appropriate treatment and care of people suffering from epilepsy in one of the CHCs that provides health care services for the study population in Cape Town.

The article is the second of the seven published peer-reviewed journal articles which is a product of this dissertation. It extends the understanding of the health systems' factors reported by practitioners in Chapter Three through detailed descriptions of the context, specific health promotion events focussing on epilepsy, epilepsy information materials and specific interactions that were observed between PWE and HCPs in a chronic illness clinic that served the study population.

Similar to Chapter Three, preliminary findings from this observation study were presented to the representative committee members of the local Epilepsy NGO, the local health committee in the study setting and the clinical health practitioners' meeting at the Community Health Centre (CHC) from which the study population receive their health care services in order to promote awareness about the problem.





# Lost opportunities to improve health literacy: Observations in a chronic illness clinic providing care for patients with epilepsy in Cape Town South Africa

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## ABSTRACT

Low health literacy (LHL) is reported globally as a barrier to achieving quality of life of patients with epilepsy. In South Africa, despite reports that epilepsy is poorly managed and understood, little attention has been paid to promote health literacy of patients suffering from the condition and those providing their care. We used observation to gain a picture of interactions between patients with epilepsy and health care providers in a chronic illness clinic serving the marginalized population groups in Cape Town. The observation data were compiled into descriptive field notes which were content analyzed. Our findings revealed some patient and health care provider health literacy-related factors affecting the understanding of epilepsy and treatment outcomes. There were also some lost opportunities where health literacy could have been promoted. However, these results cannot be generalized, but they highlight a true picture of contextual health system factors that need to be addressed.

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## 1. Introduction

Health literacy is recognized as a key element in prevention and management of chronic illnesses [1]. It is defined by Kickbusch et al. in Shaw et al. [2] as:

‘the ability to make sound health decisions in the context of everyday life, at home, in the community, at the workplace, in the healthcare system, in the market place, and in the political arena. It is a critical empowerment strategy to increase people's control over their health, their ability to seek out information, and their ability to take responsibility’ (p114–115).

Patients with low health literacy (LHL) have poor knowledge about their illness, experience difficulties in accessing health care, have poor self care, have lower levels of quality of life, and have poor health outcomes [3–5], including higher risk for premature deaths [6–8]. Low health literacy has also been reported to have a great impact on interactions between patients and health care providers (HCP) [9]. Furthermore, some health literacy researchers report that LHL is more often associated with individuals from lower socio-economic groups, among older persons and racial minorities [10], and from those living in rural areas because of low education levels, high unemployment rates, low wages, and lack of health insurance [11].

Low health literacy may, therefore, be a particular problem in low and middle-income countries as these countries have high poverty rates and low rates of education. In South Africa, Keikelame et al. [12] explored the doctors' perceptions on management of epilepsy in primary care settings in Cape Town. Their study found that epilepsy is poorly managed. Associated factors among others include illiteracy, poverty, communication difficulties, poor doctor–patient relationships, and language barriers. Taking into account the diversity of the South African population groups, health literacy becomes a real cause for concern.

Because of South Africa's diverse population and challenges for HCP, there is a need to investigate whether there may be other fine grained health literacy factors that could be affecting the understanding and management of epilepsy. As part of a larger project, we report here on preliminary observations of interactions between patients and HCP in a chronic illness clinic in Cape Town, South Africa. According to Kawulich [13], observation is a data collection method which can help researchers to fulfill that purpose. Our objective was to use the findings from the observation data to frame research questions to explore the findings in more depth through individual and focus group interviews in later phases of a broader project exploring social factors in the experience and management of epilepsy in Cape Town.

## 2. Methodology

### 2.1. Research design

A qualitative design which used observation as a data collection method was used. Observation is defined as a method which involves

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“a systematic noting and recording of events, behavior, and objects (artifacts) in a natural setting that is chosen for the study” [14]. Patients with epilepsy (PWE) attending the chronic illness clinic at Vamusa<sup>1</sup> Community Health Centre (CHC) in Cape Town were observed during their follow-up consultations by the first author, as were the personnel from the health system with whom they interacted.

## 2.2. Participants and the setting

We recruited PWE who attended scheduled appointments at Vamusa chronic illness clinic. The Vamusa CHC renders 24 h primary health care services to two predominantly Afrikaans and Xhosa speaking communities residing in one of the urban townships in Cape Town. Health services provided include maternal and reproductive health, child health, TB, nutrition, school health, oral health, sexually transmitted infections (STI's), HIV, environmental health, mental health, rehabilitation services, and chronic illnesses (epilepsy, hypertension, asthma, and diabetes). Patients needing ambulatory care in CHCs are seen by clinical nurse practitioners and doctors [15]. Residents from these townships are of low socio-economic background and have high rates of illiteracy and unemployment [16].

## 2.3. Observer interaction and ethics

After gaining ethics approval for the project from the local research ethics committees, the researcher (MJK) met with the facility manager of Vamusa CHC to establish rapport and to provide an overview of the study in order to gain entry and access to participants. Thereafter, the facility manager identified other key staff members with whom the researcher should communicate and liaise during the study period. The identified staff members advised the researcher on suitable times for doing observation in the chronic illness clinic.

The identified staff members introduced the researcher to the chronic illness clinic staff and to other key members of staff who would be able to help where necessary. Through their assistance and support, the researcher was able to establish rapport and gain access to staff and patients at the chronic illness clinic. To enhance good relationships during the study phase, the researcher maintained the conditions on which access was granted. Because observation is a very complex data collection method [17], the researcher (MJK) played the role of an “observer as participant”, an overt role through which the researcher's presence and motives are known by the key gate keepers [18–20]. Through this role, the researcher was able to engage in informal conversations with some staff members and patients to clarify issues on particular events observed [21]. Despite the fact that the overt role enabled the researcher to recruit eligible patients for individual interviews for the second phase of the project, the researcher was aware of the limitations of the overt role which may have caused some changes in attitude, opinions, and behavior of those that were observed without the researcher being consciously aware of such changes. On the other hand, the clinic staff and patients may have pretended that the observation process was not obtrusive because the researcher was known to other members of the staff [22].

## 3. Data collection methods

A total of five observations were done by the researcher (MJK) between March and June 2012. A semi-structured observation guide consisting of a list of elements which were used to guide the types of observation to be done was constructed [23–25]. The researcher

first started doing general observations to gain insight into the context and thereafter, moved to focused observation [26]. The data included observations of the following:

1. interactions between patients and HCP (including interactions across language barriers)
2. information materials made available to patients
3. patterns of verbal and nonverbal communication
4. the physical environment
5. an interaction between a patient and the pharmacist
6. the educational talk provided to patients at the reception area.

The duration of each observation was between 30 and 60 min with five-minute breaks in between to jot additional information in privacy. The researcher used a small note book in which abbreviated comments and jottings of observed interactions between patient and staff were recorded [27]. At the end of each observation, the researcher wrote detailed field notes to describe the events observed as well as the researcher's reflections on the research process [13,28].

## 4. Data analysis

Field notes were written and typed immediately after each observation and provided detailed descriptions of behaviors observed, the date, time, and place. The typed field notes were read by the two authors to familiarize themselves with the data, to identify key themes emerging from the observational data, and to start coding [27]. An inductive approach was used to start the data analysis process which included researcher's reflections, discussions of the data and diagrams, and pictures taken during the observation. Through initial and focused coding, other observed events that needed further clarification were discussed and later followed up to gain clarity and understanding. For example, the researcher wanted to check if patients understood the poster message on epilepsy and decided to assess the understanding thereof from patients. A similar process was followed to understand the meaning of a Xhosa expression that had been used between a Xhosa speaking patient and HCP during a follow-up consultation. These notes were again reorganized as they pertained to different observations to develop a story for that particular observation and to enhance the trustworthiness of the findings [27,29,30].

## 5. Findings

From the analysis of the observation data, we present descriptive findings of three significant events that were relevant for the research purpose.

### 5.1. Routine follow-up tasks

#### 5.1.1. First example: follow-up blood results by the patient accompanied by his partner

In this scenario, the HCP interacts with patient B who was coming to check his blood results. This patient was accompanied by his partner.

The HCP opens the patient's file and asks the patient in isiXhosa “*what are you coming to do today?*” The patient looks at his partner and does not respond to the question. The partner gives the HCP a white note. The HCP looks at the note and asks the patient in isiXhosa “*what blood tests were done?*” The patient answers, “*I do not know.*” The HCP asks the partner, “*What blood tests were done?*” The partner says, “*It was said that we should come back on 1 March 2012 for blood results, but we do not know the kind of test that was done.*” The HCP speaks to someone over the phone about the patient's blood results and writes something in the patient's file while answering the phone. She puts the phone down and turns to the patient and says “*your blood results show that you are not taking your medication correctly.*” The patient keeps quiet. The HCP asks the patient “*how many pills do you take?*”

<sup>1</sup> To protect confidentiality, pseudonyms are used for the clinic and the township where the study took place.

The patient keeps quiet. The partner answers: “*he takes two pills.*” The HCP tells the patient, “*You must take three pills a day.*”

5.1.2. *Second example: observation at the pharmacy*

In this scenario, the patient and the partner go to the pharmacy.

The HCP takes the patient's file, opens it, and reads something in the file. Thereafter, the HCP looks at the patient and says to him “*look, you can't get your pills today, you had two months supply on 16 February. You will get your pills on 12 April.*” The partner looks down, shakes her head, and says nothing.

5.2. *Epilepsy information materials*

5.2.1. *First example: patient education on a seizure diary*

The researcher observed a Xhosa speaking patient who interacted with a Xhosa speaking HCP who was talking to the patient about a seizure diary (Fig. 1).

The HCP calls the patient and offers him a chair to sit next to her. She looks at notes in his file. She asks him “*did you have a fit?*” He says “*no.*” She asks him “*do you have a seizure diary?*” He says “*no.*” She takes a seizure diary from the box and says to him “*this diary is for recording your seizures. If you have one, you tick under the month, if you have two fits; you tick under the same month. You must bring it with you when you come for check up.*” He says, “*Okay.*”

5.2.2. *Second example: epilepsy poster*

The researcher recorded epilepsy information conveyed via a poster that was placed on the clinic wall (Fig. 2). The message said, ‘*Take control of your epilepsy, Say NO to Seizures, Say yes✓ to taking my medication.*’ The researcher asked permission from the clinic staff to use the poster to check how the message was understood by patients and staff. The researcher asked four patients who had epilepsy and one nursing assistant who was willing to participate in the assessment of the poster information. They all agreed. Two patients were Afrikaans speaking and the other two were Xhosa speaking male patients.

The Afrikaans male speaking patient said:

“‘*Take control of your epilepsy*’ means that I must not be sick, ‘*Say NO to Seizures*’ means I must not get fits, ‘*Say Yes✓ to taking my medication*’

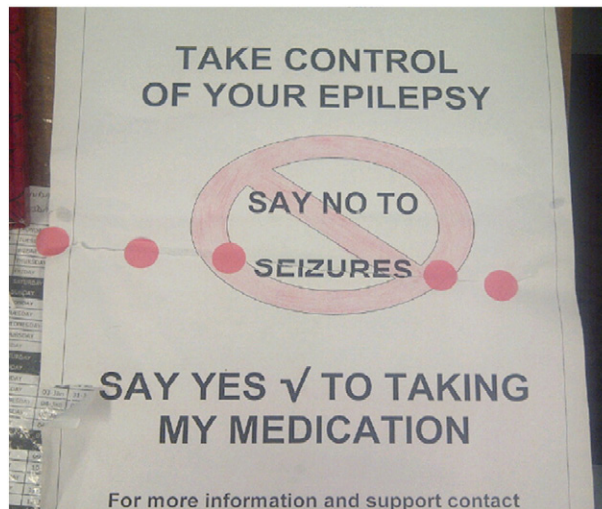


Fig. 2. Example of a poster conveying information on seizure medication.

means I must take my pills”. He then looked at the symbol ‘✓’ and asked, “*What is this? Is it a V?*” The Afrikaans speaking female said: “‘*Say NO to Seizures*’, I think it says I must not be sick. But I am not sure what ‘*seizures*’ means.” She pronounced it as “*sozure*” and asked “*is sozure fits?*” With regard to ‘*Say yes✓ to taking my medication*’, she said that the symbol looked like the HIV symbol and said, “*I always see it on HIV posters.*”

Two Xhosa speaking patients and the nurse were approached: one Xhosa speaking male patient said:

“*I am unable to read, I have problems with my eyes.*” The other one said: “*I cannot read English. The poster is written in English not Xhosa.*” The nurse said: “‘*Take control of your epilepsy*’ means you must be careful all the time in places where it is dangerous, you can get seizures anywhere. ‘*Say NO to Seizures*’ means just be normal like other people, ‘*say yes✓ to taking my medication*’ means take your medicines every



RECORD OF SEIZURES									
	Jan	Feb	March	April	May	June	July	Aug	Sept
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									
11									
12									
13									
14									
15									
16									
17									
18									
19									
20									

Fig. 1. Example of a seizure diary used by PWE.

day.” She then looked at the symbol ‘√’ and said, “It is something like more or less.” She drew the symbol “< >” to illustrate what she meant.

### 5.3. Language barrier

In this scenario, the researcher observed a Xhosa speaking male PWE who interacted with a Xhosa speaking female HCP during a follow-up consultation.

The HCP asks the patient, “Do you have anything to ask?” The patient answers “yes.” He uses a Xhosa expression and says “I want to wash the heart.” She asks him “what do you mean when you say you want to wash the heart?” He repeats emphasizing in isiXhosa and say “I say that I want to wash the heart.”

The HCP did not say anything. The patient kept quiet. The conversation ended. The researcher followed up the patient at his home to check what he meant by the Xhosa expression. The patient said:

*“I wanted to throw up because there was something bothering me. So the nurse did not understand me because she is probably not from the Eastern Cape. Probably she is born in Cape Town. Eastern Cape Xhosa is different from Cape Town Xhosa.”*

### 5.4. Epilepsy support group

From the observations done at Vamusa CHC, there was no support group for PWE or for those who had other chronic illnesses.

## 6. Discussion

From the examples of observations presented, the findings suggest that there are some lost or missed opportunities for promoting health literacy. In addition, there are some health literacy factors from patients and HCP that may affect the understanding and management of epilepsy. These findings are examined in more detail under the following themes.

### 6.1. Routine follow-up tasks

Tasks are reported as a practice which has a long tradition in nursing practice and often comprise different aspects which are assigned and completed by different HCP [31,28]. In these observations, it was clear that these tasks excluded the patients. For example, the nurse used closed-ended questions “did you have a seizure?”. On the other hand, patients were also passive in the process (keeping quiet, not asking questions, and having no eye contact). These observations are of concern as they seem to lack a patient-centered approach which is referred to by Fassin [31] as “patient- and dignity-centered” (p268). In order to promote ‘well-informed patients’, health care practitioners need to facilitate active participation of patients in their health care [32] and empower them with health literacy skills [10], to achieve better compliance and improved quality of life [33].

### 6.2. The role of pharmacists

Pharmacists have been identified as key role players in patient education and counseling to ensure the safe and effective use of chronic medications through a patient-centered model of care [34]. This model of care involves a facilitated multi-disciplinary team approach where patients are enabled to take responsibility for achieving the desired treatment outcomes. However, in a cross sectional study on knowledge attitudes of Iranian community pharmacists about pharmaceutical care for patients with epilepsy, the researchers found that eighty-five percent of pharmacists did not have enough knowledge about pharmaceutical care for female patients with epilepsy [35].

### 6.3. The role of language

Globally, literature reveals that health care practitioners render care to patients from different ethnic, cultural, and socio-economic backgrounds where language barriers may affect the interaction between the patient and the doctor as well as the treatment process and outcome [36,37]. Interestingly, from the interaction observation between a Xhosa speaking patient and HCP of the same ethnic origin as the patient, a language barrier occurred when the patient used a Xhosa expression “I want to wash the heart.” This Xhosa expression was unfamiliar to the HCP. Here, the patient expected to discuss or share something that was bothering him, which may or may not be related to the medication or the seizures, with a HCP of the same ethnic group. Unfortunately, the HCP was unable to explore what the patient wanted to say or might have lacked skills to attend to the patient's wants and experiences [38]. Therefore, culture certainly matters in every day patient encounters in the clinics, and not only when the participants are ostensibly from different cultural groups [39].

### 6.4. The role of listening

According to Maesschalck et al. [40], when patients come for follow up consultations with their health care professionals, they are concerned with a number of issues which include their treatment and care and their perceptions and feelings about their illness. The authors state that in a good communication encounter between the health care professional and the patient, “the patient has to know and understand and to feel known and understood” (p406). This means that health care professionals need to listen to each patient because their understandings of the illness will be different. Other communication researchers have highlighted that listening is an important skill which can help obtain appropriate clinical data, diagnosis, and choice of treatments, can strengthen good doctor–patient relationships, and can have a healing and therapeutic effect [41].

### 6.5. The role of epilepsy support groups and self-management

The value of support groups, particularly for a condition such as epilepsy, which is rooted in superstitious and cultural beliefs about its cause and treatment, cannot be ignored. Chung et al. [42] investigated the importance of support groups among PWE who were members and those who were not members of the support groups. They found that attendees of support groups were more knowledgeable about their condition, were able to share experiences and exchange information, and had knowledge of epilepsy resources, a positive attitude, and access to trained workers from the organization. Findings from an annual review of diabetic patients in primary care in Cape Town reveal that there is a need for support groups in chronic illness care and management. The authors further state that support groups are an important strategy for increasing patients' self-efficacy [15]. A number of strategies that can be used for structured self-management interventions have been described internationally. Some cited include Modular Service Package for Epilepsy (MOSES) [43], a modular educational program for children with epilepsy and their parents (famoses) [44], Web Ease [45], and the Coping Openly and Personally with Epilepsy (COPE) [46]. Some of those that have been currently reviewed such as counseling-based interventions for care delivery and self-management strategies for children with epilepsy showed limited impact [47]. In our context, no such groups have been developed as yet.

### 6.6. The role of health communication and pre-testing of information materials

A need for effective communication and delivery of information cannot be emphasized partly because chronic illnesses, epidemics, and emerging health problems are reported to be linked to human behavior



[48]. According to Rimal and Lapinski [49], sources of information should understand that the way people receive and interpret information is affected by various factors at intrapersonal, interpersonal, and macro-social levels. The authors further state that any health communication strategy should be preceded by formative evaluation of mass media and needs assessment of the target audience and pre-testing of the message to avoid misinterpretation of information. Failure to pre-test communication materials adequately may result in misunderstandings, a factor which is exacerbated in multilingual contexts such as South Africa. A common fallacy is that cartoons, drawings, and symbols are always easy to understand across different cultural and linguistic barriers, but this is not always the case, as previous research and our own study show. A useful recent guide to writing and designing such materials is available online by the U.S. Department of Health and Human Services [50]. Though this guideline focuses partly on design of web sites, the principles are the same.

### 6.7. The role of focus groups in pre-testing of health information materials

Focus groups with potential users of health education materials are a crucial part of the process. Perry et al. [51] used focus groups to evaluate a food safety brochure. The information from participants helped them to better understand the target audiences' views, experiences, perceptions, beliefs, knowledge, and attitudes about food safety and approaches through which they can be informed. They further put emphasis on the importance of using plain language. It is clear that such groups were not held in relation to the materials used in our study setting. Issues of translation are, furthermore, always complex, and it is essential that among those consulted on the design of materials are people very familiar with the languages (and dialects of those languages) to be used in particular contexts [52]. In summary, it is, therefore, important that information materials should be appropriately designed for the target audience to ensure understanding thereof [53].

### 6.8. The role of a seizure diary

We noted from our observation data that patient education about a seizure diary was inadequate. Questions asked by HCP from patients who had a seizure diary were closed-ended and related only to the number of seizures and whether patients took seizure medication and nothing about the seizure type. According to Fisher et al. [54], diaries are a form of 'patient-reported outcomes' and should bear important information that can help in recognizing signs of adverse effects and the efficacy of seizure medication. Furthermore, the authors report that their recommended seizure diary form can be found at <http://www.commondataelements.ninds.nih.gov>.

## 7. Conclusion

The study observed interactions between patients with epilepsy and HCP at Vamusa CHC. The study provided valuable observation data which suggest that there are some patient and HCP health literacy factors that may be affecting the quality of care of patients with epilepsy. On paper, if an audit is done of this health center, the patients are receiving care — there is no treatment gap. Fine grained observations such as those we have conducted, however, reveal a different picture.

The study had some limitations. Observations could be done only on specific days and were confined to patients with epilepsy. The number of observations was small and observations were brief. Therefore, the results cannot be generalized, but they portray a situation of multiple missed opportunities to improve health literacy. Even if what was observed were isolated events, they reveal health system issues which bear further attention. The findings of this study will be used

to inform a second phase of data collection which will form the basis for health system interventions and possible structuring of support groups which are appropriate to the particular context and target group.

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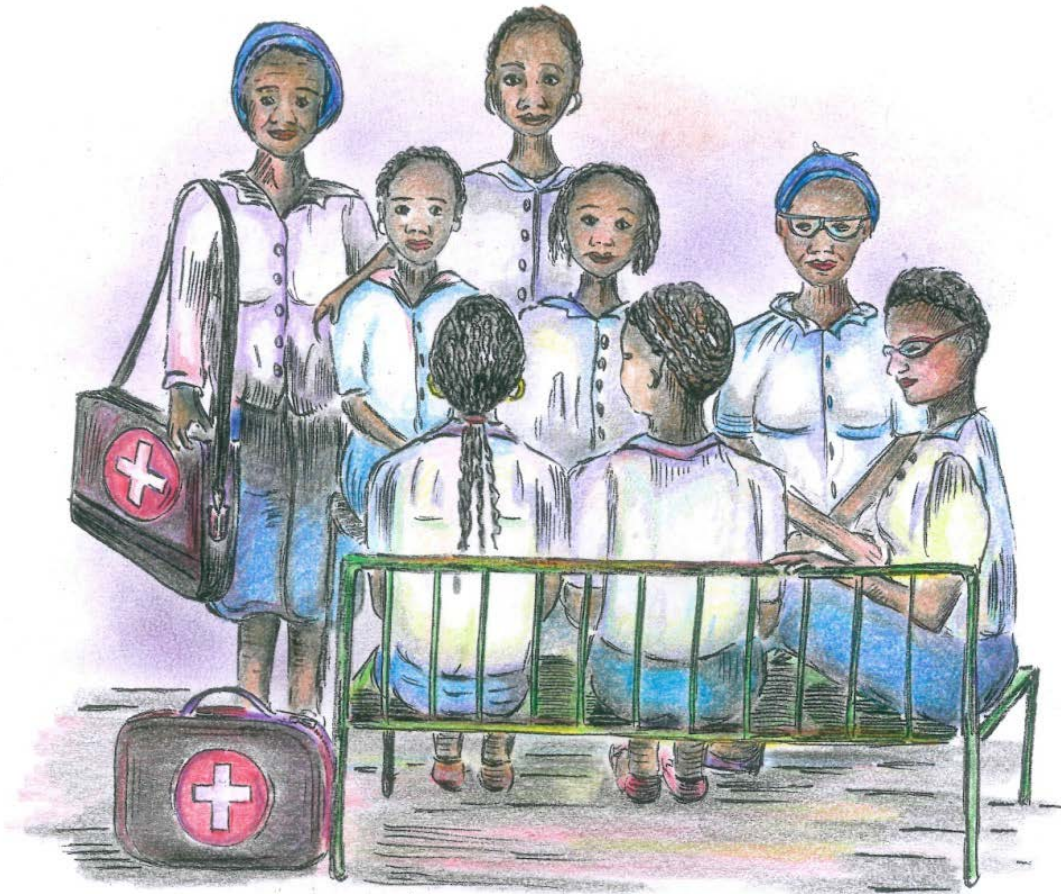
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## CHAPTER FIVE: COMMENTARY



Focus group discussion with home-based carers

***“When a person falls during a prayer healing session, people say aah, the spirit is gone.”***



## CHAPTER FIVE

### ARTICLE 3

#### ***“It is always HIV/AIDS and TB”*: Home-based carers' perspectives on epilepsy in Cape Town, South Africa**

##### **5.1. INTRODUCING ARTICLE 3**

In this chapter, I introduce to the reader the third article of the seven published peer-reviewed journal articles which are products of this dissertation. In Chapters Three and Four, I presented some health systems factors affecting management of epilepsy that were reported by medical doctors whom I had interviewed, and my personal observations of routine practices in the professional sector of health care in order to understand their nature and the context in which they occur. Thereafter, as I shall show in this chapter, I examined these factors further in one of the sectors of health care that comprise HBCs who fall between the lay and professional carers – a group not directly identified by Kleinman (1980). I then conducted two focus group discussions using Kleinman's EM guide (Appendix G) to explore the HBCs' perspectives and their subjective experiences in relation to epilepsy, as well as their perceived role in community-based epilepsy treatment and care.

The article brings home the different kinds of factors that affect management of epilepsy which HBCs perceived to be at the levels of individual, family, community and health system. The larger part of the article reports on cultural and religious practices and cultural explanations of epilepsy which HBCs thought were the main factors affecting management of epilepsy. The article further highlights the types of strategies that can be used at community level and those that can be delegated to HBCs such as task-shifting to relieve routine tasks from health care professionals.

As with Chapters Three and Four, I presented preliminary findings of this sub-study to HBCs and to the management of their organisation. Sadly, local epilepsy representatives were unable to attend the presentation. However, a training workshop on epilepsy was organised and was facilitated by members of the local epilepsy organisation for the HBCs.



## EMPIRICAL STUDY

**“It is always HIV/AIDS and TB”: Home-based carers’ perspectives on epilepsy in Cape Town, South Africa**MPOE JOHANNAH KEIKELAME, MPhil<sup>1,2</sup> & LESLIE SWARTZ, PhD<sup>2</sup><sup>1</sup>Primary Health Care Directorate, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa and<sup>2</sup>Department of Psychology, Stellenbosch University, Stellenbosch, South Africa**Abstract**

The study highlights the complex cultural religious factors affecting epilepsy and a need for integrated home-based care services. Two focus group discussions exploring home-based carers’ (HBCs) perspectives on epilepsy were conducted using a semi-structured focus group interview guide, which was based on Kleinman’s explanatory model framework. The audio-recorded data were transcribed verbatim, and a thematic analysis was done. The three main themes were epilepsy names and metaphors, religious beliefs about the cause and treatment of epilepsy, and HBCs’ perceived roles and strategies for engaging in epilepsy care. Findings provide some insights for research, policy, and practice.

**Key words:** *Epilepsy, home-based carers, focus groups, religious beliefs, South Africa*

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There is a growing concern that in low- and middle-income countries (LMICs), the weak health system, poor access to basic needs, and lack of attention to social determinants affecting health of the marginalized population groups might affect the attainment of the Millennium Development Goals (MDGs) (Nxumalo, Goudge, & Thomas, 2013). Similarly, in South Africa, the health-care system is also reported to be ill-equipped to deal with health-care challenges (Levitt, Steyn, Dave, & Bradshaw, 2011)—and this has led to the reemergence of the deployment of community health workers (CHWs) as a strategy to improve access to health care through community outreach services (Nxumalo et al., 2013; Schneider et al. 2008). These CHWs have been recognized as a potential resource to overcome the shortage of human resources in a range of health-care settings (Van Ginneken, Lewin, & Berridge, 2010). Their services have been mainly through non-profit organizations (NPOs), which are funded by the government, and their role has been noticeable within the HIV/AIDS field (Van Pletzen, Zulliger, Moshabela, & Schneider, 2013).

Whereas the South African government is putting more emphasis on the reengineering of primary

health care (PHC) and have a number of different types of CHWs estimated to be between 60,000 and 70,000, these workers have not yet received appropriate recognition (NACOSA, 2013). According to Swartz (2013), part of the difficulty with literature on these CHWs is that they are often regarded as a homogenous group without considering their differential experiences, roles, motivations, and understandings of health and health care. Another concern is that the CHW model has no standardized policy regulating their program and training (Haynes, Hunter, & Jassat, 2011).

Currently, the South African health system is faced with emerging non-communicable diseases (NCDs) in both rural and urban areas, which are characterized by poverty and marginalization (Mayosi & Benatar, 2014). Of great concern is that epilepsy is not reported as one of these emerging NCDs and may therefore not receive equal attention—yet it is among the six top NCDs which are managed in primary care settings (Lalkhen & Mash, 2015). In the provincial integrated NCDs audit report of the Western Cape Province, Cloete (2015) highlights that the prevalence of epilepsy is unknown—indicating a gap in research. The report further shows that more

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emphasis is on the biomedical aspects of epilepsy and not on the psychosocial aspects, which pose major challenges for people with epilepsy (PWE) and their carers (Bhalla et al., 2013).

There are very few studies looking at CHWs roles in epilepsy in South Africa. We are not aware of any CHW studies which explored home-based carers' (HBCs) perspectives on epilepsy in an urban township in Cape Town. Our objective was to analyze and describe their subjective experiences and perspectives on epilepsy and to provide information that can be used to guide planning and development of appropriate interventions to improve epilepsy treatment and care.

## Methods

### *Research design*

We used an exploratory qualitative design using focus group method to answer the question: "How do HBCs, working in a low-income area of Cape Town, understand epilepsy, its management, and what is their potential role in this?" This method uses group interaction to produce data and insights that would be less accessible without the interaction found in the group (Ulin, Robinson, Tolley, & McNeill, 2002, p. 92). These lay carers are regarded as important sources from which everyday ideas about the illness, support, and advice are sought and first-hand experience of suffering are gained (Kleinman, 1980).

Our Focus group discussions (FGDs) interview guide was based on Kleinman's (1980) explanatory models of illness (EMs). These EMs constitute a way of understanding how people recognize an illness, explain it, and respond to it. In addition, these EMs are shaped and influenced by culture and are held by patients and their carers, and can provide personal and social meaning with regard to the illness experience. Using Kleinman's (1980) EMs would enable us to elicit HBCs perspectives and experiences on epilepsy on how they explain, recognize, and respond to the illness and its symptoms. These HBCs provided services for patients with other chronic illnesses, but not epilepsy (see Box 1). The study was approved by the four local health research ethics committees: the University of Cape Town, Stellenbosch University, the Provincial Department of Health, and City Health.

Box 1. Example of HBCs FGD interview guide questions.

From your point of view, what do people in your community call epilepsy? Are there other names that are used to refer to epilepsy? Why are they used and what do they mean?  
What do people in your community think is the cause of epilepsy? Why do they think so?

What do you think is the cause of epilepsy? How does it affect the person having the illness?  
How serious is epilepsy? What course do you think it takes?  
What kind of treatment do you think people with epilepsy should receive? What outcomes do you expect from the treatment you mentioned?  
What are the kind of difficulties that people with epilepsy have in your community? What are the reasons thereof?  
What kind of things make it difficult for people to understand epilepsy?  
What kind of actions can be taken to address the kind of things you mentioned?  
Who should take action and why? What can enable such actions? What can make it difficult to take such actions?  
What kind of role can you play in caring for people with epilepsy?  
What are the main things that people fear most about epilepsy? What do you fear most about epilepsy?

Adapted from Kleinman (1980).

### *Study setting*

The setting is an urban township in Cape Town and is characterized by high rates of unemployment, illiteracy, and poverty, and has a population of about 52,401 (Lehohla, 2011). Although there is a national non-government organization (NGO) which supports PWE and their families, its services are currently unavailable in the study setting. There are other health services such as the local community health center (CHC), private and general practitioners, and a local clinic that does not render health-care services for NCDs (Naidoo & Irlam, 2005).

### *Recruitment and sampling*

We recruited 18 HBCs who were employed by the local NGO, which is registered with the South African Department of Labour and provides basic HBC services in the study setting. The organization is faith-based and its mission is to care for all regardless of faith background. A convenience and purposive sampling method was used for recruitment and inclusion. Prior to recruitment, MJK set up a meeting with HBCs and their manager to present the project proposal and purpose of the study to start the recruitment process and to gain informed consent. MJK was accompanied by a Xhosa-speaking female field assistant whose role was to assist in the interpretation of the informed consent and participant information regarding their responsibilities

and rights to participate and to ensure their understanding of the information in order to make informed decisions and choices to participate. MJK can speak isiXhosa but it is not her first language—having the field assistant enabled accessibility to the participants on the basis of language. The informed consent and information leaflet that stated the purpose of the study, their right to participate or withdraw, and the importance of not divulging information were read by the field assistant. Time was given for questions and clarifications. They were all given signed copies of their informed consent forms after obtaining written consent and were requested to bring them along on the date of the FGD. Kroll, Barbour, and Harris (2007) report on the importance of asking focus group participants to read the consent documents and to sign them before discussions.

Because all 18 HBCs were willing to participate and that the acceptable group size was between 6 and 12 participants in FGDs (Kroll et al., 2007)—two separate groups were arranged for each group at their convenient times. These HBCs were included because they would be in a position to provide in-depth insights (Gerrish & Lacey, 2010) on the topic and also that they might have cared for PWE or patients with other chronic illnesses who might also have epilepsy.

#### *Data collection*

Two FGDs were conducted by MJK on April 16, 2013, and April 30, 2013, at the HBCs' workplace—which was their preferred venue—and consisted of nine participants each. Although they chose to be interviewed at their place of work, we cannot guarantee confidentiality and anonymity between the participants themselves. Reporting on measures to ensure confidentiality in focus groups, Powell and Single (1996) suggest measures such as asking focus group participants to sign a written declaration that they will not divulge any information, and giving them copies signed by the principal investigator and the participants with each of them retaining a signed copy of the document.

The focus group interview guide was constructed in English and translated and was used to collect the data. It was pre-tested and no changes were made. Permission to audio-record the discussion and to disseminate findings was sought and the roles of MJK and the note taker were clarified. The duration of each FGD was between 90 and 120 min. During the two FGDs, some individual participants asked specific questions such as, “How can a PWE who has other chronic illnesses (diabetes, asthma, cardiac) be cared for?” and were given time to discuss these questions in order to capture the responses, context,

and content of the discussion and only proceeded to the next topic when the group felt that they had no additional input.

There were some participants who used “I” when they talked about their individual experience while others used “we” to include others. MJK would pose questions to determine if the issue was a collective or an individual perspective. There were instances where all participants expressed gestures such as “laughter” when they talked about the epilepsy metaphor “plucking the chicken.” MJK would check why they laughed at that point in order to clarify assumptions and misinterpretations. Because the FGD were held 2 weeks apart, MJK had time to read and to listen to the first audio-recorded discussion. This enabled MJK to follow up on some issues raised in the first FGD to gain a broader perspective.

MJK asked each participant to reflect on the process and their comments were audio-recorded, and these were completed as field notes by MJK after debriefing sessions with the note taker and were further expanded by the MJK for use in the data analysis process (Watt, 2007). Refreshments were served and each participant received a transport voucher of R20.00 (approximately two US dollars).

#### **Data analysis**

The audio-recorded data from the two FGDs were transcribed verbatim from isiXhosa into English by a Xhosa-speaking language practitioner. Consistent with Braun and Clarke (2006) thematic analysis method, MJK read the two transcripts and listened to each audio-recorded discussion of the two data sets to gain a sense of what participants talked about. During this process of familiarity and immersion, MJK listened to each audio-recorded FGD data and simultaneously read each transcript word by word and line by line to ensure that the actual participants' responses had been transcribed verbatim from isiXhosa into English, and to ensure that the transcribed data accurately reflected the perspectives of the group discussion and individual responses and used field notes to fill in any gaps in information (MacMillan, McKee, & Sadler, 2007). MJK used an inductive approach to identify common themes from the data as well as questions and topics that were raised by participants themselves (Twinn, 2000). MJK copied and pasted the coded sections of the two data sets into MS word two-column tables in order to modify, group, and regroup the themes to ensure that no code had been missed and that the described and named themes provide a clear sense of what each theme was about (Braun & Clarke, 2006).

Rigor was ensured by confirming findings with participants (Anney, 2014; Flick, 2006) and by

meeting regularly with the second author to reflect on how our own assumptions, professional orientations and backgrounds might have influenced the data analysis and interpretation thereof (Adams, McCreanor, & Braun, 2013). We did not identify any new theme from the two data sets. We were thus satisfied that we had reached thematic saturation (Onwuegbuzie et al. 2009). We also used pseudonyms to protect the identity of participants.

## Results

A total of 18 Xhosa-speaking HBCs participated in the study. Out of these, 17 were females and 1 was a male. Their mean age was 41.1 years. Their years of practice ranged from 1 to 7 years with the mean years of practice being 3.4 years and they belonged to different religious organizations. Their demographic profile is provided in Table I.

Seven key themes emerged from the data: (i) names and metaphors referring to epilepsy; (ii) religious beliefs about the cause and treatment of epilepsy; (iii) views about marriage, driving, employment, and schooling; (iv) difficulties affecting access to treatment and care; (v) difficulties caused by the illness, (vi) fears about the illness and (vii) HBCs' perceived role and strategies for epilepsy care. We report on three themes that are of central focus of this article: (i) names and metaphors referring to epilepsy; (ii) religious beliefs about the cause and treatment of epilepsy; and (iii) HBCs' perceived role and strategies for engaging optimally in epilepsy care.

Table I. HBCs FGD participants' demographic profile.

HBC, N = 18	Age	Religion	Education	No of years	Gender
C01	59	Methodist	Grade 12	7	F
C02	59	Universal	Grade 10	7	F
C03	53	Anglican	Grade 10	7	F
CO4	53	Methodist	Grade 12	3	F
C05	48	Methodist	Grade 12	1.5	M
C06	48	Zion	Grade 11	3	F
C07	46	Universal	Grade 12	3	F
C08	46	Universal	Grade 10	3	F
C09	42	Apostolic	Grade 10	3	F
C10	38	Methodist	Grade 10	3	F
C11	36	Anglican	Grade 12	3	F
C12	36	Apostolic	Grade 10	3	F
C13	35	Zion	Grade 10	3	F
C14	34	Methodist	Grade 12	2	F
C15	34	Anglican	Grade 12	3	F
C16	29	Ethiopian	Grade 12	3	F
C17	29	Roman	Grade 11	3	F
C18	25	Zion	Grade 10	1.5	F

## Names and metaphors referring to epilepsy

Participants used different Xhosa names for epilepsy —*isifo sokuxhuzula* (illness of fitting), *ukuxhuzula* (fitting or fits), and *isifo sokuwa* (illness of falling). An interesting finding was the metaphor “plucking the chicken” (*ukuhlutha inkuku* in isiXhosa). We noted that most participants enjoyed discussing this metaphor, but we thought that their explanations highlighted the dramatic nature of the tonic-clonic seizure and how people perhaps behave or act toward a person during a seizure. We also thought that their explanations for the shaking of the chicken when it is being slaughtered were about presentation and recognition of symptoms during a tonic-clonic seizure. For example, three participants discussed the metaphor as follows:

Participant (P): I was going to say ... others say to pluck the chicken ...

(Laughter).

P: Yes, to pluck the chicken, because when you are plucking the chicken you pull those feathers so when you are about to kill it you see it shaking.

P: Also when you have already killed it, when you have cut the neck, it shakes

(Laughter).

P: So it's doing what is done by a person who fits. At that time it hasn't died completely. It's still going to die. It's still in the process of dying.

When participants were probed to explain why people use this metaphor, we found that they spoke about death and laughter which we thought were indicative of the seriousness of epilepsy (that people can die from epilepsy) and the stigma toward people living with the illness (laughter, joke, thing):

P: They think he will fit and die.

P: It's death and laughter.

P: I was saying another one makes a joke about that thing.

P: But really others fit and die.

## Religious beliefs about the cause and treatment for epilepsy

There was a lengthy discussion on religious beliefs about the cause of epilepsy and its treatment. We noted that HBCs had varied perceptions on the topic and how epilepsy is perceived by the community. For example, one participant said people hold the belief that epilepsy is caused by evil spirits:

P: They (people) believe that tradition thing that it is an evil spirit that causes you to fall (to have epilepsy).



One participant challenged this view and responded that the belief about evil spirits is not held by all people. However, the same participant stated that this belief is held by his or her family and that decisions about the choice of treatment are done by significant others.

P: It goes fifty-fifty (there are those who hold these beliefs and those that do not) . . . because at my home if I'm fitting they will say "Oh, an evil spirit", and church, yes, because they believe that the church can heal me through prayers.

Another one explained that evil spirit is a "demon inside the person." This participant affirmed the previous participants' response that significant others play a role in the choice of treatment for a family member whose illness is believed to be caused by demons or evil spirits. The participant further stated that it is often very difficult to challenge these cultural beliefs probably because the participant might have noticed some PWE who had poor treatment outcomes on either western or religious treatments.

P: Yes sometimes that spirit is the demon inside you and then maybe your parents take you to this faith healing process . . . people start praying and praying and then all of a sudden now you start falling (having a seizure) because now that prayer has touched you (prayer triggered the seizures) and you sometimes vomit, then they say "Ah, it's gone out, it's gone out!" (The spirit is released). So you can't guarantee what is what (what treatment is best).

As the response below displays, another one supported the previous one's views about the challenges faced by HBCs in dealing with religious beliefs related to epilepsy. Although this participant spoke on behalf of other group members, he or she highlighted that the difficulty in addressing these cultural beliefs is because they are professed by influential and powerful religious leaders—and that people believe their treatment instructions that often result in poorly controlled seizures:

P: What concerns us is that they (Faith healers) say, "Don't take the tablets because you have been healed in the name of Jesus". Then patients do not take the tablets (seizure medication) and then they start fitting again because they are not going to church.

In view of other participants' responses, another one challenged the previous ones' views probably because the participant might be having strong religious beliefs about the cause and treatment for epilepsy:

P: Like I believe that I'm going to be right because I go to church. I'm not going to drink my tablets because I believe in church. That's what I'm saying, I'm using my faith. By praying I'm going to get healed without tablets. I'm going to get healed. I'm not going to use the tablets. By faith I'm getting healed by the prayer – the power of prayer.

Another participant disagreed with the previous participant's views and reiterated that despite the former participant's personal religious beliefs about epilepsy treatment, it is important that the particular HBC should provide appropriate advice to patients under his or her care with regard to the importance of taking seizure medication. We were of the view that this participant was probably highlighting that HBCs should not impose their personal beliefs on those under their care—but that they must give appropriate advice:

P: No, you must tell them (those who believe that their epilepsy can be healed by prayer) to take their medications.

#### *HBCs' perceived role and strategies for engaging optimally in epilepsy care*

Participants were first asked how epilepsy is understood by their community. They all thought that there was a general lack of understanding of the illness because of too much focus on HIV/AIDS and TB.

It's always HIV, HIV . . . and yet there are lots of things that are worrying people and some people don't even know what causes epilepsy. It's only TB, HIV. People are concentrating on AIDS and TB.

When asked on how the lack of information and knowledge about epilepsy could be addressed, HBCs responded to the question as a collective and gave some examples of strategies to address the problem:

We could give talks at the taxi rank.  
We can organize and do campaigns at churches, schools, train stations and give pamphlets.  
We can do short plays – it's easier when they see it.

Another one highlighted the kind of health promotion activities that would be welcomed by community members:

Here in the community they do want to be educated through campaigns, door to door



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home visits giving pamphlets, education at school and road shows.

In addition to the above-named strategies and their awareness of the knowledge gap, they suggested that epilepsy could be integrated with other chronic illnesses and that PWE should be encouraged to educate others about their illness and to demystify the illness:

It's important to have health talks on different illnesses in health center . . . then there is also a health talk about epilepsy and then have one patient saying I'm having epilepsy but I am working, I'm not dependable on my family . . . educate everyone whether a family has a person with epilepsy or not so that they can be of help to the next person.

Regarding their role in epilepsy care, HBCs highlighted that they could provide basic counseling and referral through collaborative partnerships.

The other thing as we are working for our organization, we all have patients with epilepsy. We can counsel them. We can refer them to the Epilepsy NGO maybe they (Epilepsy NGO can come once a month to our organization. We can gather our patients to meet with them to get more information from them.

Another participant thought that it was important that HBCs should receive training on epilepsy in order to increase their understanding and to gain appropriate skills such as organizing educational campaigns, conducting support groups, and assisting with some tasks in the hospital.

I was going to say we must first get educated on epilepsy so that we can educate people in the community. Then we can organize support groups. We can also go to hospitals and see what we can do to help.

## Discussion

Our study aimed to describe and analyze HBCs' perspectives on epilepsy in an urban township in Cape Town, South Africa—seventeen were women and the eighteenth one was a male. In South Africa, this type of work is done mainly by unpaid volunteers or by those who are fully employed with most being primarily women (Daniels, Clarke, & Ringsberg, 2012).

HBCs provided names that are commonly used to refer to epilepsy—*isifo sokuwa*, *isifo sokuxhuzula*, *ukuxhuzula*, and *fits* which were similar to those reported by Keikelame and Swartz (2013, 2015).

However, we note from literature that these terms often refer to epilepsy as well as seizures. In Kilifi, in the coastal region of Kenya, different terms such as *Nyumi*, *Nyago*, *Nyama ya dzuka*, *Vitsala*, and *Kifafa* are used to refer to seizures—and these are associated with different causes (Mbuba et al., 2012). According to these authors, “when medical explanations fail to help patients to understand their condition, they are most likely to believe in culture-specific meanings of the condition and its cause” (Mbuba et al., 2012, p. 480). Therefore, lay explanations cannot be ignored even though they might not be scientific (Zhu, Liu, & Tardif, 2009).

Epilepsy stigma and stigmatizing names have been widely reported in literature (De Boer, 2010). Similar names such as “it” and “a thing” were also reported in South African studies on epilepsy by Keikelame and Swartz (2013, 2015). The most disturbing new finding was the metaphor referred to as “plucking the chicken.” According to Helman (1994), illness metaphors or clusters thereof become a way through which people express their fears or anxieties about the condition. From our interpretation, we thought the use of this metaphor is probably a way of expressing the perceived seriousness of the illness. We argue that although this may be interpreted as a form of stigma, it is an African expression which can enable understanding of the presentation of symptoms and how they are explained by witnesses in order to enable appropriate diagnosis. Poor witness description has been reported as a barrier to management of epilepsy (Keikelame, Hills, Naidu, De Sá, & Zweigenthal, 2012).

The prominent theme was about religious beliefs. We thought that this could be due to the fact that the HBCs' organization is religious and that this might have accounted for its prominence. Noting from literature, Obeid, Abulaban, Al-Ghatani, Al-Malki, and Al-Ghamdi (2012) report that religious beliefs about epilepsy and spirit or demonic possession, or that an alien spirit has entered the individual, have been well documented. They have been held among different religious cultures such as the Greco-Roman, Judeo-Christian, Islamic, Hindu and Voodoo traditions (Cavanna, Cavanna, & Cavanna, 2010)—but there is very little research focusing on these aspects (Ismail, Wright, Rhodes, & Small, 2005).

An interesting finding was also on the faith healing process. HBCs explained that during this treatment, a PWE goes into a trance—and when they vomit, people believe that the spirit has left their body. This finding shows the powerful nature of faith healing. Reporting on this aspect, Truter (2007, p. 58) highlights that faith healing process is carried out

by faith healers or prophets who believe that they possess the healing powers from God “through ecstatic states and trance-contact with a spirit which they refer to as ‘umoya’.” Therefore, healers and family members who hold these beliefs may discourage PWE to take seizure treatment. We were thus concerned about the extent to which these beliefs would influence care giving practices of HBCs who value them. The findings indicate a need for mapping these religious beliefs when designing interventions (Otte et al., 2013b) including interventions that promote cultural literacy (Zarcadoolas, Pleasant, & Greer, 2006).

HBCs identified the knowledge gap in epilepsy care which they thought was due to more focus on HIV/AIDS and TB. They were of the view that integrating HIV/AIDS and TB programs with other NCDs would be beneficial. This view has also been expressed by Levitt et al. (2011) and Oni et al. (2014) and highlighted examples of the WHO frameworks that can be used—but need to be evaluated for appropriateness to local context.

Furthermore, HBCs believed that they can engage optimally in epilepsy care through collaborative partnerships with the national organization for epilepsy and task-shifting. Studies on CBR engagement in epilepsy care such as those in Guinea-Bissau (Otte et al., 2013a), in rural India (Nizamie, Akthar, Banerjee, & Goyal, 2009), and in Kilifi, Kenya (Carter et al., 2012), revealed that these workers can contribute to improving community-based epilepsy care. Our participants suggested “task-shifting” which according to Ledikwe et al. (2013) involves delegating tasks to less specialized health workers. Successful outcomes thereof were reported in Cameroon (Kengne, Fezeu, Awah, Sobugwi, & Mbanaya, 2010). In South Africa, it was explored by De Wet, Wouters, and Engelbrecht (2011) in HIV/AIDS programs and they found that nurses engaged in tasks that could be delegated to CHWs. As a result, a new policy has been developed which authorizes CHWs to do tasks such as finger-prick HIV testing.

### *Limitations*

We acknowledge that our orientations, interest, positions, and backgrounds might have affected the interpretation and analysis of the data. MJK is an older African woman who has worked among marginalized Xhosa-speaking communities and her previous research has been on epilepsy. The second author (LS) is a White man who has worked for many years in the field of culture, health, and disability, but is very much a cultural outsider.

In terms of FGDs, Smithson (2000, p. 116) states that in FGD, individuals tend to provide “socially acceptable opinions” and that the discussion might also be dominated by individuals who have power. This might have been the case in our FGD because of their organizations’ mission and their varied experiences and years of training.

### **Conclusion**

Our study explored HBCs’ perspectives on epilepsy and their perceived role in epilepsy treatment and care in an urban township in Cape Town. Our findings show different names and metaphors used to explain epilepsy and a knowledge gap which they attributed to too much focus on HIV/AIDS and TB. They further provide a glimpse of the complex nature of religious factors impacting on epilepsy and that these religious factors may affect provision of health care when held by health care workers. Our data suggest a need for an integrated approach to home-based care services in general and interventions that promote cultural literacy to enable these workers to respond respectfully and appropriately to patients under their care. Although these findings cannot be generalized, they provide some insights for research, policy, and practice.

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## Biographies

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## CHAPTER SIX: COMMENTARY



Individual interviews and focus group discussion with traditional healers (isangomas)

***“We need a memorandum of understanding and protection against exploitation...we are willing to work with western trained professionals...they cannot treat amafufunyana (evil spirits).”***

## CHAPTER SIX

### ARTICLE 4

#### ***“A thing full of stories”*. Traditional healers’ explanations of epilepsy and perspectives on collaboration with biomedical health care in Cape Town**

##### **6.1. INTRODUCING ARTICLE 4**

This chapter introduces carers from the second type of Kleinman’s (1980) sectors of health care – referred to as the folk sector. It presents a fourth article of the seven peer reviewed published journal articles on research with nine Xhosa-speaking THs or “amagqhira” in isiXhosa (Mzimkulu & Simbayi, 2006). Similar to Chapter Five, this chapter extends insights on the importance of taking into account the local beliefs, practices and explanatory models of healers and patients as well as the culture of the wider medical system (Kleinman, 1980).

In Chapter Five, HBCs reported on some cultural religious factors and metaphors affecting understanding and management of epilepsy. To explore these issues in more depth to get different viewpoints, I conducted individual in-depth face to face interviews and one focus group discussion with these healers. In particular, I was interested in gaining an understanding of the healers’ cultural explanations of the cause of epilepsy, the recognition of symptoms, their approach to treatment of epilepsy and their views about collaboration with western trained health care professionals. The chapter highlighted linguistic problems which were also highlighted in Chapter Four.

This chapter also emphasises the explanations of “amafufunyana” and bewitchment and witchcraft and that healers were of the view that bewitchment related symptoms cannot be treated by western trained HCPs – hence they regarded this issue as an important reason for collaboration. In their discussion about their approach to treatment, their emphasis was on the importance of thorough investigations into the cause of the illness and emphasis on the importance of explaining the benefits of treatment which was not the case in the professional health sector.

As with Chapters Three, Four and Five, I presented preliminary findings of this sub-study to the study participants, the local health committee in the study setting and to the local CHC that provides care for the study participants as well as to the board members of the local epilepsy organisation. In my presentation to the 2nd African International Conference on Epilepsy which was held in Cape Town, I had the privilege of being accompanied by three THs who participated in my study. I also had the privilege of organising a training workshop on epilepsy for the THs’ study and other healers who were interested in attending, which was conducted by members of the local epilepsy organisation.



# ‘A thing full of stories’: Traditional healers’ explanations of epilepsy and perspectives on collaboration with biomedical health care in Cape Town

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## Abstract

The experience of epilepsy is profoundly culturally mediated and the meanings attributed to the condition can have a great impact on its social course. This qualitative study used Kleinman’s Explanatory Model framework to explore traditional healers’ perspectives on epilepsy in an urban township in Cape Town, South Africa. The healers who participated in the study were Xhosa-speaking, had experience caring for patients with epilepsy, and had not received any training on epilepsy. Six individual in-depth interviews and one focus group with nine traditional healers were conducted using a semi-structured interview guide. Traditional healers identified several different names referring to epilepsy. They explained epilepsy as a thing inside the body which is recognized by the way it presents itself during an epileptic seizure. According to these healers, epilepsy is difficult to understand because it is not easily detectable. Their biomedical explanations of the cause of epilepsy included, among others, lack of immunizations, child asphyxia, heredity, traumatic birth injuries and dehydration. These healers believed that epilepsy could be caused by *amafufunyana* (evil spirits) and that biomedical doctors could not treat the supernatural causes of epilepsy. However, the healers believed that western medicines, as well as traditional medicines, could be effective in treating the epileptic seizures. Traditional healers were supportive of collaboration with western-trained practitioners and highlighted that the strategy must have formal agreements in view of protection of intellectual property, accountability and respect of their indigenous knowledge. The findings suggest a need for interventions that promote cultural literacy among mental health practitioners. Research is urgently needed to

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assess the impact of such collaborations between biomedical services and traditional healers on epilepsy treatment and care.

### Keywords

collaboration, epilepsy, explanatory models, South Africa, traditional healers

Epilepsy is under-treated worldwide (Meyer, Dua, Ma, Saxena, & Birbeck, 2010; Newton & Garcia, 2012). Both because of this treatment gap and because there are many indigenous cultural explanations for epilepsy in different countries, some authors have suggested that traditional healers may have an important role to play in epilepsy management (Birbeck, 2010; Njamnshi et al., 2010; WHO, 2004). In South Africa, epilepsy management is reported to be poor in the public health sector (Keikelame, Hills, Naidu, de Sá, & Zweigenthal, 2012) and access to neurologists is difficult (Eastman, 2005). As in other African countries, some patients with epilepsy in South Africa consult traditional healers (Eastman, 2005; Keikelame & Swartz, 2007). Although there have been studies concerning issues likely to affect collaboration between traditional healers and the formal health system (Bühmann, 1984), most have focused mainly on mental health, HIV/AIDS, and TB (Campbell-Hall et al., 2010; Mngqundaniso & Peltzer, 2008; Sorsdahl, Flisher, Wilson, & Stein, 2010). As far as we are aware, ours is the first study to explore these issues in relation to epilepsy in an urban South African context.

Epilepsy has been associated with many myths and misconceptions about its cause and treatment over centuries and in different cultures and parts of the world (de Boer, 2010; ILAE, 2003). In the 13th century, Christians believed that demonic spirits caused epilepsy and that the condition was contagious and could be contracted via the evil breath of patients suffering from the condition (ILAE, 2003). Patients with epilepsy (PWE) were viewed as being “possessed” or “chosen” and their affliction could be treated through prayer (Helman, 2004).

In Africa, epilepsy has been given various names that relate to specific cultural beliefs. For example, epilepsy is called by its Swahili name “*kifafa*” in Tanzania (Jilek-Aall, Jilek, Kaaya, Mkombachepa, & Hillary, 1997), Zaire (currently DRC) (Feierman & Janzen, 1992) and Kenya (Mbuba et al., 2012). Additional terms such as “*Nyuni, Nyago*”, “*Nyama ya dzula*” and “*Vitsala*” are also used in Kenya to refer to seizures (Mbuba et al., 2012). A study in Indonesia found epilepsy was referred to as “*gila babi*” meaning “crazy pig”, convulsion sickness, and bad spirits caused by black magic (Conrad, 1992). Participants in a community survey on knowledge, attitudes and practices about epilepsy in Laos called epilepsy “mad pig disease” (Tran et al., 2007). The experience of epilepsy is culturally mediated and the meanings ascribed to the condition can have great impact on its social course (Aydemir et al., 2009).

The findings we report in this paper are part of a larger project exploring patient and carer perspectives on epilepsy in an urban township in Cape Town,

South Africa. In this article, we use Kleinman's Explanatory Models (EMs) framework to explore traditional healers' understandings of epilepsy and its management. In the initial formulation of the EM concept, Kleinman (1980) emphasized the fact that in health-related encounters there are commonly negotiations, explicit or otherwise, between patients and those who care for them regarding understandings of illness. There may well be overlap between patient and healer EMs. Subsequent applications of the EM concept have been used to explore beliefs about illness held by patients and healers from a wide range of backgrounds (Helman, 1994), often focusing on how notions of cause, symptoms, severity and treatment related to an episode of sickness are used by participants in the clinical process. Understanding folk EMs is crucial to providing appropriate care (Zhu, Liu, & Tardif, 2009). There may be wide variation of EMs within groups and the EM concept is not intended to essentialize or reify cultural views on illness but to be used as a tool to understand how people understand different aspects of illness (Kleinman, 1980).

## Method

We used an exploratory qualitative research design to answer the question: "How do traditional healers understand and manage epilepsy?" This design is particularly appropriate for gathering data in the natural setting of participants because it enables the investigator to gain an "insider" perspective on the cultural contexts of participants; it also allows participants to share their views in safety and privacy (Babbie & Mouton, 2001; Gray, 2009), which is particularly important when studying a stigmatized condition such as epilepsy.

### Study setting

The study was conducted in one of the oldest suburbs of Cape Town, a culturally and historically important urban township, which was designated for Black Africans during colonial rule. The population is estimated to be 52,401 (Lehohla, 2011) and has high rates of unemployment (Naidoo & Irlam, 2005). Although the predominant spoken language is isiXhosa, the recent population census revealed that other spoken languages include Setswana, isiZulu, English and Afrikaans (Lehohla, 2011). As is the case with other chronic conditions, epilepsy is managed in Community Health Centres (CHCs), which offer health care to most patients from low-socioeconomic groups (Mash, Levitt, Van Vuuren, & Martell, 2008).

### Sample

There were approximately 160 traditional healers practising in the study setting (Naidoo & Irlam, 2005). In South Africa, there are three types of traditional healers: "*sangoma*" (diviner), "*inyanga*" (herbalist), and "*umthandazi|umprofeti*"

(faith healer/prophet) (Truter, 2007). These healers are popularly known among Xhosa-speaking people as “*amagqirha*” (Mzimkulu & Simbayi, 2006). In 2003, the South African Government formulated the Traditional Healers Practitioners Bill (THPB) to regulate their practice and to encourage them to form their own organizations (Pinkoane, Greeff, & Koen, 2008; Pretorius, 2004). This Bill was amended in 2007 (Bill 20 of 2007) and enacted into law as the Traditional Healers Practitioners Act (THPA) (No 22 of 2007) (Mbatha, Street, Ngcobo, & Gqaleni, 2012). Traditional healers such as herbalists, diviners, traditional surgeons (those who do circumcision) and traditional birth attendants can be registered under this Act, but faith healers have been excluded (Peltzer, 2009). Although these regulations are in place, only 60 traditional healers in the study setting were registered members of the South African Traditional Healers Organization (Naidoo & Irlam, 2005). As Thornton (2013) notes, there is considerable diversity amongst traditional healers and it is a mistake to view them as a homogeneous group.

Our sample consisted of 15 Xhosa-speaking traditional healers who were purposively recruited because they would be able to provide rich information to answer the research question (Babbie & Mouton, 2001; Gerrish & Lacey, 2010; Ulin, Robinson, Tolley, & McNeill, 2002). Access to these healers was gained through assistance from an executive committee member of Traditional Healers Organization (THO). This approach enabled the first author to draw a sampling frame, which was used to identify 15 potential participants. The criteria for inclusion were any traditional healer who was Xhosa speaking (whether or not they had been caring for a person with epilepsy), and was older than 18 years. Preference was given to healers who resided in the study setting, whether or not they were registered members of the THO. Only one, who was recruited via the snowball technique, did not reside in the study setting. Of the 15 traditional healers included in the sampling list, four did not participate. One died during the recruitment process. Two declined to participate and the last did not fit the inclusion criteria.

### *Data collection*

Data collection involved individual in-depth interviews and one focus group discussion.

*Individual interviews.* A semi-structured interview guide was constructed in English and translated by a Xhosa language practitioner to isiXhosa. The interview guide was used to collect data from six traditional healers, a study sample deemed sufficient for in-depth qualitative interviews (Silverman, 2013). The duration of the interviews was between 45 and 90 minutes and interviews were conducted at participants' homes or workplaces. The interview questions were based on Kleinman's eight EM questions (Fadiman, 1997; Kleinman, 1980): (i) What do you call epilepsy? What names does it have? (ii) What do you think has caused the illness? (iii) Why and when did it start? (iv) What do you think the illness does? How does it work? (v) How severe is it? Will it have a short or long course? (vi) What kind of

treatment do you think the patient should receive? What are the most important results you hope the patient will receive from this treatment? (vii) What are the main problems the illness has caused? (viii) What do you fear most about the illness?

Additional probe questions addressed the healers' perspectives on issues facing patients with epilepsy, concerning marriage, driving, employment, sports and education, and contextual factors surrounding the individual, home, community and society that may influence the understanding and treatment of epilepsy. At the end of each interview, interviewees were given some time to reflect on the interview process and offered the opportunity to share any additional information. One participant chose to be interviewed in Setswana and another in English. During the transcription process, the first author replaced the names mentioned by participants during the recorded interviews with pseudonyms to protect anonymity. Field notes were written immediately after the interview and were later extended after reflection (Ulin et al., 2002). Participants were given food vouchers for the value of R60.00 (approximately six US dollars) as a token of appreciation for their time and contribution to the research study.

*The focus group discussion.* The first author sent letters to all traditional healers listed in the sampling frame to invite them to participate in the focus group discussion. Invitation letters were delivered by the field assistant to all participants. These letters stated the purpose of the focus group and the date, time, venue and duration of the discussion. Only nine agreed to participate and four had been individually interviewed. Participants were familiar with each other and also belonged to the same traditional healers organization and this appeared to enhance their sharing of subjective experiences freely with one another in a non-threatening manner (Gerrish & Lacey, 2010; Ulin et al., 2002). According to Lehoux, Poland, and Daudelin (2006, p. 2093), when the group has "common associational and status contexts" it is likely to establish good rapport, which can enhance group interaction.

A semi-structured focus group interview guide was constructed in isiXhosa and was used to collect data during the interview. The purpose of the focus group was to validate the findings from individual interviews (Flick, 2006) and to explore and clarify any conflicting information through direct interaction (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008). The group was not informed of which of the members had been individually interviewed to avoid any influence on the participants' interaction. Where reference was made to findings from the individual interviews, no direct references were made to the focus group members who had been interviewed.

The focus group discussion was conducted in isiXhosa by the first author at a local youth organization centre that was accessible to all. The duration was 120 minutes. A Xhosa-speaking assistant moderator was trained by the first author on her role during the focus group interview and a resource pack was prepared for her for reference. Participants were informed of the importance of

confidentiality and anonymity and all agreed to sign a group informed consent form. The procedure for the focus group discussion was explained and ground rules were set and agreed upon by all. Participants' profiles were completed and primarily consisted of demographic details. Refreshments were served and each participant received a transport voucher of R20.00 (approximately two US dollars). At the end of the focus group interview, the first author and the assistant moderator reflected on the process and their observations to enable the first author to expand on the field notes that would be used in the data analysis (Watt, 2007).

### *Data analysis*

The audio-recorded data from the focus group and individual interviews were transcribed from isiXhosa into English by a Xhosa-speaking language practitioner. Each completed transcript was checked by the first author for accuracy by reading the transcript while listening to the audio-recorded interview. We used the thematic analysis method to identify key themes related to participants' explanatory models of their perspectives and subjective experiences about epilepsy, its treatment and care. Our approach to data analysis was inductive and involved the following steps: (i) reading and re-reading the transcripts and listening to audio-recorded data to gain familiarity with the data; (ii) generating data-driven codes and themes; (iii) reviewing, defining and naming themes to give meaningful explanations of the data and to provide a clear sense of what each theme was about (Bradley, Curry, & Devers, 2007; Braun & Clarke, 2006). To increase rigour in data analysis, we incorporated the framework analysis method described by Ritchie and Spencer (1994) in Rabiee (2004, p. 657). Key themes that emerged from the two data sets were organized into tables and grouped into appropriate categories with quotations from transcripts and were compared for similarities and differences. Credibility of the analysis was enhanced by regular meetings to review and refine codes and themes of the two data sets and to reflect on how our own assumptions and professional orientations may have influenced the data analysis process (Adams, McCreanor, & Braun, 2013). The first author took notes of agreed upon key themes and also presented a preliminary draft report of the findings to the participating traditional healers to confirm the findings (Flick, 2006). The feedback meeting was held on 10 September 2013 at the local community library. Seven key themes emerged from the data, four of which are the central focus of this paper.

### *Ethical considerations*

The first author presented the project proposal at a meeting held with the local executive of the traditional healers organization to inform them about the study, to gain support and to network. The first author, who is not completely fluent in isiXhosa, the most common African language spoken in Cape Town, was accompanied by a Xhosa-speaking field assistant. The field assistant aided her by interpreting the patient information leaflet and consent form to eligible participants at



each recruitment visit to ensure that the purpose of the study, the reasons for their recruitment, and their responsibilities and rights as participants were well understood. All recruited participants were given signed copies of consent forms to read and to share with family members or peers if they wished to do so. Requests for interviews to be conducted in other languages were respected. Ethical approval was gained from the four local health ethics committees: the Health Sciences Research Ethics Committee, University of Cape Town; the Health Sciences Ethics Committee, Stellenbosch University; the Provincial Government of the Western Cape (PGWC); and City Health Ethics Committees.

## Results

### *Participants' characteristics*

Six healers were interviewed individually. Two were males and four were females. Their mean age was 65 years and 59 years respectively. Two female healers had been trainees (“*umkhwetha*”) for more than 10 years. Of the remaining four, all were *sangomas* with the two males being *sangomas* as well as herbalists. All four had been practising for more than 20 years. Only one female trainee (“*umhkwetha*”) did not reside in the study area. All six healers had treated and cared for a patient with epilepsy. Another female trainee (“*umkhwetha*”) had a daughter who had epilepsy. Among the two male healers, one had a nephew who had died from epilepsy and another had personally experienced an epileptic seizure. Four were registered members of THO. Two had never attended school and four had passed grade six. Four were receiving a government pension grant. One was employed as a cleaner and another, who was a trainee, did not disclose her means of income.

Out of nine focus group participants (FGP), six were female *sangomas* and two males were *sangomas* as well as herbalists. Only one female was a trainee (“*umkhwetha*”). The mean age was 63 years for men and 61.3 years for females. Three had never attended school and six had passed grade six. Five were registered members of THO. None of the healers in the individual interviews and focus group had prior knowledge of the national Non-governmental Epilepsy Organization and some had received lay training in HIV/AIDS and TB, but not in epilepsy.

### *Names for epilepsy*

Participants in individual interviews were asked this question: “What do you call this illness (epilepsy)?” In their responses, three similar Xhosa names were reported: the illness of falling (“*isifo sokuwa*”), the illness of fitting (“*isifo sokuxhuzula*”) and fits (“*ukuxhuzula*”). Only one participant said that epilepsy is also known as “sickness of fainting”.

In the focus group discussion, Xhosa names similar to those above (with the exception of fainting) were identified as names that are used interchangeably to refer to epilepsy. An additional name “*isithuthwane*”, which is used by Zulu-speaking

people, was reported. Participants highlighted that these different names can lead to misinterpretation and confusion for those who are not familiar with them:

Another one doesn't know when you say *isithuthwane* you mean the illness of falling but really you are talking of the illness of falling. Another one doesn't know when we say the illness of falling what do we mean? Then another one says he is fitting . . . Again another one explains differently just like the names we have mentioned this way. (FGP)

Across all individual and focus group interviews, participants referred to epilepsy as "*lento*", which simply means "a thing". According to them, this use of "*lento*" reflected the fact that "epilepsy cannot be called by its name because it is a shameful illness".

The term "fainting" was further explored with participants who were asked whether fainting is another name for epilepsy. In response, they said that there is a difference between fainting and fitting and that fainting is an English word not a Xhosa word: "That fainting is not Xhosa . . . because when we talk of fainting that is not the Xhosa tongue . . . it's English" (FGP). To clarify the difference, two participants opted to explain fainting in their own African language. A Shangaan male participant explained that fainting in Xitsonga is known as "*sitsetsela*": "In Shangaan [Xitsonga] it is *sitsetsela* . . . yes. *Sitsetsela*. So fainting really, is when someone tells you something bad and you fall and you faint" (FGP). Overall, participants seemed to distinguish between fainting (which they commonly seemed to view as stress-related) and epilepsy.

### *Presentation of epilepsy*

Regarding the question, "How does it work?", participants in individual interviews explained that it is difficult to understand how epilepsy works because: (a) it is not easily detectable, (b) seizures cannot be completely controlled, (c) seizures differ in duration and frequency, and (d) seizures are unpredictable and sudden:

There are difficulties in understanding the illness because that illness is not an illness that is on the skin . . . (Female *umkhwetha*, aged 57)

Some people who do not understand this sickness . . . They found that it comes and goes . . . because some of them they do a bit [fits are brief] and they become fed up because it keeps on coming . . . (Female *sangoma*, aged 66)

You see . . . this thing is full of stories because sometimes while he is sitting like this . . . enjoying himself then all of a sudden he falls . . . (Male *sangoma*/herbalist, aged 67)

Participants further explained that there are certain warning signals prior to a seizure that their patients reported. This seemed to refer to an aura. Some patients

experience “funny feeling in the stomach”, “a throbbing sharp headache”, “dizziness” or “an ugly cry”:

A person who has fits will hear it booming a lot in the stomach. . . . You will fall and fit like that. . . . (Male *sangoma*/herbalist, aged 63)

The girl that was here would say, “Mama here is this thing”. I would say, “What do you feel?” She would answer, “It goes ‘gungxu’ [a funny sound] in the stomach. . . . Another one said he had that headache like there is lightning that happens. . . . When he is sitting with people he would give an ugly cry and then fall. . . . (Female *sangoma*, aged 71)

This one who feels themselves when they are about to fall sits down. . . . The other one will say they feel they are going to be dizzy. In fact that dizziness is when she’s about to fit. . . . (Female *umkhwetha*, aged 57)

An interesting common finding was that participants explained epilepsy as a “thing that is inside the body” which is recognized by a jerking of the body, turning of the eyes, foaming from the mouth, stiffening of fingers, urinating and losing consciousness.

### *Explanations of the cause of epilepsy*

In their response to the question, “*What do you think is the cause of epilepsy?*”, participants reported diverse biomedical and local cultural explanations of the cause of epilepsy in individual and focus group interviews.

Biomedical explanations included four broad subcategories:

- (i) blockage of the circulatory system, high temperatures, undiagnosed diabetes and stroke:

The cause for a person to fit I can say it is veins . . . something in the veins get stuck then a person fits. . . . Temperature can be high. . . . The other would be having diabetes. Probably this diabetes hasn’t been found yet, you find that they fit. . . . Another one sometimes they were about to be attacked by a stroke and fit from within [fitting from inside]. . . . (Female *umkhwetha*, aged 57)

- (ii) Lack of immunization, unavailable immunizations, child asphyxia, birth trauma due to mal-presentation of the foetus and wound infections:

This illness firstly it happens to a child . . . who didn’t do well with those injections at the clinic. . . . Another one did not get that treatment of polio and other things [other immunizations] properly from the clinic. . . . or they ended [immunizations not available] so because of that your child is attacked with that illness. . . . It may

happen during childbirth... things that didn't come out properly... clogged saliva closed him he then suffocates and fits... Sometimes a person is pregnant but the child is sitting wrong... He comes out with a certain clot in the head at birth... So I had another one with a big sore on the leg that doesn't heal... This Mama arrived with that sore that was causing those fits... (Female *sangoma*, aged 71)

(iii) Injuries to the brain:

Some of them it's according to accident... he did bang his brain and the leakage goes in his brain. It's where the nerve started to shake. (Female *sangoma*, aged 66)

(iv) Heredity:

When others speak they say you get the illness because from your family in which you were born and there is someone who had the illness... (Male *sangoma*/herb-  
alist, aged 67)

There were similarities and differences in biomedical explanations of epilepsy across interview types. Causes that were mentioned in the focus group but not individual interviews included: taking an overdose of seizure pills, poor adherence, dehydration in babies, haematoma due to internal bleeding, violence in old age, and parents not taking children who had accidental falls for early investigation:

If someone has taken overdose of pills for epilepsy... Fits can be caused by lack of taking treatment when a person has epilepsy... when a child has lost water from the body... You can get it from the family... Epilepsy can be caused by accidents to the head and the clot stays in the brain... injuries when the baby... when the mother is giving birth... When the baby falls accidentally by the head and is not checked... another one gets this baby in a way that is not right... or when we are sleeping the child falls we rub him and say, "No, it will be alright", but it stays in a person... (FGP)

On the other hand, causes such as high temperature, undiagnosed diabetes, stroke and infections were not mentioned by focus group participants.

**Local cultural explanations.** The most common themes that emerged in individual and focus group interviews were bewitchment, poison ("*idliso*"), evil spirits ("*amafufunyana*"), disobeying ancestors, punishment for moral transgression, witchcraft and African magic.

Participants believed that bewitchment could cause epilepsy. One participant related a practical example from his personal experience to illustrate what he

believed caused his fits. He also said that he had fear and odd feelings in his stomach at the time of his first fit:

I will talk about what has been happened to me . . . my uncle took off his shirt and gave it to me . . . his wife asked, “Why did you give it to him?” It didn’t take a week . . . it [fits] started. I was scared. . . I see the shirt. . . I feel a boom [sound] in the stomach and fall down . . . this thing amazed me. . . They are shocked, the people I am going with. . . A woman arrives and says, “What is happening with this child?” They say, “He just fell by himself.” . . . “Did he urinate on himself?” They say, “No . . .” She says if it was the illness of fitting he would have urinated on himself. . . I saw how illnesses come to people. . . It was the one who scolded that I shouldn’t be given the shirt . . . she had a bad heart. (Male *sangoma*/herbalist, aged 63)

Another participant reported that epilepsy can be caused by bewitchment which others refer to as “African magic”:

There is something they say is African magic. A person puts things inside of you and then once those things are inside of you they fight with your blood, they make you fit. . . In another person they [things put inside through African magic] come and they talk . . . their talking then disturbs the bones . . . it’s as if he is having a stroke . . . he fits on his side . . . walking painfully . . . (Female *sangoma*, aged 71)

The same participant further said that traditional healers’ approach to treatment of epileptic fits that are believed to be caused by bewitchment/African magic was different because these fits do not operate in the same way as fits caused by other factors:

So we [traditional healers] have different ways of helping since it comes in different ways you must first search. . . How did it enter and how did you get it? Is there a certain clot disturbing him that is going up his back or it’s in the brain or he was fed something inside? You must try and get that thing out. When that thing is out he will be able to live and become right. . . We give him herbs that will make him powerful. . . We stretch his muscles. . . We send him to the doctor so that he can check this thing in the brain what is it. . . (Female *sangoma*, aged 71)

Another participant believed that her daughter’s epilepsy was due to poisoning (“*idliso*”). She said that this was confirmed by another traditional healer with whom she consulted:

From my knowledge I think that a person maybe ate poison. . . It’s what is said to be “*idliso*” [putting something evil in the person’s food] that is done by people. . . I have a daughter who has epilepsy . . . another person [the healer] that I send her to said that



she was poisoned... she had been bewitched... witchcraft won't come to you seeing it... Maybe I will come to your house... you make me food and pour it [poison] in there [in the food]. I eat because I don't know what is in there... that's what the person [the healer] said happened to my child... (Female *umkhwetha*, aged 47)

This same participant elaborated further as to how bewitchment can cause fits:

Sometimes it is jealousy... maybe your child is studying or is clever in school... They see that they must put a spell on him [bewitch the child to cause suffering]... or your child works for you... they see that he is the one you live by at home... or you see something that you were not supposed to see with your eyes... that happens with fitting... It is said "*welamile*"... you saw something you were not meant to see... (Female *umkhwetha*, aged 47)

Another participant said that children could get epilepsy when parents did not obey their ancestors:

When parents didn't follow their calling to be a healer and then that is why the child gets that kind of sickness [epilepsy]... (Female *sangoma*, aged 66)

An interesting discussion in the focus group discussion, which was not mentioned in individual interviews, was about "*amafufunyana*" (Ensink & Robertson, 1996; Niehaus et al., 2004; Robertson & Kottler, 1993; Sorsdahl, Stein, & Flisher, 2010; Swartz, 1998). Participants explained the phenomenon as a form of witchcraft and black magic. One participant clarified the meaning thereof and said that it can cause fits. The participant further elaborated on the approach to treat a person whose fits are caused by "*amafufunyana*":

Another thing, fitting sometime there is these things called "*amafufunyana*"... a person fits having *amafufunyana*... a "*fufunyana*" is something a person is bewitched with... then now it is easy you hold him while you hold him... burn something for him even if you take an old towel or old cloth. The more he inhales that smoke he becomes lower... you see him stop more and more... that is "*ifufunyana*"... (FGP)

As the discussion progressed, another participant further explained how others view "*amafufunyana*" and that older women are usually thought to be responsible for performing such evil acts:

Others say "*ifufunyana*" is a dirty medicine that is done by people who mix dirty things from the grave all those things... other times a "*fufunyana*" speaks on its own... you hear someone talks who has "*fufunyana*" and say, "It was put in by *gogo* [old woman] or Mama" like this thing that *Tata* [father] finishes explaining... That shirt he was given... it just came. It just came... it's those kinds of magic... (FGP)

Another participant elaborated on the symptoms of “*amafufunyana*”:

When a person has “*amafufunyana*”, you will see a person running away saying that he is chased by a train. . . . He is the only person who sees the train. You [the carer or healer] do not see the train. He [the patient] is the only one who sees it . . . (FGP)

### *Views about collaboration with biomedicine*

Most participants in individual interviews and the focus group discussion were supportive of collaboration with biomedical services and provided examples of strategies for enhancing collaboration. One participant said that traditional healers have tried to initiate referrals between the two systems, but these could not be accomplished due to lack of recognition:

We have been asking for referral letters so that we refer from traditional to doctors. Because we are not licensed yet. . . . I think that’s why we haven’t got the communication . . . (Female *sangoma*, aged 67)

On the other hand, another participant emphasized that the collaborative approach must have formal agreements that incorporate freedom of expression and respect for the knowledge of traditional healers and western-trained health care providers:

Working together with the hospital is good . . . since the law is free . . . a person with the knowledge he has . . . can express it . . . this is what will make us to be able to respect each other. . . . There must be agreements . . . (Male *sangoma*/herbalist, aged 63)

All participants were of the view that collaboration is important because there are certain illnesses that either party cannot treat. In addition, they said that they could intervene where support was needed because patients’ follow up appointments were often longer than a month apart, whereas traditional healers were always accessible:

We could work together with them because there are illnesses [that we can’t treat]. . . . Doctors will be defeated by this [illness caused by bewitchment]. . . the doctor will give an appointment for the next month. . . . I am always here . . . (FGP)

## **Discussion**

In this study of traditional healers’ views of epilepsy, healers provided several different terminologies referring to epilepsy, suggesting the potential for confusion and misinterpretation. Healers had a range of explanations that included biomedical causes of epilepsy as well as notions that epilepsy could be caused by

bewitchment, witchcraft and “*amafufunyana*”. They said that epilepsy in children could be caused by ancestors as punishment for their parents. Most were supportive of collaboration with western practitioners.

Previous studies in other parts of Africa have shown that the terminology for epilepsy varies among different population groups and cultures (Millogo et al., 2004; Mugumbate & Mushonga, 2013; Mushi et al., 2011). In our study, epilepsy was referred to as “*isifo sokuwa*”, “*isifo sokuxhuzula*” and “fits”. Reference to epilepsy as a fainting illness was consistent with findings from Tanzania (Mushi et al., 2011). In addition, “*isithuthwane*”, which is a Zulu name for epilepsy, was also identified. These findings highlight the diversity of spoken languages in the study setting, which can affect the ways in which health care is accessed and engaged with. Language barriers pose many challenges, particularly in South Africa which has 11 official spoken languages, with most health care professionals being proficient in only one or two of these languages (Levin, 2007; Schlemmer & Mash, 2006; Watermeyer & Penn, 2009). Even when patients and providers are of the same ethnicity, they may use quite different idioms and terms for describing illness (Keikelame & Swartz, 2013a, 2013b).

The most common finding across all interviews was that epilepsy was referred to as a “thing”, “*lento*”. Participants explained that this was because epilepsy is a shameful illness and using “*lento*” is a way of hiding the illness. This view may reflect the stigma and secrecy that surrounds epilepsy (Baskind & Birbeck, 2005a; de Boer, 2010; Diop, de Boer, Mandlhate, Prilipko, & Meinardi, 2003).

Many of our participants’ explanations of the causes and descriptions of epilepsy were consistent with those of biomedicine, reinforcing the view that EMs do not exist in sealed-off, homogenous groups. There were also some anomalies, such as the belief that epilepsy is associated with lack of immunizations for polio and other conditions. Alongside biomedical explanations, local cultural explanations of the cause of epilepsy included bewitchment, witchcraft, poisoning and black magic. Similar findings have been reported in other studies (Baskind & Birbeck, 2005b; Kendall-Taylor, Kathomi, Rimba, & Newton, 2008; Mushi et al., 2011; Stekelenburg et al., 2005). Our participants used “bewitchment” and “witchcraft” interchangeably when they spoke about the cause of epilepsy. Ivey and Myers (2008a) distinguish between the two concepts. They state that witchcraft involves secretive and evil actions that use mystical powers to harm others or their property, while bewitchment is an epitome of evil magic, but this distinction did not seem to be held by our participants.

Our participants described “*amafufunyana*” as a form of bewitchment where “dirty things from the grave” are mixed and given to the person. This is also referred to as “ants of the grave” and is often used to refer to schizophrenia and psychosis (Lund & Swartz, 1998; Mzimkulu & Simbayi, 2006). Other authors state that “*amafufunyana*” is also referred to as “nerves” (Lund & Swartz, 1998). Its symptoms include, among others, aggression, fits, hysteria, anorexia, agitation and catatonia (Ivey & Myers, 2008a). Our participants explained that a patient whose fits were caused by “*amafufunyana*” would report hearing voices, seeing things that

others do not see, and believing that an old woman is responsible for the illness. Witchcraft or sorcery is “*ubuthakathi*” in isiXhosa and is often performed by a witch, “*umthakathi*” (Thornton, 2013). Thornton states that bewitchment accusations are rife in South Africa even though legal protection is in place. As noted in the results, one participant believed that older women, “*gogos*”, could be accused of witchcraft actions. These bewitchment accusations against older women were reported as a form of elder abuse and lack of respect for the elderly in previous research (Keikelame & Ferreira, 2000). Together, these findings suggest that older women who present with a history of fits should be examined for signs of such abuse.

Traditional healers explained epilepsy as “a thing inside the body”. Some researchers in the field of psychology have suggested that the concept of “the thing inside” may reflect what they term “the embodiment of bewitchment” (Ivey & Myers, 2008b, pp. 83–84), wherein individuals who believe in and ascribe the cause of their illness to bewitchment may report feelings of odd sensations in the stomach. One participant in this study who had a personal experience of a seizure that he thought was due to bewitchment stated that he felt a “booming sound” in his stomach and fear prior to the seizure.

As in many other African cultures, in this group ancestors are believed to play a crucial role in the lives of their families by protecting them from misfortunes (Hammond-Tooke, 1989; Munthali, 2006; Ngubane, 1977; Thornton, 2013). In previous research, it has been reported that ancestors are believed to cause suffering in children when parents disregard them (Munthali, 2006). Our participants also explained that one cause of epilepsy in children is a lack of parental respect for ancestors. According to Janzen (cited in Munthali, 2006, p. 376), in other African cultures, misfortunes caused by ancestors do not require medications but can be treated by treatments referred to as “kinship therapy”.

The majority of our participants were supportive of collaboration with western-trained health practitioners, consistent with findings reported by Pouchly (2012) in other studies conducted in South Africa. Traditional healers have been recognized as pillars of epilepsy care because of their ability to counsel patients and their position as custodians of culture (Winkler et al., 2010). In KwaZulu-Natal province in South Africa, a 48-bed hospital founded by a traditional healer uses traditional and western treatment for psychosocial disorders (Shizha & Charema, 2011). However, many challenges remain regarding the possibilities for collaboration in the health care system (Janse van Rensburg, 2009; Pinkoane, Greeff, & Koen, 2008). For example, sick certificates issued by traditional healers are not recognized. Our findings show that there are also referral and communication challenges. Regarding these challenges, our participants emphasized that collaboration must incorporate their right to freedom of expression of their indigenous knowledge and practice. The findings suggest that collaboration must be developed through a well-planned strategy that is based on inclusive participation, transparency and acknowledgement that the two knowledge systems, indigenous and biomedical, can complement each other to achieve improved health outcomes (Campbell-Hall

et al., 2010). Caution must be taken in view of strategies that may be interpreted as exploitative of traditional healers (Owusu-Ansah & Mji, 2013).

## Limitations

Our study was limited by the small sample and the results cannot be generalized to the entire population of traditional healers in the study setting. There could have been a sampling bias because the field assistant who helped in recruitment of other healers was a member of the THO and may have recruited only those who were known to her. The first author was also known by some of the participants and this may have influenced their responses during the data collection. Bias in analysis and interpretation of the data also could have resulted from the authors' cultural and professional backgrounds, including the first author's position as a board member of the local branch of the national non-governmental epilepsy organization, and her observations and informal conversations in the field.

On the other hand, because the focus group participants knew each other well, they were able to discuss contentious issues in more depth. Familiarity of participants in focus group discussions has been reported as a positive factor because it can enable active participation and openness in a non-threatening environment (Ulin et al., 2002). In addition, the focus group had some members who had been individually interviewed and this provided an opportunity to clarify and validate some issues from individual interviews (Flick, 2006).

## Conclusion

The study of cultural factors in epilepsy needs to take into account local beliefs and practices, explanatory models of healers and patients, as well as the culture of the wider medical system. The participants provided both biomedical and local cultural explanations of epilepsy and also shared their perspectives on collaboration. Our study has implications for practice in terms of working collaboratively with these healers. First, there is a need for interventions that promote cultural literacy (Zarcadoolas, Pleasant, & Greer, 2006) among mental health practitioners. Second, given the nature of the past exploitative experiences during colonization and a lack of clear guidelines on protection of traditional healers' intellectual property rights in the country (Ross, 2010), strategies and plans for collaboration must comprise formal agreements that embrace human rights. Traditional healers must also not be granted an inferior status because of their lack of professional qualifications in formal terms (Shizha & Charema, 2011). Collaboration requires a willingness to engage as equals with different areas of expertise (Rhodes, Small, Ismail, & Wright, 2008).

Part of the difficulty in this field is that traditional healers in South Africa have not yet received full recognition in western health care systems. In addition, the training of *sangomas* involves a process called *ukuthwasa*, which is undertaken over a number of years (Swartz, 1998; Thornton, 2009). According to Mlisa (2009),



*ukuthwasa* is a religious phenomenon that is difficult for outsiders to grasp and is also an integral part of indigenous knowledge systems (IKS). In order to engage in respectful collaboration and relationships with traditional healers (Berg, 2003), health care providers need to be orientated towards a culture-centred approach (Campbell-Hall et al., 2010). Further research on the process of collaboration with traditional healers is urgently needed.

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The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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## CHAPTER SEVEN: COMMENTARY



Mr Kotu – A popular carer

***“You see, this illness needs investigations as to why are these pills not working. A person is taking them for a long time but does not get well...”***

## **CHAPTER SEVEN**

### **ARTICLE 5**

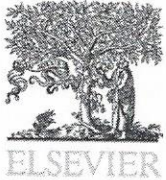
#### **A lay carer's story about epilepsy in an urban South African context: They call it an illness of falling or an illness of fitting because a person shakes and eventually falls**

##### **7.1. INTRODUCING ARTICLE 5**

In Chapters Three, Five and Six, I presented articles which focused on research among professional carers, HBCs and THs. In this chapter, I introduce to the reader the fifth article of the seven peer-reviewed published journal article which is a product of this dissertation.

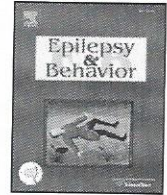
The chapter presents the story of an older adult male popular carer whose niece had epilepsy. It highlights his own personal perspectives and experiences of caregiving such as being a migrant, having no knowledge of available community resources and epilepsy support services and residing in a setting that lacks social cohesion. In addition, this single story highlights that when PWE are not well investigated and when their seizure treatment is not evaluated for appropriateness and effectiveness, they will not have seizure freedom. This single story articulates the importance of indigenous knowledge (IK), the benefits of traditional treatments, his perspectives about epilepsy and the Xhosa names that are used to refer to epilepsy. This story of an older male lay carer poses lessons which can facilitate a better understanding of gender-related experiences and perspectives on caring for PWE, since these may differ among carers from the same health care sector.





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# A lay carer's story about epilepsy in an urban South African context: They call it an illness of falling or an illness of fitting because a person shakes and eventually falls

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## ABSTRACT

In South Africa, epilepsy is poorly understood and managed. The different cultural understandings and terms used to explain the condition across the diverse population groups exacerbate this problem. In this article, we describe the findings from a single story about epilepsy which we elicited through a semistructured interview guide in the respondents' natural setting. We used Kleinman and Benson's mini-ethnographic questions to explore the lay carer's explanatory models about epilepsy. Our respondent had different descriptors for epilepsy which include 'an illness of falling', 'an illness of fitting', and 'a thing'. His explanatory models concerning epilepsy were predominantly sociocultural, psychological, economical, and political in nature and were supported by personal examples from his past and present experiences. Key to this man's story is the reality of a strong cultural base of understanding epilepsy, with the added reality of an urbanized world in which people feel alienated from one another and do not necessarily share the same cultural beliefs and practices. Instead of viewing understandings of epilepsy as either 'traditional' or 'western', community-based health promotion interventions must therefore recognize both cultural issues and urban realities and should also incorporate approaches that foster a common ground for patients and carers with very diverse views. The findings of this one interview cannot be generalized but have implications for managing epilepsy in an urban African context.

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## 1. Introduction

Good and Good [1] state that "if we are to analyse the role of culture in shaping illness experience and behaviour, it is important that we attend to the stories we hear with great care". The authors further point out that this is important, partly because "most of what we know about ... illness, we know through stories we are told". According to Reverby [2], good medical practice involves the ability of the medical doctors to elicit a "thoughtful history by listening and hearing patient's real stories", no matter how they tell them, whether they are vague, and even if doctors have limited consultation time. Referring to the work of Paget (1982), Sandelowski [3] notes that listening carefully to even one story of an illness can reveal important information not only about the illness but also about life experiences more generally.

According to Kleinman (1988:49) in Hydén [4], "the illness narrative is a story that the patient tells and significant others re-tell to give coherence to the distinctive events and long-term course of suffering. The personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering" (p.54). Hydén [4] further points out that when illness stories are told,

other people are enabled to comment on them and to provide new interpretations and suggestions. What the author means is that stories are a way of presenting, discussing, and hearing how people relate to the illness, thereby providing opportunities for articulating various events related through a story and discussing their meaning.

With regard to epilepsy, illness stories are socially and culturally constructed and may have a range of interpretations and meanings. Some of these may result in stigmatization of people with epilepsy (PWE) [5]. For example, an interesting feature of epilepsy narratives is that they are often told not by people who have epilepsy but by others. Indeed, many of the most dramatic experiences of epilepsy (grand mal seizures in particular) may not be remembered by PWE themselves and because of this, they are inserted into the narratives of those who witness and tell about seizures [1].

This story forms part of a larger study titled 'Perspectives on epilepsy on the part of patients and carers in a South African urban township', the broader findings of which will be reported separately. The study is set in one of the oldest townships in Cape Town, established in 1927 because of forced removals of Blacks by the policies of the White minority government. The burden and management of epilepsy are not mentioned in the situation analysis of the study setting, conducted in 2005 by Naidoo and Irlam [6]. Nationally, however, the burden of epilepsy is reported to be approximately 1 in every 100 South Africans [7,8]. Cultural beliefs regarding the cause and treatment of epilepsy also vary between communities in the country [9].

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### 1.1. What this study adds

There are very few studies looking at complex stories in Africa. We are not aware of any studies which look in detail at a single story which discusses issues of transition as clearly as this one. The story provides information not only about epilepsy but about the complex contextual factors that affect treatment, care, and health-seeking behavior in the context of poverty and displacement in a low-income area in Cape Town, South Africa.

## 2. Methodology

In this qualitative exploratory design, we chose to focus on particularities of a single story which is among many that we are collecting in line with Good and Good [1], who emphasize the importance of listening to stories. In particular, this story provides an in-depth exploration of relationships between different variables that affect health and health-seeking behavior. Our respondent provides a complex and multilevel perspective that we would not have gained through a larger study. Writing about the importance of listening to stories in their entirety, both Frank [10] and Charon [11] argue that a single story can open worlds of meaning. The analysis of a single story is not designed to give information about populations or groups in general. It focuses instead on the how and why of a person's experience [12]. Kleinman [13] also notes the importance of the single narrative for our understanding of the experience of illness and of caring for people who are ill. We used Kleinman's explanatory models of illness (EMs) [14,15] to conceptualize how our respondent explains epilepsy. Explanatory models constitute a way of understanding how people recognize an illness, explain it, and respond to it [16,17]. In addition, EMs are shaped and influenced by culture and are held by patients and their carers and provide personal and social meaning with regard to the illness experience [18–21]. Furthermore, EMs can affect coping, treatment choices, adherence, and therapeutic relationships [22,23].

### 2.1. Sampling procedure

Our participant was purposively recruited [24] from a group of patients with epilepsy and carers who attend a chronic illness clinic at the primary care setting that renders health-care services for the study population. We distinguished between and aimed to include different types of carers in our larger study — namely popular carers (family members, friends, or neighbors), folk carers (traditional healers such as herbalists and faith healers), and professional carers (Western-trained doctors, pharmacists, and other allied health-care professionals) [15] — in order to triangulate diverse views on the problem within the same population group. The inclusion criteria for popular carers included the following: any family member, friend, or neighbor who (i) is giving or has given care and support to PWE, (ii) speaks isiXhosa (isiXhosa is the dominant indigenous African language spoken in Cape Town), (iii) resides in the study setting, (iv) is aged eighteen years or above, and (v) is willing to participate in the study. During the recruitment process, the purpose of the study was explained to prospective participants who met the inclusion criteria. We also aimed to recruit 'information-rich' cases [24] which would provide insight and a deep understanding of the problem [24,25] and of the EMs about epilepsy. Only those who fit the criteria and aims and were interested in participating were included in the study and later visited at their homes to gain informed consent and to set interview appointments. Our participant was among the first to be interviewed. Our decision to share our respondents' story in detail was motivated by the richness of the information we obtained through the use of Kleinman and Benson's [26] mini-ethnographic questions, which may otherwise have been lost in a multistory cross-case analysis. The complexity of this person's story and cultural positioning gives a window into the multilayered experiences associated with epilepsy in an urban South African setting.

### 2.2. Ethics

A written informed consent and participant information leaflet were translated from English to isiXhosa by an isiXhosa-speaking language practitioner. This was read and interpreted to the participant by an isiXhosa-speaking field assistant to ensure that the participant understood the purpose of the study and his rights and responsibilities of participating. Confidentiality and anonymity were ensured by assigning predetermined identity numbers and pseudonyms to the audio-recorded interview data as well as the field notes to protect the identity of the participants. Written nondisclosure agreements were signed with the interpreter and the transcriber. All study documentation and transcripts were kept safely in a locked cupboard for confidentiality. The study was approved by the three local research ethics committees. Informed consent was obtained prior to the interview, and a signed copy was left with the interviewee [27–30].

### 2.3. Data collection

An in-depth individual face-to-face interview was conducted in isiXhosa (the participant's native language) at the participant's home by the first author, who is a black African female who has worked among isiXhosa-speaking communities in Cape Town for 19 years and knows the area well. A semistructured interview guide was constructed in English and translated into isiXhosa by an isiXhosa-speaking language practitioner and piloted prior to the interview at the local primary care setting by the first author among five patients with epilepsy and five carers who all speak isiXhosa. There were no questions that needed to be changed. The interview guide was based on Kleinman and Benson's [26] mini-ethnographic questions which the authors hoped would allow the participants to speak openly in an unstructured way, thereby enabling them to share experiences in the way they considered important [29,30].

Additional probe questions on psychosocial difficulties with regard to marriage, employment, and driving as well as recommendations of actions and solutions needed to address the difficulties were included. The interview commenced after gaining informed consent from the respondent and lasted for 90 min. The data were transcribed from isiXhosa into English by an isiXhosa-speaking language practitioner with experience in doing transcriptions. After the transcript was completed, the first author read the transcript and listened to the audio-recorded interview to ensure the accuracy of the transcribed data. The audio-recorded data were repeatedly listened to by the authors in order to cross-check against each other's interpretations.

While the first author is not a native isiXhosa speaker, she had enough knowledge of the language to be able to understand the thread of conversations in isiXhosa and to make herself understood in that language. The cross-cultural validity of the tool was ensured by (i) using the translated and piloted interview guide in the respondent's language during the interview, (ii) using an isiXhosa-speaking interpreter from the study setting to assist in gaining informed consent, (iii) using verbatim quotes to highlight the respondents' statements [31,32], and (iv) doing verbatim translation of the transcript to the respondent, a method Flick [33] refers to as a 'member check' (p. 205). Reflective field notes were captured by the first author after the interview to reflect on the process and to facilitate the data analysis [29,30].

### 2.4. Data analysis

After familiarizing ourselves with the data, we used Braun and Clarke's [34] thematic analysis method to analyze the qualitative data. We read the transcript to gain an in-depth understanding of the participant's story and began with open-coding of the data. As the aim was to provide meaningful interpretation of the participant's story, we attended to the words, language, and expressions used [1]. Thereafter, we selected the main categories emerging from the story and used



Kleinman's EMs [35] to identify eight codes: descriptors of epilepsy, causes of epilepsy, beliefs about contracting epilepsy, what epilepsy does to the body, difficulties caused by epilepsy, treatment of epilepsy, expected outcomes, and fears about the illness. The authors conducted the analysis separately at first in order to provide two independent perspectives on the data. Each interpretation was evaluated, unexpected findings discussed, and the process reflected upon. Thereafter, the first author used a member check strategy to verify the data with the respondent to ensure accuracy and credibility and to exclude any bias which may have occurred from the authors' interpretations [36,37].

### 3. Findings

Below, we present the key issues in the popular carer's explanatory models of epilepsy which were elicited through the use of Kleinman and Benson's [26] mini-ethnographic questions.

#### 3.1. Participant characteristics

Our participant was a 70-year-old isiXhosa-speaking male whose niece has epilepsy and who is taking Western treatment for the condition. He originates from the Eastern Cape, one of the poorest provinces in South Africa, and has been living in Bhenga Township in Cape Town, a site for many migrants from the Eastern Cape and some 1200 km away, for five years. He was married and divorced in 1990 and has three children aged 39, 37, and 35 who do not reside with him. He stopped working in 2007, is receiving government pension, and currently occupies a leadership position in his local Presbyterian Church and is also involved in a vegetable garden project. He has eight years of schooling, no training on handling epilepsy, and has no knowledge about the local nongovernmental organization supporting PWE.

#### 3.2. Descriptors of epilepsy

In response to the question "what do you call this illness (epilepsy)?", our respondent did not answer but said that some people call it 'the illness of falling' [isifo sokuwa] or the 'the illness of fitting' [isifo sokuxhuzula] because he or she [PWE] will 'shake' and eventually 'fall' as he describes below:

"... They call it the illness of falling. It is just a name that they came up with because they suddenly see a person falling. The name of fitting is not wrong because the person sort of shakes ... but ends up falling. That is why it is called in that manner..."

In his explanation of his first experience with a person with epilepsy whom he did not know had the illness, our respondent referred to the illness as 'a thing' [lento]. He described his feelings about this experience with an isiXhosa-speaking male with epilepsy who was given a rifle for hunting animals and had a seizure before shooting.

"... I didn't know that this father [in the tradition of the amaXhosa people, all older people are referred to as 'father' or 'mother'] does shoot animals ... the White likes giving him a rifle for shooting animals during winter. Now this father was confronted by this 'thing' [epilepsy] ... we ran and fled in all directions because we did not know that he had this illness. But through the work of God, we were spared. He was unable to shoot as he was shaking and fitting ... I am just saying this illness comes out like that when I first saw it..."

#### 3.3. The cause of epilepsy

Our respondent explained that he was unsure of the cause of his niece's epilepsy but thought that it could have been due to something

in her blood or maybe something in her veins that prevented the blood from flowing freely. He also personified epilepsy:

"... It just comes up even if there's never been anyone who fell or nothing happened. It does not care if a family never had it. I think it maybe the blood veins just stop and they don't flow freely. This thing suddenly comes when a person is just walking on their own even if he or she is a grown-up..."

#### 3.4. Beliefs about contracting epilepsy

The most comprehensive account of our respondent's explanations was on what others have said about contracting the illness and how to respond to PWE during a seizure.

"... It is said that the person with the falling illness ... don't come closer to their mouth because they might bring up wind ... you will be affected by that illness because that thing will get into you ... you must be careful your mouth must not be closer to theirs..."

Another interesting explanation was the belief that if a person with epilepsy was burned, they would never heal.

"... They are alone out there ... maybe they fall over the fire ... or hot water spills on them and they get burnt ... they will never get healed again. It's been time people say that thing..."

#### 3.5. What epilepsy does to the body

Our respondent further described what epilepsy does to the body, how it is recognized, and how to respond to PWE during a seizure. He explained that the hands begin to cramp and, if not stretched, PWE may not be able to use them.

"... it might be because the hand muscles and veins cramp ... so if you leave those hands ... that they will not be able to open on their own ... a thing that can lead them to shake when they hold coffee to drink ... so you must stretch their hands ... and feet..."

In addition, he said that one can recognize what epilepsy does in a person's body.

"... You will see foam coming out of the mouth ... his body shakes ... neck stiffens and their mouth twists sometimes ... and they fall anyhow ... their eyes change ... eyes turn..."

He further explained that when the above-mentioned signs are recognized, it is important to protect the person from biting the tongue to prevent swallowing it. He specifically mentioned that this was an isiXhosa belief.

"... There is something that it [epilepsy] does ... you must guard them not to bite their tongue ... that is not wanted ... you must be careful according to isiXhosa ... they might bite their tongue and swallow it..."

A mechanism for protecting the tongue was explained as follows:

"... you insert anything like a stick even a spoon [in the mouth] ... for helping them..."

#### 3.6. Difficulties caused by epilepsy

In response to the question "what are the main difficulties experienced by the PWE you were caring for?", our respondent said that his



niece and family members were always worried, anxious, and unhappy because of not knowing when seizures will occur and that this affected their health.

“... This person does not have a right health ... always has anxiety ... she is never happy among people ... people who are with her are always anxious even when she is alright and feels nothing. But you always worry that this thing might come up per chance...”

Our respondent highlighted some difficulties in marriage, driving, and employment.

“... A person with this illness must never drive because they can kill many people and he can collide with anything...”

Marriage difficulties were related to concealment of the illness in the relationship.

“... It's [marriage] still a problem ... I take your child and I marry her. This child of yours I will not tell her that I have the falling illness. This child will be surprised when she wakes up at night ... here is a person shaking and foam coming out of him ... she will be frightened. Even if they can have children ... the wife will be in more trouble...”

In terms of employment, our respondent explained that PWE cannot work alone and that the type of employment is crucial because PWE should always be guarded.

“... He can work but the place where he works must not be a place where he goes up the stairs ... it must be a place with people working there ... so that he can always be among people. He mustn't work alone ... there must be people ... so that they can guard him...”

Furthermore, our respondent explained the difficulty of providing appropriate care based on his experience as a migrant. He was articulate concerning the impact of urbanization and the lack of knowledge of available health-care services for PWE and their carers in migrant urban communities.

“... I don't know where they come from because we are from different places .... We meet here at the Cape already grown-ups all of us .... So I am unable to say ... it is their first time getting this “thing” [epilepsy] ... not unless they can explain to me ... that this ‘thing’ [epilepsy] once happened back at home...”

He further elaborated on the limitations in providing a witness description, when needed at a hospital or a clinic.

“... I will explain that I saw him having this ... I don't know where it all started ... I can only tell what time he started ... what he started doing ... I saw his eyes doing this ... and then he fell...”

### 3.7. Treatment of epilepsy

Our respondent spoke passionately with utter disappointment that black African people have disregarded their traditions because of the influence of Western thinking that traditional treatments have no value. Yet, these treatments have been used in many decades to cure and prevent illnesses.

“... people no longer use traditional medicine ... during that time when we were born ... traditional medicines were used and a person would heal ... these illnesses have long been here ... they were treated with traditional medicines. We let go of our traditional

things ... is it because of education? We ran and went to the things that belong to Whites ... like things done by black people have no value ... whereas they have value ... we left our things...”

### 3.8. Expected treatment outcomes

Our respondent explained the importance of investigating effective seizure treatments instead of the long-term use of the same medication without monitoring the effectiveness thereof. In addition, he stated a need to do appropriate investigations for the cause of epilepsy and for the appropriate choice of seizure treatment.

“... You first investigate ... then seek a solution to say what you can help with and what they can't be helped with. This illness does not want a person who will just take out medicines and treat it. It wants to be investigated as to what causes it ... doctors must see that ... we've been using this medicine for too long ... but people don't stop having this thing. Now let us decide to change and see some other way ... really people will get well then...”

In addition, our respondent raised a concern about the notable epilepsy-related deaths and negligence.

“... investigate why with this illness death [ukufa] is so much ... and the negligence thereof ... there is a need for an inquest ... here is a difficult place in a person ... the head. When a person injures the head ... there is living and non-living ... so, I can conclude and say ... it must be that ‘death is rare...’”

### 3.9. Fears about the illness

Interestingly, when asked “what do you fear most about the condition?”, our respondent explained that he fears that PWE may not be in the right sense of mind when experiencing a seizure because their behavior is similar to a ‘lunatic’ [igeza].

“A person who is fitting is fearful because they are not in their mind ... a person is similar to a lunatic [igeza] ... They can take a knife there sometime ... can jump on you to hold you ... they are not criminals [isigebenga] ... they only want a place to hold on ... they think that here is a person who will help me...”

## 4. Discussion

Our findings yielded our respondent's explanatory models of epilepsy which were based on his subjective experience of having a niece who had epilepsy and the challenges of being a migrant lay carer in an urban township in Cape Town. In our discussion, we highlight key issues raised by our respondent, incorporating his multiple perspectives on his past, present, and prospective possibilities for improved health outcomes of PWE. The following aspects were evident from our respondent's EMs on epilepsy: the different descriptors of the illness, prevailing old myths and the emergence of new ones and their influence on the other's response to the condition, psychosocial difficulties encountered by PWE, the effects of migration, the erosion of traditional indigenous knowledge, and strategies for improved health outcomes. These are elaborated on and discussed below.

### 4.1. Descriptors of epilepsy

In South Africa, there are eleven official languages, and epilepsy is explained differently among different population groups. For example, in isiXhosa, epilepsy is known as “isifo sokuxhuzula” (an illness of fitting) [38]. Interestingly, we found that even among those who may speak a common language, epilepsy is referred to differently depending on the geographical location of the community. For instance, in



Khayelitsha township in Cape Town, a group of isiXhosa-speaking parents whose children had epilepsy explained epilepsy as 'isifo sokuxhuzula' [38], while in the present study, our respondent referred to epilepsy as 'a thing' (lento), meaning something that cannot be called by name. Not wanting to call epilepsy by name could be a form of shame which may affect health-seeking behavior. On the other hand, our respondent used two terms interchangeably to refer to epilepsy: an 'illness of falling' [isifo sokuwa] and an 'illness of fitting' (isifo sokuxhuzula).

In other African contexts such as southwestern Nigeria, different terms are also used to explain epilepsy, but these terms mainly explain epileptic seizures. These terms include 'giri' (shaking or spasm), 'warapa' (wriggling or twisting), and 'ogun oru' (nocturnal warfare attributed to demonic affliction) [39]. Our respondent was also unable to explain epilepsy and only used terms that others use which explained epileptic seizures rather than epilepsy as defined from the medical point of view. This finding is consistent with the study done by Mushi et al. [40] in Hai, a rural district in Kilimanjaro, northern Tanzania. These authors found that most of their respondents were unable to explain epilepsy and used different local Kiswahili terms such as 'Kifafa epilepsy', 'ugonjwa wa kuanguka' (falling down sickness), and 'ugonjwa was kuzimia' (fainting illness) or described epilepsy as an illness characterized by loss of consciousness or memory or a type of 'degedege' (convulsion). Similarly, in Kilifi district in Kenya, epilepsy is also referred to as 'Kifafa' which means 'a problem that comes when a person falls down on the ground' [41].

In Burkina Faso, Millogo et al. [42] report that traditional healers in Bobo-Dioulasso refer to epilepsy as 'kirikiri-massien' in Dioula and 'kisenkiri' in Moore, which means 'the illness that very much shook us', which particularly concerns tonic-clonic seizures. On the other hand, Mugumbate and Mushonga [43] report that, in Zimbabwe, epilepsy is referred to as 'zvifaifa' meaning 'dying several times'. Understanding these idiosyncrasies is therefore very important as the usage of these different terms can perpetuate stigma and social discrimination of PWE [40–43] and can also influence the choices that people make about their desirable treatment and care [19].

#### 4.2. Myths about epilepsy

Myths, misconceptions, and misunderstandings about epilepsy have been widely reported and have persisted for many years [44–46]. However, despite the global initiatives of taking epilepsy out of the shadows, these myths are still affecting the objectives of the global campaign [45]. Fernandes et al. [47] report that old myths continue to exist, and new ones are emerging and that these myths not only prevail in the general public but also among health-care professionals. Myths affect the quality of life of PWE, cause them to hide their illness, and subject them to social discrimination and stigma [39,43,45]. The carer we interviewed mentioned fear of contagion through the breath of someone experiencing a seizure as a barrier to helping people with epilepsy, a view which is consistent with other African literature. As Mushi et al. [48] found in Tanzania, health-seeking behavior is affected by these myths, resulting in the use of multiple health systems, an increased burden of care, stigma, and discrimination. Myths also result in structural restrictions in terms of choosing or delegating chores or work that is deemed to be of low social value [49]. Our respondent reported that PWE should always be guarded and the type of work available to them should be determined by others.

#### 4.3. The erosion of indigenous knowledge

In South Africa, there are various plant species (more than 230,000) which are used by the different population groups in the country. However, because of factors such as education, urbanization, and changes to the sociocultural environment, farming styles, and climate, this indigenous knowledge base has been eroded [50]. According to Bhasin (2008a) in Matthews et al. [51], 'traditional medicines are seen as part

of a cultural heritage of each population group'. There are power issues in relation to indigenous knowledge, and this may be a factor. Although our respondent did not mention specific traditional treatments for epilepsy, literature reveals that there are traditional plants that have been used for the treatment of epilepsy as well as other illnesses [52]. For instance, van Wyk [53] reports that the *Hyraceum* plant referred to as *dassiepis* (rock rabbit urine) is used as a common remedy for backaches and stomachaches, hysteria, epilepsy, and other illnesses of the nervous system.

#### 4.4. Psychosocial difficulties

The disabling nature of the psychosocial aspects of epilepsy has been well documented. People with epilepsy are reported to be ostracized by their communities and are seen as 'bad bets' in terms of marriage and employment [54], and epilepsy is also reported as a contributory reason for divorce [40]. With regard to PWE perceived as violent, Collins et al. [55] report that these perceptions have not changed over the past 25 years. Strategies to overcome these difficulties have been recommended and include the following: building confidence in PWE, training PWE in coping strategies, improving self and collective efficacy, strengthening self-help groups, building social networks, and providing information to improve knowledge of PWE and their carers [56].

#### 4.5. Effects of migration and provision of health care

South Africa's health-care system is based on the Primary Health Care approach [9], but inequalities in terms of equal access to health care by the most impoverished black population groups still exist [57]. According to Vearey and Nunez [58], the country is also faced with internal and cross-border migration, yet sufficient engagement regarding migrants' health-care needs is lacking, and migrants are reported to be experiencing difficulties in accessing health care because of negative attitudes, discrimination, facility-level policies (lack of SA identity documents), poor living conditions, and language barriers. Our respondent informed us that because of migration, people do not know one another because they come from different places. They may also not know why people are having epileptic seizures and may, therefore, be reluctant to help or become involved.

#### 4.6. Strategies for improved health outcomes

Our respondent provided crucial suggestions regarding the need for appropriate investigations to improve diagnosis and treatment of PWE. While Akinsulore and Adewuya [59] echo a need to base the choice of treatment on individual needs and seizure type, they acknowledge that this may be difficult to fulfill because of the limited choice of antiepileptic drugs in developing countries. Our respondent highlighted a very important concern about sudden unexpected death in epilepsy (SUDEP) which is reported as a global concern [60]. Patients who are at high risk for SUDEP are those that have frequent tonic-clonic seizures, those who are treated with two or more seizure medications, and those whose compliance to seizure treatment is poor [60]. Some strategies for the prevention of SUDEP include appropriate seizure management, reduction of stress, participation in physical activity and sports, supervision at night, and knowledge of CPR techniques by family members [61]. Some epilepsy researchers have highlighted that the use of omega 3 may reduce the risk for SUDEP [62]. Our findings from this one story suggest that strategies for seizure management should address the myths that influence inappropriate responses during and after a seizure as these may place PWE in a vulnerable position with respect to SUDEP. It is also important to develop interventions to empower PWE to engage in work that has social value [49].



## 5. Conclusion

We have provided a rich description of a unique story which was shared through an interview with a lay carer of a person with epilepsy. We used Kleinman and Benson's [26] mini-ethnographic questions to elicit our respondent's EMs on epilepsy. Darghouth et al. [63] highlights that illness interpretations are influenced by individual relationships which are located in the family, community, broader context (psycho-social, economic, cultural, and political), and the natural and supernatural worlds. Listening to illness stories can help one understand individual experiences from living with the condition and their impact on the person in order to design appropriate strategies to improve the quality of life of PWE in general [64]. The story told by our participant illustrates clearly how traditional views on epilepsy are interwoven. It also provides a useful lens through which to understand how rapid urbanization and migration, marginalization, and lack of knowledge and skills on the part of lay carers can affect the lives of people suffering from the condition and those around them. Snape in Fernandes et al. [47] state that stories enable patients (and by implication, carers) to communicate what is significant and important to them.

### 5.1. Limitations and implications

The findings from this single story cannot, of course, be generalized. Our aim, however, was not to produce generalizable findings but, rather, to understand the dynamics of a single story. Understanding this type of a story may supplement broader knowledge about the experience of epilepsy by providing insights into how epilepsy is experienced in the totality of people's lives. It is through individual stories that we learn the texture of people's struggles in their everyday health and life encounters. These issues need to be taken into account when tailoring interventions for different contexts. Examining this one case in detail highlights the multiplicity of all people's cultural positionings regarding health and illness. Our participant relied substantially on his valuing of traditional beliefs but also recognized his place in an urban environment where people come from a wide variety of backgrounds and may not share common histories or belief systems. Interventions at the community level in such contexts cannot assume that there is just one homogeneous community defined by current geographical location or that different people living in African cities each have a single view of epilepsy. Part of the work of community-based interventions in these contexts is to develop common ground and bonds among diverse people with diverse views and experiences. It is not our intention to suggest that the story we have presented is a generalizable template for understanding epilepsy. Rather, it provides a method for engaging in many different stories which are too easily overlooked in broader presentations.

### Conflict of interest

None declared.

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## CHAPTER EIGHT: COMMENTARY



Individual interviews with popular carers  
(Wives, partners, siblings, friends, neighbours and parents)

***“The difficulty is ours – we leave it to God...”***

## CHAPTER EIGHT

### ARTICLE 6

#### ***“Whom will I give him to? The difficulty is mine”*: Psychosocial difficulties experienced by care givers of patients with epilepsy in Cape Town, South Africa**

#### **8.1. INTRODUCING ARTICLE 6**

This chapter presents the sixth article of the seven peer-reviewed published journal articles which are a product of this dissertation. Chapter Eight moves on from a single story of an older male carer from the popular sector of health care about his perspectives and experiences on epilepsy, presented in Chapter Seven. It builds on the work presented in Chapter Seven and provides insights into the lived experiences of nine female carers who comprised mothers, wives, partners and siblings who provided care for their close relatives at home who had epilepsy, mostly for more than twenty years. Among these nine carers, there was one who was disabled and who cared for her partner who had epilepsy (Example of interview guide for carers is provided in Appendix F2).

The chapter shows the impact of epilepsy on the quality of life of close relatives who live with their family members and provide care for them. It provides a picture of the multiple factors that affect these carers at different levels of the system. It shows the relationship difficulties occurring as a result of the illness, particularly due to the lack of knowledge about the illness, lack of care and support as well as lack of seizure freedom. Their verbatim accounts bring home the suffering that these carers endure and also reveal that these carers experience feelings of powerlessness and alienation. Taking into account the challenges of these carers in providing care in a context which is characterized by displacement, marginalization and poverty, one can understand the frustrations, concerns and fears about the illness as well as their fears and worries for their close relatives who suffer from epilepsy. In fact, what is of more concern is providing care under these circumstances when a carer is also disabled. It leads one to wonder how a disabled carer who cares for a partner whose seizures are poorly controlled, who lacks family support and who is unable to access available epilepsy support services copes with care giving under these circumstances, including having to deal with her own activities of daily living. The chapter further shows that care of PWE at home is rendered by carers who are known and trusted by the PWE, as family members, and provides a contrast to the issues of alienation in urban contexts described in Chapter Six.



# 'Whom will I give him to? The difficulty is mine': Psychosocial difficulties experienced by care givers of patients with epilepsy in Cape Town, South Africa

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## Abstract

Epilepsy has been reported as one condition that can cause psychological difficulties and distress to care givers of patients suffering from the condition. This study explored psychological difficulties experienced by lay care givers of patients with epilepsy in an urban township in South Africa. Nine individual in-depth interviews were conducted with lay carers who provide care to their relatives, friends and neighbours who have epilepsy. A thematic data analysis method was used. Some fears, social concerns and worries affecting care giving were reported. Community interventions that promote cultural sensitivity in mental health care and empowerment of these carers are needed.

## Keywords

epilepsy, fears, lay care givers, social concerns, South Africa

## Introduction

There has been acknowledgement that the social, psychological and behavioural aspects of epilepsy are the least understood and most neglected in epilepsy research (Hermann and Jacoby, 2009). These difficulties are not solely experienced by people with epilepsy (PWE) but also by carers (Birbeck et al., 2008; Yusuf et al., 2013). Epilepsy has been described as a condition that is characterised by an 'emotionally straining experience' (Ryan and Räisänen, 2012: 216), and can cause severe burden for PWE and their carers (Canuet et al., 2009; Schachter, 2006; Wang et al., 2009). It is also clouded by myths and misconceptions about its cause and treatment

which have been reported world-wide through many decades and in different population groups (de Boer, 2010; International League Against Epilepsy (ILAE), 2003). For example, religious people in the 13th century attributed the cause of epilepsy to demonic spirits

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and thought that it was contagious and that it could be passed on to others through the evil breath of the person suffering from the illness (ILAE, 2003). These superstitious beliefs about its cause, including the stigma related to illness, are reported as factors that have worsened the burden of care (Baskind and Birbeck, 2005; Kabir et al., 2005; Sidig et al., 2009). Because care giving involves emotional bonding, duty and guilt, and is often given under difficult contextual constraints such as inaccessible or unavailable resource in the community (Dada et al., 2011), carers are compelled to make adjustments to their different roles and responsibilities towards optimal care giving (Raina et al., 2005). They also experience a range of difficulties in their care giving roles (Oshodi et al., 2012) and have been reported as *'the forgotten patients'* (Nuhu et al., 2010). However, little attention has been paid to investigating the impact of epilepsy on family members and other informal carers (Karakas et al., 2014; Saengsuwan et al., 2013).

## Context

The South African Democratic Government has put in place policies to redress inequities caused by the past colonial rule. However, poverty, unemployment and marginalisation are reportedly increasing and have had a great impact on the health of the marginalised population groups (Pelser, 2004). This has also been exacerbated by the rapid increase in urbanisation (Stern et al., 2010), the quadruple burden of communicable and non-communicable diseases (Mayosi et al., 2012). Currently, the government has introduced a financial system referred to as the National Health Insurance (NHI) scheme which aims to enable equal access to essential health care and measures for re-engineering the Primary Health Care Approach (Oni et al., 2014). With the increasing burden of non-communicable diseases (Stern et al., 2010), epilepsy has not yet received urgent priority, as other chronic illnesses have. Although it is assumed that approximately one in every 100 South

Africans suffer from the condition (Ackermann and Van Toorn, 2011), accurate data are difficult to obtain (Eastman, 2005). Risk factors such as meningitis, HIV/AIDS and neurocysticercosis affect proper management of epilepsy (Eastman, 2005; Ocana et al., 2009; Qekwana, 2013).

Linking this background to our study setting, which is one of the oldest African townships in Cape Town, South Africa, established in 1927, the problems affecting the health of patients with epilepsy and their carers could be worse. First, the setting is characterised by crime, alcohol and drug abuse (Naidoo and Irlam, 2005). Second, the current population is 52,401 of which 99 per cent is Black African, with about 40.21 per cent being unemployed with 72 per cent of households receiving a monthly income of about R3 200.00 (US\$263.133) (Lehohla, 2011). Third, factors such as lack of knowledge about the illness, reluctance of people to engage in helping behaviours because of lack of familiarity with one another, lack of knowledge about available support services, illiteracy and language barriers all pose serious challenges in care giving and understanding of the illness (Keikelame and Swartz, 2013a; Keikelame and Swartz, 2013b). Fourth, available epilepsy support services are currently inaccessible to the study population. Based on this, we were interested to explore the lay carers' perspectives on epilepsy and their subjective experiences of caring for their relatives or friends who have epilepsy. Our objective was to analyse and describe these experiences and challenges associated with their care giving role.

## Methods

### *Design and selection of participants*

We used an exploratory qualitative design to explore subjective experiences of lay carers of patients with epilepsy and the challenges they face in their care giving role. This approach would enable us to gain insider perspectives in order to understand the carer's experiences of epilepsy in their natural setting (Babbie and Mouton, 2001; Patton, 2002). These lay carers are regarded as

important sources from which everyday ideas about the illness, support and advice are sought and first-hand experience of suffering is gained (Kleinman, 1980 in MacLachlan, 1997).

Our recruitment process commenced after gaining ethical approval from the four local research ethics committees. The first author (M.J.K.) was assisted by two Xhosa-speaking field workers to gain access to participants. These field workers were rendering volunteer home-based care services and were residing in the study setting. M.J.K. recruited some participants from the local community health centre which provides health care for the study population. Some were recruited via snowball (Gerrish and Lacey, 2010) because of the difficulty in gaining access to potential subjects and possibly because of the secrecy associated with the condition.

Our criteria stated that only Xhosa-speaking lay carers aged 18 years and older who had provided care or were currently providing care to a family member, a friend or a neighbour who has epilepsy would be included. Participants were also included even if they did not live in the same household with the person with epilepsy. They also did not have to specify the amount of time that they spend on care giving. A total of 12 participants were recruited, of whom 2 declined and 10 agreed to participate. In all, 9 were females and the 10th one was a male – whose interview findings have been reported elsewhere (Keikelame and Swartz, 2013b).

### *Ethics*

M.J.K. visited all recruited participants at their homes to gain their informed consent to participate in the study. M.J.K. was accompanied by a Xhosa-speaking field assistant whose role was to interpret the consent information leaflets. To ensure that participants were not in any way coerced to participate in the study, they were all given copies of their signed informed consent forms which they would use to consult with others if they wished to do so, and time to ask questions. Because of the sensitivity of the topic and the stigma associated with the illness, participants

were given enough time (between 1 and 2 weeks) before the interview appointment to think about their rights and responsibilities and their choice and decision to participate or to withdraw. Only two participants declined and their decisions were respected.

### *Data collection*

A semi-structured interview guide was constructed in English by M.J.K. and translated into isiXhosa by a Xhosa-speaking language practitioner. Because M.J.K. is conversant in isiXhosa and has been working among Xhosa-speaking people for more than 20 years, she conducted all nine individual face-to-face in-depth interviews at participants' homes between July 2012 and February 2013. Each interview was audio-recorded with participants' consent and lasted between 60 and 90 minutes. All interviewees were reminded of their right to participate and to withdraw. Prior to conducting interviews, M.J.K. arranged with local field assistants to visit recruited participants 3 days prior to the interview date to remind them of the set appointment date and time, because all of them did not have telephones. Each participant was given a R60.00 (US\$10) food voucher at the end of the interview as a token of appreciation for their time and for sharing their valuable personal information to enhance the purpose of study. M.J.K. made notes of the conversations before and after the interview and extended them after each interview. These also included both authors' reflections which were later used in the data analysis process.

### *Data analysis*

We used the thematic analysis approach described by Braun and Clarke (2006) to analyse the data. All audio-recorded interviews were transcribed verbatim from isiXhosa into English by a Xhosa-speaking transcriptionist. M.J.K. read all transcripts several times to get a whole sense of the data and also listened to audio-recorded data to ensure that the transcribed data captured the actual responses



**Table 1.** Summary of individual participants' characteristics.

Type of carer (N=9)	Age	Religion	Education	Employment	Income
Wife, 1	39	United Presbyterian	Grade 11	Full time	Child support grant
Wife, 2	54	Methodist	Grade 7	Part time	Child support grant
Partner, 1	54	Zion	Grade 8	Unemployed	Disability grant
Partner, 2	53	Assemblies Missionary	Grade 8	Unemployed	Disability grant
Parent, 1	42	Baptist	Grade 10	Unemployed	Child support grant
Parent, 2	62	Methodist	Grade 7	Pensioner	Pension grant
Sibling, 1	55	Dutch Reformed	Grade 12	Full time	
Volunteer, 1 carer	39	His People	Grade 11	Unemployed	Selling goods
Volunteer, 2 carer	35	Zion	Grade 6	Unemployed	Child support grant

expressed by participants. Our approach to data analysis was inductive and involved familiarising ourselves with the data, generating data-driven codes and themes and reviewing, defining and naming themes to give meaningful explanations of the data and to provide a clear sense of what the theme was about. Thereafter, the main key themes that were identified from the data were organised into tables and grouped into appropriate categories with quotations from transcripts and were compared for similarities and differences. This organisation enabled further in-depth analysis of themes to ensure that they were grounded in the data. During our regular feedback and debriefing meetings, we increased rigour by discussing, comparing and contrasting our codes and themes to gain consensus and to reflect on how our orientations might have influenced our data analysis (Adams et al., 2013). Thereafter, M.J.K. visited each participant to confirm and to verify the findings to ensure that our analysis was consistent with what they had said (Flick, 2006; Ulin et al., 2002).

## Results

### *Participants' demographics*

Nine female participants were individually interviewed: Four had husbands/partners who have epilepsy. Two parents had adolescents who had epilepsy. One sibling had a sister who had died from epilepsy and two were volunteer

carers. All belonged to different religions and only five were unemployed. Seven were receiving government grants. Their demographic background is presented below in Table 1. A summary of the type of carers and background information about their care recipients is provided in Table 2 (Appendix 1).

From our analysis of the nine interviews, seven key themes emerged. Because we were interested in the kind of fears that these carers reported, we will, therefore, provide key findings on two main themes which are central to this article: (1) carers' fears about the person's illness (epilepsy) and (2) carers' social concerns and worries about caring for a person who has epilepsy.

### **Carers fears about the person's illness (epilepsy)**

Participants provided a range of fears which they had about their relative or neighbour who has epilepsy. Partners/wives expressed fear of dying during a seizure attack, and fear of dying as a result of road accidents and from bewitchment/witchcraft related causes. Siblings' fears were related to fear of dying from the illness, fear of dying due to the course of the illness and fear of genetic disposition to epilepsy. One parent had fear of road accident deaths while a volunteer carer had fear of contagion. These themes are discussed under the following subthemes.

### *Fear of partner dying during a seizure*

We had four participants whose husbands/partners had epilepsy. However, in our analysis of their responses, we found that only two reported on three types of fears that they had about caring for their husband/partner.

One participant whose partner had epilepsy reported that she feared that her partner would die during a seizure attack. This participant's partner was 62 years of age and his epilepsy started in 1967. As articulated in her quotation below, we noted that the participants' fears may have stemmed from what she had heard from others or that she may have personally witnessed a person who actually died during a seizure attack. We also noted that besides her fears, she had strong religious beliefs which helped her to cope and to be hopeful that her partner would be relieved from suffering as a result of his epilepsy:

Things which I fear about fitting it's close to him waking up and it's close to him not waking up [fears that he may die during a fit] ... because with other people, the person fits and they never wake up again ... but you must not be without hope. In everything you must let God lead the way and say God is there and He will make him stand ... (Partner 1, aged 54 years)

### *Fear of husband dying from road accidents*

Another participant, whose 45-year-old husband had epilepsy since 1989, reported that she feared that her husband may die as a result of road accidents:

I have a fear that he would die while he is driving ... that he'd collide and get an accident ... (Wife 1, aged 39 years)

### *Fear of husband dying from witchcraft-related causes*

Only one participant stated that she feared the cause of her husband's epilepsy was due to poison or demons (*amafufunyana*) – which apparently would cause harm to her husband's body and that

her husband would eventually die as a result thereof. She reported that they were informed about the cause after consulting with some traditional healers for her husband's epilepsy:

The thing I fear about his illness is that as some traditional people said that it is poison or a demon (fufunyane) ... it eats a person from the inside ... So now I am afraid that he'll end up dead ... that's what I am afraid of ... (Wife 1, aged 39 years)

### *Fear of child dying from road accidents*

We had two parents whose children had epilepsy. One parent was 42 years of age and had a 25-year-old daughter who had epilepsy which started in 2001 when she was still attending school. The 62-year-old parent's son was 23 years old and had epilepsy when he was 7 years old, and is currently not attending school nor employed. However, only the parent whose daughter had epilepsy stated that she feared that her daughter may die as a result of road accidents:

I am afraid that one day I will be called and they will tell me that she has been hit by a car ... I really worry, especially when she is going to school because she crosses the road ..., taxis and all those things ... (Parent 1, aged 42 years)

### *Fear of dying from the illness and its course*

We had one participant who was 55 years of age and had a sister who had epilepsy when she was 7 years old and died from the illness in 2007, when she was 60 years old. She stated that she had fears about the illness itself and that a person may die from the illness because of its long course. We assume that these fears stemmed from her experience of her sister's illness and probably because of poor seizure outcomes:

I fear the illness [epilepsy] because I take it a person who has it doesn't live long ... He/she fits until you see his/her life ends ... we had hope that our sister would still be alive but she went with that illness ... (Sibling 1, aged 55 years)

In addition, this participant was of the view that her family could be susceptible to epilepsy because it runs in certain families. This perception, therefore, accounted for her family having fears that they may have a genetic disposition to the illness:

We had fear because we thought that it will be a sickness of the family because there are family sicknesses ... (Sibling 1, aged 55 years)

### *Fear of contracting epilepsy*

There were two participants who were volunteer carers. One was 39 years old and the other one was 35. One reported that she provided care to her neighbour's daughter who had epilepsy, while the other one was providing care to an older man who was her neighbour who also had epilepsy. Only one volunteer carer reported that she feared 'belching'. This perception is of concern since her fear may affect the way she responds to a person during a seizure attack:

I fear belching ... you will pick it up ... you must be alert that he does not belch towards you. (Volunteer carer 1, aged 39 years)

### **Carers' social concerns, fears and worries**

In our analysis of our participant's interview data, we noted that while they talked about what they feared most about the illness of the person they were caring for, they also talked about some social concerns which accounted for their fears and worries. Four talked about stigma-related actions towards their relatives who had epilepsy. Only one talked about her concerns with regard to her husbands' aggressive behaviour after a seizure. These are discussed below under the following subthemes.

#### *Fear of stigma*

One parent was concerned about her 25-year-old daughter's social participation and safety in

sports. She said that she was not keen to allow her daughter to participate in sport because of fear of unpredictability of her daughter's seizures and that her daughter may be excluded from participation when others realise that she has epilepsy. This may show that this parent might be keeping her daughter's condition a secret:

I am afraid for her in everything, because this thing just happens when she is not expecting it ... she likes sport but I am afraid for her ... It is always with me that she might be playing some game and fall ... other people won't understand, and maybe they will want to exclude her because they don't understand that she has this disease ... (Parent 1, aged 42 years)

Another parent whose 23-year-old son had epilepsy was concerned about her son's friends who ridicule him about his condition and this caused her emotional pain:

There are many worries because wherever he goes you are concerned whether he has not fallen ... and when you get there ... he has lost his things because all those who helped him know about his illness and before he recovers they steal his cell-phone and money ... things like that worries me ... Another thing that really pains me ... he has friends who when he has an attack, they ridicule him and insult him because of this. It hurts me ... (Parent 2, aged 62 years)

On the other hand, a volunteer carer who provided care for a neighbour whose 25-year-old daughter had epilepsy stated that she had fear of stigma-related actions towards school-going adolescents. She said that she worried because some could not continue with their schooling as a result of being prejudiced by their peers. She was of the view that there should be interventions at schools to destigmatise the condition:

I fear it [fear of epilepsy] when it comes to adolescents of about 18 years ... you see when they have fits their peers laugh at them ... I worry about them ... some even leave school because of those things because a child feels embarrassed at school and becomes a laughing stock of the whole school ... I wish the education about epilepsy

should also be directed at youth and to school children ... (Volunteer carer 2, aged 35 years)

In addition, one participant who had a partner who has been having epilepsy since 1990 highlighted her concerns on how her partner had been stigmatised by his family because of having epilepsy. She stated that her family excluded him from participating in family affairs and has been labelled as someone who is probably mentally ill or mentally challenged. According to her, her partner's exclusion causes her emotional pain. In our interpretation, we were of the view that this may be painful for her since, as an African man, he may not be able to fulfil his roles as expected from his position:

My worry and concern is that he [the partner who has epilepsy] is not staying well at his home ... to his mother he is not like her son at all because he is not treated well ... Let me give you this example: Say you are my mother ... and you don't care about me, even when others eat ... when food is served I am not served, even during discussions they don't call me ... I am ignored ... When there is a count, others will be counted and I won't be counted. When Nosi asks: 'What about him?' They'd say, 'Just leave him, can't you see this person is not alright! All those things hurt me.....'. (Partner 2, aged 53 years)

### *Worry about husbands' aggressive behaviour*

A very disturbing social issue was reported by one participant whose 62-year-old husband had epilepsy since 1981. She stated that her husband was behaviourally aggressive after a seizure. She reported that his behaviour was characterised by severe anger which led to violence. According to her, this had a negative impact on the family. Although the family sought assistance, those who intervened thought that there were domestic violence issues. However, she was of the view that her husband's behaviour was due to epilepsy. We assume that those from whom she sought support had poor knowledge about the illness or poorneffective counselling skills. This could

have probably resulted in the family adopting perseverance as a coping strategy:

My worry is that, after he fitted he becomes stubborn ... we argue very easily ... children then say 'Mama leave him because we already know him.' You see if he is waking up [recovering from a seizure] ... he is dangerous sometimes ... even a child, grandchild, makes him angry ... He is short tempered ... When he is angry he takes a sharp object and stabs me with it ... It is like he sees something sort of like a witch ... a person who will hurt him ... if I called them [police] this week they would arrive and warn him, 'Tata you are old. Don't do this' ... they don't know there is an illness at the centre ... They are looking at domestic violence. They are trying to stop that ... we just think for ourselves that it's his illness ... we persevere. (Wife 2, aged 54 years)

## **Discussion**

The findings of this study provide insights into the psychological difficulties and social concerns of care giving for patients with epilepsy. Our carers were spouses, siblings, parents and those who do volunteer care work. We found that our participants expressed a variety of the kind of fears that they had about caring for their relatives or neighbours who had epilepsy. Fears of seizures have been reported as a difficult experience for patients with epilepsy and their carers (Arthurs et al., 2010; Saengsuwan et al., 2013) – and that fear can also increase care giver stress (Cushner-Weinstein et al., 2008).

Among our participants, there was only one sibling who had fears about dying from illness, hereditability thereof and fear of its course. Although this fear was expressed by this sibling, Dunne (2013: 15) reports that most people who have epilepsy do not necessarily die as a direct result of their illness. We were of the view that her fears about the illness could be related to poor seizure outcomes and probably lack of knowledge about the illness. Our findings about fears of the illness and its long course were consistent with those reported by Ellis et al. (2000). With regard to heritability of the illness, it was interesting to note that this

finding has been reported as one of the concerns among patients with epilepsy whose seizures were poorly controlled (Choi et al., 2011). Others have reported that epilepsy has been regarded as a family illness and that it has a high heritability which is assumed to increase with age (Kjeldsen et al., 2001).

Epilepsy stigma has been well documented (Admi and Shaham, 2007; Baskind and Birbeck, 2005; de Boer, 2010; ILAE, 2003; VanStraten and Ng, 2012; Viteva, 2013). Our findings with regard to stigma-related actions towards patients with epilepsy are consistent with literature. For example, stigma-related actions towards adolescents, such as bullying, being laughed at and being treated differently, have been reported by Kerr et al. (2011). These authors further report that as a result of these actions, some parents restrict their children to stay at home – partly to protect them from being stigmatised – and also because of the unpredictability of the seizures (Ahmad, 2011). Some of these findings were also reported by Keikelame and Swartz (2007) in their study exploring parents' understanding of their children's epilepsy in Cape Town.

There were some cultural myths regarding fear of contracting epilepsy through belching. We noted that this finding was also reported by another lay carer in the same study setting (Keikelame and Swartz, 2013b). This finding is of concern since such misperceptions can increase stigma towards patients with epilepsy and may also lead to inappropriate helping behaviours when a person has a seizure attack.

An interesting finding reported, though, was about fear of bewitchment-related causes (*ufufunyana*). Authors reporting on bewitchment highlight witchcraft-related causes which are evil acts that are performed by witches and can cause harm and death (Bührmann, 1992). *Amafufunyana* 'dirty things from the grave' (Keikelame and Swartz, 2015: 14) or 'ants of the grave' is a term that is often used by Black psychiatric patients to refer to schizophrenia and psychosis (Lund and Swartz, 1998; Mzimkulu and Simbayi, 2006). Writing about the psychology of bewitchment and the experience thereof, Ivey and Myers (2008) highlight

that symptoms of *amafufunyana* include, among others, aggression, fits, hysteria, anorexia, agitation and catatonia. We are of the view that this participant's fear of bewitchment could probably be linked to some psychological symptoms that this carer may have witnessed in the process of caring for her husband who has epilepsy.

One disturbing finding was about behavioural difficulties as a result of epilepsy. A study done by Ito et al. (2007) reported on sub-acute postictal aggression in patients with epilepsy. These authors reported that this aggressive behaviour was found in one male who was 62 years of age who threatened to beat his wife with a bamboo stick – and showed remorse after the aggression had ceased. Our findings show that similar symptoms were reported by our participant whose husband was of the same age. This finding is of serious concern, more so that witness description on routine clinical investigations in primary care settings in Cape Town has been reported to be poor, thus inhibiting doctors from making a proper diagnosis (Keikelame et al., 2012). Therefore, presenting symptoms such as these may be missed if carers do not have knowledge about epilepsy and when they are not adequately counselled about the illness.

Despite these psychological difficulties and social concerns, we noted that wives/partners used coping strategies such as 'being hopeful that God will solve or change the situation', 'by perseverance' and 'endurance'. While spiritual or religious coping may be used to deal with stress – this may be a negative step when a person holds 'beliefs in a punitive God' and delegates God to solve one's problems (Tedrus et al., 2013: 386). We also noted that these women remained in the relationships despite these issues and that perhaps their strategies may be revealing their lack of power and capability to address the difficulties and concerns they had.

## Limitations

Our data were drawn from a small cohort of carers and cannot, therefore, be claimed to be



representative of the entire population. We recruited participants from only one study site in an urban township in Cape Town which is predominantly Xhosa speaking. The results can, therefore, not be generalised to the care givers of Xhosa-speaking patients with epilepsy in other urban townships. Some of the family members did not want to participate in the study. As such, their perspectives on the illness have not been captured. The importance raised by participants of broader social factors in care and illness does, however, resonate with other studies of illness and care giving in similar contexts (Kagee et al., 2011, 2014).

## Conclusion

Our study provides a glimpse of some psychological difficulties and social concerns of lay carers (wives, partners, sibling, parents and volunteers) who provide care for their relatives, friends or neighbours who have epilepsy. While these findings are from participants in one of the oldest urban settings in Cape Town, they suggest that there are some socio-economic and cultural mediating factors which affect their care giving role – especially since managing epilepsy has been reported to have a great impact on care givers (Ramagalia et al., 2007; Van Andel et al., 2011). A number of coping strategies that can help care givers have been reported (Oshodi et al., 2012; Wagner et al., 2010). However, it would be important that careful consideration should be taken to ensure that they are designed to meet specific needs of carers. The study findings provide insightful information which adds to the body of existing knowledge, especially on the importance of designing appropriate interventions for promoting cultural sensitivity in mental health care.

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## Appendix I

**Table 2.** Summary of types of carers and background information about care recipients.

Carer and age	General information
Partner, 1, aged 54	She cares for her partner aged 62 years, whose epilepsy started in 1967, and her niece, aged 27 years, who has had epilepsy since 2004. She has four children and two are attending school. Her partner receives a government pension grant and she receives a disability grant. She earns extra income from selling clothes. She attends the Zion Church and passed grade 8.
Parent, 2, aged 62	Her son, aged 23 years, has epilepsy, which started when he was 7 years old and is currently not working. She was married and her husband died. She passed grade 7 and worked as a domestic worker – but has since retired and she now receives an old age pension. She attends the Methodist church.
Partner, 2, aged 53	She has been living with her partner who has epilepsy for 38 years, and one son, aged 38 years. Her partner has been having epilepsy since 1990. She passed grade 8. She had stroke and is now receiving a disability grant. She attends the Gospel Missionary Assemblies Church.
Wife, 2, aged 54	Her 62-year-old husband has had epilepsy since 1981. They have three daughters aged 21, 18 and 17 years who are attending school. She is employed as a domestic worker and attends the Methodist church. She passed grade 7. Her husband receives an old pension grant. She also receives a child support grant for one grandchild.
Volunteer carer, 1, aged 39	She is married and has two children aged 22 and 14 years. She passed grade 6 and has been caring for a male neighbour, aged 56 years, who has epilepsy. She has not received any training in home-based care. She earns income through sewing and selling goods. She attends the Zion church.
Volunteer carer, 2, aged 35	She cares for a neighbour's daughter who has epilepsy. She is unmarried and has a 14-year-old child and receives a child support grant. She worked as a volunteer carer in one of the NGOs which rendered hospice care for HIV/AIDS and cancer patients for 5 years. She passed grade 11 and attends His People Church.
Sibling, 1, aged 55	She had an older sister who had epilepsy when she was 7 years old and died from the illness in 2007, at the age of 60. Her sister had three children who are now under her care. She is a member of the Dutch Reformed Church and passed grade 12. She is currently working as a quality control checker in one of the factories. She has one child aged 30 years old and a 4 year old grandchild.
Wife, 1, aged 39	Her husband, aged 45 years, has been having epilepsy since 1989. The husband works in a factory and she works as a cleaner in one of the hospitals and passed grade 11. She has three children aged 10, 8 and 2 years, and two are attending school. She attends the United Presbyterian Church. She also receives a child support grant.
Parent, 1, aged 42	She is unmarried and has four children aged 25, 16 and 7-year-old twins. She passed grade 10 and was a volunteer carer for 2 years. She is currently unemployed but runs a child day care and receives a child support grant. She attends the Baptist Church. Her 25-year-old daughter has epilepsy which started in 2001 and has left school because of her illness.

NGO: non-governmental organisation.



## CHAPTER NINE: COMMENTARY



Individual interviews with people with epilepsy

**Mr Slahla:** *“I wish they could ask me how I sit here at home. What I eat because I don’t work...”*



## CHAPTER NINE

### ARTICLE 7

#### ***“The others look at you as if you are a grave”*: A qualitative study of subjective experiences of patients with epilepsy regarding their treatment and care in Cape Town, South Africa**

##### 9.1. INTRODUCING ARTICLE 7

This chapter presents the seventh article which is the last article of the peer reviewed published journal articles which are a product of this dissertation. The article reports on research which explored perspectives and subjective experiences of people with epilepsy about their illness in an urban township in Cape Town. Chapters Seven and Eight showed the different factors that posed care-giving challenges to family members who cared for their close relatives who had epilepsy and the impact on their health. Chapter Nine aims to extend the understanding of the lived experiences of PWE and their perspectives about their treatment and care in order to establish the links between reports from individual interviews with their professional carers and from personal observations of practice presented in Chapters Three and Four.

In order to gain an understanding of these experiences and perspectives, I conducted twelve individual in-depth face to face interviews at their homes using Kleinman's (1980) EMs framework interview guide (Appendix F1). Among these twelve participants, there was one who participated in my observation study in Chapter Four where I observed a language barrier between the patient and the HCPs who were both Xhosa-speaking. The verbatim accounts of these patients show the kind of health systems' factors which were experienced mainly during their routine follow up clinical visits. The chapter paints a clear picture of the impact of the routine task system on patient care and the extent to which their rights to appropriate care may be jeopardized especially with PWE who are poor, vulnerable and marginalized. The chapter compels us to introspect on what care-giving and caring mean (Kleinman, 2012). It further shows that the nature of the patients' frustrations was about “a cry” (Reach, 2014, p. 18) for empathetic care where they are treated as human beings who have a soul, a mind and a body, and not as objects where the concern is only about recording the number of seizures – a notion that Henderson (1994, pp. 937-938) refers to as the “recorded bodies”. The chapter calls for a health sector which does not open and exacerbate wounds of oppression but one that can promote trust, health and well-being and that embraces respect for humankind and doing good to others. The chapter further calls for a fair and just treatment and care of PWE and a modelling of care and care giving that is appropriate and meaningful and where there are opportunities for collective and self-empowerment.

As with Chapters Three, Four, Five and Six, I presented preliminary findings of this sub-study to the local health committee members in the study setting to promote awareness about the challenges facing PWE in the community and also as a step to foster community based support for PWE and their families.

## RESEARCH ARTICLE

## Open Access



# *"The others look at you as if you are a grave": a qualitative study of subjective experiences of patients with epilepsy regarding their treatment and care in Cape Town, South Africa*

Mpoe Johannah Keikelame\* and Leslie Swartz

## Abstract

**Background:** Existing evidence shows that the majority of people with epilepsy in lower and middle income countries are not receiving appropriate treatment and care. Although this problem has been reported as one of the factors affecting the quality of lives of people with epilepsy, very few studies have investigated patients' perspectives and their experiences about the problem. This qualitative study explored perspectives and subjective experiences of people with epilepsy about their illness in an urban township in South Africa.

**Methods:** Individual face-to-face interviews included twelve people who had epilepsy. A semi-structured interview guide which was based on Kleinman (1980) Explanatory Models Framework was used to elicit participants' perspectives and subjective experiences about their illness and its treatment. Thematic analysis method was used to analyse the data.

**Results:** The main theme reflecting participants' verbatim accounts was about their perceived difficulties affecting their access to treatment and care during their routine clinical follow up visits. These concerned rushed consultations which focussed on seizure frequency and adherence to medication with no attention to personal concerns. They perceived that part of the problem could be that some health care practitioners were not adequately trained and lacked empathy, interest, respect and listening skills. We argue that in a health system where patients feel that they are not respected and their concerns are not listened to or are ignored, they may lack trust in the system and this may violate their right to access treatment and care.

**Conclusions:** The findings provide a glimpse of the extent to which the power and nature of the routine task-centred system can lead to violation of patients' health rights – especially with epilepsy which is poorly understood and stigmatized. Appropriate interventions are needed to address health system factors affecting the treatment and care of this marginalized and vulnerable group of patients.

**Keywords:** Patients with epilepsy, Treatment and care, Routine task system, Qualitative study, South Africa

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## Background

The importance of improving the quality of care for patients living with chronic illnesses is reported as a global concern [1, 2]. With respect to epilepsy, this is of particular importance because various reports highlight that most patients with epilepsy (PWE) in low and middle income countries (LMICs) are not receiving appropriate treatment and care [3, 4]. Epilepsy has been reported globally as one of the most common neurological conditions [5] which contributes to approximately 1 % of the global burden of disease [6, 7] and 20 % thereof is in Africa [8]. In LMICs per se, the provision of epilepsy treatment and care is characterized by inequalities between the public and private health care sectors [9] and a lack of adequate financial resources to address the treatment gap related factors [10]. What is of great concern is that neurological conditions in LMICs are commonly treated within the mental health sector which is described as “one of the notoriously underfunded sector” (p. 180) [5], with the median percentage of health expenditure estimated at 0.5 % in LMICs and 5.1 % in high income countries [5].

In response to the need for the improvement of epilepsy care in LMICs, evidence-based guidelines have been developed by the World Health Organization's (WHO) mental health Gap Action Program (mhGAP), but these need to be adapted and tailored for appropriate implementation in respective countries [5, 11]. Although the mhGAP puts emphasis on protection and promotion of human rights as well as the provision of community based care and support [12], it has been reported to lack focus on the social and cultural factors affecting mental health promotion [13]. This is crucial especially with a condition such as epilepsy which is rooted in superstitious beliefs about its cause and treatment [14]. While there are indicators that have been set to assess and monitor the effectiveness and appropriateness of these epilepsy guidelines [15–17], Varley, Delanty, Normand et al. [18] and Fitzsimons, Normand, Varley et al. [19] state that they do not show any major improvements in the quality of care of PWE.

In South Africa, PWE, like patients with other chronic illnesses, receive their treatment and care from the public health sector which serves most of the low socio-economic population groups [20]. While access to appropriate care is a constitutional right [21], inequitable resource allocation remains a big problem [21, 22]. With regard to epilepsy, the situation could be worse than with other chronic illnesses. First, epilepsy is perceived to be poorly managed in primary care settings in Cape Town [23]. Second, clinical audits are conducted for other chronic illnesses (asthma, hypertension, Chronic Obstructive Pulmonary Diseases (COPDs) as well as epilepsy – however epilepsy is only reported as a new area for clinical audits [24]. Third, there is also a lack

of accurate statistics on the burden of epilepsy [25] probably because epilepsy statistics are combined with other neurological conditions [26].

In this article, we present findings from twelve individual interviews with PWE as part of a larger study which explored perspectives on epilepsy on the part of patients and carers in an urban township in Cape Town, South Africa. Our research question was: How do PWE in an urban township in Cape Town understand the illness (epilepsy)?

Our study aim was to analyse and describe the subjective experiences and perspectives of PWE. The objective was to provide information that can be used to guide future policy, planning and development of appropriate interventions to address treatment and care challenges faced by PWE.

## Methods

### Research design

To explore subjective experiences of PWE and their perspectives on their illness, we used a qualitative design because it is flexible and emergent and uses a naturalistic approach [27–29].

### Study setting

The study setting is one of the oldest urban townships in Cape Town which was developed as a result of the past laws of the oppressive colonial and apartheid rule. The predominant spoken language is isiXhosa – but there are some other African languages such as Sesotho and isiZulu. Most of the residents receive health care from the local Community Health Centre (CHC) which serves the Afrikaans and Xhosa speaking communities. The setting is characterized by poverty, unemployment, illiteracy, crime, lack of proper housing, sanitation and water [30]. There is a local clinic that offers preventative health care services such as child health and reproductive health, Tuberculosis (TB), Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS). Other health care services are provided by private general practitioners, traditional healers and non-governmental organisations (NGOs) [30]. Although epilepsy support services for patients and family members are available, they are currently inaccessible to the study population.

### Recruitment and access to participants

Recruitment and access to participants was done by MJK after approval of the project by the four local ethics committees: the Health Sciences Research Ethics Committee, University of Cape Town; the Health Sciences Ethics Committee, Stellenbosch University; the Provincial Government of the Western Cape (PGWC) and City Health. Prior to recruitment, MJK presented a summary of the study background and its aims and objectives to

the local health committee and the traditional healer's organisation (THO) in order to gain support – this has been highlighted by Mack et al. [31] as an important strategy. From these meetings with the local gate keepers, additional potential PWE who were not receiving treatment and care from the local community health centre (CHC) where MJK had initially recruited were identified. Others were identified by field assistants who were doing volunteer work in the study setting and were all included in the list. We used purposive and snowball sampling methods because they fitted our inclusion criteria and the research question [31]. Our criteria stated that only Xhosa speaking PWE who were aged 18 years and older and resided in the study setting would be included.

A total of 24 potential PWE were listed and were visited by MJK at their homes to formally recruit them. Only 12 PWE agreed to participate in the study. They were all visited by MJK at their homes to formally obtain written informed consent. The informed consent forms and participant information leaflets were translated into their local language, isiXhosa (one of the predominant languages spoken in Cape Town, more commonly referred to as “Xhosa”). In the process, MJK was assisted by two Xhosa speaking field assistants to interpret the information leaflets because, although she is conversant in isiXhosa, she would not be able to read the Xhosa dialects as fluently as would a native speaker. All participants were each given their signed copies of the consent forms and were given time to acquaint themselves with the information and to discuss the documents with family members and friends to legitimize their understanding of the purpose of the study and their rights and responsibilities in the process.

#### Data collection

Data collection was done by MJK between September 2012 and July 2013 at the participants' homes on the agreed upon date and time. A semi-structured interview guide which was translated into isiXhosa was piloted and was used to collect the data. No changes were made after piloting. The instrument consisted of open-ended questions based on Kleinman (1980) EMs framework and elicited qualitative responses on participants' explanations of epilepsy in terms of what they call the illness; what they think caused their illness (epilepsy); why they think it started when it did; what they think the illness does and how it works; how severe their illness is and whether it will have a short or long course; the kind of treatment they think they should have and the expected treatment outcomes; the main difficulties caused by the illness at different levels (individual, family, community, health system and society) and what they feared most about the illness [32, 33]. According to Kleinman (1980), EMs are ways of understanding how people recognize

an illness, explain it and respond to it and are also shaped and influenced by culture and are held by patients and carers. In addition, EMs can also enable a deeper understanding of what it means to suffer from an illness in the context of the person having the illness, his or her family, community and the health care system [34].

Prior to conducting individual in-depth face to face interviews, MJK explained the purpose of the interview and how anonymity and confidentiality would be kept, including how participants' information would be disseminated. All interviews were audio-recorded with participants' written permission and were all conducted in the participants' home language, isiXhosa. The duration of the interviews was between 45 and 90 min. At the end of each interview, MJK wrote field notes immediately and these were later extended after reflection [31] – and were used by MJK in reflective meetings with the second author (LS) to gain an understanding of what participants had said. Participants were each given a R60.00 (approximately \$6) food voucher after the interview as a token of appreciation for their time and contribution.

#### Data analysis

The audio-recorded data were transcribed verbatim from isiXhosa into English by a Xhosa speaking transcriptionist. MJK designed a confidential transcription agreement to ensure that the transcriber maintained confidentiality, privacy and storage of the data during the transcription process. A signed copy was kept for record keeping by MJK. Consistent with Braun and Clarke's [35] thematic analysis method, MJK read all transcripts and listened to each individual audio-recorded interview to familiarize herself with the data and to ensure that the transcribed data captured the actual verbatim responses expressed by all participants. This process of re-reading transcripts and listening to the audio-recorded data enables the investigator to be immersed in the data and to become familiar with it [35]. Using an inductive approach [35], MJK read each transcript, noted ideas and made notes generated through familiarization and immersion. All data were coded by MJK and during open coding, data driven codes and themes were generated, reviewed, defined, described and named to provide a clear sense of what each theme is about. Thereafter, MJK organized the main key themes that emerged from the interview data into tables and grouped them into appropriate categories with quotations from transcripts and compared them for similarities and differences. MJK modified, grouped and re-grouped codes to ensure no codes have been missed in the earlier stages of the analysis and that they are grounded in the data [35].

MJK and LS had regular feedback and debriefing meetings, and discussed, compared and contrasted the

coded data to increase rigor and to gain consensus [36, 37]. Thematic maps were drawn by MJK to show links and relationships between the themes, these themes being further organized into sub-themes which had emerged from each theme. These were used by MJK and LS to further undertake a rigorous systematic analysis of the individual transcripts and thematic maps in order to search for alternative explanations [35]. MJK made appointments with all interviewees and visited them at their homes to present the draft findings and to confirm interpretation thereof [36, 38].

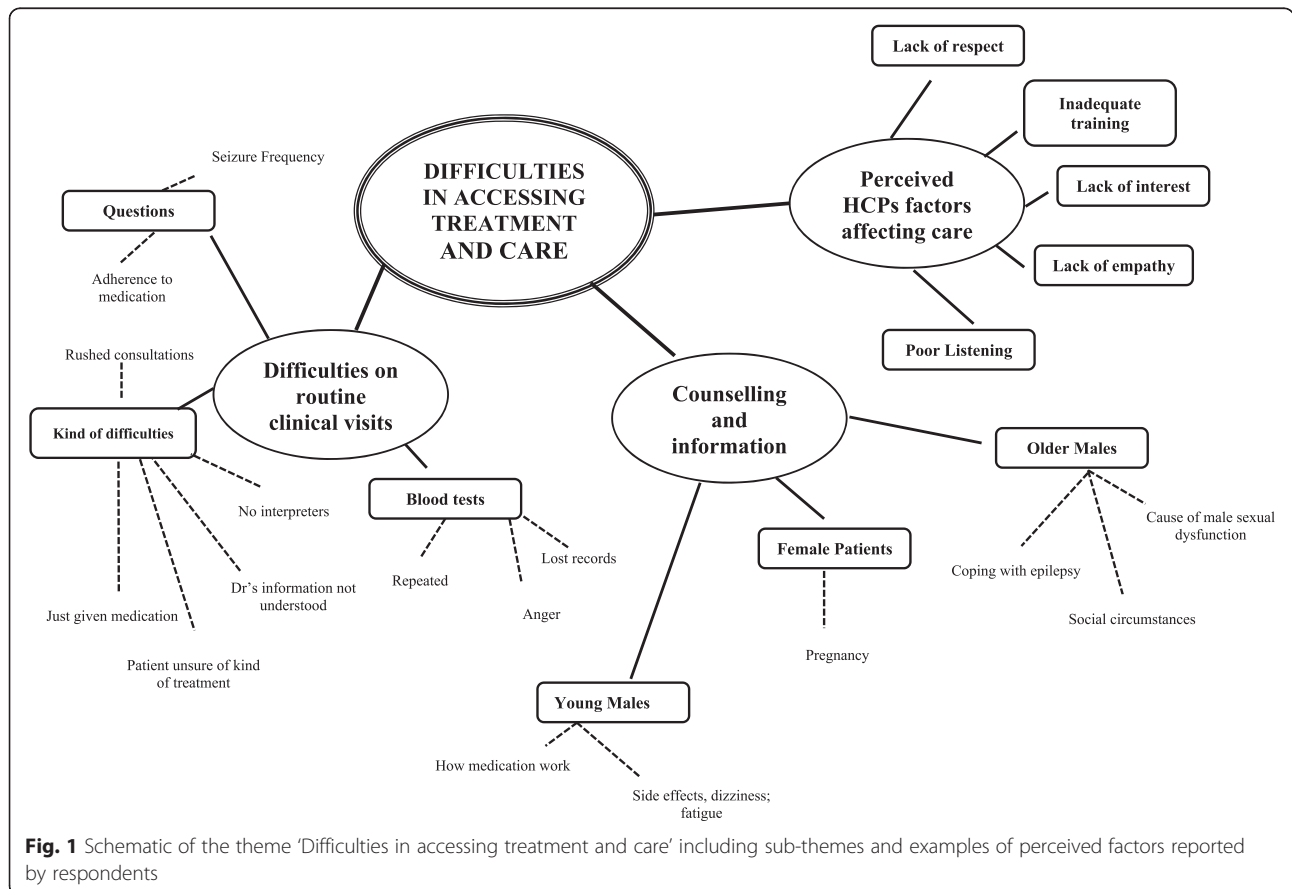
**Results**

**Participants' characteristics**

Twelve PWE were individually interviewed. Eight were males and four were females. The mean age for men was 47 years, and 37 years for females. All participants were Xhosa speaking and had been residing in the study setting for more than 20 years. All had attended school but only two had passed grade 10. The mean number of years of living with epilepsy for males was 29.9 years and 27.2 years for females. Three males were married and one lived with a partner. Only one female was married and two were youth (aged 25 and 28 years). In South Africa, the National Development Youth Agency (NYDA) Policy

[39] defines people who are aged between 14 and 35 years as youth. All participants were on seizure medication and some informed us that besides being on seizure medication, they were also receiving treatment for other conditions such as asthma and hypertension and only one reported being on Antiretroviral (ARV) treatment. Six were receiving a government disability grant as a source of income and one was receiving an old age pension grant. Three stated that they had applied for a disability grant on several occasions, but their application had been declined. Only two males were in part-time employment.

Seven key themes emerged from the data: (i) names referring to epilepsy; (ii) views about the illness; (iii) beliefs about the cause of the illness; (iv) views about the kind of treatment for epilepsy; (v) views about marriage, driving, employment and schooling; (vi) difficulties in accessing treatment and care; and (vii) fears about the illness. We report here on one key theme: "difficulties in accessing treatment and care" which is one of the key issues that all participants talked about in their interviews. We also provide a thematic map in Fig. 1 which shows this main key theme and its three sub-themes which emerged from the data: (i) difficulties on routine clinical visits; (ii) perceived health care practitioners' (HCPs) factors affecting care; and (iii) counselling and information needs.



**Fig. 1** Schematic of the theme 'Difficulties in accessing treatment and care' including sub-themes and examples of perceived factors reported by respondents



**Theme: difficulties in accessing treatment and care**

Participants were asked about the kind of difficulties they experience when seeking treatment and care. Their responses are discussed below under the following three sub-themes:

***Difficulties on routine clinical visits***

The respondents' provided varied explanations of the kind of difficulties that inhibit their access to appropriate treatment and care on routine clinical visits. Two male participants said that the clinical examinations focus on seizure frequency and adherence to medication:

*On my doctor's date, the doctor checks and asks when I last had fits... I explain that I last did [had a seizure] at a certain time. He'd say, "No, you'll just have to fetch pills..." There is nothing that they ask...* [Male participant aged 62]

*When you get there [at the clinic], you are asked when were you last sick [when you last had a seizure]...how much time has elapsed since you were sick...do you use the treatment...that's it. When you are done with they just sign whatever it is that they sign, you don't know what it is, and then they say go and get your pills, and that is all... You are not told anything...* [Male participant aged 45]

The same male participant explained that he had difficulties in comprehending doctors' explanations about the kind of surgical treatment that could be done for his seizures. He was of the view that such information can only be understood by people who are educated and who are also able to interact with doctors:

*When I went to a doctor [western trained] here... I don't know what he said...that my condition could be cured...but it sounded like there's something that needs to be done to me...something like an operation in the head... I didn't know what he meant. You see, things like that need people who are educated who will be able to ask him questions the way that he talks...* [Male participant aged 45]

This same male participant further highlighted that the situation at the CHC is very difficult because consultations are rushed with no time to listen to patients' concerns:

*The thing at CHC is not really easy, because they are in a hurry... You can explain an issue of concern [problem] many times, you can tell them today, tell them on the following month, and tell them again the following month...* [Male participant aged 45]

Another male participant provided a detailed explanation of how he was particularly angered and distressed by being informed on his routine follow up visit that his blood results could not be found. He was therefore subjected to have the blood test repeated despite this being against his will:

*They [HCPs] drew blood last year on the 13th of September, and they told me to wait, maybe two weeks and then go and check... I did that. When I went there to get my results, they couldn't find them. They told me to go to the doctor... The doctor wrote something down... They read it for me and said that the doctor says that you should have blood drawn. I asked why because I had blood drawn the week before last, now why is it getting drawn? They said he wants to see about the pills that I was given to take. They took it even though I didn't want to... I was angry about that...* [Male participant aged 28]

This participant further explained that lack of interpreters to support Xhosa patients and doctors who are not proficient in isiXhosa affects patient and doctor interaction:

*The difficulty there is that...you as a Black person have no one to speak for you because there are White doctors... They don't speak Xhosa...we don't know what they are saying...* [Male participant aged 28]

***Perceived HCPs factors affecting care***

Some respondents were critical of the way care is provided by some HCPs. According to them, factors such as lack of empathy, lack of respect, passive and poor listening, lack of interest and poor training of nurses affected their treatment and care.

One male participant was critical of the politics of the past oppressive health system and thought those who had experienced such injustices would be in the best position to render better care – but instead, it is the White doctors and nurses who provide better care:

*The nurses that are Black and Coloured, they don't care about us...they forget that they are here because of us. They don't care about us no matter that we come from White oppression...but the Whites who play that role of doctors and nurses...they care more than our Black people and the Coloureds.* [Male participant aged 45]

The same participant further elaborated that there are some health practitioners who are disrespectful and often do not provide information required by patients:

*You see the others look at you as if you are a grave... they just glance at you...even when you talk to her, she says, "I am busy," as if you don't know that. You are just asking something that you don't know... she is the one who knows...she won't even want to listen... Those things bother us... [Male participant aged 45]*

One female participant thought that doctors are passive listeners and are therefore unable to interpret what patients say and this may affect the doctors' approach to treatment and care:

*Sometimes it's like the doctors also have a problem of not hearing...you tell him everything... He doesn't hear whilst he is listening. So it is a problem there to him... Now when he doesn't hear you... The big problem you went for to the clinic didn't get attention... You find that you just went, you come out having stress... [Female participant aged 42]*

Two male respondents were of the view that some doctors are not interested in discussing patients' concerns. One said that he informed the doctor about the fatigue and dizziness that he experiences from taking seizure medication, but the doctor said that those symptoms are common. The other one said that he had been informing HCPs about his sexual health problem – but he has lost hope because they did not care about it.

*Since I started seeing the doctors it's as if they are not interested. That's the way I see it... I tell the doctor about my fatigue...but I don't know if they take note of that or if they don't. Another one said, when I told him I feel weak. I just become dizzy sometimes when I take these tablets... He said that it is something that is common... [Male participant aged 42]*

*For long, I told them about my manhood problem... I have since given up on them... They did not care... [Male participant aged 62]*

Another female respondent reported that she informed the doctor about her difficulties with regard to how she copes with her illness, but it seemed the doctor was not interested in what she was telling him:

*When I arrive there at the doctor...I tell him everything about my situation that it is this way and that way...but he likes to cut me... He doesn't listen to how I go [doctor does not listen to how she copes with the illness]... [Female participant aged 53]*

### **Counselling and information needs**

We asked our participants about the issues that they want to discuss with their HCPs on their routine clinical visits. We found that their individual needs were varied and were based on their age and gender – and included information needs on seizure medication and reasons for experiencing certain side effects, male sexual health problems and pregnancy. Two male participants said that they would like to be informed about why the seizure medication causes them to become dizzy:

*I would like them to explain to me why for such a long time since I started medication in 2006...I am still feeling dizzy when I take these pills and I have no strength... I would really like that they explain about why the medication doesn't get used to me... [Male participant aged 42]*

*I have been taking these medicines since I was young... I noticed this thing that every time I take these pills I feel dizzy... I would feel like someone who had taken an alcoholic drink and I don't even touch that... I want to know why I don't get better... [Male participant aged 28]*

An older male participant wanted to know the cause of his sexual dysfunction:

*I wanted to know what causes that if I want to meet with her [has sexual desire for his wife]...then the lights turn off first very quickly [has difficulty in maintaining an erection]...it wasn't like this before... [Male participant aged 62]*

It was interesting to note that one female participant who was of child-bearing age said that she was interested to know about pregnancy related issues in epilepsy but the doctors' response was insufficient:

*I asked the doctor if a person with epilepsy [meaning a female person who has epilepsy] can get pregnant. That doctor said yes and it ended there... [Female participant aged 25]*

A male participant who had recently been diagnosed with epilepsy said that he wished to be counselled on how to cope with the illness and the kind of treatment that can help to achieve seizure freedom:

*I wish they could ask me how I am coping with this illness... I am troubled by this illness... It is because when you are not well and being held by an illness... you're always not happy because I'm always busy thinking of how I can get a plan that can free me*

*from my problem* [meaning his illness]... [Male participant aged 56]

Another male participant said that he wished to be counselled on his socio-economic circumstances:

*I wish they could ask me how I sit here at home, what I eat because I don't work. Even when I ask for the grant they just say I haven't reached 60...* [Male participant aged 58]

## Discussion

Our qualitative analysis of our participants' explanations of the difficulties affecting their treatment and care provided a glimpse of experiences of twelve patients who have been living with epilepsy for more than twenty years. Most participants were uneducated and unemployed and very few had a reliable income. The participants' experiences on their routine clinical visits show that they have in fact experienced inappropriate treatment and care and that their individual needs or concerns were not attended to. Their verbatim accounts provide some insights on the kind of health system factors that may lead to violation of patients' health rights. Some examples of the types and nature of these violations have been reported by Vivian et al. [40] in health care settings in South Africa.

Our respondents' descriptions of their experiences of treatment and care during routine clinical visits confirm findings from the observational study of PWE conducted by Keikelame and Swartz [41] in a chronic illness clinic in Cape Town. According to Rubin et al. [42], positive health or treatment outcomes occur where patients are empowered to ask questions as opposed to questions being asked by HCPs. In our study, some participants stated that they asked questions and highlighted issues of personal concern that they wanted to discuss with HCPs – such as reproductive and gender related issues (male sexual health problems and pregnancy), socio-economic circumstances and how they cope with the illness – but these were either ignored or seen as unimportant. They also stated that they were only asked questions on frequency of seizures and adherence to their seizure medication – yet there were some who reported that they had other chronic illnesses. This finding is important since comorbidities in patients with non-communicable diseases (NCDs) have been reported to pose serious challenges for HCPs in South African primary care settings [43]. While there was only one participant who reported being on ARV treatment, the finding is of great concern because of drug interactions when anti-epileptic drugs (AEDs) and ARVs are co-administered [44]. These findings suggest a need for an integrated approach to management of NCDs in general.

There were some health systems factors which were perceived to inhibit patients' access to appropriate treatment and care which occurred through the routine task-centred system (RTCS) which Van der Walt [45] defines as a “compartmentalized system which seems to offer a degree of emotional protection to the nurses in their dealings with patients” (p. 77). The author further states that this protection seems to be a powerful means through which patients are subjected to care and which focuses on tasks rather than on engaging with the experience of illness. This type of system may lead to disempowerment of patients and may also inhibit HCPs to provide appropriate treatment and care. Writing about the influence of power on patient care, Powell and Davies [46] state that power has a great influence on patient care, especially in complex environments where it is provided by different HCPs who have their own cultures, identities, and educational backgrounds – and who are also very complex and divided [47]. Furthermore, Doherty and Stavropoulou [48] are of the view that the complex nature of the health system promotes an environment where errors that occur in a clinical process may influence patients to accept inappropriate treatment and care from HCPs as an acceptable norm. Therefore, what may be needed is the development of a “trusting and trusted health system – which is not only seen as a producer of health or health care – but as a purveyor of a wider set of societal values and norms” (p. 1461) [49]. The author further points out that the health system can contribute to achieving these values and norms when its interaction with society is based on trust.

A very disturbing finding was the expression that was used by one participant who was of the view that HCPs regard patients as “*graves*” (dead bodies). Interestingly, this issue about patients being treated as “bodies” has been explored by Henderson [50] in her observational study of clinical encounters of nurses with patients in the intensive care unit. She said that the routine charting of patients' progress in the clinical process “separates the body into physical components which can be measured... this knowledge has not only empowered particular kinds of practice, but has also invented a new patient...the recorded body – a body about which little is known at an emotional level but everything at a biochemical and physiological level...this practice therefore shapes the health care practice” (pp. 937–938). Based on our interpretation of our participants' verbatim accounts, the focus on recording of seizures and medication adherence may inhibit treatment of patients as autonomous people who are able to deliberate [51]. Therefore, in order to reduce ill care of this group of patients, there is a need to educate HCPs on strategies that promote what Thomas and McDonagh (p. 4) [52] refer to as “empathetic modelling” and interventions that can develop patients and HCPs skills in interactive and critical health literacy [53].

## Limitations

Although we used different approaches in our recruitment strategy to ensure rigour, we may have also not included those who were not known by the local gate keepers. Our study findings were from a small sample in an urban Xhosa speaking township and cannot be generalized. However, they confirm, complement and expand on findings regarding poor access to appropriate treatment and care of PWE reported in other LMICs [3, 4] and in some studies done in Cape Town [23, 41]. To ensure rigor, MJK used local gate keepers in the recruitment process and combined snowball and purposive sampling methods and also used field assistants to locate homes of listed participants who were living in shack dwellings and would be difficult to locate due to structural problems.

## Conclusion

Our study described perceived difficulties affecting access to appropriate treatment and care of PWE who were interviewed for the study. The findings show that the participants have by their accounts in fact experienced perceived inappropriate treatment and care on their routine follow up clinical visits. We argue that these experiences could be due to the power and nature of the RTCS. Our data suggest a need for appropriate interventions to address health systems factors affecting treatment and care of this marginalized and vulnerable group of patients.

## Abbreviations

AEDs: anti-epileptic drugs; AIDS: acquired immune deficiency syndrome; ARV: antiretroviral treatment; CHC: Community Health Centre; COPDs: chronic obstructive pulmonary diseases; EMs: explanatory models; HCPrs: health care practitioners; HIV: human immunodeficiency virus; LMICs: lower middle income countries; mhGAP: Mental Health Gap Action Program; NYDA: National Youth Development Agency; NCDs: non-communicable diseases; PWE: patients' with epilepsy; PGWC: Provincial Government of the Western Cape; RTCS: routine task-centred system; TB: tuberculosis; THO: Traditional Healers Organisation; NGOs: Non-governmental Organisations; WHO: World Health Organization.

## Competing interests

The authors declare that they have no competing interests.

## Authors' contributions

MJK conceptualized and designed the study and was responsible for field entry and access, data collection, analysis, write up and submission of the manuscript. LS acted as a supervisor and advisor in all phases of the project and the final draft was read and approved by both authors.

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## CHAPTER TEN: COMMENTARY



**Mama Kadoka (Interviewee):** *“You see...we had a blessed conversation.”*

**My moment of surprise:** The tortoise appears under the couch on which I was sitting after the interview had ended.

## CHAPTER TEN

### MANUSCRIPT TWO

#### ***“The tortoise under the couch”*: An African Woman’s Reflections on Critical Moments, Culture and Ethics on a Qualitative Research Project.**

#### **10.1. INTRODUCING MANUSCRIPT TWO**

This chapter is presented in manuscript form for publication in the *International Journal of Social Research Methodology*. It raises important issues for social researchers who conduct their inquiries into sensitive and stigmatized illnesses such as epilepsy. It highlights the cultural and ethical challenges of studying sensitive topics such as epilepsy in a setting that is characterized by marginalization and experiences of oppression. It shares some critical and unexpected moments in the field that provide an opportunity for self-awareness about the importance of culture, identity, position and emotions to enable researchers to provide insightful contributions to current knowledge and not just about ethical aspects such as anonymity and respect (Traianou, 2014 in Leavy, 2014, pp. 62-77), and uses the analogy of the “tortoise” to do so.

## Manuscript Two

### ***The tortoise under the couch*”: An African Woman’s Reflections on Critical Moments, Culture and Ethics on conducting a Qualitative Research Project**

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#### **Abstract**

The author uses the analogy of the tortoise to reflect on critical moments that she experienced in the field while doing a qualitative study which explored perspectives and subjective experiences of Xhosa speaking adults who have epilepsy and their carers in an urban black township in Cape Town. She provides a reflection of her subjectivity in terms of her position, identity, gender, age and cultural values and the stories that she heard from participants and how these influenced her decisions and actions in the field. She particularly reflects on unanticipated moments during her field work and how these posed some ethical challenges in the process from her point of view as a researcher: she does not share findings of the study. She provides insights on some challenges that she faced in the field from conducting a study that involved a sensitive topic among a group of marginalized and vulnerable subjects of lower socio-economic background. She shares her emotional frustrations in terms of the difficulties she encountered in her attempt to engage in advocacy actions and hopes that her paper will contribute to enable opportunities for dialogue and for an empowerment code of ethics for those engaged in qualitative research among similar population groups and the importance of embracing cultural issues.

**Keywords:** fieldwork reflections, ethics, culture, identity, position, advocacy actions

## Prologue

### **My moment of surprise: “The tortoise under the couch”**

It was on Tuesday morning at 11h30 when I had an interview with one of my participants at her home. After she welcomed me into her home, she gestured for me to sit on a couch. This couch was very comfortable. After I sat down, she also sat down on another one which was next to the one on which I was sitting. The seating arrangement enabled us to make eye contact. She then clapped her hands and greeted me and welcomed me. She said, “Good morning mother, how are you?” I replied and said, “Thank you mother<sup>1</sup>, I am also fine. I am happy to meet with you today to talk about your perspectives and experiences about epilepsy.” Thereafter, she also said that she was waiting for me and that she was happy that we were both able to meet today to talk about epilepsy. I felt very comfortable and relaxed. The home was very clean and well ventilated. After the welcome, I informed her of how the interview would proceed, and gained informed consent to audio-record our conversation. After ending our interesting conversation, which lasted for ninety minutes, I thanked her for her time and for her insightful information that she had shared with me. When I was about to stand up and leave, I was amazed to see a tortoise appearing from underneath the couch on which I sat. At that moment, I felt like screaming but I contained myself because I did not know how she would react – but I did not realize that while I was struggling to hide my fear of the tortoise, she was closely observing my facial reaction and body language. She then put her hand on my shoulder and asked me to sit down. She said to me:

Mother, don't be afraid . . . the appearance of this tortoise shows that my ancestors are happy with what we talked about today . . . they have blessed the conversation.

I then said, “Thank you, mama”. I felt happy when she said her ancestors blessed the conversation and my fear subsided. I felt relieved. Thereafter, she offered me a cup of tea. I did not want to refuse the offer because it might seem that I was disrespectful. While waiting for tea, I had the opportunity to observe this tortoise more closely. I watched its big eyes, its brown shell which had rectangular shaped squares that connected to each other, its long neck and its slow pace as it moved towards the open kitchen door. I did not take notes at this point.

After leaving her home, I reflected on the experience. I also remembered that shortly before beginning fieldwork, I had chased a tortoise out of my yard. I had no idea how it got there. My husband had said to me, “Don't chase it away, it is just a tortoise, and it could be one of our neighbours' pets.” I had also informed my son about this tortoise and how I chased it out of our yard. To my amazement, he had said to me, “Mother, why did you chase it away? It is a sign of good”. Thinking about the coincidence of encountering not one but two tortoises in an urban setting in the context of embarking on and conducting fieldwork, I began to wonder whether there could be some positive things that I could learn from these encounters with an animal I do not really like.

I could not help but recall the Aesop's fable about the hare and the tortoise. Thinking of my own age and stage of life at which I was finally embarking on a PhD (I am in my sixties), I thought of the tortoise's commitment to finish the race despite its slow pace

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<sup>1</sup> In local African culture, it is customary for older women to be addressed as “mother” or “mama” as a sign of respect.

of movement. It had a set mission that it had to accomplish despite all odds. The tortoise I had seen at my informant's home had seemed old and slow. I wrote in my research journal (all journal entries in italics hereafter):

*I was surprised to see the tortoise appearing from the couch on which I was sitting after interviewing this participant. This surprise made me aware that there will be some crucial moments that I must note and learn from during the course of my fieldwork – more specifically because of the nature of the topic that I am investigating. Perhaps there will be some things that people will want to openly share with me during the interview process or conceal. Or perhaps there might be some things that my participants may want to share with me after the interview has ended – which may be at their chosen time to do so – like the “tortoise appeared after the interview had ended”. This unanticipated surprise enabled me to embrace such moments which come unexpectedly and from which additional important information can be gained through listening, observation and reflection. For me, this meant that I should adopt a gradual approach during my fieldwork - a “slow pace of movement” similar to that of the tortoise.*

I became more curious to know about the characteristics of the tortoise from literature. Trawling the internet, I found reports that in other parts of the world it is associated with longevity, stability and myths, and that, in China, it is viewed as a black warrior with power and tenacity. I was not sure about the accuracy of these reports, but they seemed to fit. Closer to home in Africa, the tortoise is regarded as a “wise old man” or “Mzee” in Swahili (Wikipedia, 2014). Among the Zulu speaking people in my own country, South Africa, it is known as “Fudukazi” and is regarded as a problem solver and protector (Carnate, 2007). I then wanted to know what the tortoise is called in isiXhosa, the dominant indigenous language in the Western Cape Province where I now live and work. I had a conversation with my two Xhosa speaking colleagues about my experience with the tortoise. To my amazement, I found different explanations of the tortoise. One said that it is called “Lufudo” in isiXhosa – and that it is sometimes associated with laziness because of its slow pace of movement (Tsuki Xapa, personal communication, 21 January, 2013). The other colleague said that it is a sensitive, cautious, graceful, powerful, focused, committed and determined animal (Linda Ganca, personal communication, June 3, 2014).

*I was struck by my colleagues' explanations and descriptions of the characteristics of the tortoise and thought about the sensitivity of my research topic, the stigma, secrecy and superstitious beliefs related to the illness. I also recalled that my participant talked about her ancestors being pleased about our conversation – and this made me more aware of issues of culture and power in the process. I became aware on my state of powerlessness due to fear of the tortoise and how my participant used her power to alleviate my fears. I understood how a seizure attack can lead to powerlessness and thought that power can be used to enable PWE to take control of their illness. I then thought that I must adopt some of the characteristics of this animal in my field work – such as being sensitive and being aware of issues of power that may come to the fore during the course of my project.*

### **My research background**

Here I present a reflective account of moments that I experienced through my continuous interaction with my study participants. According to Bowtell, Sawyer, Aroni, Green, and Duncan (2013), ethically important moments are unanticipated



and are also not obvious. They emerge at any stage in the process of fieldwork and can pose some ethical dilemmas for researchers. Based on my interpretation of my tortoise analogy, I provide some highlights of my reflections of moments relating to: my identity and position; my actions and ethical challenges; and self-scrutiny of my emotions and how my actions may have affected my interpersonal relationships with others with whom I engaged in the process.

Before I reflect on these critical moments, I will provide a background to my research project. I used a qualitative design to explore perspectives and subjective experiences of patients with epilepsy and their carers in an urban township in Cape Town, South Africa. The carers included family members, neighbours, Home based carers (HBCs), traditional healers (THs) and medical doctors. The setting is an urban Black township in Cape Town, and the residents are predominantly Xhosa-speaking. Due to migration factors, there are other African spoken languages in the township, such as isiZulu, Xitsonga, Sesotho and Setswana (Author & Author, 2013). It is also characterized by high rates of unemployment, illiteracy, and drug and alcohol abuse (Lehohla, 2013; Naidoo & Irlam, 2005). In addition, it is one of the historical urban townships which were affected by the past policies of the colonial rule which segregated population groups by race. This accounted in part for the marginalization, discrimination and unequal distribution of resources. Despite the availability of epilepsy support services, these are currently not accessible to the study participants.

From a methodological perspective, I was interested in using a research design which could be “open and supple”, open to incorporating a range of philosophies, theories, designs and methods, as well as postmodernist social critiques (Freeman et al., 2007 in Halquist & Musanti, 2010, p. 450). In addition, an advantage of this qualitative approach is that it provides the researcher with the opportunity to gain entry into the everyday lives of participants in their natural settings, thereby enabling the researcher to discover and gain a contextual understanding of their perspectives about their social world (Marshall & Rossman, 1989). It also places emphasis on process rather than outcome and on gaining the “emic” or insider’s point of view (Babbie & Mouton, 2001; Gerrish & Lacey, 2010). However, Morse (2001) reports that this approach is not without its risks. The flexibility of the approach can allow the researcher to hide key aspects of research interactions. Morse (2001) posits that researchers should be transparent about what they did or what they could not do in order to increase the rigor and credibility of the findings.

My research project was certainly on a sensitive topic. Li (2008) defines a sensitive research topic as “a study of secretive, stigmatized or deviant human activity and behaviour involving vulnerable research subjects” (p. 102). Other researchers note that research on sensitive topics provides an opportunity for researchers to hear painful stories which they may not have otherwise been able to hear through in-depth interviews, and that these may open “a can of worms” or “a Pandora’s box” (Dickson-Swift, James, Kippen & Liamputtong, 2007, p. 338) for themselves as well as for participants (Dickson-Swift et al., 2007; Dickson-Swift, James, Kippen & Liamputtong, 2008). I worried, and worry, about this.

*What kind of worms will I release through using a semi-structured interview guide based on Kleinman’s (1980) Explanatory Models questions to elicit individual stories on subjective experiences of living with epilepsy and of caring for people living with the illness? What kind of stories will they tell me? How will*

*the person feel after telling me his or her story? How will I feel after hearing the story? Whom will I tell? Should I keep quiet about released worms, if any?*

Writing about the importance of reflexivity and ethically important moments in research, Guillemin and Gillam (2004) state that critical reflection enables the researcher to provide an account of the knowledge construction and of contextual factors that enhanced or inhibited the research process, the actions, positions and decisions of the researcher and ethical issues considered in the process. I therefore use my tortoise analogy to provide a critical reflection of “ethically important moments” (Gildersleeve, 2010, p. 408), and to provide a reflective account of how I exercised my age, gender, ethnicity, position and cultural background to respond to unanticipated moments which occurred during my study.

### **My Identity and Position**

I am an African Black older woman and I speak Setswana, one of the eleven spoken languages in South Africa, as a first language. I have lived in Cape Town for twenty years, and can speak the local language, isiXhosa, but would not regard myself as fully proficient. I am also a health promotion lecturer and a previous board member of the local branch of the epilepsy NGO. During my field entry and recruitment of participants, I was not sure whether to consider myself an insider or outsider, or a bit of both. My difficulties in negotiating isiXhosa dialects, and my professional status working with people with minimal education, all positioned me as an outsider. On the other hand, despite some changes over the past few years, most researchers in the health field in South Africa are White people, and I could position myself as an insider simply because of my being a Black South African. According to Chereni (2014), a researcher who is an insider is perceived as one who shares a range of cultural markers, which includes language, idiomatic expressions, cultural beliefs and attitudes. I found that although I am an African woman and able to converse in isiXhosa (a rarity for most researchers working in this province (Swartz, 2014), I felt different especially when discussing cultural matters. On balance, though, these differences felt for me of less importance than the commonality of my being a Black African.

I also experienced a sense of belonging, especially when those who were conversant in my language spoke to me in my own language, Setswana. I thought that probably I may have felt that way because I had honoured the invitation by one of the community members to do the study in this particular setting – where available epilepsy support services are inaccessible to patients with epilepsy and their family members.

*Being invited by one of the community members in the study setting made me aware that researchers’ interests in certain projects can also contribute to inequalities in health as well as violation of health rights of the marginalized especially when the bulk of research is concentrated in specific areas and on specific health conditions – showing the importance of equity in research.*

As a Black South African woman, I had some insider knowledge and experience of what exclusion and exploitation might mean for my participants, and it was clear that participants often saw me as an insider. Based on this experience and from my position as a health promotion practitioner, I thought findings from the study would help to engage in advocacy actions that can help to address barriers affecting access to appropriate health care services. According to Milner (2007) in Gildersleeve (2010, p. 411), it is important for researchers to provide a critical reflection on their racial and cultural backgrounds and understandings to enable them to “engage in processes that

reject exploitation, misinterpretation and misrepresentation of people and communities of colour". This was even more critical for me because I had prior experience of exploitation and marginalization – and also noting from literature that researchers' positions in the field can never be stable because they are affected by the way the study unfolds at different phases of the project (West, Stewart, Foster, & Usher, 2013, p. 62). As a result, I experienced different moments in the field which influenced my decisions and actions which posed some challenges for me as an African woman with similar experiences of oppression.

### **My Actions and Ethical Challenges**

While the choice of my naturalistic exploratory design provided me with opportunities for entering people's homes, I was always concerned about my actions and decisions which unfolded in the process. As a result of these concerns, I read an interesting article entitled, "Looking beneath the surface: a critical reflection on ethical issues and reflexivity in a practitioner inquiry" by Clayton (2013). Drawing on a range of work, Clayton (2013) notes that if researchers are not troubled by ethical tensions in their research, they are probably not paying close attention to the context – or they may not be looking far enough beneath the surface. The authors on whom Clayton (2013) draws further emphasize that researchers' reflexivity regarding the research process should not only focus on knowledge construction but should also include a reflective account of ethical challenges in the field. These involve participants' rights, ensuring confidentiality, translation and interpretation of informed consent materials, issues about transcribers and interpreters and cultural factors affecting recruitment and informed consent.

### **Ethical Challenges and Participants' Rights**

In my recruitment process, I had developed a draft of my inclusion and exclusion criteria, but this was revised because some of my recruited participants referred me to others who did not reside in the study setting – but who otherwise fitted the criteria. My motivation to include these participants was later approved by the local health research ethics committees. I worried, though, about how my decisions affected those with whom I interacted with regard to whom I should include or exclude. Because I had presented my proposal to the local stakeholders, I was also aware that they too had the power to decide who to refer me to and the power to agree or decline at any point in time during the process. They also had the power to choose whether to inform me of their reasons for declining or withdrawing. On the other hand, I had recruited some participants who were willing to take part in my study – but I had to exclude them for variable reasons: some were difficult to trace because they had no means of contact and others could not be located because of incorrect physical addresses. Some were residing in poorly structured shack dwellings and others had moved because their homes had been burnt down. I was unsure whether I had violated their right to participate by virtue of the decisions that I took.

### **Ethical Challenges Regarding Confidentiality**

I chose to use a naturalistic approach to collecting data because it would provide me with the opportunity to gain an insider's perspective of the problem that I was investigating (Babbie & Mouton, 2001; Gerrish & Lacey, 2010). Most of my participants in the study setting lived with their families in informal communal dwellings which were poorly structured. I often struggled to ensure the confidentiality which I had assured my participants when I gained their informed consent. Although I had requested them to set appointment times that would ensure privacy (when children would be at school

or when families members would be at work), this was not always possible. I was surprised during my interview with one participant when one of his family members appeared in the room, reminding me of the tortoise which appeared from the couch on which I was sitting. I did not know whether to stop the interview or not – but my interviewee stopped the conversation and introduced me to his mother and invited his mother to participate in the interview because he said she would be able to answer some questions about his illness.

At this point, I was concerned about ensuring confidentiality, but I then thanked the interviewee for introducing me to his mother and for allowing his mother to join our conversation. The same ethical challenges were raised by MacDonald and Greggans (2008) when they reflected upon the challenges of doing research in natural settings. In allowing the mother to participate in her son's interview, I was probably breaking a rule concerning the aims and boundaries of that interview. But I was also responding as rules of politeness and cultural sensitivity require. I was reminded again of my position in my research not just as an academic, but also as an African woman situated in networks of expectation and obligation.

### **Ethical Challenges with Hired Transcribers**

Despite some literature on the importance of safety issues (both psychological and physical) in research on sensitive topics (Cowles, 1988; Dunn, 1991; McCosker, Barnard, & Gerber; 2001), there is relatively little attention given in the literature to these issues as they affect interpreters, cultural brokers, transcribers, supervisors and readers of research (McCosker et al., 2001; Temple & Edwards, 2002). Transcribers are often hidden members of research teams, and their roles and subjective experiences glossed over, but they have the same rights to ethical consideration as do others (Davidson, 2009; MacLean, Meyer, & Estable, 2004).

At the start of my work with my transcriber, I entered into an agreement contract with a language practitioner whose role was to translate and transcribe the audio-recorded data. This contract included confidentiality, safety and protection of my participants' data and when transcribers should delete all data from their personal computers. However, in the process, my transcriber contacted me and informed me that he had suddenly taken ill and had been admitted to hospital. I went to see him together with another colleague. He then told me he was worried that he had not completed transcriptions of the two audio-recorded data collection sessions because of his sudden ill health. To my distress, I was informed the next day that the transcriber had passed away in the night after we had visited and prayed with him. In my understanding of our shared African culture, it would not be possible for me to request transcription work when the family was in mourning. I faced this situation of a transcriber's death during the course of the study and this remained an ethical and cultural issue that I was unable to address!

I then hired another transcriber and entered into a formal agreement with her. Due to the nature of the stories that some participants shared with me during the interviews, I was concerned about how these stories would affect this very young transcriber since transcription involves engagement with participants' feelings and thoughts. After interviewing a couple who shared with me some painful experiences during the interview, I shared with my transcriber how I was saddened by my interviewee story regarding the difficulties that she experienced while being married to a husband who has epilepsy. After she had completed the transcription of this particular participant's

audio-recorded interview, she sent me a message to confirm that, like me, she was also deeply touched by what she had heard in the interview. While I obtained ethics approval for my study, I had not thought about ethical implications for transcribers and interpreters, but I was concerned about the extent to which my transcriber might have been affected by what she had heard from this interview. MacLean et al. (2004, p. 120) have also reported on the importance of addressing transcribers' emotions and reactions to the "emotion-laden tape content". Determining what the appropriate distance should be between me and the transcriber remained a struggle for me.

### **Ethical Challenges with Regard to Translation**

The research ethics committee which approved my study appropriately required that my informed consent and participant information leaflet be translated into isiXhosa by a professional language practitioner. I had duly submitted these approved translated documents to the ethics committee for approval. Prior to gaining access to participants, I held a meeting with my field interpreters to train them on the procedure for gaining informed consent and also to give them the opportunity to acquaint themselves with the contents of the professionally translated forms in order to be able to interpret the information. One of my field interpreters raised a concern that my informed consent information materials were in "academic isiXhosa", not the dialect of isiXhosa which is spoken in the community. Processes of translation are never politically neutral, and translation and interpretation in research may involve the performance of various forms of identity and cultural politics (Drennan, Levett, & Swartz, 1991; Swartz, 2014; Temple & Edwards, 2002). It is understandable (and technically correct) that the research ethics committee required a professional translation service be used, but this led to translated informed consent forms which were in fact contextually inappropriate. In an urban South African context, where there is extensive and rapid in-migration and a need to communicate across a host of language barriers, there have been substantial changes in the way isiXhosa is spoken. In practice, there is extensive use of borrowing and code-switching, as there is with other languages.

Given the history of disrespect of indigenous languages in South Africa, however, there is considerable sensitivity around any practice which, correctly or not, may be interpreted as demeaning of such languages and their status. Language practitioners who have noted the reality of language mixing and borrowing have come under fire, with Dowling (2011, p. 346) noting, "In my experience, African language teachers generally regard any questioning of the 'standard', static varieties of African languages as tantamount to racism and as disrespectful of the culture". There is probably, therefore, pressure on professional translating services to reproduce canonical forms of isiXhosa, but these forms may not be used or understood by many isiXhosa-speakers in Cape Town. As a non-native speaker of isiXhosa, I myself was now in dangerous political territory as I certainly did not wish to appear disrespectful of the isiXhosa language. However, the realities of the research forced me across this boundary.

In the early phases of my research, I observed interactions between an isiXhosa-speaking patient with epilepsy and an isiXhosa-speaking health care professional in a chronic illness clinic. I noticed that the patient used isiXhosa expressions which the health care practitioner did not understand. The patient informed me that the isiXhosa spoken in Cape Town is different from the spoken isiXhosa in the rural area from which she came. This meant that language barriers can also occur among patients and



health care providers who speak the same language (Author & Author, 2013). Clearly, questions of translation and interpretation, and issues surrounding the politics of language and identity, cannot be solved simply by having professionals translate and interpret. To engage in these issues is to engage repeatedly in questions which cannot easily be resolved. In my reflections, I wondered whether it would not be more important for community members themselves to translate consent and other forms than for inappropriate translations to be made under the guise of professionalism and respect for indigenous languages. However, I realized that whatever I and other researchers may do, we will be on complex political and personal ground.

### **Ethical Challenges and Cultural Considerations**

As an African older woman, I have always been aware of some important cultural expressions that influenced my actions in the field. I lost two of my key stakeholders who died during my field work. One had agreed to be interviewed – unfortunately she died suddenly before the set interview appointment. Another played a key role in making it possible for me to gain entry and access to the study setting. When I received the bad news about their passing, I bought sympathy cards and also went to pay my respects at the family's homes. While literature reveals that there are different views about reciprocity in research (Dickson-Swift et al., 2007) my motivation for doing so were mainly based on my Setswana values which are part and parcel of "*ubuntu*", an African ethic of reciprocity whereby one's humanity is determined by the extent to which one is involved in the lives of others (Owusu-Ansah & Mji, 2013).

At times I was challenged by issues of culture and faith. I recruited a patient with epilepsy who was interested in participating in the study. After I gained her informed consent, she asked me to contact her religious leader and to recruit him to participate in the study. I visited the faith healer at his home together with my field assistant. After he had welcomed us, my interpreter read the participant information leaflet for gaining informed consent and explained the purpose of the study and why the faith healer would be a very important person to participate. The healer then told me that he had been praying for the patient who referred me to him because her epilepsy is caused by demonic spirits. He said to me that through the power of prayer, the patient is no longer taking seizure medication. The patient showed me the number of packets of medication that she had not been taking because she believed in the power of prayer. I was challenged by the power of the faith healer and his interpretation of the biblical verses that he read for me. Although I respectfully listened to him, I was of the view that these religious beliefs are the cause of suffering and powerlessness, and patients who hold these beliefs are therefore obliged to stop their treatment, resulting in poor seizure outcomes because of fear of losing their identity and sense of belonging.

Another moment concerns the religious beliefs of one of the researchers with whom I collaborated by chance in the study setting, and of my interpreter. I was interested to collaborate with this researcher since stroke is also one of the medical causes of epilepsy (Burneo, Fang, & Saposnik, 2010). However, during our informal conversations, she informed me that she was unable to recruit THs and visit them at their homes because of her religious beliefs. Similarly, one of my interpreters told me that he would also not be able to assist me in recruiting and interpreting the consent form for THs because of similar beliefs.

### **Self-scrutiny of my Emotions and Interpersonal Relationships with Others**

I had been critiqued by some of my colleagues when I shared with them my frustrations in the field and how I acted upon issues where I felt that participants' health rights were violated. Some felt that I must keep to my role as a researcher because my actions would bias the findings of the study. Others thought that I might lose focus on the purpose of the study. Reflecting on her actions from a feminist perspective while exploring violence against sex workers, Armstrong (2012, p. 8) said that she found herself frustrated when she felt that "she could do very little to influence social change". I was often frustrated about the reactive approach to some of these issues when seeking support for my participants. Authors such as Traianou (2014) in Leavy (2014, p. 69) stress that qualitative research, especially among marginalized population groups, should address issues of oppression and social injustice – and these were core to my actions and motives in the process – even though I feel that I had done very little to foster collaborative advocacy actions to address them.

### **Conclusion**

The choice of my methodology provided me with the opportunity to witness, interpret and to be aware of factors that may perpetuate marginalization (Stein & Mankowski, 2004). In the process, I developed close relationships and emotional connections with my study participants which in turn helped me to overcome some of my emotional frustrations through reciprocity. According to Lalor, Begley, and Devane (2006, p. 614), when researchers develop "self-awareness, close relationships and emotional connections" they engage in reciprocal actions which can help them to overcome emotional harm. Through fieldwork experience, I embraced Denzin's (2014, p. 1125) view that a "qualitative inquiry community needs an empowerment code of ethics that cross-cuts disciplines, honors indigenous voices, implements the values of love, care, compassion, community, spirituality, praxis and social justice". This kind of empowerment code of ethics is needed for researchers who conduct research among vulnerable, exploited and marginalized population groups.

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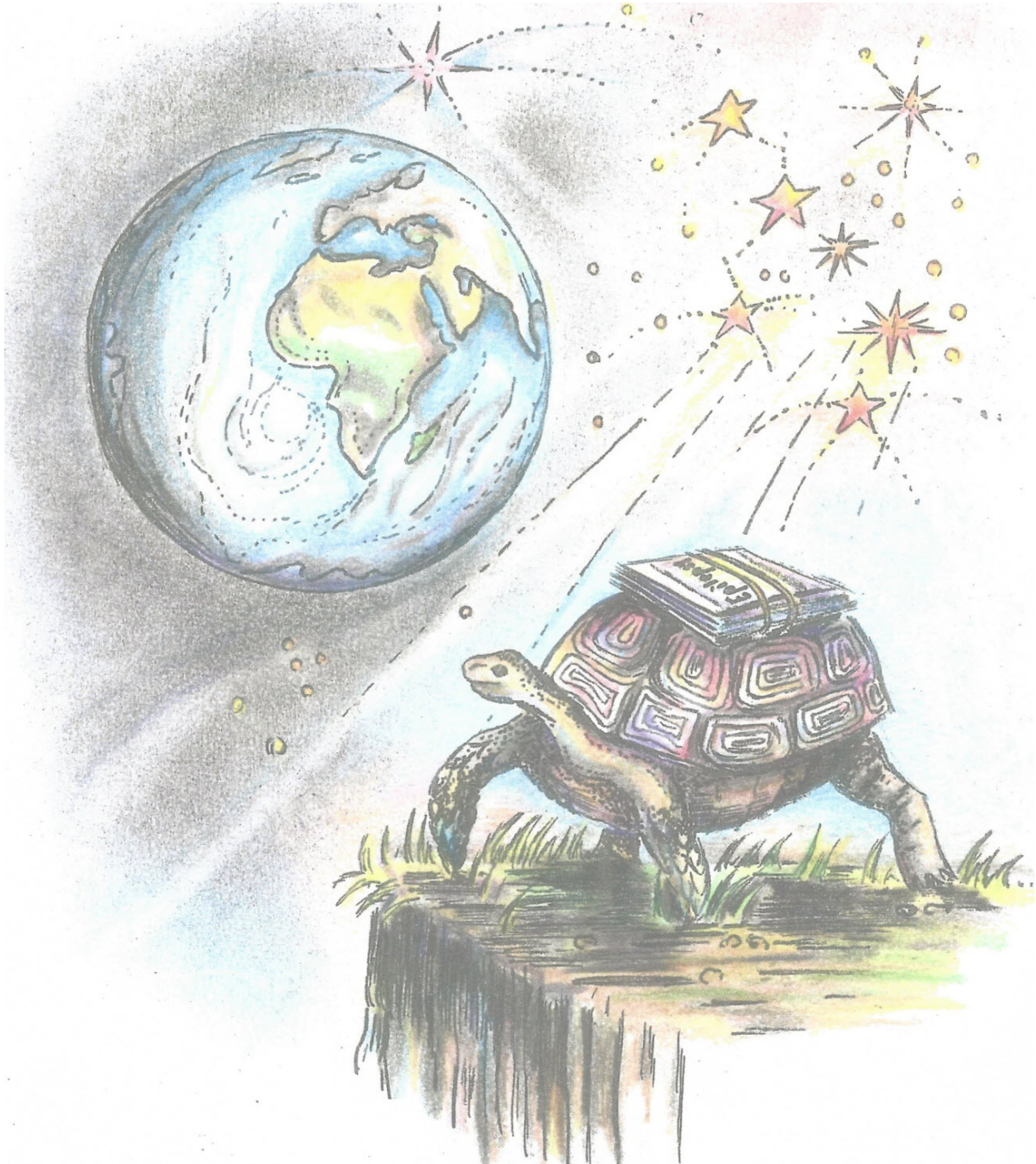
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## CHAPTER ELEVEN

### Concluding thoughts



My study aim was to explore perspectives and subjective experiences on epilepsy among PWE and their carers in an urban township in Cape Town. The objective was to describe and analyse the findings and to provide information that can be used to guide policy and future research. These aspects were elicited from individual interviews and focus group discussions with carers from sectors of health care such as the professional, home-based care, folk and popular sectors, and from patients with epilepsy, using an interview guide adapted from Kleinman's (1980) EMs framework.



In this concluding chapter, I will show how the different voices that I have heard during the process of this inquiry link together to give a broader picture outlining the landscape of the experience of epilepsy in the setting in which the study was conducted. I will draw together the various strands from Chapters Two to Nine of this dissertation, forming a whole picture of the internal and external factors of the health system that were heard, seen, felt and experienced by PWE and their carers in an urban Xhosa speaking township in Cape Town. I will also highlight both the consistencies across the chapters and the ways in which there may be inconsistencies. I will also share some issues that I reflected upon in the process of this inquiry to broaden the picture about these experiences as I bring the study to an end, of course still wondering about what to do next because I am an older tortoise, to use the metaphor of the previous chapter.

### **11.1. What does Kleinman (1980) say about systems of health care and healing?**

In my introduction section in Chapter One, I provided my motivation and the main aim of the study, which was to explore perspectives and subjective experiences of patients with epilepsy and their carers about the illness. I explained that the study is based on two theoretical frameworks: Kleinman's (1980) systems of health care and healing, and Bronfenbrenner's (1994, 2005) socio ecological framework. Kleinman's model is especially helpful because epilepsy has serious health, social and economic challenges, and context is very important to understand these (Batuista, Rundle-Gonzalez, Awad, & Erwin, 2013; Saada et al., 2015).

Epilepsy poses both physical and psychological difficulties for people living with the illness and their care providers (Akbarbegloo, Valizadeh, Zamanzadeh, & Jabarzadeh, 2015) as well as treatment challenges, partly because of comorbid conditions associated with the illness (Gattone & Lammert, 2015). A range of issues, as I have shown, may therefore influence people with epilepsy and their carers to seek health care and treatment from all sectors of health care such as the popular, folk and professional sectors, and from sectors such as home-based carers that lie between the lay and professional sector. These lay, folk and professional sectors of health care are existent in each and every society and have differences in their understandings and explanations of illness and its treatment (Aga, Nikkonen, & Kylmä, 2014; Kleinman, 1980). Therefore, using Kleinman's (1980) frameworks facilitates understanding of the kind of internal and external health systems factors that enable or inhibit treatment and care of PWE and their carers in the different sectors of health care.

Kleinman (1980) argues emphatically that health care systems are cultural systems which are guided by a set of norms and values. He contends that these cultural systems, such as religious and symbolic systems, are important to understand because they are able to provide meanings about the illness and experiences. In addition, Kleinman (1980) asserts that understanding the internal and external factors of the ecological system is important, since these can also have an impact on the health system. Let me now share the lessons that we can draw from what I have seen and heard and listened to during my interactions with carers from the professional, home-based, folk and popular sectors of health care and from the people living with the illness.

### **11.1.1. What have we learnt about the treatment and care of PWE in the professional sector of health care?**

Chapters Three and Four made us aware of the patient related factors and factors in the professional health sector that affect the understanding of epilepsy and its treatment and care of PWE. A key feature was the impact of the routine task system on the treatment and care of patients with epilepsy and their carers. The experiences of this system are further illuminated in Chapter Nine. Chapter Three shows us that access to appropriate treatment and care of PWE demands health care professionals who are competent to address the biomedical as well as the psychosocial and cultural factors of the illness. However, what we learn from Chapters Two to Five, as well as in Chapters Seven to Nine, is that factors such as lack of continuity of care, lack of skilled health care professionals in the management of epilepsy, use of impractical management guidelines and lack of patient education and counselling are barriers to effective management of PWE. These findings are consistent with literature on treatment gap related factors in LMICs (Jette & Trevathan, 2014; Wilmshurst, Kakooza-Mwesige, & Newton, 2014) and in South Africa (Eastman, 2005; Williams, Nefdt, & Wilmshurst, 2015).

The issue of health literacy has also been reported in Chapter Four of this dissertation and showed some lack of health literacy skills among health care professionals and patients themselves. Literature shows that low levels of health literacy can have a negative impact on health outcomes (Cawthon, Mion, Roumie, & Kripalani, 2014), especially since the majority of patients who receive health care in the study setting are from a low socio-economic group. In addition, health care in this setting is provided by HCPs who speak English, with some not being proficient in the predominant spoken language, isiXhosa, one of the eleven spoken languages in the country (Kilian, Swartz, & Chiliza, 2015; Killian, Swartz, Dowling, Dlali, & Chiliza, 2014; Swartz & Kilian, 2014). In addition, language barriers do also exist among patients and carers who speak the same African languages such as isiXhosa (Keikelame & Swartz, 2013) – highlighting a need for research in this area.

Chapters Three and Four further show us that language and terminology barriers can occur even between HCPs and patients who speak the same language, such as isiXhosa. This may therefore lead to challenges in cross-cultural communication, especially where there is lack of trained interpreters and translators. Further research is needed to explore language barriers and barriers of terminology, even amongst HCPs and patients ostensibly from the same language group. In addition, Chapter Four shows that lay people can also be seen as experts and that they possess their own everyday knowledge which health care professionals may not be able to understand and interpret. Henderson (2006) highlights the importance of a health system that is able to promote “well-informed citizens” who are able to understand the field in which information is being sought. This alerts us to the importance of promoting health literacy among health care professionals, as well as among patients and their carers. However, findings from Chapter Four suggest that the knowledge which some patients and carers already have may not be heard by carers in the professional sector of health care.

The lessons that we can draw from learning about health system factors affecting the professional health care sector are that health care professionals need to engage in advocacy actions for improving the treatment of patients under their care, since they have an ethical obligation to ensure that patients under their care receive appropriate

treatment and care for improved health outcomes (Dhai, 2012). It should not be care that just focuses on the number of seizures and whether patients take their medication, as observed in Chapter Four, but care that uses health promotion approaches such as enablement, mediation and advocacy (Kickbusch & Nutbeam, 1998; Nutbeam, 1998) to enable PWE and their carers to enjoy a good quality of life.

Furthermore, lessons from observations in the professional health sector in Chapter Four regarding the delivery of health education informs us that there is a need for research to examine approaches to the delivery of health education on epilepsy as well as evaluation of health information materials on epilepsy. This need was evident in literature reviewed in Chapter Two with regard to lack of evaluation of the appropriateness of the information delivered via video educational materials (Mugumbate & Nyanguru, 2013). Delivering health education to groups without the groups' consent may raise some ethical issues in terms of whether patients were interested in listening to a talk on epilepsy while waiting in the reception area or not – health education without informed participation may be compromised (Gardner, 2014). There is a need for research on health education materials used for epilepsy as well as on the approaches used in health education interventions. Koelen and van den Ban (2004) highlight ethical issues in health education and health promotion which also need to be considered.

Findings presented in Chapters Three and Four show that we need to work in multi-disciplinary teams in order to address the needs of patients and their families fully. In Canada, for example, pharmacists have been used in the role of patient education and counselling, an option that has not been fully explored in South Africa (Kennie-Kaulbach et al., 2012). Mash et al. (2008) suggest that chronic disease care can be improved by building chronic care teams, community involvement and building skills of HCPs in leadership.

Current literature shows that there is a call for an integrated and co-ordinated public health approach for epilepsy in the 21st century (Koh et al., 2014). There is also a call for epilepsy support educational training programmes such as telemedicine to enable improved treatment and care for PWE in poorly resourced countries (Patterson, 2014). Other notable actions in Africa include epilepsy training centres such as the “Centre of Excellence” that is developed through collaborative partnerships in Zambia (Birbeck, 2012). Others have suggested inclusion of epilepsy in the curriculum for training of health care professionals (Chomba et al., 2007; Njamshi et al., 2010). When we do not even have good data on prevalence of epilepsy in the Western Cape (Cloete, 2015), how can we advocate for better resources to improve the treatment and care for people with epilepsy and their carers?

### **11.1.2. What have we learnt about perspectives on and experiences of epilepsy from carers who lie between the lay and the professional?**

In South Africa, there are different types of carers who fit somewhere between professional and lay carers. They are often referred to under one umbrella term known as community health workers (CHWs). This term includes all categories such as Community Rehabilitation Workers (CRWs) and Home-based carers (HBCs) (NACOSA, 2013). However, Swartz (2013) cautions that these carers should not be regarded as a homogenous group because they do not have the same level of experience.

Chapter Five's main contribution to current knowledge on cultural factors affecting epilepsy is specifically about religious factors affecting epilepsy. We also find that religious beliefs about demonic spirit possession are consistent with literature (de Boer, 2010; Jilek-Aall, 1999; Sawant & Kinra, 2015). However, despite the impact of these beliefs on the understanding of epilepsy and their influence of health seeking behaviour of PWE and their carers, current literature reveals that not enough attention has been paid to the religious beliefs and practices regarding epilepsy (Tedrus, Fonseca, Fagundes, & da Silva, 2015). More research exploring the role of faith and religion in the beliefs and practices of health care workers and, possibly, particularly amongst CHWs or HBCs is needed.

In addition, we learned about the importance of paying attention to local metaphors used to explain epilepsy and that there are different metaphors used to explain epilepsy in different parts of Africa. In Chapter Two (Table 2.3. page 53), recent studies in Ghana highlighted metaphors such as epilepsy being explained as "death after death", while in Chapter Five home-based carers used the metaphor "ukuhlutha inkuku" (to pluck the chicken). These metaphors may not be stigmatizing, but may be explanations through which lay people can understand and recognize epilepsy.

The HBCs provided some insights, particularly regarding beliefs about demons inside the body as part of the way that epilepsy is understood. In Chapter Seven, traditional healers also talked about the "thing inside the body". According to Helman (2007, pp.11-12), images and ideas about what happens "inside the body" affect people's presentation of bodily complaints. Cultural metaphors and explanations about "things inside the body" need further exploration in our context.

Through these HBCs' knowledge of the community and of being part of the community, they were also able to identify strategies that can be used in the professional health sector, in the community, and those that can be used by HBCs themselves, by families of PWE and by people who have epilepsy.

### **11.1.3. What have we learnt about the cultural explanations of epilepsy and perspectives on collaboration from carers of PWE from the folk health sector?**

From an anthropological viewpoint, when people are sick, they want to know the name of the illness, its cause, reason for the cause and the effective treatment to cure it (Sindzingre & Zempléni, 1992). Chapter Six informs us of the different lay terminologies for epilepsy and expands our understanding of *amafufunyana* and how to recognize symptoms thereof. This is the first study in Cape Town that has examined perspectives on epilepsy among Xhosa-speaking THs in this study setting.

With regard to collaboration with western trained practitioners, healers were supportive of the idea. This finding is consistent with literature. Chapter Six sheds light on some key issues that need to be considered for collaboration which were not raised in studies conducted among healers in the literature reviewed in Chapter Two. In Chapter Six, we find that for collaboration with western trained health care professionals to work, there should ideally be a memorandum of understanding to ensure respect and equal status for the two types of knowledge systems and protection of intellectual property because of fear of exploitation. Although literature shows models of collaborative work with healers, there is a need for research to assess the impact of this collaboration in different contexts, and the urban South African context is rather different from most of the contexts studied in the literature. It is also important, as

Chapter Six shows, that western trained health care professionals develop an understanding of the training and views of traditional healers. More needs to be done on all sides to facilitate working relationships which can be beneficial to PWE and their carers.

#### **11.1.4. What have we learnt about perspectives on and experiences of carers of PWE from the popular health sector?**

Chapters Seven and Eight provide information about the care giving difficulties experienced by adult popular carers of PWE. These carers were siblings, parents, wives, partners, neighbours and friends. Nuhu et al. (2010) describe these as the “forgotten patients”. In order to help us to understand what Nuhu et al. (2010) mean by this, I will relate a story that I heard from one of my older respondents whose husband had epilepsy. This carer showed me stab wounds in her chest which were due to the husband’s violent behaviour after a seizure attack. She told me that although she had been admitted to hospital twice and had been sutured, no health care professional asked her the reasons behind her repeated admission with stab wounds. From her story, I learned that she had sought police intervention – but later blamed herself for doing so because of her understanding that her husband’s violent behaviour was due to the illness and ineffective seizure treatment. This story, sad as it is, shows us that poor management of epilepsy can result in accidents or even in death of a wife, a spouse or a child. I also found that despite this sad story, Kleinman’s (1980) EMs framework was experienced as emotionally healing for my interviewee. This is what she said at the end of the interview:

*Your questions were a medicine to me...and it will heal other people too because you get, it's not only us...I am happy and I wouldn't mind if my name would come out here. Maybe it is said I have to go and talk maybe I will find that in my talking there is another wife... it is like this with her too... I thought it was just me...but because we don't talk we don't have chances to talk...so most people are helped by talking...like now, it's a medicine that I can say we received because God sent you...we had time like this to talk and cough out because it's health in the end. So if you can have this illness and in the end if you don't talk about it you don't heal. Once you cough it out you get healthy and a person will say hey this person who fits why they are healing and they are shocked...because you had time to cough it out...*

The story further teaches us that popular carers consult police officers for support and it shows a need for collaboration with law enforcement departments. A study in Zambia examined epilepsy issues among police (Mbewe et al., 2007), but the area is largely unexplored. Issues of language and culture were central to the family carers. They are closest to their family members who have epilepsy. As do the PWE, they may struggle in their interfacing with the health care system.

#### **11.1.5. What have we learnt about subjective experiences of people living with epilepsy?**

I had an opportunity to listen to individual stories of adults who were people living with epilepsy who differed in age and were all on seizure medication. The main theme that emerged from the individual in-depth interviews on their perspectives and subjective experiences about epilepsy was mainly about their difficulties in accessing appropriate treatment and care. They highlighted the patient related factors as well as health care practitioners’ factors that they perceived as barriers to their treatment and care – and these were mainly due to the routine task system. The verbatim quote of one of my



respondents who said that some carers in the professional health sector “*look at you as if you are a grave*”, left me dumfounded. However, the actual words of this participant allows us to pause and to introspect on the kind of difficulties posed by the routine task system and how these may violate the patients’ right to access appropriate treatment and care. Kleinman (2012) reiterates that “care” should be seen as the most important aspect of life – it must not just be a critical aspect in training of health care professionals, but must be seen as a core aspect of humankind which must be embraced by all. According to him, “taking care” and “caring” means the “cultivation of the person and the relationship through practices of attending, enacting, supporting and collaborating – which means doing good for others” (p.1151).

#### **11.1.6. What can we draw from my personal experiences in this inquiry?**

Because I adopted what I termed in the previous chapter the tortoise approach, I had moments of joy and pain, moments in which I felt defeated and moments where I felt privileged to carry out this inquiry among a vulnerable and marginalized population group. Although I feel that I had not done anything substantial to change their lives, at least I had the opportunity to bring to the fore some of their struggles which they had not previously had a chance to talk about. Here are some of the issues that reflect my moments in the field:

When one PWE sent me a cell phone sms message which said: “... *the gift voucher that you gave me helped me to buy electricity...thank you so much*”.

When a carer whose spouse had epilepsy showed me packets of unlabelled seizure medications and was concerned that the spouse was forgetful...

When one older partner said: “*I have left everything to God...it’s my burden and I will carry it*”.

When I had referred some of them to gain access to epilepsy support services as they sometimes could not get help due to issues of access. This PWE said: “*I phoned the organisation and they told me that I must go to them. I do not have money and I don’t even know the place...*”

When I referred the PWE to the local organisation in the study setting, I was informed that the person must first be seen by the doctor – that is how the policy works...

When one of my interviewees said this about the powerful nature of the professional health sector: “*If a lion shows up here who will stand against it? Is it not that everybody is afraid? Everybody will run away because they see a lion. Do you see that? This is what I find kills the hospitals...*”

When one of the attendees of a community meeting in which I presented the findings said: “*I do not have anything to do with epilepsy... I do not have any members of my family who has the illness*”.

I found myself benumbed in the process. As I stated in Chapter Ten where I reflected on the tortoise under the couch, I found myself using the movements of retraction, like the tortoise when it withdraws its head and neck into its shell, and when it sticks its head and neck out of the shell and continuing slowly with its journey until it reaches its destination, which is the end of this dissertation.

This reminded me of Nelson Mandela's "long walk to freedom", as he put it in his autobiography...because the stories about subjective experiences and perspectives on epilepsy that I have heard and that I am retelling are also influenced by the political history of the past and the present as well as the culture of the health system (Kaplan-Myrth, 2007). I have presented some stories that give voice to the subjective experiences and perspectives on epilepsy of PWE and their carers in this urban township in Cape Town, South Africa. I hope that these will go some way to help us to gain an insightful grasp of how it is to live with epilepsy and to care for a spouse, a child, a sibling, a friend or a neighbour who has epilepsy. I trust that this study will show a need to prioritize epilepsy as an important public health problem like other chronic illnesses in this study setting.

### **11.2. What are the study's limitations?**

This dissertation explored perspectives and subjective experiences of Xhosa-speaking adult PWE and their carers in an urban township in Cape Town. However, there were some limitations which I need to acknowledge. Although the study yielded a range of perspectives and subjective experiences on epilepsy from the point of view of PWE and their carers using individual interviews, focus group discussions and observations, it had some limitations.

First, there were limitations that related to the sample and inclusion criteria. Only Xhosa-speaking adult PWE who were taking seizure medication were recruited. Therefore, those who were eligible and were not taking seizure medication were excluded. As a result, these results cannot be generalized to the entire population group of adult PWE in this setting as their experiences and perspectives about epilepsy might be different between those who take seizure medication and those who do not take it. In addition, another limitation was that the study used a snowball technique and local field assistants who knew some of the PWE and their carers. Therefore, only those who were known by recruited individuals and field assistants were included in the study.

Second, there were some recruited PWE and other carers who because of incorrect physical addresses and structural constraints could not be traced. There were also some recruited individuals who declined to participate and the reasons for this were not established, in view of respecting their right to withdraw after giving consent. There is also a possibility that the issue of stigma by association could have been the reason but this was not determined. With regard to recruitment of THs, there were some who were members of the local THO who were recruited via the organization. Therefore, those who did not belong to the local THO might have been missed.

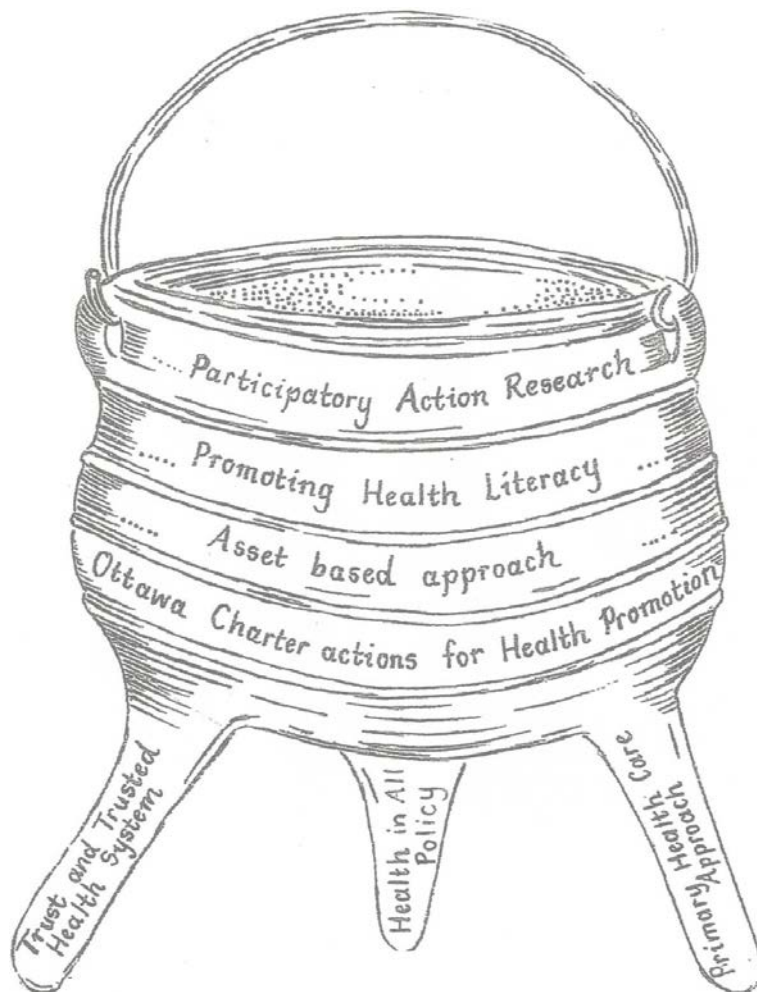
Third, recruitment of the medical doctors who were facilitating students in one of the medical universities in Cape Town was another limitation. In addition, the recruited medical doctors practiced in different contexts in Cape Town and their perceptions about management of epilepsy in primary care settings may be influenced by the settings in which they practice. Another limitation is that there was only one neurologist who was interviewed. Therefore these perceptions cannot be generalized to the population of the recruited doctors interviewed in this study.

Fourth, observations occurred at a single clinic and comprised very few observed events which were of short duration. In addition, the study sample was small and the results cannot be generalized. Only a few interactions between adult PWE and some western-trained health care professionals were observed in one setting which served the study population, and the findings may not accurately provide a holistic picture of the health system factors affecting the treatment and care of PWE. In order to gain a holistic picture of the health system, existing models such as the Donabedian model can be used to conceptualize health service delivery in terms of its health care outcomes (Ghaffari Sardasht, Shourab & Jafarnejad, 2014; Lawson & Yazdany, 2012). Therefore, to make the findings generalizable, it would be beneficial for follow up studies to extend to other settings the Western Cape as well as in the other provinces in the country.

Last, despite these limitations, from my personal reflection and from using Kleinman (1980) EMs framework, the findings show that the methods used in this study can help to provide an in-depth understanding of perspectives and subjective experiences on epilepsy. However, for researchers who may want to use these methods in similar research projects in other settings, it is important to note that the choice of my methodology could have been strengthened by using mixed ethnographic methods such as photo voice which was used by Allotey and Reidpath in 2007 in Cameroon to gain an understanding of the socio, cultural and environmental context of epilepsy as well as participant observation similar to Kendall-Taylor et al.'s (2009) study among THs in Kenya. The use of matched control groups would also be important to consider. I disseminated the findings at the end of each phase of the project. Although this may be deemed as having a potential to bias the interpretation and conclusions of the study, what I learnt is that in fact it enabled me to increase the trustworthiness of the findings by providing evidence of pictures and actual verbatim responses to support the findings - and this was welcomed by most of the stakeholders.

### **11.3. What actions can we take to map the way forward?**

The research findings of this dissertation enabled the development of a tentative conceptual model which can be used to guide action plans which can help to empower adults with epilepsy and their carers in the study setting to deal with challenges of epilepsy and to improve their health and well-being. The model can also be used to design and test interventions that have a measurable and positive impact on one or more of the studied groups, but further research would be needed. A description of this model is provided in Figure 11.3.1 (see page 98).



**Figure 11.3.1. A tentative conceptual model for actions to address challenges of adults with epilepsy and their carers in the study setting.**

This conceptual model encapsulates the iconic African image of a three legged cast-iron pot which I use to symbolize the three key pronged pillars through which the quality of life of adult PWE and their carers can be enabled: (i) a trust and trusted health system (Gilson, 2003) which is characterised by collaborative partnerships that are built on trust and are committed to sustainable projects and actions for social change (Birbeck, 2012) (ii) the Helsinki health promotion Health in All Policy (HiAP) (Khayatzadeh-Mahani, Sedoghi, Mehrolhassani & Yazdi-Feyzabadi, 2015) framework which puts emphasis on horizontal policies whose health promotion actions must be characterised by legitimacy, accountability, transparency, participation, sustainability and collaboration; and (iii) the Comprehensive Primary Health Care Approach which endorses political commitment to ensure equity, a health rights based approach and universal access to health care and an integrated approach to health care in general (Labonte, Sanders, Packer et al., 2014). It further highlights strategies such as community-based participatory action research which emphasises transformative learning (Wallerstein & Duran, 2010); an asset based approach (Morgan & Ziglio, 2007) and the WHO (1986) Ottawa Charter actions (Nutbeam, 1998) to empower adults with epilepsy and their carers.

On the other hand, the model can be used to assess the impact of a specific intervention focusing on adult PWE and their carers with a view of testing the model with a pilot intervention that targets either adult PWE or combining adult PWE and carers. Thereafter, depending on whether the model has been validated, then it could be used to predict and measure the impact of well-validated interventions that target one or more of these issues especially individual adults with epilepsy in the urban township setting, thereby providing a way forward that builds on the findings from this dissertation. Finally, there were some unreported themes in some of the published articles in this dissertation. Another step would be for the author and co-authors to pursue these themes with the aim of submitting manuscripts for peer review to suitable journals.

#### **11.4. The last word**

The stories that I have heard from all my participants, all resonate around care and quality of care. In South Africa, the Primary Health Care Approach (PHC) was adopted after 1994 (Dookie & Singh, 2012) and speaks to patient empowerment. The principle of “people first” is embodied in the Batho Pele approach, a cornerstone of public service policy in South Africa (Kaisara & Pather, 2011). There is a constitutional right to health care in South Africa, and a patients’ health rights charter that is endorsed by the Health Professions Council of South Africa (HPCSA, 2008). However, the main challenge faced by the SA health system is that the actual design of the health system and its processes and procedures is not aligned with the espoused values, and an effort is needed to address this challenge. In addition, there is evidence for a call to train medical generalists in community orientated primary health care (COPC) in order to respond effectively to the health care needs of the majority of the country’s population groups who seek care from the public health sector (Howe, Mash, & Hugo, 2013).

This study has shown evidence of awareness of these issues, but there is something of a gap between ideals seen in policy and people’s experiences on the ground. This study is by no means the first to identify the need for a health care system that extends beyond just focusing on statistical numbers of patients being seen (Moosa, 2014), and that seeks to improve the patients’ and health care providers’ experiences of care, interactions and actions (Ononeze, Murphy, MacFarlane, Byrne, & Bradley, 2009). In order to provide a meaningful understanding of care and what care is about and to complement what Kleinman (2012) says about care, I shall quote what one of the traditional healers said about care before I bring the study to an end. He said:

*From my knowledge and experience, care is when a patient arrives I ask him, who you are, where do you come from? Why I do that is because I will also tell you who I am you see? Where I come from. So that when you get well after being helped you will know who helped you and where he came from. You would say, “I was attended this way and that way to people and even when you go around you will tell...that is why people say one person is liked by people... It is not that... but it is his contributions or the works they do that makes people to like them.... If you can make a fool of a person, and you do not care for people, even a child will be afraid. You will not be able to take care of him because he is afraid.*



*Care for me means that I should not be concerned about myself and not care for the sick...I must care for the patient more than I care about myself.... He will say "I have been around, I went to so and so and I got help...people there like other people so much.... It means a person gets well even before taking medication.... Just your care made that person to get well.... But if you ill-treat a person, how will he get well?*

In conclusion, I thank this father (I would call him father, or Tata in isiXhosa tradition) for teaching us about care and what it means to care. I now feel that we do have a true grasp on the experiences of living with epilepsy and caring for adults who have epilepsy in this urban township in Cape Town, South Africa. I hope that this dissertation has made some valuable contributions which have a potential to inform and influence local policy, research, teaching and practice and design of health promotion interventions that can empower adult PWE and their carers to be able to enjoy a good quality of life.

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## APPENDIX B1

## CO-AUTHOR'S DECLARATION

## CO-AUTHORS DECLARATION

Title		General practitioners' perceptions on management of epilepsy in primary care settings in Cape Town, South Africa: An exploratory pilot study.	
Authors		Keikelame MJ, Hills RM, Naidu C, de Sá A, Zweigenthal V (2012)	
Journal		<i>Epilepsy &amp; Behavior</i> 25: 105-109	
Student name		Mpoe Johannah Keikelame	
Student number	Name of institution	Department	
US17366356	Stellenbosch University	Psychology	
<ul style="list-style-type: none"> <li>• I hereby declare that I am the co-author of the published peer reviewed article stated above and that I am aware that the publication will form part of the PHD dissertation by the PHD student who made major contributions to this manuscript.</li> <li>• I authorize the inclusion of this publication in the students' PHD thesis entitled: 'Perspectives on epilepsy on the part of patients and carers in a South African urban township'.</li> <li>• Contributions by the student to this manuscript: Conceived, planned and implemented the study design. Collection and analysis of the data. Drafting of the manuscript. Feedback and preparation of the manuscript for publication until its acceptance.</li> </ul>			
Co-authors name		Co-authors signature	Date (d/m/y)
Claudia Naidu			04 August 2015

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CO-AUTHOR'S DECLARATION

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Journal		<i>Epilepsy &amp; Behavior</i> 25: 105-109	
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Student number	Name of institution	Department	
US17366356	Stellenbosch University	Psychology	
<ul style="list-style-type: none"> <li>I hereby declare that I am the co-author of the published peer reviewed article stated above and that I am aware that the publication will form part of the PHD dissertation by the PHD student who made major contributions to this manuscript.</li> <li>I authorize the inclusion of this publication in the students' PHD thesis entitled: 'Perspectives on epilepsy on the part of patients and carers in a South African urban township'.</li> <li>Contributions by the student to this manuscript: Conceived, planned and implemented the study design. Collection and analysis of the data. Drafting of the manuscript. Feedback and preparation of the manuscript for publication until its acceptance.</li> </ul>			
Co-authors name		Co-authors signature	Date (d/m/y)
Angela de Sa			<div style="border: 1px solid black; padding: 5px;"> <p><b>Dr. A de Sa</b>  <b>MB ChB, MCFP</b>  <b>MP0384836</b></p> <p><b>11 DEC 2015</b></p> <p><small>11<sup>th</sup> Ave Retreat, 7945                      Practice No: 5603080                      Ph: 021 - 713 9800                      Fax: 021 - 712 1493</small></p> </div>



## APPENDIX B3

## CO-AUTHOR'S DECLARATION

Title	General practitioners' perceptions on management of primary care settings in Cape Town, South Africa: An exploratory pilot study.	
Authors	Keikelame MJ, Hills RM, Naidu C, de Sa A, Zweigenthal V (2012)	
Journal	<i>Epilepsy &amp; Behavior</i> 25: 105-109	
Student name	Mpoe Johannah Keikelame	
Student number	Name of institution	Department
US17366356	Stellenbosch University	Psychology
<ul style="list-style-type: none"> <li>• I hereby declare that I am the co-author of the published peer reviewed article stated above and that I am aware that the publication will form part of the PHD dissertation the PHD student who made major contributions to this manuscript.</li> <li>• I authorize the inclusion of this publication in the students' PHD thesis entitled: 'Perspectives on epilepsy on the part of patients and carers in a South African urban township'.</li> <li>• Contributions by the student to this manuscript: Conceived, planned and study design. Collection and analysis of the data. Drafting of the manuscript. and preparation of the manuscript for publication until its acceptance.</li> </ul>		
Co-authors name	Co-authors signature	Date ( <i>dimly</i> )
Virginia EM Zweigenthal	'~UU	30 July 2015

## Appendix B4

## CO-AUTHORS DECLARATION

Title		General practitioners' perceptions on management of epilepsy in primary care settings in Cape Town, South Africa: An exploratory pilot study.	
Authors		Keikelame MJ, Hills RM, Naidu C, de Sá A, Zweigenthal V (2012)	
Journal		<i>Epilepsy &amp; Behavior</i> 25: 105-109	
Student name		Mpoe Johannah Keikelame	
Student number	Name of institution	Department	
US17366356	Stellenbosch University	Psychology	
<ul style="list-style-type: none"> <li>• I hereby declare that I am the co-author of the published peer reviewed article stated above and that I am aware that the publication will form part of the PHD dissertation by the PHD student who made major contributions to this manuscript.</li> <li>• I authorize the inclusion of this publication in the students' PHD thesis entitled: 'Perspectives on epilepsy on the part of patients and carers in a South African urban township'.</li> <li>• Contributions by the student to this manuscript: Conceived, planned and implemented the study design. Collection and analysis of the data. Drafting of the manuscript. Feedback and preparation of the manuscript for publication until its acceptance.</li> </ul>			
Co-authors name		Co-authors signature	Date (d/m/y)
RICHARD M. HILLS		R.M. Hills	18/8/15

## APPENDIX C

## DECLARATION OF AUTHOR'S CONTRIBUTION

For every published journal article in this thesis, I have taken full responsibility as first author and a summary of my contributions are outlined below:

Section of thesis	Description	My contribution and contribution of others	Submission dates and publication status
Chapter 1: Introduction	Conventional thesis introduction	100% (with supervision)	
Chapter 2: Literature review on psychosocial and cultural issues of adult PWE and their carers in Africa.	Manuscript 1: Psychosocial and cultural issues affecting adults with epilepsy and their carers in Africa.	<u>First author (MJK):</u> Designed the search strategy and methodology according to principles of systematic review and assisted by supervisor and information science professionals.  Analysis of the review data, and write up of the manuscript.	Manuscript to be submitted to a suitable journal
Chapter 3: Article on professional carers' perceptions on management of epilepsy.	1 <sup>st</sup> Article which was an exploratory pilot study published in <i>Epilepsy &amp; Behavior</i> - and co-authored with a skilled researcher and three medical doctors, one of whom was a neurologist and the other, a family physician.	<u>First author (MJK):</u> <ul style="list-style-type: none"> <li>• I conceptualized the study as this was based on my previous work</li> <li>• I wrote the proposal and incorporated inputs from all co-authors</li> <li>• I conducted the literature review and designed data collection instruments</li> <li>• I conducted individual interviews with the second author.</li> </ul>	Published in 2012.

		<ul style="list-style-type: none"> <li>• Transcriptions were done by the third author.</li> <li>• I conducted data analysis of all transcripts with the third author and I was responsible to ensure feedback meetings on findings from the analysed data.</li> <li>• I was assisted by the fourth author to recruit eligible participants and I was responsible for sending invitation letters to recruit participants and to set appointments for the interviews; to clarify the purpose of the study and to gain informed consent.</li> <li>• I was responsible for communicating the findings and presenting them to different audiences; writing the annual report and identifying and selecting the appropriate scientific journal; and responding to reviewers' comments until acceptance of the article.</li> </ul>	
Chapter 4: Observations of clinical context of epilepsy care.	2 <sup>nd</sup> article: Published in <i>Epilepsy &amp; Behavior</i> and co-	<u>First author (MJK):</u> <ul style="list-style-type: none"> <li>• Gaining field entry to study setting and access to participants and</li> </ul>	Published in 2013.

	<p>authored with supervisor.</p> <p>Co-author was my primary supervisor and he helped design the methods as part of his role as a supervisor, and edited the final write-up (as he would have done had this been a chapter in a conventional thesis).</p>	<p>for recruitment of eligible participants and informed consent.</p> <ul style="list-style-type: none"> <li>• Clarifying purpose of the study and communication channels.</li> <li>• Designing the observation guide, pre-testing and administration thereof.</li> <li>• Writing field notes and keeping a reflective journal; typing field notes and analysis of observation data.</li> <li>• Discussing the findings with my supervisor; presenting preliminary findings to stakeholders to ensure trustworthiness of the findings and incorporating stakeholders' comments and feedback.</li> <li>• Doing literature review on observations, ethics in the field and reflexivity.</li> <li>• Writing up the findings and disseminating via annual report and peer-reviewed article.</li> <li>• Identifying and selecting the appropriate scientific journals for publication.</li> </ul>	
--	---	--	--



		<ul style="list-style-type: none"> <li>• Responding to reviewers' comments with assistance from supervisor until acceptance of the journal for publication.</li> </ul>	
Chapter 5: Article on home-based carers perspectives and experiences on epilepsy	3 <sup>rd</sup> Article published in the <i>International Journal of Qualitative Studies on Health and Well-Being</i> and co-authored with supervisor.	My role as primary author is as above, and I have once again made use of the skills of my supervisor as a methodologist and editor for his co-authorship role.	Published in 2016.
Chapter 6: Article on traditional healers' views on epilepsy.	4 <sup>th</sup> article published in <i>Transcultural Psychiatry</i> - and co-authored with supervisor.	My role as primary author is as above, and I have once again made use of the skills of my supervisor as a methodologist and editor for his co-authorship role.	Published in 2015.
Chapter 7: Article on a single story of a popular carers' experiences and perspectives on challenges for caring for PWE	5 <sup>th</sup> article published in <i>Epilepsy &amp; Behavior</i> – and co-authored with supervisor.	My role as primary author is as above, and I have once again made use of the skills of my supervisor as a methodologist and editor for his co-authorship role.	Published in 2013.
Chapter 8: Article on care giving difficulties experienced by popular carers of patients with epilepsy (family members, neighbours)	6 <sup>th</sup> article published in the <i>Journal of Health Psychology</i> and co-authored with supervisor.	My role as primary author is as above, and I have once again made use of the skills of my supervisor as a methodologist and editor for his co-authorship role.	Published in 2015.
Chapter 9: Article on patient experiences on epilepsy.	7 <sup>th</sup> article published in the <i>BMC International Health and Human</i>	My role as primary author is as above, and I have once again made use of	Published in 2016.

	<i>Rights Journal</i> and co-authored with supervisor.	the skills of my supervisor as a methodologist and editor for his co-authorship role.	
Chapter 10: Manuscript on personal reflections on challenges in the field	Manuscript 2: 'The tortoise under the couch' An African woman's reflections on critical moments, culture and ethics on conducting a qualitative research project.	I am 100% author of this article. I do acknowledge expert advice from my supervisor.	This manuscript was submitted to the <i>International Journal of Social Research Methodology</i> in July 2016 and is currently under review.
Chapter 11: Conclusion	This is a conventional conclusion to a thesis, drawing together the strands from the articles.	100% author (with supervision).	

## **APPENDIX C1**

### **DECLARATION OF ILLUSTRATIVE ARTWORK IN THIS DISSERTATION**

Illustrative fictional artwork of figures and hand drawn pictures herein my dissertation are my own designs and ideas and does not overstep the boundaries of any third party infringement. Illustrative fictional artwork of figures and hand drawn pictures herein my dissertation was assisted by Ms Anthea Heald, and the copy right thereof resides with me.

Signature

Date

## APPENDIX D1

### OBSERVATION GUIDE/RECORD SHEET FOR PATIENTS WITH EPILEPSY ATTENDING LOCAL CHC

Project title: Perspectives on epilepsy on the part of patients and carers in a South African Urban Township.

Principal Investigator: Ms Mpoe Johannah Keikelame, Primary Health Care Directorate, University of Cape Town

#### **Section 1: Introduction**

- Hello, I am Johannah Keikelame. I work in the Directorate of Primary Health Care at the University of Cape Town and I am currently studying at Stellenbosch University. I am doing a study to investigate how people with epilepsy understand and experience the illness.
- I would like to see what you do at the waiting area when you come for your check- up at the epilepsy clinic at Vanguard.
- If you agree, I will not ask you to give me your personal information. I will only ask you to give me permission to sit with you and see what you say you do when you come for your check-up and after your check-up.
- You may refuse to give me permission if you do want me to see what you do here at the clinic. This will not affect your health care.
- I will take a few notes that will help me to see what other things to include in my research question.
- If you agree, will you kindly sign that I have explained to you why I would like to see what you do before and after check-up.

Patients ID \_\_\_\_\_

Observer \_\_\_\_\_

Date \_\_\_\_\_

Place \_\_\_\_\_

*Once again, thank you very much for agreeing to let me see what you actually do when you come for check-up.*

#### **Section 2: Individual information and observation information**

1. Gender: M \_\_\_\_\_ F \_\_\_\_\_
2. Race: Black \_\_\_\_\_ Coloured \_\_\_\_\_ Other \_\_\_\_\_ Unsure \_\_\_\_\_
3. Who accompanied the patient? \_\_\_\_\_

---

4. Patient behaviours

- What do you do at the waiting area before you go for check-up?

- 
- 
- What do you do after you have had your check-up?
- 

5. Observed behaviour:

- Description of what the participant actually does at the waiting area before the check-up
- 

- Description of what the participant actually does after check-up
- 
- 

6. Duration of the check-up: Hurried \_\_\_\_\_ Estimated duration \_\_\_\_\_

7. Who attended to the patient before, during and after check-up?

---

8. Description of the waiting area \_\_\_\_\_

9. Number of patients at the waiting area \_\_\_\_\_

10. Language used \_\_\_\_\_

**Section 3:** Researchers reflection (what I heard, saw, touched, how I felt, my expectations/disappointments; anything new that I learnt, any barriers)

---

---



## APPENDIX D2

### OBSERVATION SHEET/GUIDE FOR PATIENTS WITH EPILEPSY ATTENDING THE EPILEPSY SUPPORT GROUP AT LOCAL CHC

**Project title: Perspectives on epilepsy on the part of patients and carers in a South African Urban Township.**

**Principal Investigator:** Ms Mpoe Johannah Keikelame, Primary Health Care Directorate, University of Cape Town

#### 1. Introduction

- Hello, I am Johannah Keikelame. I work in the Directorate of Primary Health Care at the University of Cape Town and I am currently studying at Stellenbosch University. I am doing a study to investigate how people with epilepsy understand and experience the illness.
- I would like to see what you do during your support group meetings here at the CHC so that I can learn more about the kind of things that you discuss in your support group.
- If you agree, I will not ask you to give me your personal information. I will only ask you to give me permission to sit with you and see what say you do here at the support group.
- You may refuse to give me permission if you do want me to see what you do here at the clinic. This will not affect your health care.
- I will take a few notes that will help me to see what other things to include in my research question.
- If you agree, will you kindly sign that I have explained to you why I would like to see what you do in your support group.

Observer\_\_\_\_\_

Date\_\_\_\_\_

#### 2. **Observation information**

##### 2.1. Characteristics of the support group of people with epilepsy

- Number of people with epilepsy attending the support group\_\_\_\_\_
- Number of females:\_\_\_\_\_ Number of males\_\_\_\_\_
- Race: Black\_\_\_\_\_ Coloured\_\_\_\_\_ Other\_\_\_\_\_
- Language used in support group\_\_\_\_\_

2.2. Topics discussed:

---

---

---

---

2.3. Source of information (who gives information?)

---

---

---

---

2.4. Content covered

---

---

---

---

2.5. Questions asked (by whom?)

---

---

---

---

2.6. Answers given (what kind of answers given and by whom?)

---

---

---

---

2.7. Documents used in support group (e.g. attendance register)

---

---

---

---

2.8. Information materials. (e.g. leaflets, posters)

**3. Characteristics of setting/venue**

---

---

---

---

**4. Duration of support group meeting:**

Starting time.....Ended.....Date.....

**Section 3:** Researchers reflection (what I heard, saw, touched, how I felt, my expectations/disappointments; anything new that I learnt, any barriers)

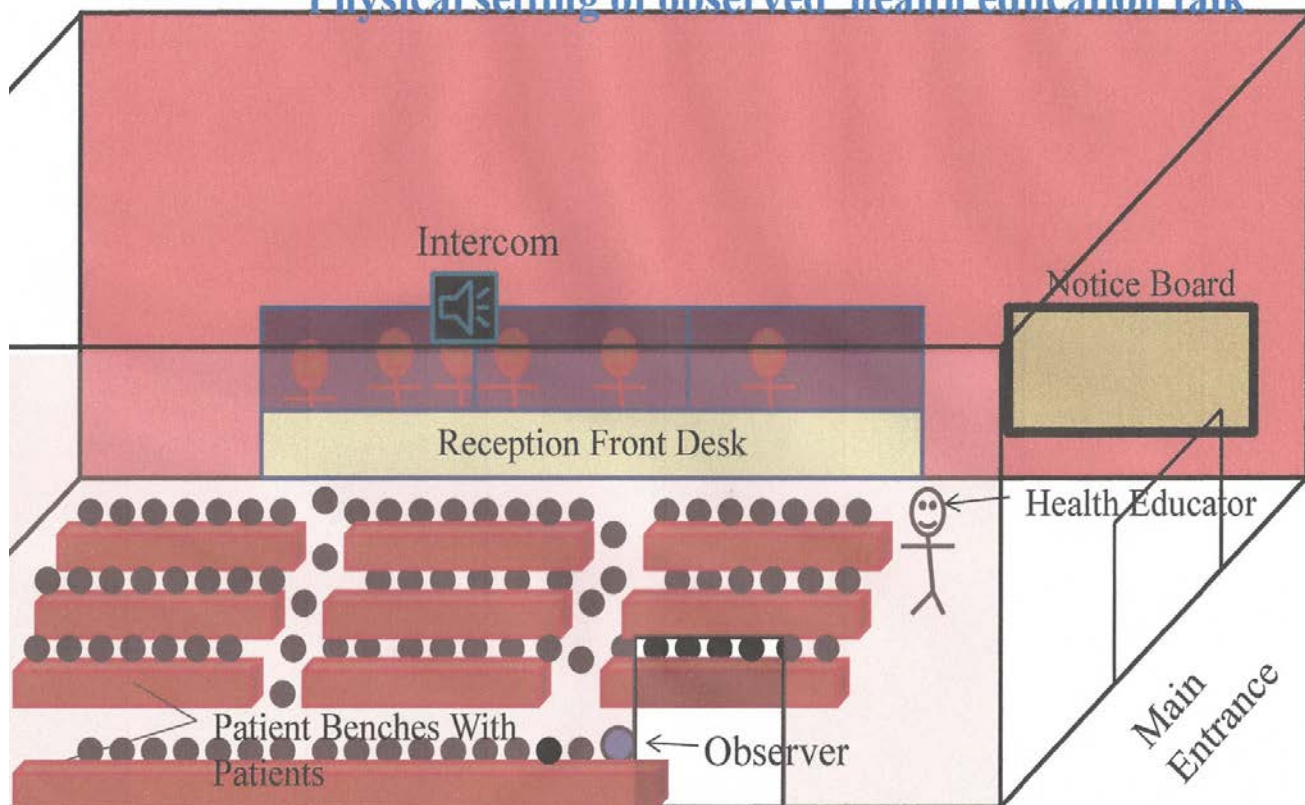
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## APPENDIX E

### Physical setting of observed health education talk



## APPENDIX F1

### INTERVIEW GUIDE FOR PEOPLE WITH EPILEPSY (PWE)

***Project title: Perspectives on epilepsy on the part of patients and carers in a South African Urban Township.***

Principal Investigator: Ms Mpoe Johannah Keikelame, Primary Health Care Directorate, University of Cape Town.

---

#### Introduction

- Thank you very much for agreeing to speak to me today. First, I will introduce myself and will also invite you to do the same. After the introductions, I will explain the purpose of my visit to gain your consent for the interview. I am Johannah Keikelame. I work in the Directorate of Primary Health Care at the University of Cape Town and I am currently doing my doctoral degree at Stellenbosch University. Because of my interest in epilepsy, I decided to do this study to learn more about the condition from people suffering from epilepsy and their carers. You are.....

#### Study background and purpose

- I am doing a study in a Black urban township to investigate how people with epilepsy and their carers (for example family members or friends, traditional healers, doctors, nurses, social workers and others) understand and experience epilepsy.
- The information you share with me today may help to better understand perspectives and subjective experiences of people with epilepsy and their carers and to improve the poor understanding of the condition, its treatment and care.

#### Interviewee information

- Thank you for agreeing to participate in the study. I have a core set of questions that I will be asking you which will help you to share your perspectives and experiences about epilepsy. You do not have to answer all questions. Your participation is voluntary and you may also withdraw from the interview at any point in time.
- As I may not be able to take detailed notes during the interview, I will ask your permission to record the conversation. The recorded information will be assigned a number and a false name to protect your identity and will be kept safe in a locked cabinet.
- The information you share with me will be transcribed and content analysed and it will be disseminated in reports and published in scientific journals and your name will not be used without your permission.
- I would like to assure you that anything that you tell me will be kept in strict confidence and your name will also NOT be linked to any information.
- I will therefore ask for up to 90 minutes of your valuable time for this interview.
- At the end of the interview, I will ask you some questions about your personal information and your household and the name of the person who may be family

or friend and a traditional healer that you may want me to recruit for the interview and the persons contact details.

- If at any point you do not want to answer any particular question, please feel free not to do so. I am not going to ask any personal information but would like to gain more insight about the problem from your perspective as a person suffering from epilepsy.
- Before we begin, do you have any questions to ask? If not, I will ask you to sign below, stating that you have fully understood the explanations given to you by me, and that your participation is voluntary.

Permission to record the interview?.....

Permission to use information?.....

Interviewee's signature:.....

Date:.....Place.....

Interviewer's signature:.....

Date.....Place.....

*Once again, thank you very much for agreeing to participate in the interview.*

Section 2: Perspectives and experiences on epilepsy.

2.1. Some people experience an illness that is sometimes called epilepsy. What do people in your community call this illness? *[Probe for other names used to refer to epilepsy, what the names mean and why they are used]*  
.....

2.2. From your point of view, what do you call your illness? Are there other names that you use to refer to your illness? If yes, what names do you use and why?  
.....

2.3. What do you think has caused your epilepsy? Are there other things that you think may have caused your epilepsy? If yes, please tell me more about them.  
.....

2.4 When did you get epilepsy? Why do you think your epilepsy started at that time it did?  
.....

2.5. What do you think the illness does to your health? How does the illness work?  
.....

2.6. From your personal point of view, how serious is your illness? Do you think your illness [epilepsy] will have a short or long course? *[Probe for reasons]*  
.....

2.7. What kind of treatment do you think you should receive for your illness? *[Probe for reasons] What outcomes do you expect from your epilepsy treatment?*  
.....

2.8. What are the main difficulties you have experienced from having epilepsy? *Can you please give examples of difficulties you experience from having epilepsy [Probe for difficulties for you, at home, community, society?]*  
.....



2.9. How does epilepsy affect your life? [Probe for issues on driving, married life, employment]

.....  
2.10. Now I would like you to share with me the things that make it difficult for you to understand your illness. What things make it difficult for you to be able to understand your illness [epilepsy?] [Probe: Can you please give me examples things that make it difficult for your family, your friends, your community and your society to understand epilepsy].

.....  
2.11. In your opinion, what kind of actions should be taken to address the kind of things that makes it difficult for you to understand and live with the illness? Who should take action and why? What are some of the things that may help taking such actions? What are some of the things that may make it difficult to take such actions?

.....  
2.12. What are the main things that you fear most about your illness? [Probe: fears about treatment, life in general, working, driving, having children, marriage, working/employment].

.....  
Section 3: Supplemental information and conclusion

I have now come to end of our conversation. Before I end the conversation, I would like to know if there is anything else that I did not ask that you may have wanted to share with me.

If Yes: Please tell me about it

.....  
If NO, I would like to thank you very much for your time and for the important information that you shared with me today.

- I will present the results of the study to all participants, to the Department of Health, Epilepsy South Africa, local health structures, conferences and workshops and will publish findings in peer reviewed journals.
- I will inform you in due course of the date, time and place where I will be presenting findings of the study for you to come and hear what you and other participants that I interviewed have said about epilepsy next year.
- I will inform you if there are any issues that I may want to follow up with you after reading your recorded interview. I will set an appointment with you to come and clarify those issues with you.
- In the event that I may use your own words that you used in this interview, I will use a false name to protect your identity.

*Thank you once again for your time. I will now proceed to take information about yourself and your household.*

Section 4: Interviewers impression/notes

Date of interview \_\_\_\_\_ Place \_\_\_\_\_

ID \_\_\_\_\_ Pseudonym \_\_\_\_\_

Observations/ Reaction to questions/other important information.

## APPENDIX F2

### INTERVIEW GUIDE FOR CARERS OF PEOPLE WITH EPILEPSY

***Project title: Perspectives on epilepsy on the part of patients and carers in a South African Urban Township.***

**Principal Investigator:** Ms Mpoe Johannah Keikelame, Primary Health Care Directorate, University of Cape Town

---

#### **Introduction**

- Thank you very much for agreeing to speak to me today. First, I will introduce myself and will also invite you to do the same. After the introductions, I will explain the purpose of my visit to gain your consent for the interview. I am Johannah Keikelame. I work in the Directorate of Primary Health Care at the University of Cape Town and I am currently doing my doctoral degree at Stellenbosch University. Because of my interest in epilepsy, I decided to do this study to learn more about the condition from people suffering from epilepsy and their carers. You are.....

#### **Study background and purpose**

- I am doing a study in an urban township to investigate how people with epilepsy and their carers (for example family members or friends, traditional healers, doctors, nurses, social workers and others) understand and experience epilepsy.
- The information you share with me today may help to better understand perspectives and subjective experiences of people with epilepsy and their carers and to improve the poor understanding of the condition, its treatment and care.

#### **Interviewee information**

- Thank you for agreeing to participate in the study. I have a core set of questions that I will be asking you which will help you to share your perspectives and experiences about epilepsy. You do not have to answer all questions. Your participation is voluntary and you may also withdraw from the interview at any point in time.
- As I may not be able to take detailed notes during the interview, I will ask your permission to record the conversation. The recorded information will be assigned a number and a false name to protect your identity and will be kept safe in a locked cabinet.
- The information you share with me will be transcribed and content analysed and will be disseminated in reports and published in scientific journals and your name will not be used without your permission.
- I would like to assure you that anything that you tell me will be kept in strict confidence and your name will also NOT be linked to any information.
- I will therefore ask for up to 90 minutes of your valuable time for this interview.
- At the end of the interview, I will ask you some questions about your personal information and your household and the name of the person who may be family

or friend and a traditional healer that you may want me to recruit for the interview and the persons contact details.

- If at any point you do not want to answer any particular question, please feel free to do so. I am not going to ask any personal information but would like to gain more insight about the problem from your perspective as a person suffering from epilepsy.
- Before we begin, do you have any questions to ask? If not, I will ask you to sign below, stating that you have fully understood the explanations given to you by me, and that your participation is voluntary.

Permission to record the interview?.....

Permission to use information?.....

Interviewee's signature:.....

Date:.....Place.....

Interviewer's signature:.....

Date.....Place.....

**Once again, thank you very much for agreeing to participate in the interview.**

**Section 2: Perspectives and experiences on epilepsy.**

2.1. Some people experience an illness that is sometimes called epilepsy. What do people in your community call this illness? **[Probe for other names used to refer to epilepsy, what the names mean and why they are used]**  
.....

2.2. From your point of view, what do you call the illness [epilepsy]? Are there other names that you use to refer to epilepsy? If yes, what names do you use and why?  
.....

2.2. What do you think is the cause of the illness [epilepsy] of the person you are caring for? Are there other things that you think may have caused this person's epilepsy? If yes, please tell me more about them.....

2.3 Why do you think epilepsy affected the person that you are caring for?  
.....

2.4. What do you think epilepsy does to the person that you are caring for? How does it[epilepsy] affect him or her?  
.....

2.5. From your personal point of view, how serious is epilepsy? Do you think the person's epilepsy will have a short or long course? **[Probe for reasons]**  
.....

2.6. What kind of treatment do you think a person with epilepsy who you are caring for should receive? **[Probe for reasons] What outcomes do you expect from the treatment you mentioned?**  
.....

2.7. What are the main difficulties you have experienced from caring for a person with epilepsy?  
**[Probe for the kind of difficulties you have experienced from the person, family, in the community and society at large]**  
.....

2.8. Now I would like you to share with me the things that make it difficult for you to understand epilepsy. What things make it difficult for you to understand epilepsy?

***[Probe for things that make it difficult for a person with epilepsy, for you, family, community and society to understand the condition].***

.....  
2.9. In your opinion, what kind of actions should be taken to address the kind of things that makes it difficult for you to understand epilepsy? Who should take action and why? What are the likely challenges or barriers that may affect taking such actions?

**2.10.** How does epilepsy affect the life of the person you are caring for? **(Probe for issues on driving, married life, employment)**

.....  
.....  
.....  
**2.11.** In your opinion, what kind of actions should be taken to address the kind of things that makes it difficult for you to understand epilepsy? Who should take action and why? What are some of the things that may help taking such actions? What are some of the things that may make it difficult to take such actions?

.....  
**2.12.** What are the main things that you fear most about epilepsy? ***[Probe: fears about treatment, driving, having children, marriage, and working/employment].***

**Section 3: Supplemental information and conclusion**

I have now come to end of our conversation. Before I end the conversation, I would like to know if there is anything else that I did not ask that you may have wanted to share with me.

**If Yes:** Please tell me about it

.....  
.....  
**If NO,** I would like to thank you very much for your time and for the important information that you shared with me today.

- I will present the results of the study to all participants, to the Department of Health, Epilepsy South Africa, conferences, workshops and will publish findings in peer reviewed journals.
- I will inform you in due course of the date, time and place where I will be presenting findings of the study for you to come and hear what you and other participants that I interviewed have said about epilepsy next year.
- If, there are any issues that I may want to follow up with you after reading your recorded interview, I will set an appointment with you to come and clarify those issues.
- In the event that I may use your own words that you used in this interview, I will use a false name to protect your identity.

***Thank you once again for your time. I will now proceed to take information about yourself and your household.***

**Section 4: Interviewer's impression:**

Date of interview \_\_\_\_\_ Place \_\_\_\_\_

ID \_\_\_\_\_ Pseudonym \_\_\_\_\_

**Observations/reaction to questions/other important information:**

.....



## APPENDIX G

### EXAMPLE OF FOCUS GROUP (FGD) GUIDE QUESTIONS WITH CARERS

1. From your point of view, what do people in your community call epilepsy? Are there other names that are used to refer to epilepsy? Why are they used and what do they mean?
2. What do people in your community think is the cause of epilepsy? Probe their personal views about the cause of epilepsy?
3. Why do you think epilepsy affects the people having the illness? What do you think epilepsy does to people having this illness? How does it work in him or her? (In the body, mind and soul)
4. How serious is epilepsy? What course do you think it should take?
5. What kind of treatment do you think people with epilepsy should receive? What outcomes do you expect from the treatment you mentioned?
6. What are the kind of difficulties that people with epilepsy have in your community? What are the reasons for thereof?
7. How does epilepsy affect the lives of people living with the condition?
8. What kind of things make it difficult for people to understand epilepsy?
9. What kind of actions can be taken to address the kind of things that makes it difficult to understand epilepsy?
10. Who should take action and why? What can help to take such actions? What things can make it difficult to take such actions?
11. What kind of role can you play in caring for people with epilepsy?
12. What are the main things that people fear most about epilepsy?

**Adapted from Kleinman (1980)**

## APPENDIX H1

### UCT ETHICS COMMITTEE PERMISSION



UNIVERSITY OF CAPE TOWN

---

Faculty of Health Sciences  
Human Research Ethics Committee  
Room E52-24 Groote Schuur Hospital Old Main Building  
Observatory 7925  
Telephone [021] 406 6626 • Facsimile [021] 406 6411  
e-mail: lamees.emjedi@uct.ac.za

11 November 2011

HREC REF: 440/2011

Mrs MJ Keikelame  
Primary Health Care Directorate  
E 47  
OMB

Dear Mrs Keikelame

*PROJECT TITLE: PERSPECTIVES ON EPILEPSY ON THE PART OF PATIENTS AND CAREERS IN A SOUTH AFRICAN URBAN TOWNSHIP*

Thank you for submitting your response to the queries raised by the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the FHS HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year until 28th November 2012.**

Please send us an annual progress report (website form FHS 016) if your research continues beyond the approval period. Alternatively, please send us a brief summary of your findings so that we can close the research file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

**Please quote the REC. REF in all your correspondence.**

Yours sincerely

A handwritten signature in blue ink that reads "Wesley Henery".

pp

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, HSF HUMAN ETHICS**

Federal Wide Assurance Number: FWA00001637.  
Institutional Review Board (IRB) number: IRB00001938

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## APPENDIX H2

### UCT ETHICS COMMITTEE PERMISSION

UNIVERSITY OF CAPE  
TOWN

Health Sciences Faculty  
Research Ethics Committee  
Room E52-24 Groote Schuur Hospital Old Main  
Building  
Observatory 7925  
Telephone [021] 406 6338 • Facsimile [021]  
4066411  
e-mail: [sumayah.ariefdien@uct.ac.za](mailto:sumayah.ariefdien@uct.ac.za)

**29 October 2009**

**REC REF: 447/2009**

**Mrs M Keikelame**  
Primary Health Care Directorate

Dear Mrs Keikelame

**PROJECT TITLE: GENERAL PRACTITIONERS' PERCEPTIONS ON  
MANAGEMENT OF EPILEPSY IN PRIMARY CARE SETTINGS IN CAPE TOWN.**

Thank you for submitting your study to the Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.


**Approval is granted for one year till the 30<sup>th</sup> October 2010.**

Please submit an annual progress report if the research continues beyond the expiry date. Please submit a brief summary of findings if you complete the study within the approval period so that we can close our file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

**Please quote the REG. REF in all your correspondence.**

Yours sincerely



**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON.HSF HUMAN**

### **ETHICS**

Federal Wide Assurance N1..1111ber:  
FWA00001637.  
Institutional Review Board (IRB)  
number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50,56 and 312.

## APPENDIX H3

### STELLENBOSCH UNIVERSITY ETHICS COMMITTEE PERMISSION



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

#### Approval Notice New Application

04-  
May-  
2012  
Keikel  
ame,  
Johan  
nah  
MJ  
Stelle  
nbosc  
h, WC

#### Protocol #: HS73912011

#### Title: Perspectives on Epilepsy on the part of patients and carers in a South African Urban Township

Dear Ms Johannah Keikelarne,

The **New Application** received **on17-Nov-2011**, was reviewed by Research Ethics Committee: Human Research (Humanities) via Committee Review procedures on **24-Nov-2011** and has been approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **24-Nov-2011 -23-Nov-2012**

#### Present Committee Members:

De  
Villiers.  
Mare  
MRH  
Hattingh  
,  
Johann  
es JP  
Thesna  
ar,  
Christoff  
el CH  
Theron,  
Carl CC  
Somhla  
ba,  
Ncebaz  
akhe  
NZ  
Viviers,



Suzette  
S  
Bitzer,  
Elias  
EM  
Engelbr  
echt,  
Sidney  
SF  
Van Zyl,  
Gerhard  
Mkhont  
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### **Standard provisions**

1. The researcher will remain within the procedures and protocols indicated in the proposal, particularly in terms of any undertakings made in terms of the confidentiality of the information gathered.
2. The research will again be submitted for ethical clearance if there is any substantial departure from the existing proposal.
3. The researcher will remain within the parameters of any applicable national legislation, institutional guidelines and scientific standards relevant to the specific field of research.
4. The researcher will consider and implement the foregoing suggestions to lower the ethical risk associated with the research.

You may commence with your research with strict adherence to the abovementioned provisions and stipulations.

Please remember to use your **protocol number (HS739120 11)** on any documents or correspondence with the REC concerning your research protocol.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

### **Aftel' Ethical Review:**

Please note that a progress report should be submitted to the Committee before the approval period has expired if a continuation is required.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) number REC-050411-032.

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

### **Provincial and City of Cape Town Approval**

Please note that for research at a primary or secondary healthcare facility permission must be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za) Tel: +27 214839907) and Dr Helene Visser at City Health ([Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za) Tel: +27214003981) Research that will be conducted at any tertiary academic institution requires approval from the relevant parties. For approvals from the Western Cape Education Department, contact Dr AT Wyngaard ([awyngaar@pgwc.gov.za](mailto:awyngaar@pgwc.gov.za), Tel: 0214769272, Fax: 0865902282, <http://wced.wcape.gov.za>).

Institutional permission from academic institutions for students, staff & alumni. This institutional permission should be obtained before submitting an application for ethics clearance to the REC.

Please note that informed consent from participants can only be obtained after ethics approval has been granted. It is your responsibility as researcher to keep signed informed consent forms for inspection for the duration of the research.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at 0218089183.

## APPENDIX H4

### WESTERN CAPE PROVINCIAL ADMINISTRATION PERMISSION



STRATEGY & HEALTH SUPPORT  
healthres@pawc.gov.za  
tel: +27 21 483 7907; fax: +27 21 483 9895  
1st Floor, Norton Rose House, 8 Kieboek Street, Cape Town, 8001  
[www.capegov.gov.za](http://www.capegov.gov.za)

REFERENCE: RP 163/2011  
ENQUIRIES: Dr V Applah-Balden

Primary Health Care Directorate, Old Main  
Building, Groote Schuur Hospital, E47-67  
Observatory  
7925

For attention: Mrs Mpoe Johannah Keikelame

Re: Perspectives on epilepsy on the part of patients and carers in a South African Urban Township.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries.

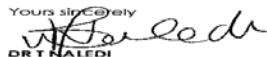
Vanguard CHC                      Dr L Mbanga                      (021) 694 5540

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator ([healthres@pawc.gov.za](mailto:healthres@pawc.gov.za)).
3. The reference number above should be quoted in all future correspondence.

We look forward to hearing from you.

Yours sincerely

  
DR T MALEDI  
DIRECTOR: HEALTH IMPACT ASSESSMENT  
DATE: 22/02/2012

CC                      DR K GRAMMER                      DIRECTOR: SOUTHERN/WESTERN

## APPENDIX H5

### CITY OF CAPE TOWN CITY HEALTH PERMISSION



CITY OF CAPE TOWN | ISIXEKO SASEKAPA | STAD KAAPSTAD

Civic Centre  
12 Hertzog Boulevard  
Cape Town 8001  
P O Box 2815, Cape Town 8000  
Ask for: Dr G H Visser  
Tel: 021 400-3981  
Cell: 083 298 8718  
Fax: 021 421-4894

Iziko loLuntu  
12 Hertzog Boulevard  
Cape Town 8001  
P O Box 2815, Cape Town 8000  
Cela: Qrh G H Visser  
Umnxeba: 021 400-3981  
Cell: 083 298 8718  
Ifeksi: 021 421-4894

Burgersentrum  
Hertzog-boulevard 12  
Kaapstad 8001  
Postbus 2815, Kaapstad 8000  
Vra vir: Dr G H Visser  
Tel: 021 400-3981  
Sel: 083 298 8718  
Faks: 021 421-4894

E-mail: [helene.visser@capetown.gov.za](mailto:helene.visser@capetown.gov.za)  
Website: <http://www.capetown.gov.za>  
Ref:  
Filename: G:\Research\IKeikelame 10272.docx

CITY HEALTH — Specialised Health

2012-02-02

re: Perspective on Epilepsy on the part of patients and careers in a South African Urban Township (ID NO: 10272)

Dear Mrs Keikelame

Permission has been granted to do your research as per your protocol.

**Western Sub District:**  
Contact People:

Langa Clinic  
Mrs G Sifanelo (Sub District Manager)  
Tel/Cell: (021) 514-4122 / 084 630 2903  
Mrs M Stanley (Head: PHC & Programmes)  
Tel/Cell: (021) 514-4124 / 072 329 6361

Please note the following:

1. All individual patient information obtained must be kept confidential.
2. Access to the clinic and its patients must be arranged with the relevant Manager such that normal activities are not disrupted.
3. A copy of the final report must be sent to the City Health Head Office, P O Box 2815 Cape Town 8001, within 3 months of its completion and feedback must also be given to the clinics involved.
4. Your project has been given an ID Number (10272). Please use this in any future correspondence with us.

Thank you for your co-operation and please contact me if you require any further information or assistance.

Yours sincerely

DR G H VISSER  
**MANAGER: SPECIALISED HEALTH**

cc. Mrs Sifanelo & Mrs Stanley  
Dr K Jennings

**APPENDIX I-1****Participant information leaflet and consent form**

**Title of the research project: Perspectives on Epilepsy on the part of Patients and Carers in a South African Urban Township**

**Reference number: 17366356**

**Principal investigator: Ms Mpoe Johannah Keikelame**

**Address: Primary Health Care Directorate, Old Groote Schuur building; E47Room 67, Medical campus, University of Cape Town**

**Contact number: Tel: 021 406-6342/6761 (w) Cell: 082 775 6824**

**Email: [johannah.keikelame@uct.ac.za](mailto:johannah.keikelame@uct.ac.za)**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study principal investigator (Johannah Keikelame) any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Research Ethics Committee (Non-Health) at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

**What is this research study all about?**

I am conducting a study to investigate how people with epilepsy and their carers understand and experience the condition. Carers are people like family members, friends; traditional healers like isangomas, herbalists, spiritual healers and doctors, nurses, social workers, physiotherapists and others who support and care for people with epilepsy.

- *Where will the study be conducted; are there other sites; total number of participants to be recruited at your site and altogether.*
- The study will be conducted in the urban township and in the local Community Health Centre which serves communities of the study setting. Twenty people with epilepsy who live in the township and are Xhosa speaking, will be recruited from the epilepsy support group and epilepsy clinic at the CHC and via the local health committee and non-governmental organization that supports people with epilepsy.
- A total number of sixty-five people will be recruited to participate in the study. I will first recruit twenty people who have epilepsy, who are older than 18 years. Thereafter, I will ask each one of the twenty recruited people who have epilepsy to identify a family member or friend and a traditional healer. This means that I



will now have twenty people with epilepsy, twenty carers like family members and twenty traditional healers like isangomas, spiritual healers and others. I will recruit the additional five carers who are trained in health care like a doctor, a nurse, a social worker, a counsellor, a physiotherapist from health structures in the study setting.

**Explain in participant friendly language what your project aims to do and why you are doing it?**

I am doing this study because in 1998, while I worked at one of the projects in a peri-urban township in Cape Town, I did a study among parents who had children with epilepsy. I found that parents did not understand the cause and treatment of their children's epilepsy. They also did not know what to do when their children had fits and also how to give epilepsy medicines. Because I did not include people with epilepsy in my study, I did not get to hear from them what they understood about the cause and treatment of their condition. Their voices were therefore unheard. I then decided to do this study to give them the chance to share how they understand and experience the illness because it is important to learn from people living with the condition and those caring for them.

*Explain all procedures.*

- I have gained ethics approval for my study from Stellenbosch University where I will be studying and from the UCT's Faculty of Health Sciences Human Research Ethics Committee and from the Department of Health (Provincial Administration of the Western Cape) to do the study.
- To meet the purpose of the study, I will explain to you the following things that I will do and what you should do.

*Draw up a checklist:*

I have drawn up a check list of the type of individuals that I will ask to take part in the study. This check list will help me to choose individuals who will be able to give information about the problem.

- any person who has epilepsy, who speaks isiXhosa, who lives in study setting and who may be receiving care at CHC or elsewhere in the township who is older than 18 years.
- Any traditional healer who lives in the township and is a Xhosa speaking person who may be caring or not caring for a person with epilepsy and is older than 18 years
- Any family member, friend or neighbour who may be giving care and support to a person having epilepsy, who is a Xhosa speaking person and stays in the setting and is older than 18 years.
- Any doctor, nurse, social worker, physiotherapist, pharmacist who may be working at the CHC who may or may not be staying in the township and is older than 18 years.

*Number of people that I plan to have for the study*

- I plan to have a total of sixty-five individuals that I will recruit for the study. This means that I will have twenty people with epilepsy, twenty family members or friends, twenty traditional healers and five people who are trained in health.

- After recruiting each person who has epilepsy from the epilepsy support group and epilepsy clinic at the CHC I will ask each one of them to identify one carer who is a member of the family or friend or neighbour and another one who is traditional healer like isangoma, spiritual healer, and herbalist.
- If a person with epilepsy is unable to identify other carers, I will ask other people from the health Committee and other NGOs in the setting to identify people that fit the checklist for the study.
- I will visit them, inform them about the study and why I am doing it and if they are interested and fit the check list, I will recruit them to take part in the study.

#### Observations at epilepsy support group

- Because the CHC serves two Afrikaans and Xhosa speaking communities, it is important that I go and see what people with epilepsy do at their support group and when they attend the clinic so that I can learn about what they do and see whether they have a list of people with epilepsy who attend the support group and also to see if I will be able to get the number of people with epilepsy that I plan to recruit for the study.
- I will introduce myself and tell them the purpose of my study and will ask if they agree that I should attend their meetings and that I plan to join their meetings once a week for one month.
- This will help me to be able to know the members and to give me time to learn and see what they do in their meetings and also to have a chance to ask a few questions on things that I do not understand and to see whether I will be able to get the number of people that I would like to select and recruit for my study and the kind of questions that I can ask to learn about what people with epilepsy and their carers understand and experience the illness.
- I will inform all members of the support group that they must feel free to tell me if they do not want me to sit with them and see what they do in their support group. This will not affect their health care.
- If they agree, I will ask each one of them to sign that I have explained to them in their own language why I would like to sit with them and see what they do in their support group and that their names will not be used in the information they share with me.

#### Observations at epilepsy clinic

- Because I would like to know more about epilepsy, I will ask permission to go and see what people with epilepsy do when they go for check-up at the epilepsy clinic.
- This will help me to understand the kind of questions that I need to ask in my study that I will be doing to learn how people with epilepsy and their carers (for example family members or friends, traditional healers, doctors, nurses, social workers and others) understand and experience the condition.
- I will not ask a lot of questions but I will only sit at the waiting area and will ask those who agree that I sit with them and see what they do when they go for check-up with the doctor or nurse and I will ask them a few questions to make sure that I understand what they do before check-up and after check-up.
- I plan to sit at the clinic one day per week for one month and will ask two people who are interested to let me see what he/she does before and after check-up.

- I will not take a lot of their time and will not need their personal information.
- Any person who agrees that I see what he/she does before and after check-up will not be forced to let me see what he/she does.
- You must feel free to tell me if you do not want me to sit with you and see what you do. This will not affect your health care.
- If you agree, I will ask you to sign that I have explained to you in your own language why I would like to sit with you and see what you do when you come for check-up and after you have seen the doctor or nurse and that your name will not be used in the information you have given me.

### Individual face- to face interviews

- I plan to have a total of sixty-five interviews with people who have agreed to take part in the study. Interviews will take up about ninety minutes of your time.
- I will interview you at the place, time and date that you will choose.
- I will draw up a set of questions and will ask them in IsiXhosa and English and will ask them in your own language to help you share with me how you understand epilepsy and your experiences from living or caring for someone with the illness. This will help me to get a picture about the problem from different people.
- Because I do not want to miss any information that you will be sharing with me, I will ask you if you agree that I should record our conversation.
- I will also take some information about you and your household as well as your contact details so that I can set another appointment with you in case I want to follow up some issues with you after listening to your interview.
- After each interview, I will listen to the interview to hear what you have said when answering questions.
- I will use false names to hide your personal information and all information that you shared with me will be kept in a safe place.

### Focus group discussions

After getting a picture of what all participants have said, I will invite eight to ten people from each group that I have interviewed to share with them what I have heard and found from your interviews. This will give you the chance to hear what you said, to check if the information is true and to ask questions that you may have.

- I will have a set of questions that I will ask the group and will record the information that they share with me in the group
- I will put twenty numbers of all groups in three different hats and I will mix the numbers and ask one of the people that I work with to pick up ten numbers from each hat.
- Thereafter, I will check the names that are linked to the numbers and will invite those people to take part in the three focus group discussions which will be about two hours long.
- I will find a suitable place in the study setting and will write letters to invite them to participate and to inform them about date, time, place, how long the focus group interview will be.
- Because I may not be able to understand IsiXhosa properly in a group interview, I will find a Xhosa-speaking person who will help me to conduct the interviews.

- I will also ask you not to share what the group talked about or to tell others about what others said during the interview.
- Thereafter, I will ask you if you agree that the group interviews be recorded and will ask you to sign a group consent form.

### Data analysis

- All information that you shared with me will be transcribed and translated from IsiXhosa into English by a Xhosa-speaking person that I will hire. I will read through all information that you shared with me through individual interviews, observations and focus group discussions to hear what you said and to make sense of what you have said.
- I will also use personal notes that I took during the study and will use the information to help me to get a clear picture on issues that may be similar, different or any new information that I will find when reading your information on how you understand and experience epilepsy and also to share reasons for my actions, decisions and choices that I made during the study.
- I will also not use your names when I use the words that you used in the interview to hide your identity. I will also keep all your information in a safe place
- Since I will collect information from different people, I will share it with each and every group so that you can have a chance to hear what I found and ask questions or clarify any issues and also agree that the information is true.
- Thereafter, I will write a report and will also publish papers so that I can share this information with other parties to help improve the understanding and care of people with epilepsy. Because I plan to interview different people, I will first attend epilepsy support group meetings and epilepsy clinic at the CHC to go and see what people with epilepsy do during meetings and when they go for check-up. This will help me to see whether I will be able to get the number of people with epilepsy that I need and also whether there is a support group register which I can use to draw up a list of people with epilepsy. Because it is important to allow people who have given me information to check what I found, I will invite eight to ten people from each group of people that I interviewed to take part in a focus group interview. This will give them chance to hear what I found, to ask questions and to address issues that may need to be clarified.

*Explain any randomization process that may occur.*

Because the focus group cannot take more than 12 people, I will write numbers from one to twenty on a piece of paper and fold them individually, put them in three separate hats and mix them. Thereafter, I will ask a person that I work with to pick up ten folded pieces of paper and will check which numbers are linked to each interviewed person. Those will be the people that I will invite to participate in the focus group discussions.

*Explain the use of any medication, if applicable.*

There will be no use of medications

### **Why have you been invited to participate?**

- *You have been* invited to participate in the study because you are the most likely person to provide insightful information about epilepsy because you are suffering from or you are caring for a person with epilepsy. You are therefore the best

person to tell me about how you understand epilepsy and about your experiences of having the illness or caring for someone who has epilepsy.

**What will your responsibilities be? If you agree to participate in the study, I will ask you to do the following:**

- Take your time and read all information in this leaflet so that you can understand why I am doing the study or ask me questions where you are not clear. If you cannot read, you can ask me to read the information to you.
- To know if there are benefits or risks for taking part in the study
- To tell me the date, time and place that will suit you for the interview.
- To know the duration of the interview, language that will be used, who will do interviews and how interviews will be recorded.
- To contact the people in this leaflet to address concerns that you might have.
- To contact me should you have commitments on the set appointment date so that we can arrange another time.
- To tell the people that you identified for me to recruit for the study that I will contact them and will visit them to introduce myself, to inform them about the study and why you chose them, and to recruit them for the study.
- To keep safe a signed copy of your consent form for your records.
- To ask me if you want to read or listen to your recorded information at the end of the interview.
- To ask for the report about the study and for the report to be translated into isiXhosa, if you want it.
- To tell me any time if you decide that you do not want to take part in the study any longer.
- To share this information with your family members so that they should know that you will be taking part in the study and that I will be coming to interview you at your home so that you can make the necessary preparations. For example, if you have children at home, you may want to be interviewed when they are at school or at crèche.

**Will you benefit from taking part in this research?**

- There are no immediate benefits. But because epilepsy is a poorly understood condition, your participation and input in this study will help improve the understanding of epilepsy, its treatment and care in the future.

**Are there in risks involved in your taking part in this research?**

- There are no risks involved in the study.

**If you do not agree to take part, what alternatives do you have?**

Your participation is voluntary. You will not be forced to take part in the study. You will not be judged for refusing to participate. Nothing will happen to you. It is your right to agree or not to agree to participate in this study. If you want to satisfy yourself about what I said to you, you can contact the following people at Stellenbosch University where I am studying.



My supervisor: Professor Leslie Swartz at the Department of Psychology at Stellenbosch University. Email: [lswartz@sun.ac.za](mailto:lswartz@sun.ac.za); Tel work: 021 808 3465; Cell: 0824593559

OR

Ms Maléne Fouché at the Division for Research Development at Stellenbosch University

Email: [mfouche@sun.ac.za](mailto:mfouche@sun.ac.za); Tel work: 021 808 4622

### **Who will have access to your medical records?**

*Explain that the information collected will be treated as confidential and protected. If it is used in a publication or thesis, the identity of the participant will remain anonymous. Clearly indicate who will have access to the information.*

- The information will be accessed by me. However, because I am not fully conversant in isiXhosa, I will hire a Xhosa speaking person to transcribe and translate your information from IsiXhosa to English. Therefore, this person will have access to the information. Also, because my supervisor needs to check if I am conducting this study according to the rules of research, he will also have access to information.

### **What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?**

Your participation in this study will not subject you to any form of injury.

***If no, then explain what compensation will be available and under what conditions.***

There are no financial costs regarding your participation in the study. You will also not be given any compensation for participating in this study.

Will you be paid to take part in this study and are there any costs involved?

- You will not be paid if you take part in this study because I will be interviewing you at your home, there will be no costs for transport or meals.
- Only those people who will participate in focus group discussions will be given back their taxi fee after they have been interviewed in a focus group which will involve about eight to ten people.

### **Is there anything else that you should know or do?**

- You should inform your family practitioner or usual doctor that you are taking part in a research study. *(Include if applicable)* NOT APPLICABLE
- You should also inform your medical insurance company that you are participating in a research study. *(Include if applicable)* NOT APPLICABLE
- You can contact my supervisor Professor Leslie Swartz at Tel: 021 808-3465 if you have any further queries or encounter any problems.

- You can contact the Health Research Ethics Committee at Stellenbosch University: 021 938-9207 if you have any concerns or complaints that have not been adequately addressed by the principal researcher Ms Johannah Keikelame.
- You can also contact me (Johannah Keikelame) at Tel: 021 406-6342 or 021 406-6761 if you have any further queries or encounter any problems.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I ..... agree to take part in a research study entitled (*insert title of study*).

**I declare that:**

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2012.

.....

Signature of participant

.....

Signature of witness

Declaration by investigator

I (*name*) ..... declare that:

- I explained the information in this document to  
.....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) ..... on (*date*) .....  
2012.

.....

.....

Signature of investigator

Signature of witness

**Declaration by interpreter**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) .....using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*)  
.....

.....  
Signature of interpreter

.....  
Signature of witness

**APPENDIX 1-2**

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY  
jou kennisvennoot • your knowledge partner

**STELLENBOSCH UNIVERSITY  
CONSENT TO PARTICIPATE IN RESEARCH**

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***Title of the study.* Perspectives on epilepsy on the part of patients and carers in a South African Urban Township**

***Sub title:* patients with epilepsy and carers**

I am asking you to participate in a study which I Johannah Keikelame, [MPhil Education Support; BSocSc (Psychology); BSocSc (Psychology & Sociology)] will be conducting in the township. I work at the Directorate of Primary Health Care at the University of Cape Town. I am studying for my doctoral degree at the Department of Psychology at Stellenbosch University. The results of the study will contribute to research paper, thesis or dissertation. You were selected as a possible participant in this study because you are the most appropriate person to provide insightful information about epilepsy and your experiences about the illness. The information you give me will help me to gain an in-depth understanding about the illness.

**PURPOSE OF THE STUDY**

- The purpose of the study is to explore perspectives on epilepsy and subjective experiences from living and caring for the condition from people with epilepsy and their carers in the township. The study aims to describe and analyze perspectives on epilepsy and subjective experiences of patients and their carers in the township
- Definition of terms:
  - For this study, “Patients” are defined as people with epilepsy (PWE)
  - Carers include three types: folk carers like isangoma, spiritual healers, herbalists; popular carers like family members, friends, neighbours and professional carers like doctors, nurses, physiotherapists, social workers, pharmacists.

**PROCEDURES**

- I will first gain ethics approval for my study from Stellenbosch University where I will be studying and from the UCT’s Faculty of Health Sciences Human Research Ethics Committee and from the Department of Health (Provincial Administration of the Western Cape) and City Health to do the study.

- To meet the purpose of the study, I will explain to you the following things that I will do and what you should do.

#### Draw up a checklist:

I have drawn up a check list of the type of individuals that I will ask to take part in the study. This check list will help me to choose individuals who will be able to give information about the problem.

- any person who has epilepsy, who speaks isiXhosa, who lives in the township and who may be receiving care at the local CHC or elsewhere in the township and who is older than 18 years.
- Any traditional healer who lives in the township and is a Xhosa-speaking person who may be caring or not caring for a person with epilepsy and is older than 18 years
- Any family member, friend or neighbor who may be giving care and support to a person having epilepsy, who is a Xhosa-speaking person and stays in the township and is older than 18 years.
- Any doctor, nurse, social worker, physiotherapist, pharmacist who may be working at the local CHC, who may or may not be staying in the township and is older than 18 years.

#### Number of people that I plan to have for the study

- I plan to have a total of sixty-five individuals that I will recruit for the study. This means that I will have twenty people with epilepsy, twenty family members or friends, twenty traditional healers and five people who are trained in health.
- After recruiting each person who has epilepsy from the epilepsy support group and epilepsy clinic at the local CHC. I will ask each one of them to identify one carer who is a member of the family or friend or neighbor and another one who is traditional healer like isangoma, spiritual healer, and herbalist.
- If a person with epilepsy is unable to identify other carers, I will ask other people from the local structures and NGOs in the township to help me to identify people that fit the checklist for the study.
- I will visit them, inform them about the study and why I am doing it and if they are interested and fit the check list, I will recruit them to take part in the study.

#### Observations at epilepsy support group

- Because local CHC serves two communities who are predominantly Afrikaans and Xhosa speaking, it is important that I go and see what people with epilepsy do at their support group so that I can learn about what they do and see whether they have a list of people with epilepsy who attend the support group and also to see if I will be able to get the number of people with epilepsy that I plan to recruit for the study.
- I will introduce myself and tell them the purpose of my study and will ask if they agree that I should attend their meetings and that I plan to join their meetings once a week for one month.
- This will help me to be able to know the members and to give me time to learn and see what they do in their meetings and also to have a chance to ask a few questions on things that I do not understand and to see whether I will be able to



get the number of people that I would like to select and recruit for my study and the kind of questions that I can ask to learn about what people with epilepsy and their carers understand and experience the illness.

- I will inform all members of the support group that they must feel free to tell me if they do not want me to sit with them and see what they do in their support group. This will not affect their health care.
- If they agree, I will ask each one of them to sign that I have explained to them in their own language why I would like to sit with them and see what they do in their support group and that their names will not be used in the information they share with me.

### Observations at epilepsy clinic

- Because I would like to know more about epilepsy, I will ask permission to go and see what people with epilepsy do when they go for check up at the epilepsy clinic at Local clinic.
- This will help me to understand the kind of questions that I need to ask in my study that I will be doing to learn how people with epilepsy and their carers (for example family members or friends, traditional healers, doctors, nurses, social workers and others) understand and experience the condition.
- I will not ask a lot of questions but I will only sit at the waiting area and will ask those who agree that I sit with them and see what they do when they go for check up with the doctor or nurse and I will ask them a few questions to make sure that I understand what they do before checkup and after checkup.
- I plan to sit at the clinic one day per week for one month and will ask two people who will be interested to let me see what he/she does before and after checkup.
- I will not take a lot of their time and will not need their personal information.
- Any person who will agree that I see and what he/she does before and after checkup will not be forced to let me see what he/she does.
- You must feel free to tell me if you do not want me to sit with you and see what you do. This will not affect your health care.
- If you agree, I will ask you to sign that I have explained to you in your own language why I would like to sit with you and see what you do when you come for checkup and after you have seen the doctor or nurse and that your name will not be used in the information you have given me.

### Individual face- to face interviews

- I plan to have a total of sixty-five interviews with people who have agreed to take part in the study. Interviews will take up about ninety minutes of your time.
- I will interview you at the place, time and date that you will choose.
- I will draw up a set of questions and will ask them in IsiXhosa and English and will ask them in your own language to help you share with me how you understand epilepsy and your experiences from living or caring for someone with the illness. This will help me to get a picture about the problem from different people.
- Because I do not want to miss any information that you will be sharing with me, I will ask you if you agree that I should record our conversation.

- I will also take some information about you and your household as well as your contact details so that I can set another appointment with you in case I want to follow up some issues with you after listening to your interview.
- After each interview, I will listen to the interview to hear what you have said when answering questions.
- I will use false names to hide your personal information and all information that you shared with me will be kept in a safe place.

#### *Focus group discussions with individuals who participated in the individual interviews*

- After getting a picture of what all participants have said, I will invite eight to ten people from each group that I have interviewed to share with them what I have heard and found from your interviews. This will give you chance to hear what you said, to check if the information is true and to ask questions that you may have.
- I will have a set of questions that I will ask the group and will record the information that they share with me in the group
- I will put twenty numbers of all groups in three different hats and I will mix the numbers and ask one of the people that I work with to pick up ten numbers from each hat.
- Thereafter, I will check the names that are linked to the numbers and will invite those people to take part in the three focus group discussions which will be about two hours long.
- I will find a suitable place in the township and will write letters to invite them to participate and to inform them about date, time, place, how long the focus group interview will be.
- Because I may not be able to understand isiXhosa properly in a group interview, I will find a Xhosa-speaking person who will help me to conduct the interviews.
- I will also ask you not to share what the group talked about or to tell others about what others said during the interview.
- Thereafter, I will ask you if you agree that the group interviews be recorded and will ask you to sign a group consent form.

#### *Focus group discussions with individuals who did not participate in the individual interviews*

- I will invite eight to ten people from local NGOs that provide community based health care services in the study setting and will present my proposal to them about the study and will invite them to participate in the study.
- I will make a list of the names of individuals who are willing to take part in the focus group interview and will set the date and time and venue for the interview in the township and will invite them to participate in the focus group interview.
- Thereafter, I will ask a Xhosa-speaking interpreter to read the participant information leaflet and the Stellenbosch University informed consent to the group and will give them time to ask questions to clarify any issues or concerns and will give them each of them a signed copy for their records.
- I will also prepare a group oral informed consent which will be translated from English into isiXhosa and will read it to the group before the interview.
- I will also write a set of ground rules for the group- which involve the issues about confidentiality, anonymity and methods of ensuring that everyone get a chance to participate in the interview.

- I will inform the group about the roles of the facilitator and note taker and will get permission from the group to record the focus group proceedings.
- I will ask the identified individuals to identify a suitable place for the interview and will inform them about date, time and how long the focus group interview will be.
- Because I may not be able to understand isiXhosa properly in a group interview, I will find a Xhosa speaking person who will help me to conduct the interviews.
- I will also ask you not to share what the group talked about or to tell others about what others said during the interview.
- Thereafter, I will ask you if you agree that the group interviews be recorded and will ask you to sign a focus group consent form.

### Data analysis

- All information that you shared with me will be transcribed and translated from isiXhosa into English by a Xhosa-speaking person that I will hire. I will read through all information that you shared with me through individual interviews, observations and focus group discussions to hear what you said and to make sense of what you have said.
- I will also use personal notes that I took during the study and will use the information to help me to get a clear picture on issues that may be similar, different or any new information that I will find when reading your information on how you understand and experience epilepsy and also to share reasons for my actions, decisions and choices that I made during the study.
- I will also not use your names when I use the words that you used in the interview to hide your identity. I will also keep all your information in a safe place
- Since I will collect information from different people, I will share it with each and every group so that you can have a chance to hear what I found and ask questions or clarify any issues and also agree that the information is true.
- Thereafter, I will write a report and will also publish papers so that I can share this information with other parties to help improve the understanding and care of people with epilepsy.

If you volunteer to participate in this study, I will ask you to do the following things:

### Before signing consent form:

- Read the consent form first and make sure that you understand everything about the study and your participation in it.
- Know why you have been selected, what is going to happen to the information, how will the information be used, by whom and where.
- Ask questions that you have about the study and get clarity on any concerns before signing the consent form.
- Sign the consent form ONLY after being satisfied that you have understood everything about the study.
- Request a copy of a signed consent form which you will keep for your own records.
- You should contact people whose names appear in this consent form if you have any other issue that you may have after signing the consent form.

### Identification of carers

- You do not have to identify any person that you would like me to recruit for the study if you do not want to.
- If you identify some one that you think I should recruit for the study, you should tell the person that you have given me his/her name so that I can contact them. You can also show them your information leaflet about the study so that they can read what the study is about.
- You should give me their home address and telephone numbers so that I can contact them and make appointment to visit them, to introduce myself, to tell them about the purpose of the study and to recruit them if they want to take part.

#### Appointment for interviews:

- You should choose the place, time and date for your interview and write it in your calendar or in some place to remind yourself.
- You should phone me or ask your family member to phone me in case you have other pressing commitments to attend. I will gladly change your appointment time to another time that will suit you.
- You should know how long the interview will be in case you have other commitments

#### When you are being interviewed:

- You should speak slowly so that I can hear what you say when you answer the question and ask me to repeat the question if you did not hear it properly.
- You should take your time to think about what you want to say and how you want to answer the question.
- You should choose to speak in the language that you prefer.
- You should not answer questions that you are not comfortable with.
- You should sign that you have agreed to be interviewed and that I should record the interview.
- You should sign that I should not link your name to the information that you shared with me.

#### **POTENTIAL RISKS AND DISCOMFORTS**

- There are neither potential risks nor discomforts to study participants. However, because my study involves people with epilepsy I might have others who may fit during the interview. Because I am a registered nurse, I will be able to attend to the person, reassure him/her and inform the person of what I observed before the fit and what I did during and after a fit. Thereafter, I will reschedule the appointment if the participant agrees.
- I do not anticipate any significant physical or psychological risks that may cause the study to be terminated.

#### **POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

- There are no immediate benefits. But because epilepsy is a poorly understood condition and that very few studies have investigated perspectives and subjective experiences of people with epilepsy and their carers, your participation and input in this study will help improve the understanding of epilepsy, its treatment and care in the future.

- The study will also contribute to local, national and global initiatives of improving the poor understanding of epilepsy and fighting the stigma against people with epilepsy.

### **PAYMENT FOR PARTICIPATION**

- Only subjects who participate in the focus group discussions will be paid an amount of **R40.00 or less** for transport depending on the location of the venue. I will also provide refreshments for participants because of the group interview can last from one and half hours to two hours.
- Participants will only be paid for their transport after the interview.

### **CONFIDENTIALITY**

- I will ask participants before beginning the interview if he/she would like to listen to the recorded interview and I will gladly do so at the subjects' request.
- Because I am not fully conversant in isiXhosa, the recorded information will be accessed by me and a Xhosa-speaking person that I will hire to do transcriptions and translations of the information that you shared with me.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

- Confidentiality will be maintained by means of using false names to hide your identity and the information that you share with me will be recorded via a digital recorder and will be labeled and transferred into my personal computer for filing.
- Because I am not fluent in isiXhosa, I will hire a person who is able to do transcriptions of your recorded interviews from isiXhosa to English. I will draft a consent form which the hired person will sign that she/he will transcribe all information and will treat all information as confidential and will not discuss or disclose the information with anybody. He/she will ensure that all data is deleted after being verified by me and when no follow up interview is needed. He/she will not ask anyone to do transcriptions on his/her behalf and that by signing the agreement, he/she will respect the information and will take a signed copy for his/her own record and I will also take the signed copy for my own records.
- All recorded information, hard copies of transcripts and data collection instruments will be destroyed and deleted from my personal computer after the study has ended in 2014.
- After each transcription, the transcriber will send me each transcript which I will file in my personal computer for data analysis and will also save it in a back-up file which will be stored in a locked cabinet in my office.
- The information will be accessed by me, the transcriber and my supervisor. All other hard copies of your personal information and back up files will be kept in a locked cabinet in my office.
- Information will be released to my supervisor to check whether I have complied with ethical requirements and to ensure the scientific integrity of the project.
- Information will be released to health care providers of different sectors to hear findings about the study in order for stakeholders to engage with the findings at the respective levels.
- Since questions that I will ask will provide responses on perspectives and experiences on epilepsy, these findings may help the organization to develop health information materials that address perspectives on epilepsy and



community strategies that can address barriers to care and also knowing community structures that they can partner with in the township.

- Names of all participants will not be linked to their direct verbatim quotes during presentation of findings, in reports and in publications. False names will be used to protect participant's identity.

## **PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

- Where you may have seizures during the interview, I may reschedule the appointment; but where your seizures may be frequent or when your family may not want you to be interviewed, I may decide to terminate your participation without your consent.
- When after the interview you feel that you do not want me to use your information, I will discard it and will not use it for the study.

## **IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact:

- The Principal Investigator: Ms Johannah Keikelame; Tel work: 021-406-6342/6761; Email: [johannah.keikelame@uct.ac.za](mailto:johannah.keikelame@uct.ac.za)
- Supervisor: Professor Leslie Swartz; Tel work: 021 808 3465; Cell: 0824593559; Email: [lswartz@sun.ac.za](mailto:lswartz@sun.ac.za)

## **RIGHTS OF RESEARCH SUBJECTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [[mfouche@sun.ac.za](mailto:mfouche@sun.ac.za); 021 808 4622] at the Division for Research Development.

## **SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE**

The information above was described to [*me/the subject/the participant*] by [Johannah Keikelame] in [*Afrikaans/English/isiXhosa/other*] and [*I am/the subject is/the participant is*] in command of this language or it was satisfactorily translated to [*me/him/her*]. [*I/the participant/the subject*] was given the opportunity to ask questions and these questions were answered to [*my/his/her*] satisfaction.

[*I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.*] I have been given a copy of this form.

**Name of Subject/Participant**

\_\_\_\_\_

**Name of Legal Representative (if applicable)**

\_\_\_\_\_

\_\_\_\_\_

**Signature of Subject/Participant or Legal Representative**

**Date**

**SIGNATURE OF INVESTIGATOR**

I declare that I explained the information given in this document to \_\_\_\_\_ [*name of the subject/participant*] and/or [his/her] representative \_\_\_\_\_ [*name of the representative*]. [He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/\*English/\*Xhosa/\*Other*] and [*no translator was used/this conversation was translated into \_\_\_\_\_ by \_\_\_\_\_*].

\_\_\_\_\_

\_\_\_\_\_

**Signature of Investigator**

**Date**

## APPENDIX J

### INFORMED CONSENT FOR SUPPLEMENTAL INFORMATION

**Project Title:** Perspectives on epilepsy on the part of patients and carers in a South African Urban Township.

**Principal Investigator:** Mrs Mpoe Johannah Keikelame, Primary Health Care Directorate, University of Cape Town,  
**TELEPHONE:** 021 4066342/0827756824

#### Introduction:

- I would like to ask your permission to take pictures of objects that you think may help to support the information that you have shared with me. For example, pictures of objects such as seizure medication that you use, a seizure diary or any other important issue that you may show me that can provide a better understanding of the issues that you shared with me.
- You will keep a signed copy of the consent form and the type of pictures I have taken for your records.
- You understand that I will use the pictures that I took to support the information that you shared with me and that your name will not be assigned to the pictures.
- You also agree that by signing this form, you are not jeopardizing your rights in any way.

#### **I give permission for:**

The researcher to take pictures of objects shared with her. Yes   
No

Type of picture to be taken..... Yes   
No

#### **I understand that by signing this form:**

I have not given up any legal rights to which I am entitled. Yes  No

I will receive a copy of this signed consent form. Yes   
No

Interviewee's signature:.....

Date:.....Place.....

Interviewer's signature:.....

Date.....Place.....

***Once again, thank you very much for agreeing to participate in the interview.***