Developing an improved seizure diary as a monitoring tool for epileptic patients in South Africa

by

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DECLARATION

I submit this thesis in a published manuscript format to the University of the Free State for the Philosophiae Doctorate in Family Medicine. The manuscript is the result of my independent investigation. I further declare that this work is being submitted for the first time at this university and faculty and has not previously been submitted to any other university or faculty to obtain a qualification or degree.

I have endeavoured to use the research sources cited in the text responsibly and give credit to the authors and compilers of the references for the information provided, as necessary. This thesis does not contain other authors' writing unless expressly acknowledged, quoted, and referenced. I have also recognised those persons who have assisted me in this endeavour.

I also declare that all information study participants provide will be treated with the necessary confidentiality.

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DEDICATION

Praise be to the Lord our God, without whom this study wouldn't have been possible IJN Amen. I dedicate this work to my loving wife, Uju, my beautiful daughters, Chizaram, Chikamso and Uchechi Egenasi, and my parents, Alphonsus and Rose Egenasi. I thank you for all your support and encouragement throughout this study.

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LIST OF ABBREVIATIONS AND ACRONYMS

CINAHL	Cumulative Index to Nursing and Allied Health Literature
EEG	Electroencephalogram
ILAE	International League Against Epilepsy
MEDLINE	Medical Literature Online
RMSH	Robert Mangaliso Sobukwe Hospital
STATS SA	Statistics South Africa
WHO	World Health Organization

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SELECTED DEFINITIONS AND TERMS

Adult: According to the Children's Act, any person 18 years and above is an adult (South Africa, 2005).

Delphi: A Delphi survey is a technique for achieving convergence of opinions concerning real-world knowledge solicited from experts within certain topic areas (Dalkey, 1969).

Diary: A book in which one keeps a daily record of events and experiences (Oxford Learner's Dictionaries, 2019).

Epilepsy: The presence of two or more unprovoked seizures, occurring more than 24 hours apart (Fisher *et al.*, 2014).

Seizure: A seizure is a sudden surge of electrical activity in the brain (Fisher *et al.*, 2014).

Seizure diary: A paper or electronic journal with a calendar that can be used in tracking seizures (Epilepsy Foundation, 2014).

Monitoring tool: A device or implement that is used to carry out a particular function, to watch and check something over a period of time, to improve it (Skumar, 2020).

Consensus: General agreement among a group of people (Collins English Dictionary, 2019).

Thesis by publication: The University of the Free State (2016:3) defines it as follows in its policy:

> *Document for masters and Doctoral studies:*
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> *A doctoral thesis is the sole research component of a doctorate. It must demonstrate that the candidate has made a specific contribution to the enhancement of knowledge in the chosen field while providing evidence of independent critical ability. A PhD by publication requires three publishable articles.*

ABSTRACT

Background

Epilepsy is a debilitating disease with a high risk of morbidity and mortality globally. A seizure diary is one of the methods described in the literature that can be used to manage patients living with epilepsy. These diaries are available in two formats, paper-based and electronic diaries. This study aimed to develop an improved seizure diary and determine patients' perception of its use in the management of patients with epilepsy in South Africa.

Methods

In the first phase of this study, a scoping review of literature was performed. An extensive search of appropriate literature was conducted using online databases, such as MEDLINE, Scopus, CINAHL, Cochrane and EBSCOhost. Key phrases, such as seizure diary, paper diary, and seizure tracker, were used to identify and retrieve relevant themes, categories, and subcategories of literature for examination.

In the second phase of the study (a cross-sectional study), cohorts of patients with epilepsy were identified at the casualty and local clinics of a hospital in Kimberley, and the neurology specialist epilepsy clinic in Bloemfontein. Questionnaires were distributed to patients, to gather data on their perceptions of and attitudes to the epilepsy diary, and their opinions on what must be included in a seizure diary.

The third phase of the study involved a modified Delphi survey with a panel of 10 local and two international experts, who deliberated on what they believed were the required contents of a seizure diary.

In the fourth phase, a longitudinal study, a new seizure diary was developed, based on the suggestions of the expert Delphi panel and the recommendations of patients living with epilepsy. The new seizure diary was distributed to patients who had completed the initial questionnaire, and they were requested to use it for six months.

In phase 5a (cross-sectional study), patients, relatives, and caregivers (participants) were requested to complete a questionnaire about their experiences of the new seizure diary.

Finally, in phase 5b, a final version of the new seizure diary was designed.

Results

In phase 1, 1 125 articles were identified from the database search, of which 23 were selected for review by the study.

In phase 2, 182 patients with epilepsy were recruited for the study, 65 were patients who had previous exposure to a seizure diary, and 117 were unexposed. Of the patients who had previous exposure to the seizure diary, 64 (98.5%) found the diary useful, but 15 (23.1%) reported facing various challenges with using the seizure diary.

In phase 3, the modified Delphi survey had three rounds, with 12 expert panellists completing each round. Consensus for any item was set at 70%. Eighteen items were suggested as the required contents of a seizure diary.

The seizure diary, designed in phase 4, was distributed to 139 patients (81 previously diary-unexposed and 58 who had previous exposure to a seizure diary) to use for six months.

In phase 5a, of the 139 patients who received the new seizure diary,100 (67 previously diary-unexposed participants and 33 participants who had previous exposure to a seizure diary) completed questionnaire 2. Participants who had previous exposure to a seizure diary were predominantly very positive about the new diary because it had more information. However, 21.2% preferred the old one, because it was easier to complete.

In phase 5b of the study, the final draft of the new seizure diary was designed for use by patients with epilepsy.

Conclusion

An expert panel of specialists, patients, caregivers, and relatives participated in developing a new seizure diary. Despite a few patients reporting that they preferred the old seizure diary, most participants preferred the new seizure diary and were willing to use it.

Keywords: Epilepsy, Seizure diary, South Africa, Clinics, Modified Delphi, Experience, Perceptions, Attitudes, Unexposed, Previously exposed

CHAPTER 1: BACKGROUND AND LITERATURE REVIEW

1.1 INTRODUCTION

Epilepsy is a neurological disorder that affects numerous people of all age groups in Africa and worldwide. The World Health Organisation (WHO) estimates that of the 50 million people with epilepsy worldwide, 80% are from low- and middle-income countries. Though about 10% of people will experience a seizure during their lifetime, this does not mean they have epilepsy. In low and middle-income countries three quarters of people diagnosed with epilepsy will go untreated. Seizures can be prevented in about 70% of people with epilepsy if they receive anti-seizure medications (WHO, 2019).

According to a controlled study in five African countries, the incidence of epilepsy varies between 83 and 156 per 100 000 of the population (WHO, 2004). The International League against Epilepsy (ILAE) updated the definition of epilepsy in 2014, to make it more practical. Epilepsy may be considered if a person meets any of the following criteria (Fisher *et al.*, 2014):

1) At least two unprovoked seizures occurring more than 24 hours apart;
2) One unprovoked seizure and a possibility of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures occurring over the next ten years; or
3) Diagnosis of an epilepsy syndrome.

The management of patients with epilepsy aims to control the seizures, and to reduce morbidity and mortality from this medical condition. According to Loiseau and Jallon (1995), a patient’s seizures are controlled if the patient is seizure-free for at least 12 months, and uncontrolled if the patient has one or more seizures a year. Berg (2009) provides a more limited definition of uncontrolled seizures, as at least one seizure every month for 18 months (Berg, 2009). However, due to a lack of proper medical record-keeping and statistics on seizures amongst patients with epilepsy, no definition for controlled or uncontrolled seizures in Africa has been published (WHO, 2004).

The level of education and socio-economic circumstances of patients are significantly different in Africa than in the developed world. Education is a significant component of well-being; it measures a society's socio-economic development and quality of life. The mean education ratio in Africa is 0.55, versus 0.9 in the developed world (United Nations Development Programme, 2016). This difference will have an impact on the definition of controlled or uncontrolled epilepsy in the African populace compared to the developed world. Most patients and clinicians in Africa accept the definition of uncontrolled epilepsy of Fisher (2013), namely that “epilepsy is uncontrolled if seizures are frequent and severe enough to interfere with the patient’s quality of life”.

Medication adherence can influence the frequency of seizures in patients with epilepsy (Egenasi *et al.*, 2015) and may help reduce morbidity and mortality. Different ways of improving medication adherence have been practiced, such as pill counting and direct observation of patients (Farmer, 1999). The proper use of a diary is another method that has been proposed to improve adherence and reduce seizure frequency in patients with epilepsy (Ernst *et al.*, 2016).

A diary is an annual journal with dates of the month and space for writing, which can be used for keeping daily records of events and experiences in one’s life. The Oxford Learner’s Dictionaries (2019) defines a diary as a book where one records daily events and occurrences. It is a common tool that has been used for centuries and is still used today to help people keep track of appointments and remember events. Diaries are commonly paper-based, but due to advances in technology, most paper-based diaries have been converted to electronic ones. The electronic format can be found in electronic devices such as phones, laptops, and computers. Most patients would have encountered a diary at some point in their lives, and one can assume that it would be easy for patients to accept using a diary. If a diary is modified for use in a clinical setting, it can help patients record their seizures and provide information to healthcare workers to help them manage their patients better. If patients with epilepsy start using diaries, it will help family physicians realize the ideal of shared decision-making, in so doing making the patients partners in decisions concerning their care (Pickrell *et al.*, 2015; Epilepsy Foundation, 2016).

In this research project, the researcher did an extensive study to develop an improved seizure diary that can be used to manage and monitor seizures of people with epilepsy in South Africa.

The researcher used a Delphi survey and questionnaires for data collection. An improved diary that patients can use was developed from analysing the patients’ opinions as provided in a first questionnaire, and from experts' views provided in the Delphi survey. The diary was distributed to participants for daily use, and after six months, a second questionnaire was used to obtain the patients' opinions about the new diary.

The new diary was pronounced to be an improvement on the current basic calendar diary distributed by pharmaceutical companies in South Africa that are currently used in some epilepsy clinics as a patient monitoring tool.

1.2 BACKGROUND

In South Africa, the prevalence of epilepsy is 3.7 per 1 000 of the population (WHO, 2004). Epilepsy South Africa (2020) estimates that epilepsy affects about 500 000 people in South Africa, which is 1 per 1 000 South Africans. Patients with epilepsy frequently attend health centres; these patients represent all age groups. Epilepsy in adults may be secondary to traumatic brain injuries, and in elderly people, due to events such as stroke. Thanks to modern medicine, state-of-the-art equipment such as video electroencephalograms, neuromodulation devices and medical alert bracelets exists that make it easier to diagnose, treat, and monitor epilepsy.

When patients have seizures, it is sometimes observed by relatives, guardians, and friends. These observers may remember the events, but they cannot always recall the details of the seizures, especially when children are involved, due to different caregivers being involved at school and at home. Children with multiple caregivers at a time may be more challenging to monitor. A seizure diary will help these patients, their relatives, and caregivers keep record of these episodes and help them observe the seizure frequencies more carefully if medications are changed (Fisher *et al.*, 2012).

The Epilepsy Foundation (2022) describes a seizure diary as a "self-management tool for seizures and epilepsy, used for the purpose of self-monitoring and tracking seizures and other symptoms". It helps to manage medication and other therapies, recognise triggers and health events that may affect seizures and wellness, and communicate with providers of care (Epilepsy Foundation 2022; Fisher *et al.*, 2015). Fisher *et al.* (2012) describe seizure diaries as a type of patient-reported outcome. Marino *et al.* (2003) and Watson (2002) describe the diary as a research tool, which requires respondents to record their daily activities and responses. It helps to capture "life as it is lived" (Bolger *et al.*, 2003) by the patient. The diary can help patients track their seizures and provide valuable information for healthcare workers involved in managing patients who have epilepsy.

There are various types of seizure diaries. The electronic diary is the preferred diary used in developed countries; the paper-based diary can be in the form of a calendar or an event diary. The calendar diary asks basic questions about patients' seizure types and frequency, which is the industry standard (Fisher *et al.*, 2012). In the calendar, patients can tick off the days they had seizures. It is simple and easy to use, but does not provide details. The current calendar diary fails to provide relevant information about the patient that can help healthcare providers understand their condition, their treatment, and how it has been adjusted over time. It is not interactive and fails to motivate and provide patients with information, which can help them become more involved in the management of their own epilepsy.

The electronic diary is more detailed and accurate, but there are challenges with its use in Africa. Due to poor socio-economic circumstances, few patients can afford smartphones with internet capabilities, smart devices, and expensive data to download internet apps. Many live in rural settings (WHO, 2004), where internet facilities are not always available, which makes it difficult for them to use electronic diaries. In communities where the population is uneducated, people may struggle to understand mobile devices and computers. In contrast, paper-based diaries can be made available readily, they are easy to use, patients can train themselves to use them, and paper diaries do not require any internet access or the user to possess computer skills (Ohly *et al.*, 2010). It can also be successfully used in even predominantly illiterate communities (Wiseman *et al.,* 2005).

A modified seizure diary that involves patients actively in its design can be a useful tool to help patients, and their relatives keep records of events related to epilepsy, such as seizures, in their own words. The diary may also help them narrate their experiences, so that healthcare workers can understand how the disease impacts them and their families. Using information obtained from patients with epilepsy in the development of a diary could reveal patients' opinions about their care, which clinicians sometimes overlook. If patients living with epilepsy are taught how to use it properly, the diary can help healthcare workers access important information about their patients, which may otherwise not have been available. The information available could lead to better management of patients and less waste of scarce resources (Blachut et al. 2015., Egenasi et al. 2022).

No studies have been done in South Africa concerning developing a seizure diary for epileptic patients. However, certain clinics, such as the epilepsy clinic in Bloemfontein, used versions of diaries distributed by pharmaceutical companies to help doctors monitor patients (Keikelame and Swartz, 2013).

Online library searches conducted on databases such as Medline, CINAHL, PsycINFO, journals, theses and dissertations for information about seizure diary turned up very little, due to a lack of adequate research in this area.

Certain studies that were reviewed, such as Neugebauer (1989), found daily diary methods to be reliable in the clinical setting. This finding is supported by Glueckauf *et al*. (1990), who found the diary method to be a highly reliable method for both recall and prospective self-reporting by subjects. Detyniecki and Blumenfeld (2014) report that studying patients' documentation of their seizures is the most often used scientific method for measuring patients' awareness of seizures. Caregivers should be encouraged to improve seizure reporting, especially for psychiatric patients and those who are mentally challenged, where seizure reporting can be problematic, due to multiple seizure types, and because a large number of family members act as caregivers, as available. Training will be required for each caregiver so that they can help the patient complete the diary. Blachut *et al.* (2015) report a self-estimated documentation rate of 8.7 out of 10 for daytime seizures, and 7.7 for nocturnal seizures; they found that patients who thought that a seizure diary would benefit their clinical treatment were more likely to keep one. Fisher *et al.* (2012) found a seizure diary to be an effective monitoring tool for clinical research and practice with the benefit of low cost, allowing locus of control for the patient and testing in a real-world environment. These authors also found it useful to provide a descriptive snapshot of a population. Patient diaries have been described as a low-cost means of providing psychological support, and a tool that can improve a patient's quality of life (Combe, 2005; Egerod *et al.*, 2007).

A study published widely by the ILAE in 2016 investigated medication adherence by women with epilepsy who were planning pregnancy by analysing entries in electronic diaries (Ernst *et al.*, 2016). The women were followed up over 12 months, and the study found that 75% of the participants were compliant with the electronic diary. This finding shows that the diary may be useful for tracking adherence in the clinical setting. Medication adherence was 98% in patients tracked by the study, showing that the diary had a positive role to play in improving patients' medication adherence. According to Fisher (2010), tracking epilepsy with an electronic diary makes it easier for physicians to track medical history and record improvements caused by medications. Patient focus is an important concept in family medicine, which requires clinicians to respect patients' perspectives (Hudson *et al.*, 2011). A diary also reflects the patients' opinions about their seizures. A diary will help promote the concept of shared decision-making in patient management.

Most of the scientific papers reviewed support the notion that a properly designed seizure diary has a role to play in the management of epilepsy patients and improving medication adherence in the clinical setting (Van Berge Henegouwen *et al.*, 1999; Haut *et al.*, 2013; Ernst *et al.*, 2016).

In countries such as the United States and Australia, an electronic version of the seizure diary known as My Seizure Diary® is used by thousands of epileptic patients to help track seizure history. My Seizure Diary was available online until 2022, and has since been replaced by a new seizure diary app launched by the Epilepsy Foundation called The Nile®, which helps patients or their caretakers log auras, track their medication or get reminders, follow their progress over time and help doctors interact with their patients (Epilepsy Foundation, 2022). The Nile allows users to import their details from My Seizure Diary. Other popular electronic diaries and mobile applications include mySeizureDiary.com® by Neuropace,[1] EpiDiary®,[2] Epistemic®,[3] My Epilepsy Diary,[4] and Seizure Tracker®[5] (Fisher *et al.*, 2015; Gray *et al.,* 2022). Seizure Tracker is an online seizure diary that has over 10 000 registrants. It enables patients and caregivers to track seizures, medications and important clinical data electronically.

In Africa, one of the most challenging healthcare problems is adequate data collection in healthcare facilities. There is no standard way of collecting data, which introduces bias

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[1] https://www.myseizurediary.com/diary_login

[2] https://www.epidiary.com/login-page.php

[3] ttps://www.epistemic.com.br/#/

[4] https://www.epilepsy.org.au/my-epilepsy-diary/

[5] https://seizuretracker.com/Seizure_Log_Printable.php

(WHO, 2004). In the Western world, patients are better educated and can provide adequate information using readily available web-based applications to monitor their seizures and medications. The availability of these resources helps to provide continuous data for epilepsy-based clinical research purposes (WHO, 2004).

In South Africa, not much is known about seizure diaries, and a literature search about the topic failed to reveal any standard format for the diary used in South African medical facilities. A simple calendar version of the diary, provided by pharmaceutical companies, is being used by patients attending the neurology specialist epilepsy clinic at Universitas Academic Hospital in Bloemfontein. Patients using the diary tick the days they have seizures, to help the managing physician understand their seizure frequency.

The benefits of paper-based diaries include their user-friendliness, as they require minimal training or technological expertise to utilize. They are accessible to a diverse population, including those unfamiliar with digital devices or apps. Moreover, paper-based diaries operate independently of technology or internet connectivity, eliminating the possibility of technical issues or disruptions. This can be especially crucial in our remote and resource-constrained areas where reliable digital infrastructure is lacking (Fisher et al., 2012, Wiseman *et al.*, 2005).

Paper-based diaries offer a level of privacy and security when compared to digital platforms. Data in paper diaries are physically confined to the user, reducing the risk of unauthorized access or data breaches, which can be a concern with digital health tools. In a study by Kumar et al. (2018), Patients suffering from mental health conditions raised apprehensions regarding the privacy and data security aspects associated with the utilization of digital health applications.

The physical nature of a paper diary can give users a tangible sense of accomplishment and progress as they fill it out. It can serve as a visible reminder of their efforts and a source of motivation to continue tracking their condition.

While electronic diaries have their benefits, a paper-based diary can still offer unique advantages in specific contexts.

Certain populations have never been exposed to the seizure diary in any format, and they are naïve about the workings of the seizure diary and how it impacts patient management. Fisher *et al.* (2012) report that the act of self-reporting observations might itself impact observations by causing the individual to be more attentive about seizures after adjusting medications (Fisher *et al.*, 2012). Van Berge Henegouwen *et al*., in a study published in 1999, found a positive association between the completion of a diary and medication intake by patients. Higgins *et al*. (2018) found a daily patient-reported outcome diary to be a reliable and valid measure for determining the severity of symptoms in patients with ulcerative colitis. This measure could be incorporated to help clinicians improve the outcome of their care.

By developing an improved seizure diary that can effectively monitor and manage patients with epilepsy, the researcher aimed to improve care for patients with epilepsy in South Africa.

1.3 PROBLEM STATEMENT AND KNOWLEDGE GAP

In South Africa, epilepsy affects over 500 000 people (Epilepsy South Africa, 2004). The prevalence of active convulsive epilepsy in rural areas is reported as 7/1 000 of the population (Wagner *et al*., 2014). These patients with epilepsy present with seizures to various casualty departments nationwide. In the Robert Mangaliso Sobukwe Hospital (RMSH) casualty department in Kimberley, they are often brought in by the emergency services, alone, without relatives, mostly confused and unable to give any history. If confronted by a breakthrough seizure or a non-adherent patient, most nurses and doctors find it difficult and frustrating to understand what is wrong with the patient. Further information about what medications the patient may be using at the moment and how the treatment had been adjusted by various healthcare workers responsible for managing the patient, is not always readily available.

Doctors at RMSH often attempt to retrieve patients’ pharmacy records, sometimes unsuccessfully. However, some patients may have obtained their medications from the hospital and local clinics, whichever is more convenient, making the available hospital pharmacy records inaccurate. This dilemma results in doctors withdrawing blood to check for drug levels, to guide them about the likely medications being used and to determine if the drug levels in the patient’s blood are therapeutic. These investigations run up huge costs. Worse, some healthcare workers may load the patient with whatever medication is readily available. This could lead to drug toxicity if the patient was already taking the same medication, which could be life-threatening. This scenario happens multiple times daily when patients with epilepsy present to emergency and casualty departments. It increases the challenges for doctors involved in the management of these patients. It also creates an unhappy experience for the patients and their relatives, because they have to stay in the hospital longer. It increases the cost of running the hospital for the government, due to more extended stays for patients awaiting laboratory results. It exacerbates the frustrations for medical staff managing these patients. It eventually leads to precious and scarce resources, which could be used for other patients' management, being wasted.

Looking at this situation, it is clear that a gap exists in relation to doctors and nurses working in healthcare facilities obtaining relevant and accurate information from patients. This study addressed the gap that exists in the care of patients with epilepsy. The gap made it necessary to develop a diary that patients with epilepsy could use for seizure documentation and medication use, thereby making it easier for healthcare workers to obtain relevant information to manage their patients better.

Furthermore, no known published study has been done to create a seizure diary in South Africa.

1.4 STUDY IN FAMILY MEDICINE

Epilepsy is a broad, chronic, debilitating disease that requires patients to be managed by healthcare personnel representing various specialities. Most patients with epilepsy are usually managed in primary healthcare facilities in communities by primary care physicians and nurses, and neurologists in tertiary facilities (Chin, 2012). Using a seizure diary will assist healthcare workers to monitor seizure frequencies, and improve the quality of care provided for patients with epilepsy. This study is domiciled in family medicine, which plays a crucial role in managing patients with epilepsy in primary healthcare facilities in communities across the country, and emergency departments of district hospitals.

1.5 RESEARCH QUESTIONS

In order to address the problem, the following research questions were formulated:

- What are the current norms and international practices for the use of a seizure diary for managing epilepsy?
- What are patients' perceptions of and attitudes towards the use of a seizure diary to manage patients with epilepsy?
- What should be the content of a seizure diary that can be used for the monitoring and management of patients with epilepsy in South Africa?
- What were the patients' experiences of an improved seizure diary for the management of people with epilepsy?

1.6 AIM OF THE STUDY

This study aimed to develop an improved, new seizure diary and determine patients' perceptions regarding its use for managing patients with epilepsy in South Africa.

1.7 OBJECTIVES OF THE STUDY

The objectives of the study were the following.

- To determine and review the current norms and international practices for the use of seizure diaries to manage epilepsy (Scoping review).
- To determine the perceptions and attitudes of patients with epilepsy in South Africa on the use of a seizure diary to manage patients with epilepsy (Questionnaire 1).
- To develop a new seizure diary that can be used to manage patients with epilepsy in South Africa, based on expert opinions of the members of a Delphi panel, and contributions by patients (Delphi survey and Questionnaire 1).
- To determine the patients' evaluation of the new seizure diary, and to use the information to revise the diary further and present a final, improved seizure diary (Questionnaire 2).

1.8 RATIONALE OF THE STUDY

The study arose out of the inability of most patients to provide relevant information required by healthcare workers involved in managing patients with epilepsy. A patient does not see the same healthcare worker every time. The patients are often unaware of the type of epilepsy they were diagnosed with, their seizure frequency or medications, and their dosage. The absence of data makes it difficult for most doctors to make informed decisions concerning their patients.

A seizure diary helps provide basic data about the patients. A healthcare worker seeing a patient for the first time can access the patient's information from the diary. Information, such as the type of seizures and medications, can be obtained from the diary. The diary also helps healthcare workers to monitor patients' adherence to medications and seizure control; this will help improve the care offered to patients with epilepsy by the Department of Health.

The diary may help improve interactions between patients and healthcare workers, since it is a tool that requires patients, family, and relatives to be involved in the patients' management, thereby improving the family bond. Family awareness about how well or badly the patient is doing and the need for further care may improve. If patients provide information that can improve their quality of care, the diary enhances a patient's direct involvement in their own management.

If it is successful in improving patient care, the diary may lead to fewer patients reporting to the emergency department with seizures. This may reduce the cost of healthcare provided for patients, which helps save money for the health department and improves the productivity of patients who have jobs.

Penetration of smartphone data is improving; it is our hope as smartphones and ICT access improve, app-based models of the diary can be used in remote monitoring and informing healthcare providers and policymakers with data-driven decision-making tools (Statista 2023).

1.9 RESEARCH PARADIGM

The concept of research paradigms has been around for a long time. A research paradigm is a term used to refer to the fundamental set of beliefs that direct the actions and define the worldview of the researcher (Lincoln *et al.,* 2011). It is an approach, model, or framework from which to conduct research.

Conceptual and practical ideas from paradigms are used to solve specific research problems (Abbott 2004). It helps to form a research philosophy, which in turn informs the research methodology. Various worldviews are applied in research today, such as postpositivism, constructivism, participatory action frameworks, or pragmatism. These are all essentially philosophical and encompass the following common elements: ontology (how reality is viewed), epistemology (how the nature of knowledge is conceived), axiology (the role and values of the research process), methodology (how the paradigm defines processes associated with conducting science), and rigour (the criteria used to justify the quality of research in the paradigm) (Park *et al.*, 2020).

Each paradigm provides a different perspective on axiology (Beliefs about the roles of values and morals in research), ontology ‘assumptions about the nature of reality’, epistemology ‘how we gain knowledge’, methodology ‘shared understanding of the best ways to gain knowledge’, and research rhetoric ‘shared understanding of the language of research’. (Kaushik and Walsh, 2019). The positivist researcher believes in realities that can be measured and understood, and knowledge achieved through experimentation and observation. The positivism paradigm depends on the hypothetico-deductive method to verify a priori hypotheses, which are often stated quantitatively, and prove relationships between causal factors and outcomes (Park *et al.,* 2020). An interpretivist researcher tries to understand how people make sense of their social world and act in it. It also considers the practical implications and usefulness of the research findings. An interpretivist approach in pragmatism uses both qualitative and quantitative data. (Kaushik and Walsh, 2019).

Pragmatism originates from the Greek word *pragma*, which means action, which is the central concept of pragmatism (Pansiri, 2005). The pragmatic researcher uses a mixture of positivist and interpretivist approaches in a single research study. They use the philosophical and methodological technique that works best for the research problem being investigated (Kaushik and Walsh, 2019). The pragmatic researcher is focused on solving practical problems.

This study design and methodology of this study were structured using a positivist philosophical method, because this study mainly used a quantitative approach in all its phases to measure, understand and gain knowledge in this research. The study outcome is based on the philosophy of pragmatism, because a new seizure diary needed to be implemented for patients with epilepsy. The research focused on developing a new seizure diary, which is a practical tool that can help solve real-world problems related to epilepsy seizure management, in keeping with the pragmatic philosophy. Understanding this philosophical method is important for describing how the researcher approached and reported the findings of this study.

1.10 CONCEPTUAL FRAMEWORK/SELF-MANAGEMENT THEORY

A conceptual framework synthesises and guides research analysis and intervention in a particular field (Shahin *et al.*, 2020). It guides researchers in explaining the significance and relevance of their study and how their research methods address the research question (Ravitch and Riggan, 2016).

If requested information is not available, healthcare workers can be prevented from making crucial treatment choices for patients with epilepsy. Patients can enhance their health outcomes by participating in self-care activities, such as tracking their seizures, taking their medication as prescribed and getting support from family, caregivers and relatives (Brinkmann *et al.*, 2021).

Several theories can guide research on seizure diaries. The self-management theory postulates that patients have an active role in their health, based on their behaviours and attitudes (Grady and Gough, 2014). The self-efficacy theory suggests that personal confidence in patients' capacity to do a certain behaviour affects their motivation, effort and persistence (Lippke, 2020). The health belief model elucidates how individuals' perceptions of their susceptibility, disease severity, barriers, actions, and benefits affect their health-related behaviours (Houlden *et al.,* 2021).

The self-management theory guided this study, which was suitable and useful for answering the research questions about the role of the seizure diary in helping patients with epilepsy manage their condition. This theory also recognizes the role of family, caregivers, relatives, and the healthcare system in supporting or hindering self-management practices (Grady and Gough, 2014).

The study methods of qualitative data collection and analysis were aligned with the self-management theory. The study instruments were questionnaires and a seizure diary, which collected data on the frequency, duration, and severity of seizures, as well as the patients' experiences, perceptions, and challenges of using the seizure diary. The data analysis techniques included descriptive statistics, inferential statistics, and thematic analysis. The write-up and discussion of the findings followed the self-management theory framework. The study reviewed the literature on previous studies on seizure diaries, as well as the theoretical background and rationale for the current study. The study reported its method and results clearly and concisely, using tables, graphs, and quotes to illustrate the data. The study also discussed its implications and contributions to the epilepsy research field, its limitations and suggestions for future research. Figure 1.1 below shows the research framework used in this study.

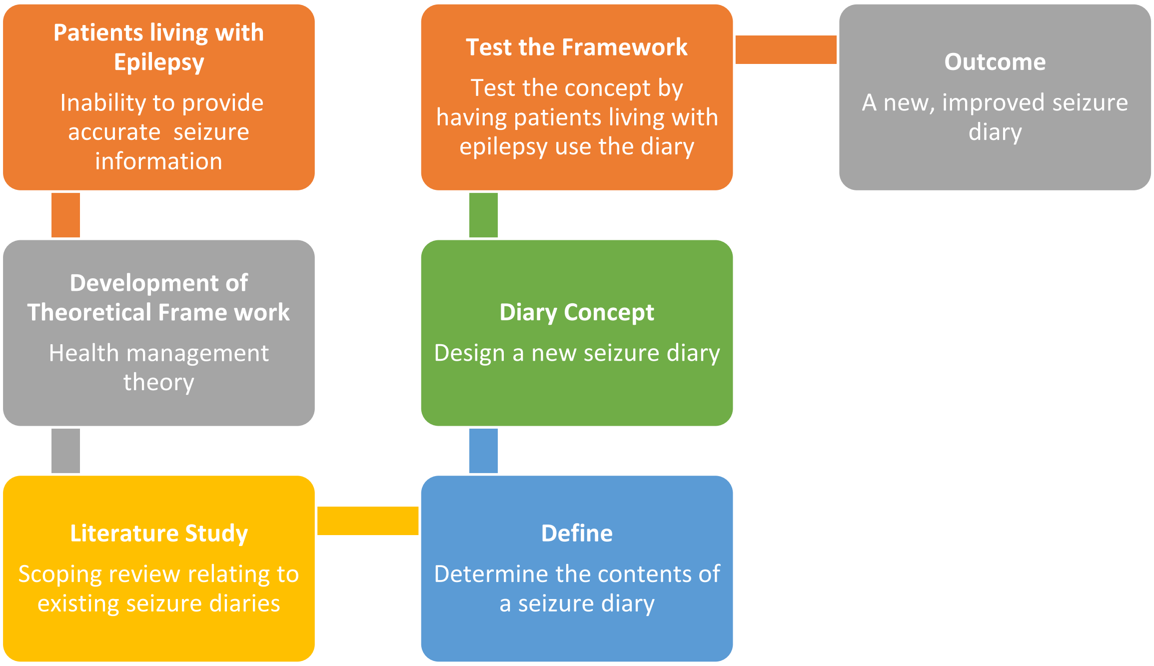

Figure 1.1: Schematic diagram of the conceptual framework (compiled by the researcher Egenasi 2023)

1.11 RESEARCH DESIGN

The research used a multiple-design quantitative research method to obtain data. The study had five phases, with phase five divided into 5a and 5b. Each phase had a study design and the phases occurred consecutively.

For this study, two locations were identified for the research: Kimberley and Bloemfontein.

1.11.1 Study locations

1.11.1.1 Kimberly, Northern Cape

The Northern Cape covers an area of about 372 889 square kilometres, mostly rural. Kimberley is the capital of South Africa's Northern Cape province and is situated approximately 110 km east of where the Vaal and Orange Rivers meet. Kimberley is an old mining town well past its glory days of diamond mining. According to the 2016 community survey, it had a population of 255 041 at the time (Statistics SA, 2016) – mostly Blacks, whites, and mixed-race people. The predominant languages spoken are Afrikaans, English, and Setswana.

Kimberley has ten municipal clinics scattered across Sol Plaatje municipality, which provide primary health services to the population of Kimberley. City clinic is located in Kimberley's central business district and caters for patients who work in the area, and residents of the business district. Beaconsfield clinic is located in the suburb of Beaconsfield, which is a middle-working-class area populated mainly by a white and mixed-race community. Betty Gatsewe is a large clinic located on the outskirts of Kimberley, is a mostly African community. These three clinics are quite busy providing primary healthcare services. Patients with epilepsy usually attend local clinics to refill their prescriptions and follow up for other chronic conditions.

City clinic has a monthly average attendance of 3 394, with an annual total of 42 993 in the year 2019. Beaconsfield clinic serves an average of 1 606 patients who seek healthcare services monthly; a total of 24 883 patients were seen at the clinic in 2019. Betty Gatsewe has a monthly clinic average attendance of 4 500 patients, and 45 075 patients attended the clinic to access healthcare services in 2019.

The RMSH is a regional/tertiary hospital in the Northern Cape; it is the only referral centre in the province, and receives referred patients from all over the province. On arrival at the hospital, patients are usually seen in any of the casualties, which are managed by the Family Medicine Department. The South African Triage Protocol is used to rank the patients (South African Triage Group, 2012). Patients are divided into different categories: green, yellow, and blue (dead on arrival) cases are channelled to the Gateway Centre, while orange and red cases are referred to the Emergency Department, to be seen urgently.

According to the South African triage scale (South African Triage Group, 2012), patients with epilepsy are generally classified as red cases, though cases considered to be not very serious may will be seen in the gateway centre as yellow cases. Patients with epilepsy who are seizure-free or controlled are seen in specialised clinics and primary healthcare clinics for follow-up appointments and to receive chronic medications.

Every month, on average 42 adult patients with epilepsy are seen at Betty Gatsewe clinic, 39 at City clinic, 25 at Beaconsfield Clinic, and 36 in RMSH casualties.

1.11.1.2 Bloemfontein, Free State

The other location for the study is the city of Bloemfontein, which is the capital of the Free State province and the judicial capital of South Africa. The city has a population density of 80 people per square kilometre and a population of 787 803 (Statistics SA, 2016). Bloemfontein has three major state hospitals: National Hospital, the district hospital; Pelonomi Hospital, the regional hospital; and Universitas Academic Hospital, a tertiary centre. They are all located within the metropolis of Mangaung – the municipal area of Bloemfontein city. Epileptic patients are usually seen at National Hospital if their cases are not complicated; complicated cases will be seen, based on referral, at Universitas Academic Hospital by the Neurology Department, which is a specialist department.

The neurology clinic is a tertiary epilepsy clinic; patients who attend the clinic usually have complicated seizures, difficult-to-diagnose epilepsy, and uncontrolled seizures. These patients are referred from various hospitals in the Free State and from outside the province for specialist opinions and management. Registrars normally run the clinics in the Neurology Department under the supervision of specialists in neurology.

About 60–80 adult epilepsy patients attend the specialist neurology clinic every month. The epilepsy clinic is usually conducted on Fridays; patients seen in the clinic get follow-up appointments to ensure the continuation of care by the specialist managing their epilepsy.

1.11.2 Overview of the study

Figure 1.2 provides an overview of the phases of the study.

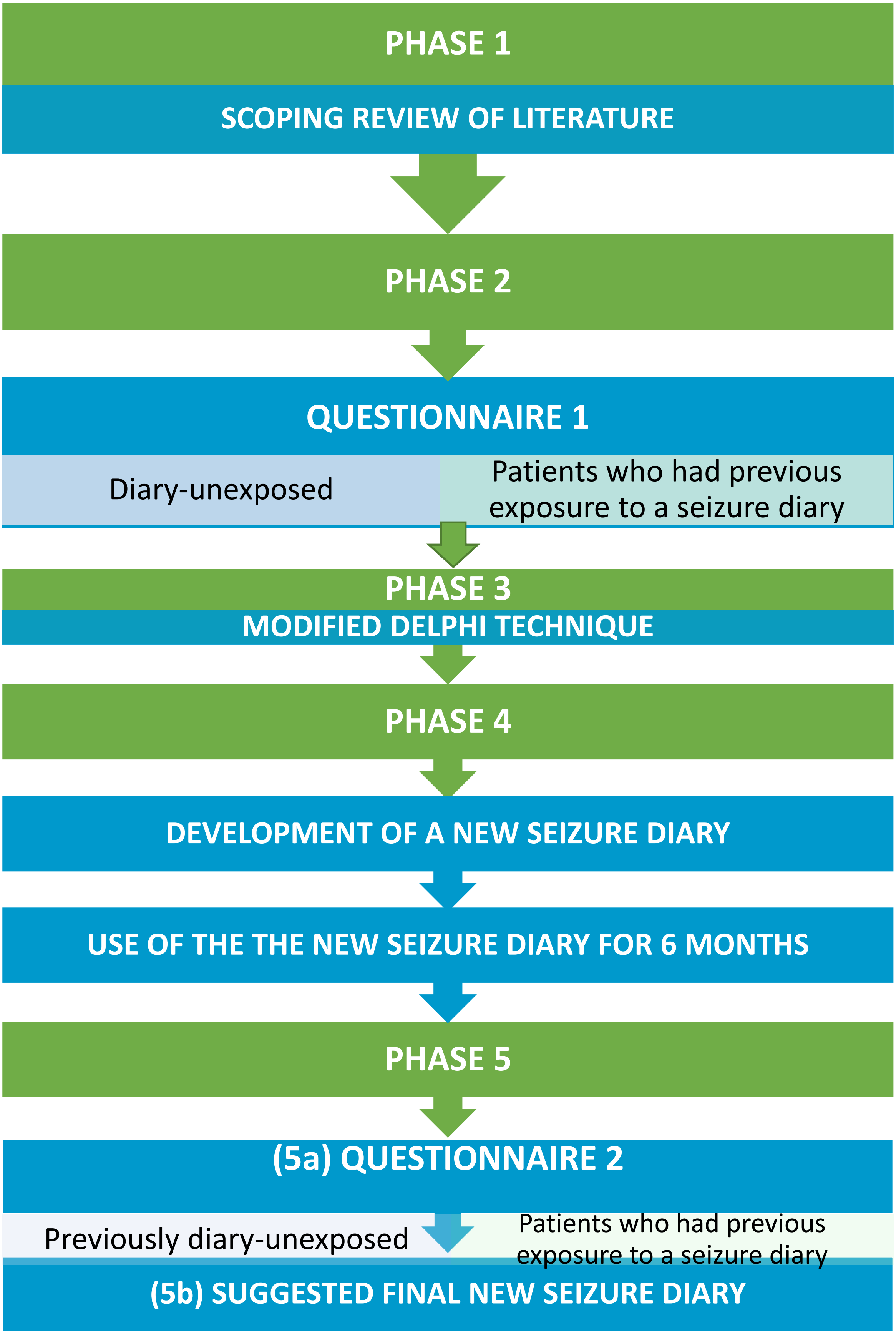

Figure 1.2: Overview of research method (Compiled by the researcher Egenasi 2023)

1.11.2.1 PHASE 1 (Scoping review of literature)

A wide-ranging literature search was done to understand the current norms and international practices on the use of seizure diaries for the management of epilepsy. A scoping review is a process of describing existing literature or evidence base (Arksey and O'Malley, 2005). It helped to summarize evidence from literature on using the seizure diary for managing patients with epilepsy.

Article 1: *Current norms and practices in using a seizure diary for managing epilepsy: A scoping review*, describes the findings of this study and was published in a peer-reviewed journal, *South African Family Practice Journal*, on 22 September 2022.

The information obtained from the scoping review helped design the Delphi questionnaires.

1.11.2.2 PHASE 2 (Questionnaire 1 Perceptions and attitudes to the use of the seizure day)

The quantitative scientific questionnaire-based method of gathering data was used for Questionnaires 1 and 2. This was the preferred approach because it does not require patients to have a mobile device, internet access, or computer skills to use it. A properly designed questionnaire can be used by literate and illiterate patients (Wiseman *et al.*, 2005) if assistance is provided.

A confidential, structured questionnaire was administered to the study participants in Bloemfontein and Kimberley. The Bloemfontein population were patients who had been exposed to a seizure diary before, while the Kimberley population had not been exposed. The questionnaire for patients who had previous exposure to a seizure diary helped us understand their perceptions and attitudes toward the current diary better. The questionnaire also helped us understand what the diary-naïve population knew about the seizure diary and if some had been exposed to it before. The questionnaires were the same for both study populations. The participants completed only the questions that were relevant to their situation.

After completing Questionnaire 1, the responses were analysed, and relevant information obtained assisted to finalise the Delphi questionnaire and Questionnaire 2.

Article 2: *The perceptions and attitudes of patients with epilepsy to the use of a seizure diary, South Africa*, describes the patients' views on a seizure diary and was published in the peer-reviewed journal, *South African Family Practice Journal,* on 9 January 2023.

1.11.2.3 PHASE 3 (Delphi survey)

A Delphi technique is a consensus-building technique that seeks expert opinion on a topic in a structured and iterative manner that involves controlled feedback (Diamond *et al.,* 2014, Vogel *et al.,* 2019). The technique is designed as a group communication process, with the aim of merging opinions on a specific real-world issue (Hsu and Sandford, 2007). It is useful in areas where evidence-based literature is inadequate, since it can unearth collective knowledge from experts in that field without the researcher being physically present at the same location (De Villiers *et al.*, 2005, Humphrey-Murto *et al.*, 2017). A series of rounds are used to clarify, refine, and ultimately achieve consensus on a given topic under discussion. Consensus methods are founded on the principle that an accurate and consistent assessment may be reached by consulting a group of experts and accepting the group consensus (Humphrey-Murto *et al.,* 2017).

In a conventional Delphi survey, a series of questionnaires are used to generate expert opinion anonymously; this takes place over a series of rounds. In each round, every participant works through a questionnaire and returns it to the researcher, who collects, edits and returns to every participant a statement on the position of the whole group (Ludwig, 1994). The process continues until consensus, as defined, is determined to have been reached.

In the modified Delphi survey, the expert panel does not generate the study question. The researcher generates the questions through literature reviews and expert consultation, which are then presented to the panel to start the consensus-seeking process. The panellists are allowed to contribute through responses to open-ended questions to the list prepared by the researcher (Jünger *et al.,* 2017; Keeney *et al.*, 2021).

In this study, a modified Delphi survey was completed, using questionnaires designed for the Delphi participants around what was important to include in the diary design. The Delphi required three rounds to achieve consensus (Hsu and Sandford, 2007).

After completing the Delphi survey, the diary was designed, based on the consensus reached during the Delphi. Information that was acquired during the Delphi survey was used to develop the improved seizure diary.

Article 3: *A modified Delphi study to determine the contents of a seizure diary for patients living with epilepsy in South Africa*, describes the processes of the Delphi, and was published by *The Journal of Public Health in Africa* on 29 May 2023.

1.11.2.4 PHASE 4 (Development and use of the new seizure diary)

The new seizure diary was created and introduced to the study participants. Written permission to distribute the diary to patients was obtained from the Free State and Northern Cape health departments. The diary was then introduced to study participants – both patients who had not been exposed to a seizure diary before, and patients who had previous exposure to a seizure diary who had completed the first questionnaire. The study participants were contacted telephonically to request them to visit their relevant clinics to receive the diary on the day they reported to receive follow-up medication. The researcher and an assistant did home visits for patients they could not reach in the clinics or telephonically. The researcher and research assistants taught the patients and their relatives how to use the diary. Relatives and caregivers were permitted to assist cognitively impaired patients to use the diary. The study participants were required to complete the diary and were followed up each time they came to collect their chronic medications. Patients usually refilled chronic medications every month at the clinics, which would have made it easier to follow up with the patients. However, the COVID pandemic caused this situation to change, and patients only visited their local and specialist clinics every six months.

Details of this aspect of the study are described further in Article 4.

1.11.2.5 PHASE 5a

(Questionnaire 2: Patients' perception of the new improved diary)

Participants who received a diary after using the newly introduced seizure diary for six months were requested to complete a second questionnaire. The questionnaire sampled their opinions on the new, improved diary, whether it was helpful, whether they would consider to continue using it and what they thought should be changed. Information and data obtained from analysing Questionnaire 2 were used to develop the final version of the improved seizure diary.

Article 4: *Experience of the new seizure diary in the Free State and Northern Cape of South Africa*, describes the opinions of patients, relatives, and their caregivers regarding the diary. It was published by the *South African Family Practice Journal* on 26 May 2023.

1.11.2.6 PHASE 5b (Suggested final version of the improved seizure diary)

This was the final part of phase 5, and transpired after the second questionnaire had been completed by study participants.

The relevant information obtained from the analysis of Questionnaire 2 by the Department of Biostatistics was integrated into the new seizure diary used by participants. The information was used to develop a final version of the new seizure diary. The new seizure diary can now be presented as the study's outcome.

This final version of the diary was referred to the Department of Health for consideration and adoption as a tool for managing all adult patients with epilepsy in South Africa. The details of the new seizure diary are also described in Article 4.

1.12 QUALITY OF THE STUDY

To ensure that the research was of good quality, the study had to be systematic and transparent. This was ensured by selecting an appropriate research method, collecting the correct data, using a suitable method of analysis, and accurately reporting the data (Edwards, 2010; Belcher *et al.*, 2016).

1.12.1 Internal validity

The concept of validity can be applied to all types of scientific research, and it relates to how well a study result corresponds with the true findings. This study's internal validity refers to confidence that the measured results represent the truth in relation to the study population, and are not the result of methodological errors (Patino and Ferreira, 2018). Internal validity can be improved by ensuring careful planning, adequate assessment, and implementation of research strategies.

1.12.2 External validity

External validity is the extent to which study results can be applied to a similar study population in a different setting (Patino and Ferreira, 2018). Ensuring this study is feasible and easy to apply will help improve its external validity.

1.13 SCOPE OF THE STUDY

This study can be regarded as interdisciplinary, as it reaches across the fields of neurology, internal medicine, and family medicine.

1.14 VALUE AND SIGNIFICANCE OF THE STUDY

1.14.1 Value of the study

The value of this study can be described as the degree to which the research process produces useful information and knowledge that will stand the test of time. This knowledge can be applied to a wide variety of situations (Piccoli and Wagner, 2003).

1.14.2 Significance of the study

The significance of this study is the description of why it was needed and its importance in furthering knowledge that will benefit health workers and patients.

1.14.3 Contribution

The contribution outlines the extent to which this study added significant and new knowledge to the existing body of knowledge in the field of family medicine and neurology (Gill and Dolan, 2015). This innovation will help to improve practice in family medicine and neurology.

1.15 ETHICAL CONSIDERATIONS

1.15.1 Approval

The protocol of the study was submitted to the Health Sciences Research Ethics Committee of the University of the Free State and was approved with reference number UFS-HSD2020/1385/2411. It was approved for all five phases of this study. Written approval for data collection was obtained from the management of RMSH, the Northern Cape Department of Health, the Free State Department of Health, and Department of Neurology at Universitas Academic Hospital.

1.15.2 Informed consent to participate in the study

Informed consent was obtained from all participants involved in the study during the following phases.

- Phase 2: The completion of Questionnaire 1 (Perceptions of and attitudes towards the use of the seizure diary) by the diary-unexposed patients, and patients who had previous exposure to a seizure diary (*cf.* Appendix I)

Participants and their relatives received information about the study, the names of the researchers, the reason for the study, their role in the study, the expected duration, and how they would be followed up during the study. They were informed that participation was voluntary, and that they could withdraw at any time. An information sheet with the researcher's contact details and that of the Health Sciences Research Ethics Committee of the University of the Free State was provided to all participants in their preferred language. The relatives of cognitively impaired participants were permitted to complete the informed consent form before completing the questionnaire (*cf.* Appendix J).

- Phase 3: The Delphi survey for developing a seizure diary by the expert panel of local and international specialists

The panel of experts for the Delphi survey received an electronic information document with the research title, the researcher's name, the name of his supervisors, and the purpose of the study. The information document discussed the aims and objectives of the study, the confidentiality of information provided, the role of a panellist, and the process all panellists are required to observe in the Delphi survey. The researcher received an electronic confirmation of availability and acceptance from the panellists who participated in the study (*cf*. Appendix M).

- Phase 4: Introduction of participants in the study to the improved seizure diary

Participants and relatives who had earlier consented to complete Questionnaire 1 were followed up and requested to participate by using the diary. The researcher and trained assistants provided information about the diary and how to complete it. The informed consent form for using the diary contained information about the study, the name of the researcher, and the telephone number of the Health Sciences Research Ethics Committee of the University of the Free State. They could contact the committee if they believed that their rights had been violated. Before receiving the new seizure diary, participants completed an informed consent form that was available in English, Afrikaans, Sesotho, and Setswana.

- Phase 5: The completion of Questionnaire 2 (Experience of the new improved seizure diary) by the previously diary-unexposed patients and patients who had previous exposure to a seizure diary (*cf*. Appendix L).

Participants and relatives who participated in completing Questionnaire 1 and had used the diary for six months were requested to complete Questionnaire 2. They were provided with an information sheet, and the researcher and his assistants explained the details to the participants. The informed consent form explained to the participants and relatives the reason for the study, and gave the researchers' contact details and the telephone number for the Health Sciences Research Ethics Committee of the University of the Free State. The participants completed the informed consent form before they were allowed to complete the questionnaire. In situations where a participant was cognitively impaired, relatives or caregivers completed the informed consent form on their behalf (*cf.* Appendix J).

1.15.3 Right to privacy and confidentiality

Number coding was used to ensure the confidentiality of the participants' responses. No names or personal identifiers appear on any research-related information or datasheet sent for statistical analysis.

All paper-based records are kept in a secure location by the researcher; the records can only be accessed by the personnel involved in the study. Data captured on computer were only accessible to personnel involved in the study through the use of access privileges and passwords.

All personnel involved in the study signed a statement agreeing to protect the security and confidentiality of identifiable data. All data was managed in a strictly professional and confidential manner. Refusal to participate in the study did not lead to participants being penalised in any way.

1.15.4 Minimising potential misinterpretation of results

The potential for misinterpretation of results was reduced by ensuring that data were collected correctly. Patients incapable of completing their questionnaires were assisted by the researcher and his assistants, who had already been trained on how to complete the forms. The researcher captured data accurately. The Department of Biostatistics ensured that mistakes were minimised when the data were analysed with appropriate software.

1.15.5 Ethical procedures regarding data reporting

Ethical procedures, such as confidentiality, were applied in the process of reporting the data, by ensuring that participants' details were protected and only relevant data concerning the study were reported. Participants' confidentiality was maintained at all times.

1.15.6 Precautions to prevent the spread of COVID-19

As the study/data collection occurred during the COVID-19 pandemic, the researcher took various steps to minimise the risk of COVID-19 infection among the study participants and research assistants. The researcher and study assistants adhered to the Republic of South Africa's lockdown rules to prevent the spread of COVID-19.

All study participants were screened at the study sites on arrival at the clinics by asking questions to determine if they had any of the common signs and symptoms of COVID-19, and a temperature check was done for all participants.

The researcher and study assistants were screened daily, with daily temperature checks charted. The researcher ensured that face masks and sanitisers were available at the entrance to the study sites, for patients and assistants to use.

The researcher also ensured that participants were informed and encouraged to adhere to the common preventive measures for the spread of COVID-19, such as regular hand washing, using sanitisers, 2 meters of social distancing, and wearing face masks.

1.16 SCHEMATIC OVERVIEW OF THE STUDY

- Preliminary literature study
- Protocol
- Faculty of Health Sciences Evaluation Committee
- Permission from Northern Cape Department of Health
- Permission from Free State Department of Health
- Ethics Committee (Health Sciences Ethics Committee)
- Article 1: Scoping review of literature
- Questionnaire 1 survey
- Article 2: Perceptions and attitudes of patients to the seizure diary
- Modified Delphi survey with 12 experts
- Article 3: Modified Delphi survey to determine seizure diary contents
- Development of the diary
- Introduction of the diary to patients to use for 6 months
- Questionnaire survey 2
- Article 4: Experience of the new seizure diary
- Suggested final new improved seizure diary
- Referal to the Department of Health for implementation
- Finalisation of the thesis

Figure 1.3: Schematic overview of the study (Compiled by the researcher Egenasi 2023)

1.17 CHAPTER SUMMARY

Chapter 1 oriented the reader by introducing the study, describing the background to the study, the methods followed, and the context and contents of the study. This chapter identified the existence of a gap in epilepsy management and the steps taken to address this gap.

The study's research design was described, and the study population and area were identified. The study's ethical implications, procedure to obtain research approval, study quality, validity and rigour were discussed. The chapter concluded by providing a graphic overview of the study.

Chapters 2–5 will describe the results of the first four research objectives of the study in the form of articles. Chapter 6 will present the study's conclusion, implications, recommendations, and limitations.

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CHAPTER 2:

ARTICLE 1 – CURRENT NORMS AND PRACTICES IN USING A SEIZURE DIARY FOR MANAGING EPILEPSY: A SCOPING REVIEW

This article was prepared according to the submission guidelines of the South African Family Practice journal.

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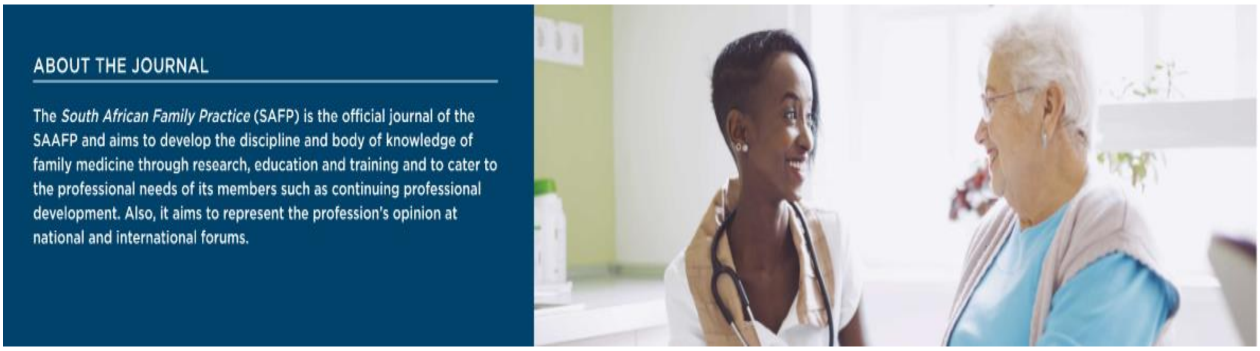

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(Image from South African Family Practice Journal)

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Current norms and practices in using a seizure diary for managing epilepsy: A scoping review

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Background: Epilepsy is a chronic and debilitating condition affecting people of all ages in many nations. Healthcare practitioners look for effective ways to track patients' seizures, and a seizure diary is one of the methods used. This scoping review sought to identify current norms and practices for using seizure diaries to manage epilepsy.

Method: A scoping review was performed by screening relevant studies and identifying themes, categories and subcategories.

Results: A total of 1125 articles were identified from the database; 46 full-text articles were assessed for eligibility, of which 23 articles were selected. The majority (48%) of the studies were prospective studies. The majority (65%) of the articles were studies conducted in the United States. The themes identified were types of seizure diaries used in clinical practice, contents and structure of a standardised seizure diary, the use and efficacy of seizure diaries in medicine and challenges relating to using a seizure diary for patient management.

Conclusion: The study revealed that a seizure diary remains a relevant tool in managing epilepsy. The two forms of diaries in use are electronic and paper-based diaries. The high cost of data and the expensive devices required to access electronic diaries make it unsuitable in a resource-limited setting. Despite its disadvantages, imperfections and inadequacies, the paper-based diary is still relevant for managing patients with epilepsy in resource-limited settings.

Contribution: This study reviewed the literature to find the current norms and practices in using seizure diaries. The benefits of the different formats were emphasised.

Keywords: seizure diary; epilepsy; paper-based seizure diary; electronic diary; seizure frequency; scoping review; articles; literature.

Introduction

Epilepsy is a common chronic medical condition which is associated with physical risk and psychological and socio-economic consequences that may impair the quality of life of an individual. In some cases, in the absence of medical intervention, it could be life-threatening.[1] Epilepsy occurs in all age groups, and it is considered to be one of the most debilitating neurological disease conditions globally.[2] According to the World Health Organization's (WHO) estimate, around 50 million people are affected by epilepsy globally, and nearly 80% (40 million) live in low- and middle-income countries.[2] At present, the number of people living with epilepsy in the African continent is unknown, as a result of marked variations in prevalence data between and within countries, which is a consequence of poor record-keeping and the use of different diagnostic and recruitment protocols by epidemiology researchers in different countries.[3] According to a 2004 WHO African region report, approximately 10 million people of all ages were affected by epilepsy in the African continent.[4] The management of patients with epilepsy requires a long-term commitment from the general practitioner and/or specialist, carer and/or family and the patient.[1] While in most cases, the use of antiepileptic drugs is considered to be the mainstay of treatment, using self-reporting diaries has been considered an important tool in the long-term management of epilepsy.[5,6]

Seizure diaries are a type of patient-reported outcome that is used to record seizure activity in the day-to-day life of the patient, to obtain insight into patients' seizure triggers and events that may affect seizures, to monitor medication side effects and promote medication adherence and to communicate with the healthcare provider.[5,7,8] The seizure diary requires the patients to self-report in the diary their seizure occurrence, duration of seizures, types of seizures and the day of occurrence of the seizures. Caregivers can also assist with diary entries.[5] Seizure diaries are currently available in two major formats: paper and electronic. The paper-based diary is a basic calendar asking questions about patients' seizure types and frequency, which is the industry standard.[5] Patients can indicate the days of the month they had seizures by circling the dates in the calendar. Alternatively, the electronic diary (e-diary) comes in a digital format that can be uploaded online. It is a more detailed and accurate diary with time-stamped patient entries. Information on patients' seizure types, frequency, duration, triggers, mood, medications and side effects can be logged with graphical reports and tabular summaries available to patients, caregivers and healthcare workers.[5]

Electronic-based seizure diaries are the most widely used and are reported to have several potential advantages over paper-based diaries.[5] Despite their reported value in monitoring seizures and managing epilepsy, little information exists about the accuracy or validity of these tools or current norms and practices guiding the use of seizure diaries for managing epilepsy. In the present study, current international norms and practices were examined guiding the use of seizure diaries in the management of epilepsy and their implications for the management of epilepsy in Africa.

Methods

A scoping review was conducted for the purpose of this study in order to explore the breadth of the literature and evidence available on the research topic, to summarise the evidence and to inform future research on the topic.[9] In order to take a structured approach to investigating the current norms and international practices that guide the use of seizure diaries in the management of epilepsy, this review used the five-point framework for data interrogation and analysis proposed by Arksey and O'Malley, namely (1) identify research questions, (2) identify relevant sources or studies, (3) select relevant literature, (4) chart data and (5) collate and analyse the literature.[10] We found no previously published scoping review protocol for this review or the topic of interest. Hence, a protocol was developed for the study.

Identification of research questions

This review aimed to identify a wide range of literature relating to the use of seizure diaries for the management of epilepsy. Based on the initial literature search results, a research question was formulated. The main research question that guided this study is as follows: 'what are the current norms and international practices guiding the use of seizure diaries in the management of epilepsy?'

Identification of relevant sources or studies

An initial search was conducted using Medical Literature Analysis and Retrieval System Online (MEDLINE) and Cumulative Index to Nursing and Allied Health Literature (CINAHL), with the aim of identifying common keywords or phrases in the titles and abstracts of retrieved and relevant articles. Identified keywords or phrases were then used to develop full-search strategies adapted for each information source. Reference lists of sources included were reviewed to determine if potential sources had been overlooked by the search strategy. A literature search was conducted on the following databases: EBSCOhost, Scopus, Cochrane, MEDLINE, CINAHL, Web of Science, Academic Search Ultimate, Africa-Wide Information, American Psychological Association (APA) PsycArticles, APA PsycInfo, Centre for Agriculture and Bioscience (CAB) Abstracts, Communication & Mass Media Complete, Educational Research Information Center (ERIC), Health Source – Consumer Edition, Health Source: Nursing/Academic Edition, Humanities Source Ultimate and Sociology Source Ultimate. Keyword entries used were 'epilepsy diary', 'seizure diary', 'fit charts', 'seizure records', 'paper diaries', 'seizure tracker' and 'international updates on epilepsy'. Keywords were used singly or in combination. Grey literature was examined using Google and Google Scholar search engines in an attempt to identify any unpublished studies relevant to the research question. Identified citations were imported into EndNote X9 (Clarivate Analytics, Chandler, Arizona, United States).[11] Articles were initially screened for inclusion after a quick review of the title and abstracts against the inclusion criteria. If doubt existed regarding its suitability, the article's full text was retrieved and reviewed for possible inclusion. If doubt still existed and reviewers could not reach an agreement, an independent colleague was consulted for deliberation. The first search was conducted on 22 February 2021; this was followed by a serial search every four months for any recent publication on the topic of interest. The last search was conducted on 31 December 2021.

Selection of relevant literature

This scoping review included articles, randomised clinical trials, reviews and conference proceedings published in English since 1981, from any geographical location, as long as it related to the use of seizure diaries for clinical management of epilepsy and seizure monitoring (Table 1). The concepts of interest were standards for an ideal seizure diary, models or types of seizure diaries currently used in clinical practice, how diaries are being used to manage epilepsy and the efficacy of diaries for patient management. Sources of evidence were quantitative and qualitative research that reported on using diaries or seizure monitoring charts for the management of epilepsy and published in peer-reviewed academic journals and verifiable sites or web pages. A search was made on electronic databases, such as EBSCOhost, Scopus, Cochrane and Web of Science, for published articles and relevant reviews that addressed this study's research question. The inclusion and exclusion criteria are presented in Table 1.

TABLE 1: Inclusion and exclusion criteria.

Inclusion criteria	Rationale
Study type	Human studies
	Qualitative studies
	Quantitative studies
	Randomised clinical trials
	Experimental studies
Year	Studies published from 1981 to 2021
Language	English
Location	Any geographical location
Publication type	Research articles
	Reviews
	Randomised clinical trials
	Conference proceedings
	Published in peer-reviewed journals and verified online reports or web pages
	Unpublished studies relevant to the topic
Context	Literature discussing the use of diaries or seizure records for managing epilepsy or seizures
Exclusion criteria	
Study type	Nonhuman studies
Language	Reports not published in English
Publication type	Non-peer-reviewed studies
	Social media reports
	Unverified reports
Context	Studies not discussing the use of diaries to manage patients with epilepsy.

The selection process provided the basis for identifying 1125 potentially relevant sources. After removing duplicate articles (*n* = 385), the lead author screened the titles and abstracts for eligibility. A total of 694 articles were rejected because of a lack of relevance to the subject. All authors reviewed the remaining 46 articles, and 23 articles were agreed on for inclusion. The selection process is presented in Figure 1.

Charting of data

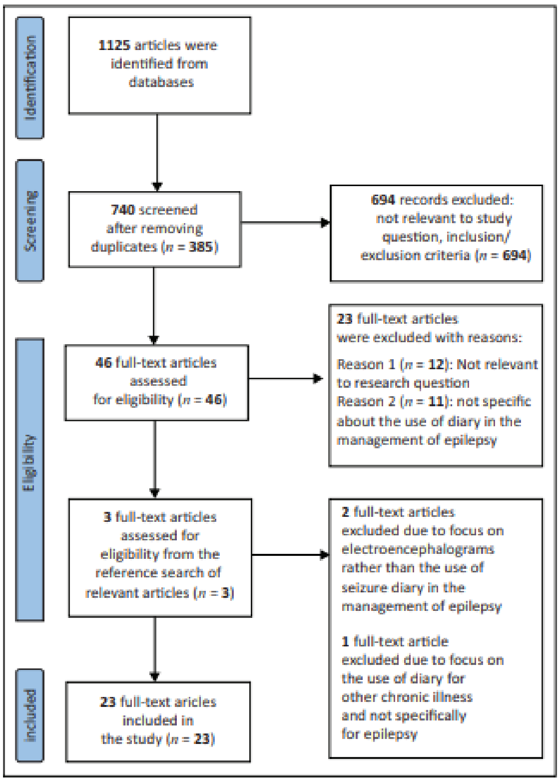
Each article included in the search was summarised and is presented in Table 2 under the following headings: authors, title of article, journal, author location, research design, sample size and comments relevant to the use of seizure diary.

Ethical considerations

Ethical clearance to conduct the study was obtained from the Health Sciences Research Ethics Committee of the Faculty of Health Sciences at the University of the Free State (ref. no. UFS-HSD2020/1385/2411).

Results

As reported in Table 2, of the 23 articles, almost half (48%; *n* = 11) were prospective studies (Table 2). The majority (65.2%; *n* = 15) were studies conducted in the United States of America, while 21.7% (*n* = 5) of the studies were conducted in Europe (Denmark 1, Germany 3 and the United Kingdom 1). No article of relevance was found for a study conducted in Africa, suggesting that very limited research has been conducted on the use of seizure diaries as a tool for managing epilepsy in Africa. An analysis of the publication years of studies revealed that the majority (87%; *n* = 20) had been published between 2006 and 2018, while three (13%) had been published between 1987 and 1990.



Source: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. BMJ. 2021;372: n71. https://doi.org/10.1136/bmj.n71

FIGURE 1: Flow chart of article selection.

Themes identified

Identified themes, categories and subcategories are presented in Table 3.

Discussion

Theme 1: Types of seizure diaries used in clinical practice

The use of patient diaries to assist with clinical management and patient care is a standard practice that has been incorporated into medical practice over the years.[40,41,42] Diaries have been used to document symptoms and factors that may have precipitated the symptoms, patient responses to symptoms, efficacy of treatment response and medication adherence.[40,41,42] Diaries are regarded as the backbone of clinical epilepsy management and therapeutic trials.[5] The findings of the review by Fisher et al.[5] revealed that seizure diaries are available in two formats, namely paper-based diaries and e-diaries.

TABLE 2: Overview of articles used in this review.

Authors	Title of articles	Journal	Author location	Research designs	Sample size (n)	Authors' comments about the diaries
Blachut et al.[13]	Counting seizures: The primary outcome measure in epileptology from the patients' perspective	*Seizure*	Germany	Retrospective survey	170	Almost two-thirds of patients in this study reported keeping seizure diaries. Patients appeared to know that they underreported seizures, which reduced the validity of patient seizure counts.
Blachut et al.[14]	Subjective seizure counts by epilepsy clinical drug trial participants are not reliable	*Epilepsy and Behavior*	Germany	Prospective (noninterventional) study	100	Epilepsy patients who participate in clinical trials underreport seizures, as do patients in general.
Corey et al.[15]	The accuracy of the self-reported history of seizures in Danish, Norwegian and US twins	*Epilepsy Research*	Denmark, Norway, US	Retrospective survey	47 626	The accuracy of self-reported epilepsy and febrile seizures was high across all populations in this study.
Detyniecki et al.[16]	Prevalence and predictors of seizure clusters: A prospective observational study of adult patients with epilepsy	*Epilepsy and Behavior*	US	Prospective (observational) study	247	Patients may have been more or less likely to accurately document information in seizure diaries, depending on seizure burden.
Fisher et al.[5]	Seizure diaries for clinical research and practice: Limitations and future prospects	*Epilepsy and Behavior*	US	Narrative review	0	Diary-based observational studies have the advantage of low cost, allowing locus of control by the patient, and testing in a real-world environment. It is useful as a descriptive snapshot of a population.
Ernst et al.[7]	Medication adherence in women with epilepsy who are planning pregnancy	*Epilepsia*	US	Prospective (multicentre observational) study	86	Diary-compliant patients reported a high rate of anti-epilepsy medication adherence.
Ferastraoaru et al.[17]	Characteristics of large patient-reported outcomes: Where can one million seizures get us?	*Epilepsia Open*	US	Longitudinal (observational) study	10 186	Using electronic patient-reported seizure diary databases presents challenges and limitations, of which the most important is the reliability of data. Reported seizures may be nonepileptic, overreported or underreported.
Fisher et al.[18]	Use of an online epilepsy diary to characterise repetitive seizures	*Epilepsy and Behavior*	US	Descriptive (observational) survey	5098	A limitation of the study was the observational and uncontrolled nature of the data and subjective reporting of events.
Fisher et al.[19]	Tracking epilepsy with an online seizure diary	*Acta Paediatrica*	US	Narrative review	0	After thousands of users have entered data longitudinally into the diary, it will become possible to make observations on patterns.
Glueckauf et al.[20]	Consistency of seizure frequency estimates across time, methods, and observers	*Health Psychology*	US	Mixed methods (retrospective and prospective study)	32	The reliability of self-reporting seizures using the recall or prospective diary methods is high.
Goldenholz et al.[21]	Is seizure frequency variance a predictable quantity?	*Annals of Clinical and Translational Neurology*	US	Longitudinal (predictive survey)	3124	By using data from three independently collected patient diary databases, variance in seizure frequency was predictable, based on knowledge of the mean seizure frequency.
Hall et al.[22]	Early follow-up data from seizure diaries can be used to predict subsequent seizures in same cohort by borrowing strength across participants	*Epilepsy and Behavior*	US	Prospective study	71	Three models were developed using 30 days of nightly seizure diary data in 71 patients to predict subsequent seizures in the same patients over 30 days. The use of paper-based diaries was a limitation because of the absence of time stamping.
Haut et al.[23]	Seizure occurrence: Precipitants and prediction	*Neurology*	US	Prospective study	71	In a paper-based diary study, seizure prediction based on precipitants, premonitory features and self-prediction may provide a foundation for pre-emptive treatment.
Haut et al.[24]	Modeling seizure self-prediction: An e-diary study	*Epilepsia*	US	Prospective study	19	Seizure self-prediction is possible for a subgroup of patients with epilepsy in an e-diary study.
Haut et al.[25]	Clinical features of the pre-ictal state: Mood changes and premonitory symptoms	*Epilepsy and Behavior*	US	Prospective study	19	Diary studies rely entirely on self-reports. Lack of patient accuracy in self-reporting may limit reliability.
Haut et al.[26]	Predicting seizures: A behavioral approach	*Neurologic Clinics*	US	Predictive study	N/A	Analysis of data from paper and electronic diaries suggests that patient seizure prediction is feasible.
Hoppe et al.[27]	Epilepsy: Accuracy of patient seizure counts	*Archives of Neurology*	Germany	Randomised controlled trial	91	Patient seizure counts are not valid information.
Illingworth et al.[28]	A method for identifying associations between seizures and possible trigger events in adults with intellectual disability	*Epilepsia*	United Kingdom	Prospective study	5	The study's limitation was the unreliability of data collected using a pen- and paper-based diary.
Karoly et al.[29]	Are the days of counting seizures numbered?	*Current Opinion in Neurology*	Australia	Narrative review	0	Diaries are highly unreliable; nevertheless, manual diaries are exclusively relied on for clinical trials.
Milton et al.[30]	Timing of seizure recurrence in adult epileptic patients: A statistical analysis	*Epilepsia*	Canada	Prospective study	24	Seizures reoccur in patients randomly and may involve factors such as stress, having missed nights of sleep, skipping medications or consuming alcohol.
Le et al.[31]	An online diary for tracking epilepsy	*Epilepsy and Behavior*	US	Descriptive study	1944	Anonymous data from diaries provided a snapshot of the characteristics of a segment of the epilepsy community.
Neugebauer[32]	Reliability of seizure diaries in adult epileptic patients	*Neuroepidemiology*	US	Prospective study	54	The daily diary is a reliable method for securing data on seizure counts.
Poochikian-Sarkissian et al.[33]	Patient awareness of seizures as documented in the epilepsy monitoring unit	*Canadian Journal of Neuroscience Nursing*	Canada	Prospective study	138	Incomplete data in seizure diaries is probably a widespread problem and may have an important impact on treatment, safety and quality of life.

US, United States; N/A, not applicable.

TABLE 3: Identified themes, categories and subcategories.

Themes	Categories	Subcategories	References
Types of seizure diaries used in clinical practice	Paper-based diary	Advantages of a paper-based diary	5, 34
		Disadvantages of a paper-based diary	5, 19, 28, 31
	Electronic diary	Advantages of an electronic diary	5, 18, 19, 25, 31
		Disadvantages of an electronic diary	5
Contents and structure of a standardised seizure diary	Seizure types	–	5, 18, 31, 35, 36
	Seizure frequency	–	5, 13, 14, 16, 17, 18, 20, 21, 27, 29, 31, 33
	Days of seizure occurrence	–	5, 18, 19, 30, 31
	Others	Seizure duration	5, 17, 18, 31
		Time of seizure	13, 14, 18, 19, 27, 31
		Seizure triggers	5, 18, 31
		Seizure clusters	16, 18, 37, 38
		Medication history	5, 18
The use and efficacy of seizure diaries in medicine	Use of seizure diary in clinical practice	–	5,13,14,19,36,39
	Use of seizure diary for clinical research	–	7, 16, 17, 21, 22, 24, 25, 26, 27, 30, 31
Challenges facing the use of seizure diaries for patient management	Patients' compliance	–	7, 16, 20, 24, 27
	Reliability of patient-reported seizures	–	13, 14, 16, 18, 28
	Validity of patient-reported seizures	–	7, 14, 17, 22, 23

Category 1.1: Paper-based diary

A paper-based diary is a hard copy document that is used to record information such as patients' seizure types and frequency.[5] This type of seizure diary requires the patient or caregiver to manually write in the required information. A paper-based diary is the preferred choice in a resource-limited setting where patients have limited access to the Internet or electronic devices.[5,34]

Subcategory 1.1.1: Advantages of a paper-based diary: Documented advantages of the paper-based diary are that they are cheaper to create, as they do not require Internet access or expensive devices; it is easier for patients to learn how to use; it is easier to use because it does not require great intellectual capabilities or specialised skills (i.e. computer skills) to complete.[5] In addition, a paper-based diary can be successfully used by a predominantly illiterate community and can easily be made available to patients.[34]

Subcategory 1.1.2: Disadvantages of a paper-based diary: The disadvantages of a paper-based diary include that it can easily be lost, misplaced or not brought along by patients to clinic visits[5,31] and that patient data cannot be backed up or reconstructed if the diary is lost.[5] Paper-based diaries can be completed retrospectively, and it is prone to recall bias, which calls into question the validity of patient-reported data.[28] Written data are difficult to transform into electronic data, making it difficult to visualise trends and relationships between listed factors.[19]

Category 1.2: Electronic diary

In contrast to paper-based diaries, an e-diary can be accessed via different online browsers on devices such as computers, laptops and smartphones.[5,41] An e-diary can record more detailed data than a paper-based diary. Among its various features are that programming can improve data validity, real-time transmission of patient information is possible and reminders can be sent to subjects.[5,43]

Subcategory 1.2.1: Advantages of an electronic diary: The literature reports several advantages of using an e-diary. An online database serves as a safe storage site for storing patients' information anonymously.[18] An e-diary is not prone to being easily lost or misplaced,[19,31] and data can be made available in graphical or tabular format for easy visualisation of trends.[31] Electronic diaries are easily accessible via handheld devices like smartphones and computers.[5] The e-diary allows for precise time recording; an entry is time-stamped and it is difficult to backfill or complete retrospectively.[25] The e-diary can be adapted to prevent information entered into the diary from being edited.[25] An e-diary can be programmed to provide reminders to improve patient compliance.[19] Large online databases to which patients contribute information can serve as a rich data pool for authorised researchers.[5]

Subcategory 1.2.2: Disadvantages of an electronic diary: Reported disadvantages of electronic diaries are that an e-diary requires the user to be technologically proficient and to have access to electronic devices – which patients cannot always afford.[5] It may be difficult to use an e-diary for patients who are children, as it will require a caregiver's input, which may be problematic because of the presence of multiple caregivers.[5] If multiple caregivers have access to the diary, it may compromise patients' privacy.[5]

Theme 2: Contents and structure of an ideal seizure diary

While there is little empirical evidence or a theoretical foundation to inform the content of patient diaries, the design and contents of most patient diaries are tailored to achieve the goal of clinical management.[41] In the design of diaries for clinical drug trials, one type of diary will not be appropriate for all clinical studies because of the inconsistency of the questions posed. Trying to predict all possible data will lead to requesting too much information, which may make the diary impractical to use. The best diaries ask only what is needed with an efficient and user-friendly design.[5]

The findings of the present study revealed that a standardised seizure diary must contain three vital, basic pieces of information, namely seizure type, seizure frequency and days of seizure occurrence.[5]

Category 2.1: Seizure type

The management of epilepsy recognises various seizure types, which may affect different age groups. Children, more than adults, have been reported to present with multiple seizure types.[5] Treatment is often tailored to consider seizure types; hence, accurate description and categorisation of seizure types are important for proper management. To this end, some researchers[5,18,31] consider information on seizure type to be an essential component of a seizure diary. The International League Against Epilepsy (ILAE) provides a detailed operational classification of seizures.[35] Fisher et al.[5] suggested that seizure types may be recorded using codes such as A, B and C to represent different types of seizures known to the diary developers and the patients.[5] Other researchers suggest writing out the common types of seizures in full if the space is available in the diary.[36]

Category 2.2: Seizure frequency

Seizure frequency is another important piece of information that must be captured in a seizure diary, as reported by most of the literature reviewed.[5,13,14,16,17,18,20,21,27,31,33] Patients document their seizure occurrence, which can be used in estimating the seizure frequency. The estimation of seizure frequency is a cornerstone of clinical epilepsy management and evaluation of new therapies.[29] Self-reported seizure counts of patients with epilepsy guide treatment decisions and are often the primary outcome measure of clinical trials in epilepsy.[14,27] Patients' medication dosages and clinic visit frequency are adjusted according to the trends of patient-reported seizure frequencies.[33] Some scholars[16,18] reported that information on seizure frequency could be used to identify seizure clusters.[37] Karoly et al.[29] reported that seizure counts remain the primary way of quantifying patients' epilepsy. Seizure counting does not require specialised equipment or tests and is entrusted to patients or caregivers, commonly using a seizure diary.[29]

Category 2.3: Days of seizure occurrence

Days of seizure occurrence is one of the three most important pieces of information that must be captured in a standardised seizure diary.[5,18,19,30,31] Researchers suggest that a seizure diary must contain a suitable calendar for charting days with seizures in order to eliminate patient recall bias.[5,18,19,30,31] Calendars are available as hard copy (paper-based diary) or electronic calendars (e-diary). Several events can be recorded on a calendar diary, such as seizures, mood, menstruation, medications and side effects, by day or time of day.[18,19]

Category 2.4: Other information

Additional information that can be recorded in the seizure diary includes seizure duration, time of seizure, seizure triggers, seizure clustering, medication regimens, missed medications, medication side effects and patient mood. A seizure diary may include the duration of seizures as additional information provided by the user of the diary and caregiver. Authors of the reviewed literature[5,17,18,31] described seizure duration as additional information that could be provided by users as part of patient history. Prolonged seizure duration increases the risk of progression to status epilepticus, which has been reported to account for increased morbidity and mortality of patients with epilepsy.[44] Time of the seizure can be recorded in a seizure diary.[13,14,18,19,27,31] Seizures can occur in the daytime or at night. Night-time seizures are more likely to be undocumented by patients because of unawareness.[13,27] Seizure triggers are additional information that can be recorded in the seizure diary.[5,18,31] Some patients are familiar with events that may trigger their seizures, but it is common for a patient not to know what triggered a seizure. Successfully identifying triggers can help decrease seizure frequency in patients. Some authors of the reviewed literature reported using a seizure diary to monitor common seizure triggers.[16,17,23,24,25,26] Stressful life events, mood changes, missed or changed medications, altered sleep, alcohol consumption, menstruation, anxiety, bright or flashing lights and constipation are some of the seizure precipitants commonly reported in the literature.[17,18,22,25,28,30,31] Seizure clusters are patterns of seizures that occur multiple times a day,[18] although there is no consensus on the definition of seizure clusters.[18,37] Detyniecki et al.[16] defined seizure clusters as two or more seizures in 6 h, while Haut et al.[38] used an alternative definition, defining seizure clusters as three or more seizures in any given 24-h period. Fisher and colleagues reported that seizure clusters are additional information that can be ascertained from recorded data in a seizure diary.[5,19] Diary data that include seizure time from online electronic seizure diaries, such as Nile (Nile AI, Inc., Los Angeles, California, United States) and Seizure Tracker (Seizure Tracker LLC, Springfield, Virginia, United States), are used to identify repetitive seizure patterns that signify clusters in patients with epilepsy.[17,18] People with high daily seizure counts are likely to experience clusters every day.[18] Medication regimens can be recorded as additional details in seizure diaries.[5,18] The 'best dose' of medication is the one that controls seizures and is associated with the least side effects.[43] Information on other chronic medications used for medical conditions apart from epilepsy may be vital in order to avoid medication errors because of drug–drug interactions.[45] Information on medication adherence is important for seizure control, and daily diary inputs may act as reminders to promote medication adherence.[23] Ernst et al.[7] found seizure diaries to be helpful in tracking patients' medication adherence in a subset of women with epilepsy who were planning pregnancy. Some electronic diaries allow users to document their medication names and doses; users can also indicate if they missed medications or took extra doses.[18,19]

Theme 3: The use and efficacy of seizure diaries in medicine

Information synthesised from the reviewed literature reveals that seizure diaries are used in two major forms: clinical practice and research.

Category 3.1: Using seizure diaries in clinical practice

A seizure diary is a self-management tool for patients living with epilepsy.[8,39] Some researchers[13,14] reported on using paper-based diaries for the clinical management of patients with epilepsy. Although prone to recall and response bias, a basic paper-based diary can provide a history of a patient's seizure types, seizure frequency and the calendar dates of seizure occurrence.[5,19] A paper-based diary can be used as a source of patient information that is useful when patients migrate to other locations or when a lack of continuity regarding healthcare providers causes patients to see a different doctor every time they visit a clinic. Electronic diaries are online applications for patients living with epilepsy.[39] Examples of popular web-based diaries include Nile (formerly My Seizure Diary, available at https://www.epilepsy.com/)[39] and Seizure Tracker (available at https://seizuretracker.com/).[17,36] Both diaries allow patients and caregivers to log seizures of different types, medication dosages, events by time, seizure duration, missed medication, additional medication and medication side effects, and they provide graphical and tabular summaries of information that can be assessed by a medical team via the physician portal or e-mail, if permitted.[5]

The use of seizure diaries in predicting seizures was reported by six researchers.[21,22,23,24,25,26] Haut et al.,[25] in a study using the e-diary, reported that changes in mood such as happiness, sadness and nervousness and premonitory features such as blurred vision, dizziness and light sensitivity contribute to the prediction of seizures over 12 h. In another study using an electronic diary, Haut et al.[24] reported that 9 of 19 (43%) participants with epilepsy were able to accurately predict their seizures, drawing on awareness of mood and premonitory symptoms.

Category 3.2: Using seizure diaries for clinical research

Diaries can be used for clinical research; almost all the studies reviewed commented on the use of seizure diaries for clinical research.[7,16,17,21,22,24,25,26,27,30,31] Seizure diaries could be used in investigator-supervised research, such as randomised controlled trials of novel epilepsy therapies, prospective observational studies, or unsupervised studies, such as *ad hoc* analysis of self-reported anonymous diaries.[31] Longitudinal data entered into seizure diaries can be used to make observations, and observational data can be used to generate hypotheses to be tested in clinical trials.[19] In addition, information such as demographic data, seizure types, seizure precipitants and medication usage that is captured in diary-based studies can be used to develop descriptive snapshots of the population.[31]

Theme 4: Challenges related to using seizure diaries for patient management

Category 4.1: Patients' compliance

Compliance means to adhere to something; clinicians expect patients to comply regarding diary use. In this scoping review, we found that compliance was often discussed as one of the major challenges relating to the use of seizure diaries for patient management.[7,13,14,16,19,20,22,23,24,26,27] Nevertheless, patient-reported compliance was high in most of the literature reviewed. Blachut et al.[13] stated that the majority of patients in their study reported keeping a seizure diary, most keeping the diary themselves, and in some cases, patients were assisted. The high level of compliance documented by these studies may be the result of various strategies used by the researchers to enhance compliance. Documented strategies to enhance patient compliance include sending electronic reminders[7,16,20,24,27] and training patients on how to use the diary.[23,25,28] Despite these strategies, Hoppe et al.[27] reported that in their study, reminding participants did not enhance seizure documentation.[27] It is also reported that severe epilepsy, such as drug-resistant seizures and increased seizure frequency, could enhance compliance with diary use as opposed to patients with well-controlled epilepsy who may have little motivation to utilise the diary.[17,31]

Keeping a seizure diary empowers the patient to be actively involved in controlling their health. Maintaining a diary may help improve compliance with treatment.[7] Blachut et al.[14] stated that patients are compliant with documentation if they feel it is important for monitoring their disease and may affect their treatment.

Furthermore, healthcare practitioners' interest in the patients' seizure diary has been suggested to improve patient compliance with diary use. Blachut et al.[13] reported a strong positive correlation between patients' commitment to seizure documentation and doctors' behaviour. Doctors taking time to review the diary reinforced positive diary behaviour by patients,[13] which should be encouraged to improve patient compliance.

Category 4.2: Reliability of data on patient-reported seizures

Data on seizures, self-reported using either paper-based or electronic diaries, have long been relied upon in clinical drug trials and clinical management of patients with epilepsy. The accuracy of subjective self-reporting continues to be debated.[23] Thirteen of the studies reviewed described the accuracy of patient-reported seizures as being a limitation in their studies.[13,14,16,18,28] Some researchers suggested that inaccuracies in seizure reporting were because of patients' inability to recognise their seizures (seizure unawareness), which leads to underreporting.[13,14,27] Poochikian-Sarkissian et al.[33] reported that patients in their study recognised only 44.5% of complex partial seizures and generalised tonic-clone seizures, thus leading to questions about the reliability of patients' diary-reported seizures. These findings are supported by other researchers.[46,47] Patients also complete their diaries retrospectively, thus affecting the reliability of the data.[7,23]

In contrast, three of the studies reviewed found patients' self-reported seizure estimates to be reliable and relevant.[15,20,32] Glueckauf et al.[20] evaluated the consistency of seizure frequency estimates among patients and caregivers. The study reported that patients provide more reliable seizure frequency estimates than caregivers. Neugebauer[32] reported that using the diary in clinical settings still enjoys high reliability in dedicated patients. Corey et al.[15] reported that the accuracy of self-reporting of epilepsy and febrile seizures was high among patients providing health histories in all population groups studied. Detynieki et al.[16] reported that following up paper-based diary patients, collecting and reviewing the diary at regular intervals (electronic diaries being reviewed on a monthly basis) and comparing the provided information with diary entries help ensure the accuracy of data. However, most researchers described self-reported diaries as being inaccurate and unreliable. Karoly et al.[29] stated that using video electroencephalogram (EEG) is a more accurate and modern technique of monitoring and reporting seizures. However, this technique may not be suitable for all patients and clinics because of affordability. Patients are less likely to accept a more invasive monitoring technique in exchange for more accurate information.

Category 4.3: Validity of data on patient-reported seizures

Subjective data reflect patients' reported perspectives via their seizure diaries, while objective data reflect verifiable facts using clinical events correlated to electrographic seizures.[29] Seizures can be verified using video EEG, ambulatory EEG, implantable recording devices, smartwatches and other modern devices.[5,36,48,49] Researchers reported that patient-reported seizure diary data are subjective and not verifiable.[7,14,17,22,23] Patient-reported, subjective data are prone to inaccuracies and being unreliable. Some of the difficulties experienced in using objective methods in validating seizure diary data, as reported by some researchers, include problems with electrode placement, the high cost of EEG equipment, safety concerns and practical difficulties.[20,28] Despite these difficulties, some studies reviewed validated diary data.[15,21,27,33] These authors reported that combining diary data with EEG readings can help validate diary data.

Limitations

A limitation of this study is the paucity of literature on the use of the seizure diary in epilepsy management in low-income countries of the world in general and the African continent in particular. More information would have enabled the documentation of trends in the use of seizure diaries in managing epilepsy in a resource-poor setting.

Conclusion

This scoping review showed that seizure diaries remain relevant for epilepsy management in a resource-poor setting where modern devices for objective detection and recording of seizures are unaffordable. Without feasible alternatives, affordable seizure diaries are essential for monitoring epilepsy in a resource-poor setting, despite its challenges. Electronic- and paper-based diaries are the two forms of diaries in use. The high cost of data and the expense of devices required to access an e-diary make this form unsuitable for resource-limited settings.[48,49,50] Patient compliance and the reliability and validity of patient-reported data are some of the challenges associated with the use of seizure diaries in clinical practice. Training patients to use the seizure diary, encouraging them to complete the diary as soon as possible after a seizure and motivating them to use the diary to keep track of seizures, which influences their treatment, may help improve the use of the seizure diary.

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Competing interests

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Authors' contributions

C.K.E. conceptualised the study, conducted the literature search, selected the articles and drafted the manuscript. A.A.M. supervised the study, verified the articles and edited the manuscript. W.J.S co-supervised the study, verified the articles and edited the manuscript. A.O.A. provided expert input in drafting the manuscript.

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Data availability

The data that support the findings of this study are available from the corresponding author, C.K.E., upon reasonable request.

Disclaimer

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CHAPTER 3:

ARTICLE 2 – THE PERCEPTIONS AND ATTITUDES OF PATIENTS WITH EPILEPSY TO THE USE OF A SEIZURE DIARY, SOUTH AFRICA

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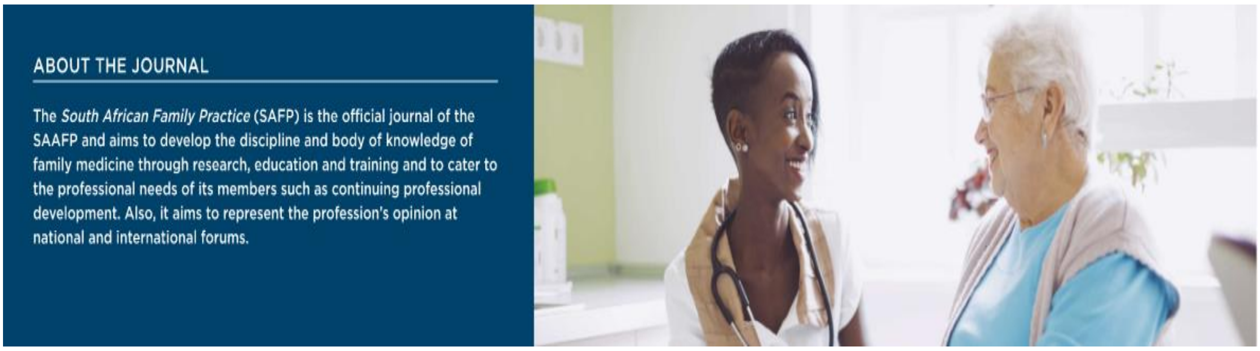

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(Image from South African Family Practice Journal)

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The perceptions and attitudes of patients with epilepsy to the use of a seizure diary, South Africa

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Background: Epilepsy is responsible for a significant proportion of the world's disease burden, affecting around 50 million people globally. A seizure diary is a self-management tool for epilepsy focusing on self-monitoring, tracking seizures and other symptoms. This study aimed to determine the perceptions and attitudes to the seizure diary in patients with epilepsy in the Free State and Northern Cape of South Africa.

Methods: This cross-sectional survey method included adult patients with epilepsy attending Universitas Academic Hospital Specialist Epilepsy Clinic in Bloemfontein and local clinics in Kimberley (City, Beaconsfield and Betty Gatsewe), as well as the casualty department of Kimberley hospital (Robert Mangaliso Sobukwe Hospital). The Kimberley patients were diary-unexposed, while the Bloemfontein patients were patients who had previous exposure to the seizure diary.

Results: A total of 182 patients with epilepsy were recruited for the study, of whom 65 were patients who had previous exposure to the seizure diary, and 117 were unexposed. In the patients who had previous exposure to the seizure diary, 64 (98.5%) found the diary useful, but 15 (23.1%) reported having various challenges with using the seizure diary. Almost all of the patients who had previous exposure to the seizure diary, 64 (98.5%), were willing to continue to use the diary, while 112 (95.7%) of the diary-unexposed patients were also willing to use the diary.

Conclusion: Information from some patients using the diary confirms various challenges with its use; however, most patients support the continued usage of the diary.

Keywords: seizure diary; epilepsy; paper diary; electronic diary; seizure frequency; patients who had previous exposure to the seizure diary; unexposed.

Introduction

The World Health Organization (WHO) estimates that epilepsy affects about 50 million people worldwide, of which about 10 million reside in Africa.[1] In South Africa, epilepsy affects about 500 000 people.[2] The WHO also estimates that about 100 million people will have a seizure at some point at least once in their lifetime;[1] about 50 million will have recurrent seizures, of which 40 million will go untreated.[1] About 70% of people with epilepsy can live a seizure-free life if resources are readily available to treat them.[1] The WHO estimates that 80% of the 10 million patients with epilepsy residing in Africa will go untreated despite the availability of effective medications.[1] Management aims to control the seizures to reduce morbidity and mortality associated with epilepsy.[3]

A diary is a tool meant to capture patients' experiences close to the point of occurrence in order to provide more accurate data.[4] A seizure diary is a self-management tool for epilepsy focusing on self-monitoring, tracking seizures and managing anti-seizure medications.[5] It helps manage medication and other therapies, recognise triggers and health events that may affect seizures and wellness and communicate with the patient care providers.[6] The seizure diary helps to capture the patients' 'life as it is lived'.[7] The diary comes in two formats, the paper format and the electronic format. The paper diary is a basic calendar asking basic questions about patients' seizure types and frequency, which is the industry standard.[8] Patients can indicate the days of the month they had seizures by circling the dates in the calendar. On the other hand, the electronic diary is a digital format that can be uploaded online. It is a more detailed and accurate diary with time-stamped patient entries available to patients, caregivers and healthcare workers.

In countries such as the United States (US), Australia and Canada, various free online electronic seizure diaries are used, such as My Seizure Diary and Seizure Tracker.[9,10]

Many patients with epilepsy are already using them to help track seizure history, symptoms and medication management and help patients interact with their healthcare providers.[11] Seizure Tracker is an online seizure diary with over 20 000 registrants tracking their seizures electronically.[12] In a country like the US, patients have access to personal electronic devices;[13] however, in impoverished communities in South Africa, mobile device usage is severely constrained due to the high cost.[14] It also diverts income from more productive uses in resource-poor settings.[14] Some people live in rural locations[15] where Internet coverage is not always available, making it difficult for them to use electronic-based diaries. In such communities, the paper diary can be used, given sufficient reading and language skills.[16] It does not require any Internet access or basic computer skills for the patients to use.[16]

In South Africa, there is no standardised format for the seizure diary. A calendar format of the diary is used in some South African medical facilities. Most of the scientific papers reviewed support the concept that a properly designed seizure diary has a role in managing epilepsy patients and improving medication adherence in the clinical setting.[17,18,19]

If modified for patient use with the active involvement of patients, the seizure diary can be a useful tool to help the patients and their relatives keep records of events related to epilepsy, such as seizures, in their own words. The diary may also help them relate their experiences so that the healthcare workers can understand how the disease impacts them and their families. The diary can help healthcare workers access essential information about their patients which otherwise may not have been available. The available information may eventually lead to better management of patients, with minimum wastage of scarce resources. By developing a seizure diary that can be effectively used to monitor and manage patients with epilepsy in South Africa, this study aimed to determine patients' perceptions and attitudes to the use of the seizure diary in managing patients with epilepsy in the Free State and Northern Cape of South Africa.

Methodology

Study design

The study was part of a more extensive study conducted in phases. This study was Phase 2, a cross-sectional study. Other phases consisted of Phase 1 (scoping review of literature), Phase 3 (Delphi study), Phase 4 (introduction to the new, improved seizure diary), Phase 5a (patients' perceptions of the new, improved seizure diary) and Phase 5b (suggested final version of the seizure diary).

Study population

The study population consisted of adults with epilepsy in Kimberley and Bloemfontein currently attending Universitas Academic Hospital Specialist Epilepsy Clinic in Bloemfontein and local clinics in Kimberley (City, Beaconsfield and Betty Gatsewe), as well as the casualty department in Kimberley's Robert Mangaliso Sobukwe Hospital from January 2021 to July 2021. The Bloemfontein population were previous diary users (exposed) to a basic calendar diary, while the Kimberley population were unexposed to the diary. Relatives and caregivers involved in taking care of the patients could help complete the questionnaire. Questionnaires completed by relatives or caregivers were noted as such.

Inclusion criteria

Patients diagnosed with epilepsy by a medical practitioner attending the facility for follow-up and 18 years and above were recruited for the study. Patients with cognitive impairment were included, as relatives provided information. Recruitment sites included Universitas Academic Hospital Specialist Epilepsy Clinic in Bloemfontein, local clinics (City, Beaconsfield and Betty Gatsewe) and the casualty department in Kimberley's Robert Mangaliso Sobukwe Hospital. Informed consent was obtained from patients or caregivers when patients were disabled owing to cognitive impairment.

Exclusion criteria

Patients with seizures not diagnosed as epilepsy were excluded.

Sampling method

Consecutive sampling was used in selecting patients meeting the inclusion criteria, depending on patients' availability and willingness to be enrolled in the study. Patients were enrolled in the study until the required sample size was attained.

Sample size

Given the number of patients available, it was decided to include 80 patients in each group. Patients who had previous exposure to the seizure diary from Universitas Academic Hospital epilepsy specialist clinics versus diary-unexposed patients from the Kimberley hospital (Robert Mangaliso Sobukwe Hospital) casualty department, City, Beaconsfield and Betty Gatsewe clinics. Thus, no formal sample size calculation was performed, and this study had no main outcome on which to base such a calculation, but this group size gives sufficient power (80%) to detect large differences between the groups (e.g. 60% vs. 80%) and fairly precise estimates within groups.

Measurement

A confidential, structured questionnaire with 33 questions was administered to the study patients in the Bloemfontein and Kimberley populations. The questionnaire was designed from information obtained from literature on the use of the seizure diary after an extensive literature search. It consisted of five sections, A–E. Section A consisted of seven demographic questions, mostly requiring 'Yes' or 'No' answers, and one question on patients' location. Section B had two questions about the patient's epilepsy. Section C consisted of six questions about the patient's seizures. Five questions required the patient to choose the most appropriate option for them, and one question required a 'Yes' or 'No' answer. Section D had 16 questions, 14 of which required a 'Yes' or 'No' answer, and two open-ended questions.

The initial two questions asked the patients if they had ever heard or used the diary; if the response to using the diary was 'No', the patient was then requested to move on to Section E. If the response to the use of the diary was 'Yes', the patient was then requested to answer the rest of the 14 questions on the use of the seizure diary. Section E had two questions about the future use of the diary, requiring a 'Yes' or 'No' answer. The same questionnaire was used for both populations. The questionnaires were available in English, Afrikaans, Setswana and Sesotho. Two research assistants with healthcare experience were trained to assist the researcher. They were required to assist with studying patients only when off duty. They were able to communicate in English, Afrikaans, Setswana or Sesotho; and they were willing to work with patients with epilepsy and ready to travel to different research sites in Kimberley and Bloemfontein.

The questionnaires were manually distributed by the first author or the assistants in City, Betty Gatsewe and Beaconsfield clinics and Kimberley hospital (Robert Mangaliso Sobukwe Hospital) casualty while patients were in the waiting area. In Bloemfontein, questionnaires were distributed to patients attending the neurology clinic while waiting to be called into the consulting room by the doctor to prevent wasting the patients' time after consultation. The first author and his assistants individually explained the process and obtained informed consent from the patients. All patients were required to immediately complete the questionnaires and return the completed questionnaire to the researcher or his assistants while still in the waiting area. Illiterate patients were assisted by their relatives, caregivers, the researcher or trained assistants fluent in one of the spoken languages. Cognitively impaired patients were assisted by their relatives or caregivers. The first author and his assistants also used the opportunity to educate diary unexposed patients, their relatives and caregivers about the seizure diary.

Pilot study

A pilot study was done on epilepsy patients in Kimberley hospital casualty and Universitas Academic Hospital neurology specialist clinic. It included five patients who met the inclusion criteria. This tested the questionnaire and the project processes. Data from the pilot study was not used in the main study because of changes made in the questionnaire.

Statistical analysis

Categorical variables were summarised by frequencies and percentages and numerical variables by median and interquartile ranges (IQRs) because of skewed distributions. Groups were compared regarding categorical variables using chi-square or Fisher's exact tests (in the case of sparse cells). The significance level was set at 0.05. Analysis was performed using SAS version 9.4.

Ethical considerations

The protocol for the study was approved by the Health Sciences Research Ethics committee (HSREC) of the University of the Free State (re. no. UFS-HSD2020/1385/2411). Approval for data collection was also obtained from the Northern Cape Health Department and the Free State Health Department.

Number coding was used to ensure the confidentiality of the participant's responses. No names or personal identifiers appeared on any research-related information or datasheet sent for statistical analysis. All paper-based records were kept in a secure location by the researcher and were only accessible to those involved in the study. All information was managed in a strictly professional and confidential manner.

Results

A total of 186 patients were recruited for the study from January 2021 to July 2021 from Universitas specialist hospital in Bloemfontein and the Kimberley casualty department and clinics. A final sample size of 182 was obtained after four patients were excluded for incomplete questionnaires. Only 65 patients who had previous exposure to the seizure diary were available for recruitment and 117 unexposed. More patients than the initially intended 160 patients were recruited to compensate for possible dropouts in-between phases.

The median age was 31 (range 18–76 years) in the patients who had previous exposure to the seizure diary and 38 (range 18–68 years) in the unexposed group. The *p*-values for age were <0.01, 95% confidence interval (CI) for median difference patients who had previous exposure to a seizure diary versus not exposed, −10; −2.

Table 1 summarises patients' demographic data. There were significantly more women and pensioners in the patients

TABLE 1: Demographic characteristics.

Variable	Patients who had previous exposure to the seizure diary (*n* = 65)		Diary-unexposed (*n* = 117)		*p*
	n	%	*n*	%	
Gender					< 0.01*
Male	25	38.5	75	64.1	
Female	40	61.5	42	35.9	
Occupation					0.03*
Employed	5	7.7	17	14.5	
Pensioner	35	53.9	42	35.9	
Student	5	7.7	4	3.4	
Unemployed	20	30.8	54	46.2	
Education					< 0.01*
Below Grade 12	37	56.9	72	61.5	
Matric	5	7.7	27	23.1	
Others	19	29.2	15	12.8	
University	4	6.2	3	2.6	

*, Statistically significant difference.

who had previous exposure to the seizure diary group, and a large percentage of patients in the diary unexposed group had below Grade 12 education.

Figure 1 shows the distribution of people completing the patient questionnaire. The majority of the patients who had previous exposure to the seizure diary and the unexposed patients completed the questionnaire themselves.

Table 2 illustrates patients' reported responses regarding their disease. The disease duration of patients who had previous exposure to the seizure diary was significantly longer. The patients who had previous exposure to the seizure diary group had a significantly larger percentage with unknown seizure types, and the unexposed group had a significantly larger percentage reporting generalised tonic-clonic seizures.

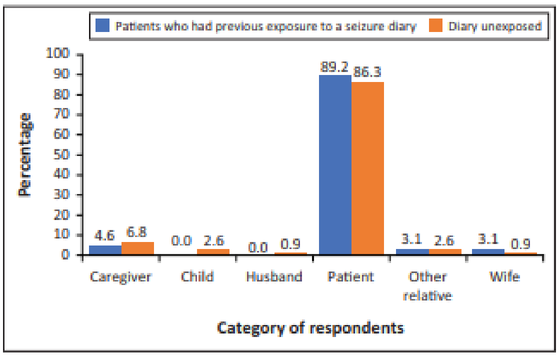

FIGURE 1: Persons completing the questionnaire.

TABLE 2: Disease characteristics.

Variable	Patients who had previous exposure to a seizure diary (%)	Diary unexposed (%)	*p*
Disease duration (in years)			0.04*
Less than 1	0.0	11.1	
1–5	16.9	19.7	
6–10	16.9	12.8	
More than 11	66.1	56.4	
Types of seizure			**< 0.01***
Absence seizures	9.2	6.8	
Focal seizures	0.0	7.7	
Generalised tonic-clonic	6.2	27.4	
Don't know	86.4	57.3	
Others	0.0	0.9	
Annual seizure frequency			0.77
None	7.7	9.4	
Once	9.2	12.0	
More than once	83.1	78.6	
Treatment with anti-epilepsy drugs			0.09
No	0.0	5.1	
Yes	100.0	94.9	

*, Statistically significant difference.

Table 3 reports patients' responses to questions about seizure awareness and recall of seizures.

A few diary-unexposed patients (6.8%) have heard of the seizure diary. When asked whether they knew the diary was free, 63 (96.9%) of the patients who had previous exposure to the seizure diary knew it was free. Almost all 64 (98.5%) of the patients who had previous exposure to the seizure diary were willing to continue to use the diary, while 112 (95.7%) of the diary-unexposed group were willing to use the diary ($p = 0.42$). All our patients who had previous exposure to the seizure diary were on anti-epileptic treatment except for one omission, while 111 (94.9%) of the diary-unexposed patients reported being on treatment with anti-epileptic medications.

Of all the patients using the diary, 65 (100.0%) were recommended it by their doctors, 64 (98.5%) reported that they understood the diary and 56 (86.2%) used the diary every time they had seizures. Almost all 62 (95.4%) liked using the diary, 64 (98.6%) of patients who had previous exposure to the seizure diary found the diary helpful in monitoring their epilepsy and 65 (100.0%) reported that the diary helped them keep track of their seizures and how often they had seizures. Of the patients using the diary, 34 (52.3%) did not find the diary helpful in taking their medications compared to 31 (47.7%) who found it useful for that purpose. Most patients, 50 (76.9%), did not report any challenges with completing the diary, while 15 (23.1%) reported some challenges, as described in Table 4.

When patients who had previous exposure to the seizure diary were given multiple options to choose from about what information they think is essential to be in the diary, 48 (73.9%) requested the date of the seizure, 25 (38.5%) frequency of the seizure, 35 (53.9%) asked for the type of the seizure to be included. Medication and dosages were only chosen by 17 (26.2%) of patients, 21 (32.3%) emergency contact details, 15 (23.1%) doctors details. Only one patient (1.5%) requested space on the diary for more than one seizure per day. Almost all of the patients who had previous

TABLE 3: Awareness and recall of seizures.

Questions	Patients who had previous exposure to the seizure diary						Diary unexposed						*p*
	Always		Sometimes		Never		Always		Sometimes		Never		
	n	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%	
Are you able to remember you had a fit after an episode?	15	23.1	16	24.6	34	52.3	24	20.5	47	40.2	46	39.3	0.10
Do you need someone to inform you that you had a fit?	40	61.5	8	12.3	17	26.2	60	51.3	44	37.6	13	11.1	**< 0.01***
Are you able to recall how many seizures you have in a month?	28	43.1	21	32.3	16	24.6	25	21.4	51	43.6	41	35.0	**0.01***

*, Statistically significant differences.

TABLE 4: Challenges with keeping a seizure diary.

Challenges	*n*	%
Don't usually remember to complete it	6	9.2
It is not important to me	4	6.2
No time to complete the diary	3	4.6
Not trained to use the diary	3	4.6
Don't find the diary useful	3	4.6
Not motivated to complete it	3	4.6
It is difficult to complete	3	4.6
Having to complete the diary makes me tired	3	4.6
Nobody to help them complete the diary	2	3.1
Diary got lost	2	3.1
Doctor does not check the diary	1	1.5
It reminds me of my condition	1	1.5

exposure to the seizure diary, 63 (98.4%), felt it was important to hand the diary over to their healthcare providers during each visit.

Discussion

The study investigated patients' perceptions and attitudes to the seizure diary in Kimberley and Bloemfontein. Uncontrolled epilepsy with seizures of more than one a year was reported by more of the patients who had previous exposure to the seizure diary than the diary-unexposed patients. A possible explanation may be that patients who had previous exposure to the seizure diary attending the Universitas specialist hospital have more complex seizures with a higher seizure burden. They are more likely to monitor and document their seizures than patients with less complex seizures and a lower seizure burden. Detyniecki et al.[20] reported in a study on patients with epilepsy that patients with a higher seizure burden are more likely to report their seizure activities.

Patients generally did not have a good knowledge of their epilepsy diagnosis. However, the diary-unexposed group had a better understanding of their type of seizure diagnosis than the patients who had previous exposure to the diary group. This may be because of the rigorous and extensive investigation required to diagnose the complicated situations of patients who had previous exposure to the seizure diary. The complicated syndromes may cause them to have less understanding. It can also be that the doctors, because of the complex nature of their diagnosis, may not have the time to inform, educate and ensure that patients with complicated epilepsy understand their diagnosis. A study done among cancer patients in Turkey revealed that a high number of patients, 44%, did not know their diagnosis, which did not worsen their quality of life.[21] In another study from Cuba, patients aware of their diagnosis had significantly better scores with respect to symptoms, patient anxiety, information and support than patients not aware of their diagnosis.[22] It is expected that patients with epilepsy who are aware of their diagnosis will be better informed about managing their medical condition and accessing available support.

Most patients in both groups had problems remembering if they had a seizure after an episode. These findings are supported by reports from other authors, such as Blachut et al.[23] and Poochikian-Sarkissian et al.,[24] who stated that a significant number of seizures go unnoticed by patients. If a patient cannot remember having a seizure, they will certainly not document it.

Many patients from both groups needed to be informed when they had a seizure, although more patients in the diary-unexposed group than those who had previous exposure to the seizure diary group needed to be informed about a seizure. Blachut et al.[23] stated that 28% of patients required a seizure witness to remind them that a seizure occurred. Blum et al.[25] reported that 30% of patients in a study were never aware of their seizures. This is in keeping with the report from this study's patients, who reported that they needed to be informed about their seizures. The patients may not be aware of their seizures, more so with nocturnal seizures than daytime seizures; this was reported by several past studies.[13,23,26,27]

A more significant percentage of patients reported being able to recall their seizures in the patients who had previous exposure to the seizure diary group than the diary-unexposed groups. This may be because of the patients who had previous exposure to the seizure diary group being able to keep track of their seizure frequencies to complete their diaries. Some authors found seizure recall among patients with epilepsy to be unreliable.[23,24,25,27]

Most of the patients in both groups agreed that documenting their seizures would help them remember they had a seizure; it is expected that documenting their seizures will help patients keep track of the trend of their seizures. However, Hoppe et al.[27] reported in their study that only a few patients were able to document most of their seizures accurately; a significant part of their seizures were undocumented. The accuracy of patient-documented seizures affects the validity of patient-reported seizures, as most patient reports are seen as subjective, requiring objective methods such as ambulatory electroencephalogram (EEG) to validate the accuracy of the information provided by patients.[23,24,27,28,29] In the South African environment, this is unlikely to be suitable, as the affordability of the equipment is a challenge in a country with a significant disease burden that will make it unsustainable in the long run.

It was encouraging to see that almost all the patients who had previous exposure to the seizure diary and unexposed groups were willing to use or continue to use the diary. This shows a high level of acceptance of the seizure diary among the patients involved in the study. Schülin et al.,[30] in a study on experiences with the use of pain diaries in chronic pain management, had a similar finding where most of the patients participating in the study were willing and able to use the pain diary and kept it voluntarily. More than half of the present study's participants in the diary-exposed group did not find the diary useful in helping with their medication adherence. This is different from findings reported by Henegouwen et al.,[17] suggesting that completing a daily diary is positively correlated with patient compliance with medication intake. Most of the current study's patients already using the diary found it to be important and useful in their lives; this report was similar to findings from other literature.[23,30]

A few patients who had previous exposure to the seizure diary had various challenges that discouraged them from using the diary; they ranged from doctors not checking the diary to the diary being a painful reminder of their medical conditions. Most of the patients in this study felt it was important to hand the diary over to the healthcare practitioner managing them. Doctors are encouraged to show interest in the patient's seizure diary; many authors have reported that if the patient senses that it is important in treatment decisions, it enables them to use the diary, as well as patients being motivated to fill out the diary because of their doctors. A study on the use of a diary in an intensive care unit (ICU) setting was found to positively impact the patients, relatives and the doctors and nurses involved in patient care.[31]

Healthcare practitioners can also train patients and relatives on using the diary. Bingham et al.,[32] in their study on patient-reported outcomes (PRO) in patients with rheumatoid arthritis, revealed that appropriate training to use the electronic diary was one of the factors associated with high compliance. Training patients on how to use the diary will ensure that they understand it and remain motivated to use it.

The diary is meant to be a tool to help patients manage their epilepsy; it is not meant to hurt a patient by acting as a constant reminder of a medical condition a patient would prefer to rather forget. Patients need to be encouraged to avoid the denial of their medical condition and rather see the diary as a tool that can help improve their conditions. Healthcare practitioners should find exciting ways to motivate patients to use the diary and discuss any challenges they have with the diary to prevent noncompliance.

Limitations of the study

The emphasis of the study was on patients from Kimberley and Bloemfontein, so it may have been subject to selection bias. This may make it difficult to generalise the findings of the study. The method used to collect the data may have further subjected the study to bias since consecutive sampling was used. Patients were selected based on meeting the inclusion criteria until the required sample size was achieved, which may not represent the population. The difference between the two samples may have caused some bias. The number of patients who had previous exposure to the seizure diary available for the study was smaller than expected. The number of patients attending our clinics was also reduced because of the advent of covid infection; rather than come to the clinic monthly for medications, patients now receive monthly six medications to reduce the number of patients attending the clinic daily.

Conclusion

Almost all the patients involved in the study are willing to use the seizure diary. Patients who had previous exposure to a seizure diary enjoyed using the diary and found it helpful in monitoring the trend of their epilepsy. Many patients from both groups needed to be informed when they have a seizure. Patients who had previous exposure to the diary recalled their seizures better than diary-unexposed patients. The findings from this study confirm patients' support for the use of the paper diary in the management of patients living with epilepsy.

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Competing interests

The researchers involved in this study are academic staff of the University of the Free State and the University of KwaZulu-Natal. The researchers have no conflict of interest to declare.

Authors' contributions

C.K.E. developed the research concept, conducted a literature review, planned a protocol, developed the questionnaire, collected the data and prepared the manuscript. A.A.M. supervised the project from planning to report writing. W.J.S. co-supervised and provided input from concept development to report writing. G.J. provided input in protocol development, questionnaire design, the pilot study, data analysis and reviewing this manuscript.

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Data availability

The data supporting this study's findings are available from the corresponding author, C.K.E., upon reasonable request.

Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

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CHAPTER 4:

ARTICLE 3 – A MODIFIED DELPHI STUDY TO DETERMINE THE CONTENTS OF A SEIZURE DIARY FOR PATIENTS LIVING WITH EPILEPSY IN SOUTH AFRICA

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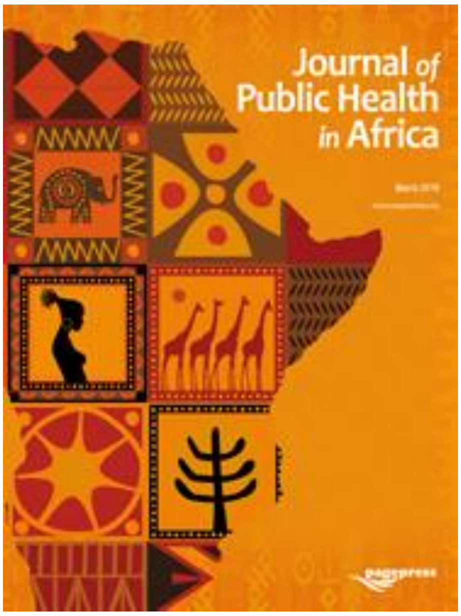

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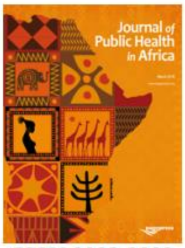

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A modified Delphi study to determine the contents of a seizure diary for patients living with epilepsy in South Africa

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Abstract

Background. Epilepsy is a debilitating chronic medical condition affecting many patients globally. A seizure diary is used in monitoring and managing patients with epilepsy. In South Africa, no standardized diary is currently being used.

Objective. This study intended to develop a consensus among experts managing patients with epilepsy on the content of a seizure diary.

Methods. The modified Delphi method consisted of three survey rounds spanning six months. Using a three-point Likert scale questionnaire, in round one, the panelists were required to choose an option (definitely required, optional, and not required) for 50 items and comment on the contents of the diary. In round two, three items were added based on comments from the panelists. In round three, panelists were allowed to deliberate further on unresolved items and change their responses in view of the group responses. The consensus was determined as an a priori threshold of >70% on items definitely required, optional, or not required.

Results. Eleven local and two international panelists were enrolled in this study. Twelve completed all three rounds. The consensus was achieved in 21 of 50 items in round 1, three of seven items in round 2, and one of two items in round 3, of which 18 were definitely required as contents of a seizure diary.

Conclusions. Based on expert opinions, the modified Delphi study determined the essential contents of a seizure diary for use by patients with epilepsy in South Africa.

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Key words: seizure diary, epilepsy, paper diary, electronic diary, expert panel, consensus, Delphi method, South Africa.

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Introduction

The World Health Organisation (WHO) estimates that epilepsy affects over 50 million people worldwide, with 10 million residing in Africa.[1] The Global Campaign against epilepsy estimates the prevalence of epilepsy in Africa at 11.29 per 1,000 population and the prevalence of epilepsy in South Africa at 3.7 per 1,000.[2] Epilepsy South Africa estimates that epilepsy affects 1 per 1,000 South Africans, which is approximately 500,000 people.[3]

Patients living with epilepsy are unable to provide adequate seizure history in certain instances.[4] The seizure diary can help in the management of patients with epilepsy; it helps with managing medication and other therapies, recognizing triggers and health events that may affect seizures and wellness, and communicating with patients' care providers.[5]

The seizure diary comes in either a paper or an electronic format. A seizure diary is a self-management tool that helps patients record their seizures, monitor the frequency of attacks, and promote medication adherence among its users.[6,7] In developed countries like The United States of America, the electronic diary is preferred due to easy access to personal electronic devices.[8] In Africa, some people stay in rural communities,[2] where internet access is limited, making it difficult to use electronic diaries. The paper-based diary is easier to use in a resource-poor setting as it does not require computer skills or internet access.[9]

In sub-Saharan Africa, the majority of people with epilepsy are treated by primary healthcare providers, such as family physicians at the community level and neurologists who are physicians specializing in epilepsy.[10] The neurologist can help facilitate any required diagnostic testing such as EEG, CT, and MRI and recommend appropriate anti-epileptic medication. Primary care physicians are responsible for managing the patient's condition, such as tracking seizure frequency (using the seizure diary), monitoring medication compliance and side effects, ordering laboratory tests and drug levels, and providing education and social support.[10]

In South Africa and the rest of the African continent, we were unable to find any published studies concerning the creation of a seizure diary for the use of patients living with epilepsy.[11] However, some primary health care clinics, specialized epilepsy clinics in Bloemfontein, and other neurology clinics in South Africa use a basic paper calendar version distributed by pharmaceutical companies to help doctors monitor patients.[12] These paper diaries lack much information and ask basic questions about patients' seizure types and frequency, which is the industry standard.[13] Most of these diaries were designed for patient use in developed countries such as the United Kingdom and may not have much relevance for patients in our African setting.[14] Most scientific papers explored to support the concept that a properly designed seizure diary has a role in managing epilepsy patients and improving medication adherence in the clinical setting.[6,15,16]

Aim

This study was initiated to help develop a standard seizure diary using a panel of local and international experts across various specialties conversant with managing patients with epilepsy.

Materials and Methods

This study is the 3rd phase of an extensive project. Other phases consisted of Phase 1, a scoping review of literature;[11] Phase 2, a cross-sectional study of patients living with epilepsy;[17] Phase 4, six months of use of the new seizure diary (Figures 1 and 2) by patients included in Phase 2; Phase 5a, patients' perceptions of the new seizure diary; Phase 5b suggested final version of the new seizure diary.

A modified Delphi method was used to obtain a consensus among experts on the important contents of a seizure diary using an online questionnaire. The Delphi method is a consensus-building technique that seeks expert opinion on a topic in a structured and iterative manner.[18,19] It is useful in areas where evidence-based literature is inadequate since it can unearth collective knowledge from experts in that area.[20,21] A series of rounds are used to clarify, refine and ultimately achieve consensus on a given topic under discussion.[22] Participants provide information anonymously (for participants) and independently with the overbearing influence of any individual or group during each round.[18,20]

In the modified Delphi method, the expert panel does not generate the study question. The researcher generates the questions through literature reviews and expert consultation and presents them to the panel to begin the consensus-seeking process. The panelists can contribute through open-ended questions to the list prepared by the researcher.[23,24]

The Delphi method involves 6 stages according to the approaches described by Humphrey-Murto *et al.*: i) identifying a research problem; ii) completing a literature search; iii) developing a questionnaire of statements; iv) conducting an anonymous iterative mail or email questionnaire round; v) providing group feedback between rounds; vi) summarising the findings.[21] We reported our process following this guideline.

Step 1: identifying the research problem /question

In numerous emergency departments and primary health care clinics across South Africa, patients living with epilepsy are seen, but they are unable to provide details about their seizures or medication use. Healthcare workers have to carry out expensive tests to help determine which drugs they are using in other to treat them. This often causes a delay in treatment. The existing seizure diaries are basic calendar diaries that fail to provide adequate information. The researchers (CKE, MA, WJS) are family physicians and a neurologist actively involved in caring for patients with epilepsy. The project was to determine the content of a seizure diary that can be used in monitoring and managing patients with epilepsy in South Africa.

Name and surname:

Patient's hospital number:

Date of birth:

___/___/___

Gender:

Current home address:

Patient's phone number:

Emergency phone number for next of kin:

Name of local clinic and contact number:

Medication allergies:

Patient's chronic conditions:

Current medication & dosages:

Instructions

After each seizure, encircle the day on the **Seizure Calendar** and provide more information in the **Seizure Details** section.

Complete the diary immediately after each seizure.

Figure 1. Seizure diary.

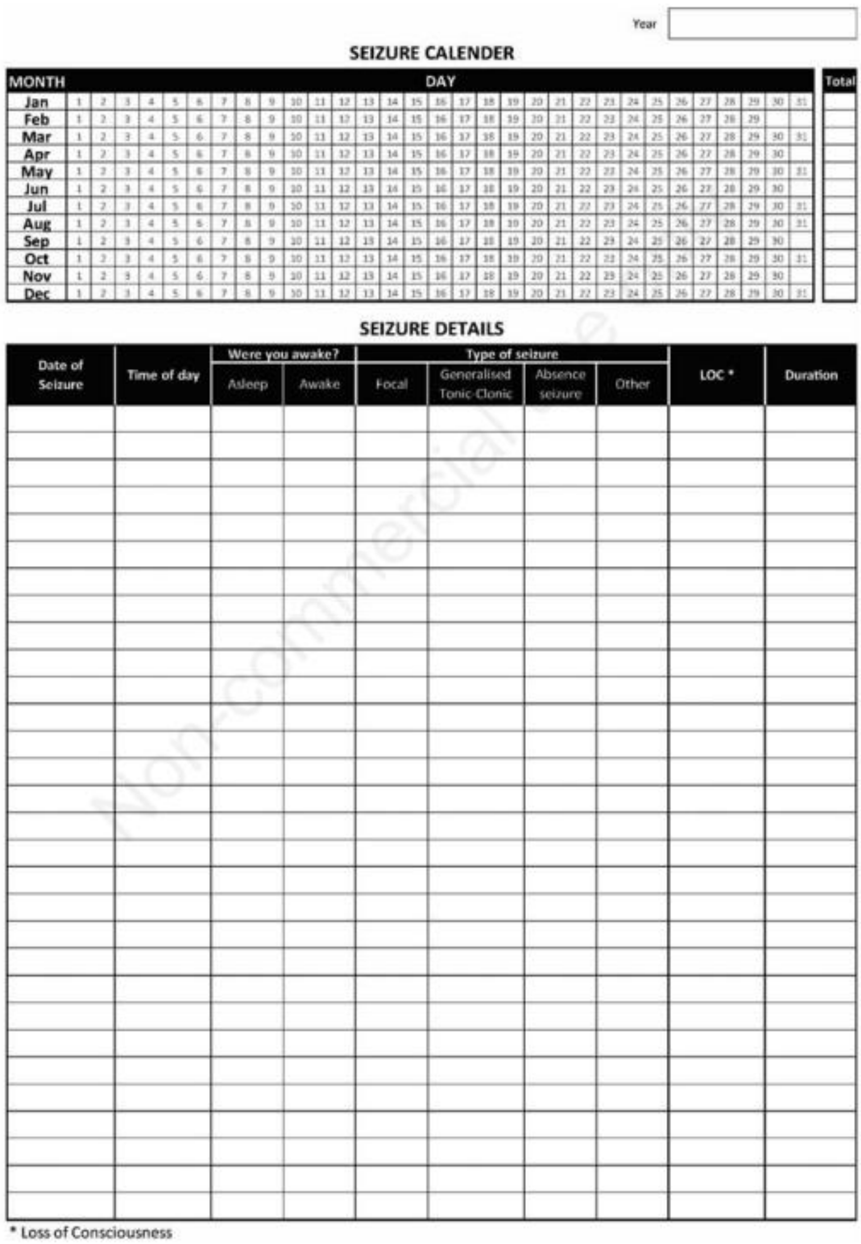
Step 2: literature search

The protocol development and the 1st phase of this study required an extensive search of relevant literature on epilepsy and Delphi techniques describing the methodology for reporting a Delphi study.[11,18,20,21]

Step 3: developing a questionnaire of items

The first author (CKE), after an extensive search of relevant literature on the seizure diary,[11] generated a list of possible relevant items as contents for the seizure diary. The research team met to review the generated items and add additional relevant items, resulting in a list of 50 items for the Delphi questionnaire.

The questionnaire had two sections; section 1 consisted of eight questions about the demographic information of the panelists, such as gender, specialty, country of practice, years of practice, and place of employment (public or private). They were also asked to answer yes or no if they worked with patients with epilepsy. Section 2 consisted of 50 stated items using a 3-point Likert scale with options (required, optional, and not required). Twelve items were grouped as items required once, while thirty-eight



Year ☐

SEIZURE CALENDER

MONTH	DAY																															Total
Jan	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Feb	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29			
Mar	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Apr	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
May	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Jun	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Jul	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Aug	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Sep	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Oct	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Nov	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Dec	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	

SEIZURE DETAILS

Date of Seizure	Time of day	Were you awake?		Type of seizure				LOC *	Duration
		Asleep	Awake	Focal	Generalised Tonic-Clonic	Absence seizure	Other		

* Loss of Consciousness

Figure 2. Seizure diary.

items were grouped as regularly required items. One of the items required the panelist to choose one from the A, B, or C options provided. An open comment space was provided for panelists willing to comment about what they felt was relevant to be included in the diary.[25] The consensus was set at 70% a priori for definitely required, optional, or not required items.

The round 2 questionnaire was developed after analysis of the round 1 results and the panelists' comments. The round 3 questionnaire was developed from the analysis of the round 2 questionnaire.

The study questionnaire was piloted with two specialists experienced in managing patients with epilepsy. The pilot was analyzed, and minor changes were made to the questionnaire. The data from the pilot study was not used for the Delphi study. The questionnaires were in English, and all entries into the online questionnaire on Evasys were time-stamped.

Step 4: conducting anonymous three iterative rounds

We recruited 13 expert panelists from the fields of family medicine, neurology, and internal medicine. A total of 11 panelists were local, and two were international. In a Delphi study, a minimum of 10-18 respondents is generally sufficient to achieve consensus.[19,24,26,27] Convenience sampling was used in selecting panelists.[26,28] The number of international and local experts selected from each province in South Africa was based on the individuals' availability and willingness to partake in the study.[26]

The specified inclusion criteria were as follows: panelists must be proficient in English and registered with the relevant authorities in the country where they practice. They must have experience using the seizure diary to manage patients with epilepsy in their field of practice and sign an informed consent form to participate in the study.

All panelists were individually identified by the first author and supervisors based on their area of expertise and meeting the inclusion criteria. Local experts were Individually identified from different provinces in South Africa. International experts from various countries were identified via the International League Against Epilepsy website. Electronic mail was sent out to all the experts identified, informing them about the study and inviting them to participate. Those who responded in the affirmative were then sent a detailed background information letter providing details such as the study title, problem statement, aim of the study, description of the Delphi technique, how to use the online Evasys system, time frame for a response, what is consensus, the duration of the study and consent form. All emails were sent individually to the panelists to maintain the anonymity of every member of the panel to each other but not to the authors.[25,27] They were required to respond to the email and return the completed consent. All panelists were required to participate in the prior round in order to be invited to participate in the subsequent round. The number of rounds required for the modified Delphi was not predetermined, and the study was terminated once adequate consensus or stability of responses on items was achieved. Stability is achieved when all panelists have the same response from round to round. A time frame of 4-6 months was allocated for the study. Electronic and telephonic reminders were used to encourage non-responders to complete the questionnaire.[25]

Round 1 commenced from January to February 2021, round 2 was from March to April 2021, and round 3 was from May to June 2021. In each round, panelists were required to follow a provided online link to complete the confidential survey questionnaire on Evasys.[29] After completing the questionnaire, the survey was electronically submitted. The research team reviewed responses consolidated and new items were incorporated into the list for the next round. After round 3, sufficient consensus was reached on the items to terminate the study.

Step 5: provide individual feedback to panelists

Each panelist after round 1 received an information sheet with feedback on consensus and further information that new items were added for deliberation based on expert recommendation. Panelists could change their opinions and were requested to follow the online link to participate in round 2. All panelists also received a comprehensive summary of round 2 responses, consensus items so far, and which questions were returned for further deliberation in round 3. They also received a summary of their individual

Table 1. Quality characteristics for a Delphi study.[18,21]

Reporting quality characteristics	Our study
Literature review conducted	Yes
Background information provided to participants	Yes
Purpose is Item generation	Yes
No of participants indicated	Yes
No of respondents for round 1 indicated	Yes
No of respondents for round 2 indicated	Yes
Polling email described	Yes
Private decisions collected (Anonymity)	Yes
Formal feedback	Yes
Number of rounds 2 or more	Yes
Number of rounds determined a priority	No
Predetermined definition of consensus	Yes
Consensus forced	No
Were the criteria for participants reproducible?*	Yes
Stopping criteria other than rounds specified?*	Yes

*Quality criteria according to Diamond *et al.*[18]

Table 2. Demographic data of Delphi panelists.

Demographic data	n (%)
Gender	
Males	6 (50%)
Females	6 (50%)
Specialties	
Family medicine	6 (50%)
Neurology	6 (50%)
Current positions	
Specialist Family med/Neurology	8 (67%)
Heads of academic departments	4 (33%)
Country of practice	
South Africa	10 (83.3%)
Malaysia	1 (8.3%)
Nigeria	1 (8.3%)
Place of Employment	
Public	11 (92%)
Private	1 (8%)
Years of experience	
0-4 years	0
5-10 years	0
More than 10	12 (100%)
Works with patients with epilepsy	
Yes	12 (100%)
No	0

responses in the previous rounds via personalized emails with the option to change their opinions if they wished and an email request to participate in round 3 of the study.

Step 6: summarize the findings

The research team grouped the consensus items after each round, as reported in the result section. We report in Table 1 the quality criteria for the Delphi studies as proposed by Humphrey-Murto *et al.*[21] with additional criteria from Diamond *et al.*[18]

Ethics

Ethical approval for the study was obtained from the Health Sciences Research Ethics Committee of the University of the Free State (HSREC) with reference number UFS-HSD2020/1385/2411. All panelists gave written informed consent to participate in the study and were free to withdraw at any point they wished. All data provided were confidential, and no names or identifiers were associated with the data.

Statistical analysis

Data was captured on an Excel spreadsheet and analyzed. Information obtained was analyzed using descriptive statistics to describe demographic characteristics and responses during each round of the Delphi (Table 2).

Results

In round 1 of the Delphi study, 13 email links were sent to the panelists; 12 out of the 13 panelists participated with a response rate of 92% and subsequently completed rounds 2 and 3 with a response rate of 100%. The majority of the panelists from all rounds were from South Africa, with some involvement of specialists from other countries. Almost all panelists were public sector employees – all with more than ten years of experience, and have worked with patients living with epilepsy.

Round 1

The modified Delphi in round 1 had 50 items, with item 32 subdivided into parts A and B. The total items with consensus definitely required, often, and not required responses from the panelists were (n=21; 42%) of all items. As indicated in Table 3, most of the items on which consensus was reached were definitely required. Item 32 was misunderstood in round 1 by the majority of the panelists. They only responded to part A, overlooking part B. The core research team met (3 specialists from family medicine and neurology) to review the responses and comments of the panelist. Items with 70% consensus responses definitely required, often, and not required were assumed to be finalized and were not returned for round 2.[30] Seven near consensus definitely not required items (≥66%) were removed, and new items were identified based on comments from the panelists, and misunderstood items were modified for inclusion in the round 2 questionnaires.[31] Eighteen Items with near-even or split responses were also excluded because consensus will be unlikely in the next round.[19] This ensures the diary is not large while remaining practical for patients.

Comments from panelists include adding items to the diary, namely, the use of folic acid, where to keep the diary at home, how soon after a seizure the diary should be completed, and not including too much in the diary, so it is not cumbersome for the patients.

Table 3. Items with the consensus reached during rounds 1, 2, and 3.

Item no from questionnaire 1	Items	Definitely required n (%)	Optional n (%)	Not required n (%)
Round 1				
1	Name of patient	11 (91.7%)	1 (8.3%)	0
2	Date of birth	11 (91.7%)	1 (8.3%)	0
3	Gender of patient	10 (83.3%)	2 (16.6%)	0
5	Highest educational qualifications	2 (16.7%)	9 (75%)	1 (8.3%)
6	Current home address	9 (75%)	1 (8.3%)	2 (16.6%)
7	Patients phone number	11 (91.7%)	1 (8.3%)	0
8	Emergency phone number for next of kin	9 (75%)	3 (25%)	0
9	Name of local clinic and contact number	9 (75%)	3 (25%)	0
11	Medication allergies	11 (91.7%)	1 (8.3%)	0
13	Patients' chronic conditions	9 (75%)	3 (25%)	0
15	Current epilepsy medications	12 (100%)	0	0
16	Patients' current medication dosages	11 (91.7%)	1 (8.3%)	0
22	Frequency of patients' seizures	12 (100%)	0	0
25	Duration of seizures	9 (75%)	3 (25%)	0
35	Instruction to circle days of the months with seizures on the calendar	9 (75%)	3 (25%)	0
38	Space for comments on EEG reports	1 (8.3%)	10 (83.3%)	1 (8.3%)
44	Commercial adverts on every page of diary	0	1 (8.3%)	11 (91.7%)
45	Commercial adverts on selected pages only	0	2 (16.6%)	10 (83.3%)
46	Different dairy colours for males & females	0	2 (16.6%)	10 (83.3%)
47	Coloured diary background	0	2 (16.6%)	10 (83.3%)
48	Background pictures in the diary	0	3 (25%)	9 (75%)
Round 2				
14	Patients' other chronic medications	11 (91.7%)	8.3%	0%
24	Time of the day patient had a seizure	9 (75%)	25%	0%
27	Seizures occurred while sleeping or awake	11 (91.7%)	8.3%	0%
Round 3				
32	How often should the diary be completed? (A)=25%	Daily regardless of seizures (B)=9 (75%)	Immediately after a seizure	Monthly (c)=0%

Round 2

In round 2, seven items were included for deliberations; four were returned from round 1, one of which was rephrased and returned because it was misunderstood, while three new items derived from panelists' suggestions were included. A consensus of 70% was achieved for three of the seven items (See Table 3); the core research team reviewed the responses, and items with stability were not returned for round 3.

Round 3

In round 3, two unresolved items from the previous round were returned for deliberation. Panelists were asked to reconsider their responses in line with the group majority responses with the option of changing their answers. A consensus of >70% was achieved for one item (See Table 3); the other item reached stability; hence a 4th round was unlikely to change their opinions. Some panelists provided comments supporting their response on how often the diary should be completed. These comments were, amongst others, "the practicality of completing the seizure diary immediately after a seizure and always having a family member around is difficult", "Not completing the diary daily may lead to non-documentation of subtle seizures", "Patients may lose interest due to being compelled to complete the diary daily", "daily completion of the diary may be cumbersome, but monthly will cause problems with recall", "The diary needs to be simple and mundane for patients, completing the diary after a seizure is adequate".

Based on the feedback of the expert panelists, 18 items were selected as the required contents of a seizure diary. They were ranked according to the strength of their consensus opinion (See Table 4).

Discussion

This study, with the use of a Delphi method, was focused on establishing the contents of a seizure diary for patients with epilepsy. Hasson *et al*. stated that for a Delphi method to maintain its rigors, a response rate of 70% must be maintained.[32] The study met this with a reasonable response rate of 92% in round 1 and 100% in subsequent rounds. The total duration for the study was six months, which was a bit above the 45 days to 5 months recommended duration for completing a Delphi study.[27] This was due to the delay caused by waiting for some panelists to complete and return their completed questionnaires well outside the discussed time frame. Okoli *et al*. supported this assertion by reporting that in a Delphi study, delays may be caused by researchers waiting for the return of completed questionnaires before sending out another.[27]

The study results demonstrate the strong agreement among the expert panel concerning the basic biodata of patients, such as name, address, date of birth, *etc*., as very important items for the diary. This is consistent with similar information found in other diaries from other organizations, such as the United Kingdom-based Epilepsy society.[14] Information such as current medications, medication allergies, and chronic medications was also important enough to include in the diary. This is consistent with comments by Fisher *et al*. on what information should be recorded in a seizure diary.[13] Information on the seizure type was not required by the expert panel, which is inconsistent with the findings of Fisher *et al*., who reported that the seizure types should be documented in the seizure diary.[13] Patients' seizure frequency is one of the most reported findings from many articles on patient-reported seizures in Epilepsy.[13,34-36] It is a key reported outcome measure important for individual treatment and pharmacological clinical trials.[36,37] The expert panel recognized the importance and voted overwhelmingly to support this being included as an item in the seizure diary. Details about seizures, such as duration, time of occurrence, and awake or sleeping, were also included in the diary in keeping with reports from most authors.[13,36-39]

Our expert panel agreed that the seizure diary for patients with epilepsy must be completed immediately after each seizure. This statement is supported by the reports from other studies on epilepsy showing the reporting patterns of patients with epilepsy. In the study of Blachut *et al*., 41% of patients reported recording their seizures after recovery, while a further 36% reported recording

Table 4. Final list of the selected items from highest consensus rating to lowest.

No	Items	(%) Definitely required
1	Current epilepsy medications	100
2	Frequency of patients' seizures	100
3	Name of patient	91.7
4	Date of birth	91.7
5	Patients phone number	91.7
6	Medication allergies	91.7
7	Patients' current medication dosages	91.7
8	Patients' other chronic medications	91.7
9	The seizure occurred while sleeping or awake	91.7
10	Gender of patient	83.3
11	Current home address	75
12	The emergency phone number for the next of kin	75
13	Name of a local clinic and contact number	75
14	Patients' chronic conditions	75
15	Duration of seizures	75
16	Instruction to circle days of the months with seizures on the calendar	75
17	Time of the day patient had the seizure.	75
18	How often should the diary be completed (Immediately after a seizure)	75

their seizures right after the seizure.[36] In another study, Blachut *et al*., looked at self-reported seizure counts by patients with epilepsy using a diary, 40.7% of patients documented seizures immediately after their seizures, 20.9% the same day in the evening, and 27.9% the next morning.[37]

For the purpose of the Delphi method, the questionnaire presented to national and international professionals was in English. The questionnaires of phase 5 of the study that explored how the patients experienced the diary were available in the languages most commonly spoken in the study setting,[17] and the seizure diary can be made available in other languages if needed.

The responses from the expert panel and data obtained from patients' questionnaires from phase 2 about what information they think should be in a seizure diary will be merged and used to develop a seizure diary for use by patients with epilepsy in South Africa.

Strengths and limitations

The strength of this study is the inclusion of independent panelists from various disciplines and different provinces in South Africa who are conversant with the management of patients with epilepsy.

Including international experts in epilepsy helped broaden the variety of opinions and did not limit the conclusions in the study to a single geographic view. This may help bring the diary's contents in line with what is obtainable internationally.

Bias was minimized by maintaining the anonymity of the expert panel members to avoid dominance and conducting multiple rounds of the survey with controlled feedback of responses.[40]

The small number of international panelists limited this study; this may make it difficult to generalize the study results, especially to western countries, since the focus was more on Africa.

Conclusions

The Delphi study recruited an independent panel of both local and international experts. The consensus was achieved on 18 items definitely required as the content of a seizure diary to be used in managing patients living with epilepsy in South Africa. Implementing the newly developed seizure diary should be encouraged among healthcare practitioners and health authorities responsible for managing patients with epilepsy. The outcome of this study will help guide future research toward using an electronic diary, and cell phone application for patients living with epilepsy in South Africa should be done.

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CHAPTER 5:

ARTICLE 4: EXPERIENCE OF THE NEW SEIZURE DIARY IN THE FREE STATE AND NORTHERN CAPE OF SOUTH AFRICA

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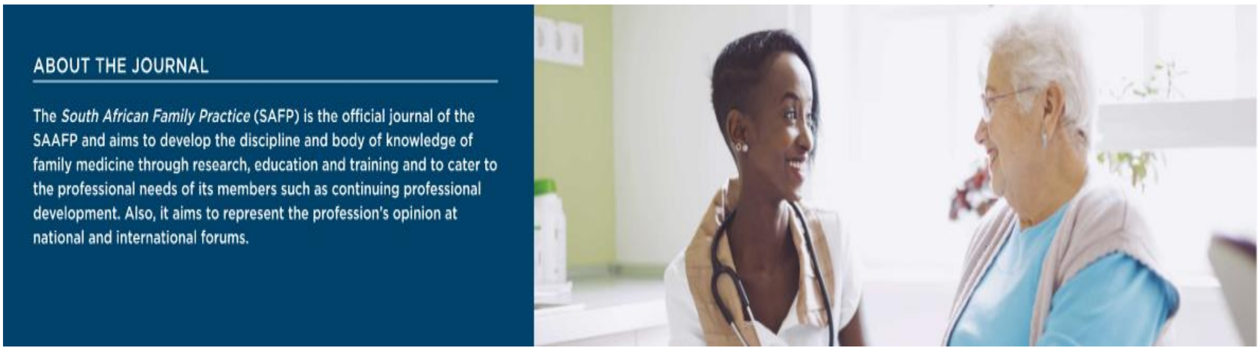

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The *South African Family Practice* (SAFP) is the official journal of the SAAFP and aims to develop the discipline and body of knowledge of family medicine through research, education and training and to cater to the professional needs of its members such as continuing professional development. Also, it aims to represent the profession's opinion at national and international forums.

(Image from South African Family Practice Journal)

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AOSIS

Experience of the new seizure diary in the Free State and Northern Cape

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Background: Epilepsy is a neurological disease affecting adults and children globally. A seizure diary is one of the self-management tools for tracking seizures. This study aims to ascertain the experience of a new seizure diary by persons completing the diary in the Free State and Northern Cape of South Africa.

Methods: Adult patients with epilepsy attending Universitas Academic Hospital epilepsy clinic in Bloemfontein, clinics in Kimberley and the casualty department of Kimberley hospital (Robert Mangaliso Sobukwe hospital) received a new seizure diary. After using the diary for 6 months, participants (patients, relatives or caregivers) completed a questionnaire.

Results: A total of 139 epilepsy patients received a new seizure diary; 67 previously diary-unexposed participants and 33 participants who had previous exposure to a seizure diary. The majority of participants, namely 91% of previously diary-unexposed and 84.9% of participants who had previous exposure to the seizure diary, understood the new seizure diary. Participants who had previous exposure to a seizure diary were predominantly very positive about the new diary because it had more information. However, 21.2% indicated that they preferred the old one because it was easier to complete.

Conclusion: Patients, caregivers or relatives from both groups used the new seizure diary and provided important information about their experience with the new diary. Despite a few complaints about using the new diary, most participants who had previous exposure to a seizure diary preferred the new seizure diary.

Contribution: This study explored participants' opinions of the new seizure diary.

Keywords: seizure diary; epilepsy; paper diary; electronic diary; seizure frequency; participants who had previous exposure to a seizure diary; previously diary-unexposed participants.

Introduction

Epilepsy is common and one of the most dynamic disorders in neurology.[1] It affects millions of people worldwide, of which about 80% live in low- and middle-income countries.[2] Epilepsy contributes about 0.5% of the global disease burden.[3] Globally, about 5 million people are diagnosed with epilepsy each year. It is estimated that in high-income countries, 49 per 100 000 people are diagnosed with epilepsy yearly; in low- and middle-income countries, it can be as high as 139 per 100 000.[2] In South Africa, the prevalence of active convulsive epilepsy in rural areas was reported as 7 per 1000.[4] Treatment gaps exist in South Africa, as in most low-income countries, and anti-seizure medication adherence remains low despite adequate diagnosis and access to healthcare facilities.[5] Factors such as lack of adequately trained primary healthcare practitioners, neurologists, healthcare facilities, poor medication adherence and socioeconomic and cultural beliefs may adversely affect epilepsy treatment.[3,6] Furthermore, epilepsy is poorly understood, and the different cultural understandings and terms used to explain the condition across the various population groups compound the problems of these patients.[7] The management of epilepsy in our environment must aim to control the seizures to reduce morbidity and mortality associated with epilepsy.[8]

Seizure types and frequencies are important outcomes reported in epilepsy clinical care and research.[9] Seizure documentation is an important aspect of care for patients living with epilepsy; in certain situations, patients may be unable to document their seizures because of being seizure free, so they have no seizures to document or other reasons.[9] If patients with epilepsy know when and how their seizures occur, it can aid in diagnosis and treatment.[10] A seizure diary is a self-management tool designed to help patients with epilepsy track their seizures and side effects, manage anti-seizure medications and see their progress over time.[11] It can be used in clinical drug trials, monitoring seizure clusters and predicting seizures.[12,13,14,15,16,17,18]

Diaries are known to be either paper based or electronic diaries. The paper diary is a basic calendar with seizure types and frequency, which is the industry standard.[18] Paper diaries have historically been used to document the seizure frequencies of patients with epilepsy.[10] Inherent inadequacies have been reported with paper diaries, such as being easy to misplace, lose or damage.[10,19] On the other hand, electronic diaries are online or mobile applications with more details and time-stamped patient entries available to patients, caregivers (persons caring for the chronically ill, elderly or children), relatives (members of the family) and healthcare workers.[18] They can be downloaded from android (Google play) and IOS (Apple mobile operating system) application stores. The electronic diary can also send reminders to patients to take their medications or log their seizures and are available in different languages.[10,20]

In our previous publications of this study,[21,22] we discussed the advantages of the paper-based seizure diary in that it does not require Internet access or expensive devices; it is easier for patients to learn how to use; it is less complex because it does not need great intellectual capabilities or specialised computer skills to complete. In addition, a paper-based diary can be successfully used by a predominantly illiterate community and can easily be made available to patients.[23] Accurate seizure documentation entails patients and caregivers recognising their seizures and being compliant with keeping a seizure diary.[9] Some of the drawbacks of the seizure diary are the under-reporting or over-reporting of self-reported seizure counts by patients and caregivers because of a lack of awareness.[12,24,25,26]

In South Africa, there is no documented standard format for the seizure diary. A calendar format of the diary, designed by pharmaceutical companies, is used in some South African medical facilities,[27] such as the Bloemfontein neurology clinic. Other available formats are intended for patient use in western countries such as the United Kingdom.[28] An extensive literature review has shown that a properly designed seizure diary is still relevant in managing patients with epilepsy if they are adequately trained to use it.[21,29] Motivating the patients and their caregivers to use the diary will further help improve compliance with diary usage.[21] Patients can use this opportunity to reflect on their seizure experiences by commenting on the diary, thereby giving the healthcare provider a window of opportunity to understand the disease from the patient's view more holistically. Clinicians should manage their patients holistically based on the principles of patient-centred care using the biopsychosocial approach.[30]

The development of new patient diaries, electronic applications and mobile software requires the input of patients living with epilepsy and caregivers to make them more effective in documenting and managing the disease.[9] The user experience of seizure management tools can help to gauge patients' satisfaction,[31] and the data obtained can be helpful in future epilepsy research.[9]

Our study aimed to gather information on the experience of patients living with epilepsy with a new seizure diary in the Free State and Northern Cape of South Africa. The new seizure diary was developed based on expert opinions and patient inputs about the contents of a seizure diary for monitoring and managing patients living with epilepsy. The new diary had more detailed information, such as seizure types, frequencies, duration, current seizure medications and other information.[32]

Research methods and design

Study design

This study was part of a more extensive study with five phases, some of which have been published.[21,22] Earlier phases consisted of Phase 1 (Scoping review of literature),[21] Phase 2 (The perceptions and attitudes of patients with epilepsy to the use of a seizure diary in managing patients with epilepsy),[22] and Phase 3 (Delphi study).[32] This manuscript reports on Phase 4, a longitudinal study (Use of the new, improved seizure diary for 6 months), 5a, a cross-sectional study (Experience of the new seizure diary) and 5b (Suggested final version of the seizure diary).

Study population

The study population consisted of adults with epilepsy in Kimberley and Bloemfontein, currently attending Universitas Academic Hospital Specialist Epilepsy Clinic in Bloemfontein and local clinics in Kimberley (City, Beaconsfield and Betty Gatsewe), as well as the casualty department in Kimberley hospital (Robert Mangaliso Sobukwe Hospital). Participants in the study were patients, relatives and caregivers who assisted in completing the diary. They also assisted with completing the questionnaires. Patients could be previously (before the study) diary-unexposed or have had previous exposure to a seizure diary.

Inclusion criteria

Patients diagnosed with epilepsy attending the facility for follow-up, 18 years and above, were recruited for the study. The patient must have participated in Phase 2 of the study and received the new seizure diary. Patients with cognitive impairment were included as relatives provided information. Informed consent was obtained from patients or caregivers when patients were disabled owing to cognitive impairment.

Sampling method

All patients who had taken part in Phase 2 of the study were included.

Sample size

The intended sample size for the study was 182 patients (117 previously diary-unexposed and 65 who had previous exposure to a seizure diary).[32] No formal sample size calculation was performed, and this study had no main outcome on which to base such a calculation, but this group size gives sufficient power (80%) to detect large differences between the groups and fairly precise estimates within groups. However, once the new diary was designed, only 139 patients (81 and 58 patients, respectively) could be traced to receive and use the new diary.

Measurement

We used a confidential, structured questionnaire with 22 open- and closed-ended questions. It explored the persons' experience of using the new seizure diary and consisted of two sections A and B.

Section A consisted of seven demographic questions about the person responsible for completing the diary. Section B had 15 questions about the participants' use of the new seizure diary, requiring a 'Yes', 'No' or 'Not Sure' response and a question exploring the reasons for not understanding the diary. Further questions were asked when the diary was completed, where the diary was kept, if the patients want to continue using the diary and what they want to be improved.

Participants were asked if they had previously used a seizure diary; if the answer was yes, they were required to proceed to the last question and if no, they had completed the survey. The last question required the participants to choose their preferred diary and explain why. The questionnaires were available in English, Afrikaans, Setswana and Sesotho. Two research assistants with healthcare experience were trained to assist the first author. They could communicate in English, Afrikaans, Setswana or Sesotho and were willing to do home visits in Kimberley and Bloemfontein.

The first author or the assistants tracked and manually distributed the questionnaire in City clinic, Betty Gatsewe, Beaconsfield Clinic, Robert Mangaliso Sobukwe Hospital casualty and Bloemfontein neurology clinic while patients were in the waiting area waiting to be called to see the doctor. The first author and his assistants explained to the patients and caregivers that this was a follow-up on the diary they were using and obtained informed consent from the participants. All participants were required to complete the questionnaires and return the completed questionnaire to the researcher or his assistants while still in the waiting area. Patients were assisted by their relatives, caregivers, the researcher or trained assistants fluent in one of the spoken languages. Cognitively impaired patients were assisted by their relatives or caregivers. As a result of patients not attending the clinics monthly since the coronavirus disease 2019 (COVID-19) pandemic, the number of patients found in the clinic was relatively low. The first author and research assistants repeatedly visited the homes of many patients not found during previous visits. They also tried to locate the patients by asking the neighbours to inform them of their visits and leaving their contact details.

Pilot study

The questionnaire was piloted on epilepsy patients in Kimberley Hospital casualty and Universitas Academic Hospital neurology specialist clinic. It included four patients who received the new diary. This tested the questionnaire and the project processes. Data from the pilot study were not used in the main study because of changes in the questionnaire to further clarify who is completing the seizure diary.

Statistical analysis

Categorical variables were summarised by frequencies and percentages and numerical variables by median and interquartile ranges (IQRs) because of skewed distributions. Groups were compared regarding categorical variables using chi-square or Fisher's exact tests (in the case of sparse cells). The significance level was set at 0.05. Analysis was performed using SAS® Version 9.4.

Ethical considerations

The amended protocol for the study was approved by the Health Sciences Research Ethics committee (HSREC) of the University of the Free State with reference number UFS-HSD2020/1385/2411. Approval for data collection was also obtained from the Northern Cape Health Department and the Free State Health Department.

Number coding was used to ensure the confidentiality of the participant's responses. No names or personal identifiers appeared on any research-related information or datasheet sent for statistical analysis. The researcher kept all paper-based records in a secure location, and these records were only accessible to those involved in the study. All information was managed in a confidential manner.

Results

A total of 139 patients (81 previously diary-unexposed and 58 who had previous exposure to a seizure diary) received and used the diary for 6 months, after which they were asked to complete a questionnaire from August 2022 to November 2022. Responses of 100 participants (67 previously diary-unexposed and 33 who had previous exposure) were available. There was a dropout rate of 28.1% because of multiple factors such as change of address, change of phone numbers or missed appointments. Eleven patients were seizure free and could not complete the diary, and five patients died after receiving the seizure diary (see Figure 1).

The median age for patients, caregivers or relatives completing the questionnaire was 45 years (range: 19–76 years) in the diary-unexposed group and 41 years (range 24–75 years) in the participants who had previous exposure to the seizure diary ($p = 0.463$).

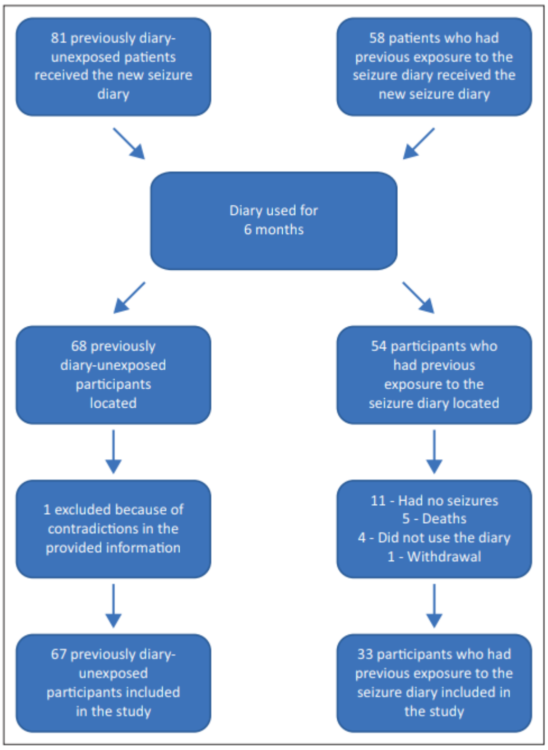

FIGURE 1: A flow diagram of participantsin the study.

TABLE 1: Demographic characteristics of persons completing the seizure diary.

Variables	Previously diary-unexposed		Participants who had previous exposure to a seizure diary		*p*
	n†	%	*n*‡	%	
Gender	-	-	-	-	0.015
Male	18	26.9	2	6.1	-
Female	49	73.1	31	93.9	-
Occupation	-	-	-	-	0.809
Employed	14	20.9	5	15.2	-
Pensioner	13	19.4	6	18.2	-
Student	2	3.0	2	6.1	-
Unemployed	38	56.7	20	60.6	-
Educational qualification	-	-	-	-	0.012
Below Grade 12	38	56.7	18	54.6	-
Matric	25	37.3	6	18.2	-
University	3	4.5	5	15.2	-
Others	1	1.5	4	12.1	-

†, $n = 67$; ‡, $n = 33$.

Table 1 indicates that most of the persons completing the diary were females, unemployed and had below Grade 12 education in both study groups. A statistically significant difference was found between previously diary-unexposed participants and participants who had previous exposure to a seizure diary regarding gender and educational qualifications.

Figure 2 shows the distribution of participants completing the diary. A small number of patients completed the diary in the previously diary-unexposed and participants who had previous exposure to a seizure diary group. No significant differences were observed between the two groups ($p = 0.244$).

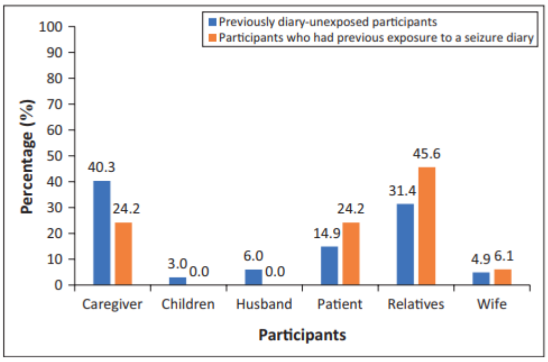

FIGURE 2: Persons completing the new seizure diary.

Table 2 and Table 3 show that almost all persons completing the diary found the new seizure diary to be useful in managing their epilepsy. No significant differences were found between previously diary-unexposed participants and participants who had previous exposure to a seizure diary except for the size of the new diary ($p = 0.010$).

Six previously diary-unexposed participants and five participants who had previous exposure to the seizure diary reported that they did not understand the diary (see Table 2 and Table 3). Of those participants previously diary-unexposed, three (50%) said, 'it was too confusing for me', two (33.3%) previously diary-unexposed and one (20%) participant who had previous exposure to the seizure diary said, 'How to use it was not explained to me', another one (20%) participant who had previous exposure to the seizure diary and one (16.7%) previously diary-unexposed participant stated, 'I don't know what to do with it'. Two participants who had previous exposure to the seizure diary (40%) reported, 'I find it too difficult to understand', and one reported, 'The language was too difficult to understand' (20%).

Table 4 shows that most of the participants from both groups were satisfied with the size of the new seizure diary because it is easy to carry around. A few participants who had previous exposure to a seizure diary ($n = 4$; 12.1%) reported that they did not like the size of the new seizure diary because 'It was too small to record in full' ($n = 2$; 50%), 'would like it to be bigger' ($n = 1$; 25%), and 'it was too long'($n = 1$; 25%).

Some of the previously diary-unexposed participants and participants who had previous exposure to a seizure diary requested changes to the new seizure diary (see Table 2 and Table 3). The changes requested by previously diary-unexposed include 'space for management after an attack' ($n = 1$; 100%), while participants who had previous exposure to a seizure diary requested 'extra columns for remarks' ($n = 1$; 20%), 'want the diary to be available in the

TABLE 2: Use of the seizure diary: Part 1.

Questions about the use of the new seizure diary	Previously diary-unexposed participants (*n* = 67)						Participants who had previous exposure to a seizure diary (*n* = 33)					
	Yes		No		Not sure		Yes		No		Not sure	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
Do you understand the new seizure diary?	61	91.0	4	6.0	2	3.0	28	84.9	2	6.1	3	9.1
Do you like the size of the new seizure diary?	67	100.0	0	0.0	0	0.0	29	87.9	4	12.1	0	0.0
Do you think the new seizure diary is useful?	66	98.5	1	1.5	0	0.0	33	100	0	0.0	0	0.0
Do you enjoy completing the new seizure diary?	64	95.2	1	1.5	2	3.0	32	97.0	0	0.0	1	3.0
Does the new seizure diary help track your/patient's seizures?	67	100.0	0	0.0	0	0.0	33	100.0	0	0.0	0	0.0
Does the new diary help relatives/caregivers keep track of your/patient's seizures?	67	100.0	0	0.0	0	0.0	33	100.0	0	0.0	0	0.0
Do you find the new diary useful in helping to provide information about your/patient's current medications?	64	95.5	2	3.0	1	1.5	33	100.0	0	0.0	0	0.0
Does the new diary help to provide information when you meet with your/patient's doctor?	65	97.0	1	1.5	1	1.5	33	100.0	0	0.0	0	0.0
Do you want to continue using the new seizure diary in future?	66	98.5	1	1.5	0	0.0	32	97.0	1	3.0	0	0.0
Do you think anything should change in order to further improve the new diary?	1	1.5	66	98.5	0	0.0	5	15.2	28	84.9	0	0.0

TABLE 3: Use of the seizure diary: Part 2.

Questions about the use of the new seizure diary	Previously diary-unexposed participants (*n* = 67)		Participants who had previous exposure to the seizure diary (*n* = 33)	
	n	%	*n*	%
After a fit, when do you complete the new diary?				
Immediately	51	76.1	27	81.8
1 day later	13	19.4	5	15.2
2 days to ≤ a month	3	4.5	1	3.0
1–2 months	0	0.0	0	0.0
3–5 months	0	0.0	0	0.0
≥ 6 months	0	0.0	0	0.0
Where do you keep the new seizure diary?				
Handbag	21	31.3	11	33.3
In the drawer	17	25.4	14	42.4
On the table	15	22.4	7	21.2
On the fridge	3	4.5	0	0.0
In the office	1	1.5	0	0.0
Others				
File	5	7.5	0	0.0
Bible	1	1.5	0	0.0
Medication bag	1	1.5	0	0.0
Car	1	1.5	0	0.0
Under the mattress	1	1.5	0	0.0
Wardrobe	1	1.5	1	3.0

Note: Why do you think the new seizure diary is useful? – previously diary-unexposed participants *n* = 66; participants who previously used a seizure diary *n* = 33.

TABLE 5: Preferred seizure diary (*n* = 33).

Participants who had previous exposure to a seizure diary	*n*	%
Prefer new seizure diary: reasons†		
More information	18	69.2
A better understanding of the new diary	3	11.5
More detailed diary	3	11.5
More space	1	3.8
Documents multiple seizures	1	3.8
Prefer old seizure diary: reasons‡		
Easier to use	6	86.0
More useful	1	14.0

†, *n* = 26 (78.8%); ‡, *n* = 7 (21.2%).

TABLE 4: Reasons explaining the response to questions about the use of the diary.

Reasons categorised	Previously diary-unexposed participants		Participants who previously used a seizure diary	
	n	%	*n*	%
Why do you like the size of the new seizure diary?				
Easy to carry around/hold	52	77.6	16	55.2
Fits my handbag	8	11.9	8	27.6
Like the size	4	6.0	1	3.4
Others	3	4.5	4	13.8
Why do you think the new seizure diary is useful?				
Helps to track seizure	55	83.3	26	78.8
Provides information	5	7.6	4	12.1
Helps Drs keep record	4	6.1	2	6.1
Others	2	3.0	1	3.0
Why do you enjoy completing the new seizure diary?				
Helps family monitor seizures	25	39.0	19	59.4
Provides information about seizures	30	46.9	10	31.3
Helps Drs understand the seizures	3	4.7	-	-
Easier to use	6	9.4	3	9.4
Others	0	0.0	0	0.0

Note: Why do you like the size of the new seizure diary? – previously diary-unexposed participants *n* = 67; participants who previously used a seizure diary *n* = 29. Why do you think the new seizure diary is useful? – previously diary-unexposed participants *n* = 66; participants who previously used a seizure diary *n* = 33.

TABLE 6: Associations between responses to questions: Part 1.

Responses	Previously diary-unexposed participants (*n* = 67)			Participants who had previous exposure to a seizure diary (*n* = 33)		
	Frequency	%	*p*	Frequency	%	*p*
Type of persons completing the diary indicating that they understood the diary	-	-	**0.828**	-	-	**0.810**
Caregivers	23	85.2	-	8	100.0	-
Children	2	100.0	-	0	0.0	-
Husband	4	100.0	-	0	0.0	-
Patient	9	90.0	-	6	75.0	-
Relatives	20	95.2	-	12	80.0	-
Wife	3	100.0	-	2	100.0	-

TABLE 7: Associations between responses to questions: Part 2.

Responses	Previously diary-unexposed participants ($n = 67$)							Participants who had previous exposure to a seizure diary ($n = 33$)						
	Frequency (%)						p	Frequency (%)						p
	Immediately		1 day later		2 days to ≤ 1 month			Immediately		1 day later		2 days to ≤ 1 month		
	n	%	n	%	n	%		n	%	n	%	n	%	
Where patients keep their diary when compared with when they complete the seizure diary after a seizure	-	-	-	-	-	-	**0.407**	-	-	-	-	-	-	**0.515**
In a handbag	18	42.9	3	25.0	0	-	-	8	30.8	2	40.0	1	100.0	-
In the drawer	9	21.4	6	50.0	2	66.7	-	11	42.3	3	60.0	0	-	-
In the office	1	2.4	0	-	0	-	-	0	-	0	-	0	-	-
On the fridge	3	7.1	0	-	0	-	-	0	-	0	-	0	-	-
On the table	11	26.2	3	25.0	1	33.3	-	7	26.9	0	-	0	-	-

Afrikaans language' ($n = 1$; 20%), and 'explain the types of seizures better' ($n = 3$; 60%).

Only the participants who had previous exposure to a seizure diary were asked to compare the previous diary to the new seizure diary. The majority, ($n = 26$; 78.8%, 95% confidence interval [CI]: 61.1% to 91.0%), preferred the new seizure diary, while 7 (21.2%) preferred the old seizure diary. A summary of the reasons is represented in Table 5.

There was no association between the type of person completing the diary and whether they indicated that they understood the diary (Table 6 and Table 7, previously diary-exposed participants $p = 0.828$, participants who had previous exposure to a seizure diary $p = 0.810$). There was also no association between where the person keeps the diary and when the diary is completed after a seizure in previously diary-unexposed ($p = 0.407$) and participants who had previous exposure to a seizure diary ($p = 0.515$).

Discussion

In this study, we explored how participants (patients, relatives and caregivers) in Bloemfontein and Kimberley experienced the new seizure diary after using the diary for 6 months. Differences were found in the demographic characteristics of persons completing the seizure diary, such as more females were involved in completing the new diary than males. This may be because of the dominant roles females play in caring for sick family members; many studies support the assertion that more females are involved in playing the role of caregivers in the family.[33,34,35] Pokharel et al. reported a female-to-male ratio of 2.5:1.[34]

Only a few patients with epilepsy could complete the new seizure diary themselves. Most often, relatives and caregivers were responsible for regularly documenting the seizures in the diary. This is in contrast with reports from other studies on patient-reported seizures. Blachut et al., in a study about patient-reported seizure counts, showed that of the 104 patients who reported keeping a seizure diary, 78% of patients reported completing their seizure diary themselves.[36] Most of our patients may have required assistance completing their diaries because of the brief postictal state characterised by confusion and disorientation after their seizures.[37] Most of the participants in both groups in this study (including patients) understood the new seizure diary. Fisher et al. reported that patients might be unable to understand or complete the seizure diary.[18] The few participants who reported not understanding the diary gave reasons that point to poor communication and language barriers. This is similar to findings by Keikelame et al., who reported that communication difficulties, poor doctor–patient relationships and language barriers were perceived by doctors to affect epilepsy patient management in the primary care setting in Cape Town.[38] The education of these patients about the seizure diary was inadequate.[27]

All participants who were previously diary-unexposed and a majority who had previous exposure to a seizure diary reported that they liked the size of the new seizure diary mainly because it was easy to hold or carry around. Fisher et al. reported that requesting too much information may make the diary impractical to use; the diary must have an efficient and user-friendly design.[18] All the participants who had previous exposure to a seizure diary and most of the previously diary-unexposed participants reported that the new seizure diary was useful for them. The main reasons given were that it 'helped to track seizures', 'provided information', and 'helps Drs to keep records'. These were similar to findings reported by Blachut et al. in their studies, as the main reasons stated by patients with epilepsy for documenting their seizures.[25,36] Most participants in this study enjoyed completing the new seizure diary because it helped their families to monitor their seizures, provided more seizure information and other reasons. This was supported by reports from Blachut et al. stating that patients document seizures if they feel it is important.[25,36] About 50% of diary documenters in that study reported that the diary provided valuable information for the doctors' treatment decision-making and 80% found the diary easy to use.[36]

Most persons from both groups in this study completed the new seizure diary immediately after their seizures. Seizure documentation behaviour plays a significant role when it comes to underreporting seizures. The main reason for the non-documentation of observed seizures was a failure to complete the diary immediately and later forgetting.[25,36] Many previously diary-unexposed persons kept their new seizure diary in their handbags, making it easy to carry them around. In contrast, most persons who previously used the seizure diary kept their diaries in a drawer at home. Fisher et al. reported that the seizure diary may not be at hand after a seizure event.[18] Patients with epilepsy must be encouraged to keep the diary in a place where caregivers and family members can easily have access to the diary.

Almost all the participants from both groups were willing to continue to use the new seizure diary in future. This was similar to findings reported in our previous study on the seizure diary.[22] The majority of participants from both groups were happy with the current format of the new seizure diary; however, a few had challenges with the new diary and wanted changes made, such as an extra column for remarks after a seizure, types of seizure explained and the diary being available in the Afrikaans language. Healthcare workers provide care for patients from different ethnic, cultural and socioeconomic backgrounds, and language barriers can easily affect the quality of care.[27,39,40] Fisher et al. described the availability of seizure diaries in various languages for patients' use[20] could assist in overcoming language barriers or poor communication patterns that cause poor management of patients living with epilepsy.[38] The researchers will ensure the final version of the new seizure diary is available in different languages (English, Afrikaans, Sesotho and Setswana) for patients and their caregivers.

Beghi, in a study about addressing the burden of epilepsy, reported on the views of patients, and caregivers of patients with epilepsy that adults with epilepsy had difficulties with marriage, driving and finding jobs in the labour market.[41] Caregivers experienced increased stress, fear during seizures, depression, helplessness and joblessness because they have to care for the patients.[41] Providing space for remarks in the seizure diary will enable patients and caregivers to express their views and describe the burden of epilepsy on them and their families so that healthcare workers reviewing the diary can better understand and find ways to assist them.

Participants who had previous exposure to a seizure diary had the opportunity to be exposed to both seizure diaries. Most of them preferred the new seizure diary to the old one because it contained more information. Blachut et al. stated that the provided information, if used for decision-making, strongly reinforces patients completing the diary and gives them treatment satisfaction.[36] Most participants who chose the old seizure diary (Basic calendar diary) revealed that their reason for doing so was because it was easier to use. The basic calendar diary lacks the details that can assist healthcare professionals in making important clinical decisions. Fisher et al. described the information provided by the basic calendar diary as far from comprehensive in understanding longitudinal relationships in seizure events.[18]

Almost all participants agreed that the new seizure diary is useful for tracking patients' seizures and providing information. This information is available for doctors and other healthcare workers to use in improving the quality of care they provide to their patients. Blachut et al. described seizure documentation as strongly related to doctors' behaviours. If doctors take sufficient time to analyse and discuss the diary, it motivates the patients to continue to complete it because they know it can contribute to treatment decisions.[25,36] This view has been supported by other studies about the seizure diary.[19,27]

The diary used during this study was designed based on recommendations from the Delphi expert panel[32] and the recommendation of patients with epilepsy on what they think should be the content of a seizure diary.[22] In addition to the recommendations of the Delphi experts, patients, relatives and caregivers of patients with epilepsy impacted by the disease actively participated and made recommendations they felt were important and would help motivate them to use the new diary. The changes recommended by participants from both groups in this study were incorporated into the diary to create the final version of the new seizure diary. This new seizure diary (Appendix 1) was created based on patient-centred care principles. Epstein and Street stated that patient-centred care should help patients know more about their health and facilitate taking ownership of their health.[42]

The final version of the new diary will be proposed to the Department of Health, seeking their permission to allow its distribution and use by patients with epilepsy.

Recommendations

To improve the acceptance of the diary, the new seizure diary should be made available in different African languages for patients with epilepsy, their caregivers and relatives to use in their local dialect.

As smartphones, portable electronic devices and the cost of data become more affordable and accessible in our urban and rural areas. Future research should be geared towards partnering with international and local organisations to create an indigenous, culturally acceptable African Epilepsy mobile application for the use of patients living with epilepsy, relatives, caregivers and healthcare professional involved in their care. This will go a long way in improving the quality of care we provide for our patients and support for their families.

Limitations of the study

This study was on patients from Kimberley and Bloemfontein, which may be subject to selection bias making it difficult to generalise the study's findings. The change in clinic bookings to a 6-monthly schedule because of the COVID-19 pandemic impacted the ability to find and follow up with patients. The number of patients attending the clinics was significantly reduced during this time.

The focus of this study was only on the experience of the new seizure diary; the diary was checked to see whether the patients or caregivers were documenting the seizures in the diary, but we did not investigate the accuracy of the reported seizures. The feedback received from some participants was not informative; it lacked details.

Conclusion

This study looked at the experience of the seizure diary by participants who used the diary for 6 months. The study included participants who were previously diary-unexposed and who previously used a seizure diary. The study provided valuable information about the experience of patients, caregivers and other family members from both groups while using the diary. Our findings show that all participants found the new seizure diary helped them to keep track of seizures. Most participants from both groups found the new seizure diary useful and were willing to continue using it.

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contributions

C.K.E. developed the research concept, conducted a literature review, planned a protocol, developed the questionnaire, collected the data and prepared the manuscript. A.A.M. supervised the project from planning to report writing. W.J.S. co-supervised and provided input from concept development to report writing. G.J. provided input in protocol development, questionnaire design, the pilot study, data analysis and reviewing this manuscript.

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Data availability

The data supporting this study's findings are available from the corresponding author, C.K.E., upon reasonable request.

Disclaimer

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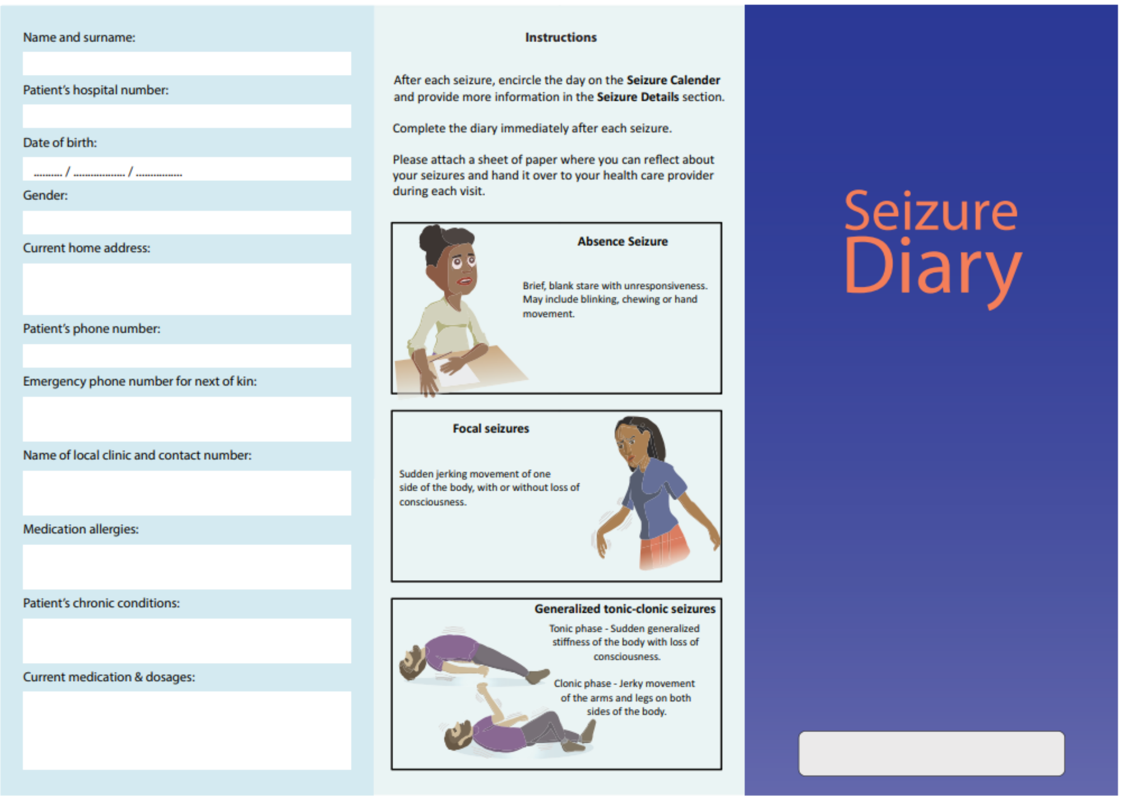
Appendix starts on the next page →

Appendix 1: Seizure diary



Name and surname:

Patient's hospital number:

Date of birth:

.... / .... / ....

Gender:

Current home address:

Patient's phone number:

Emergency phone number for next of kin:

Name of local clinic and contact number:

Medication allergies:

Patient's chronic conditions:

Current medication & dosages:

Instructions

After each seizure, encircle the day on the **Seizure Calender** and provide more information in the **Seizure Details** section.

Complete the diary immediately after each seizure.

Please attach a sheet of paper where you can reflect about your seizures and hand it over to your health care provider during each visit.

Absence Seizure

Brief, blank stare with unresponsiveness. May include blinking, chewing or hand movement.

Focal seizures

Sudden jerking movement of one side of the body, with or without loss of consciousness.

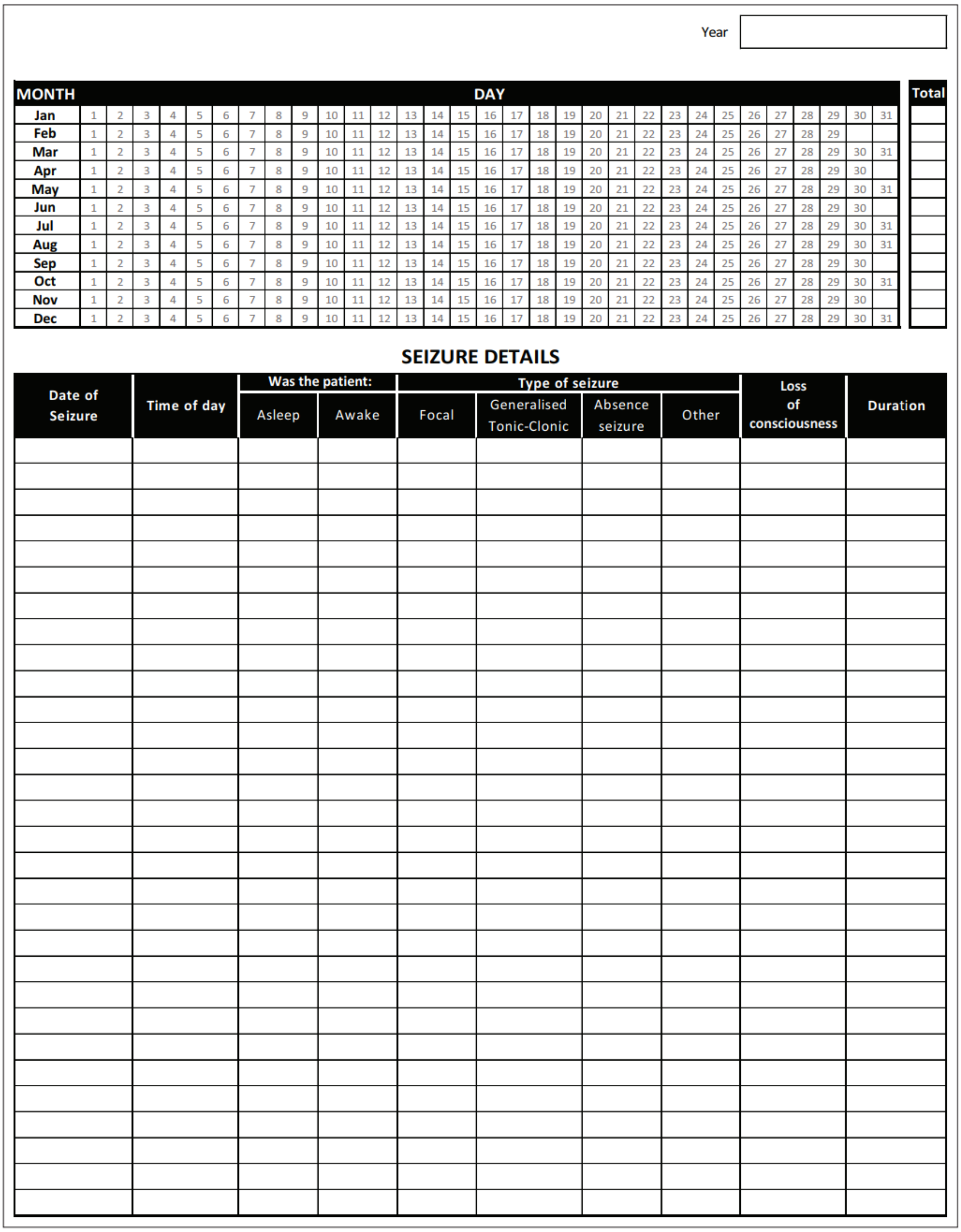
Generalized tonic-clonic seizures

Tonic phase - Sudden generalized stiffness of the body with loss of consciousness.

Clonic phase - Jerky movement of the arms and legs on both sides of the body.

Seizure Diary

FIGURE 1-A1: Seizure diary front.



Year

MONTH	DAY																														Total
Jan	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Feb	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29			
Mar	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Apr	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
May	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Jun	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Jul	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Aug	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Sep	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Oct	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Nov	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Dec	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	

SEIZURE DETAILS

Date of Seizure	Time of day	Was the patient:		Type of seizure				Loss of consciousness	Duration
		Asleep	Awake	Focal	Generalised Tonic-Clonic	Absence seizure	Other		

FIGURE 2-A1: Seizure diary back.

CHAPTER 6: CONCLUSION,IMPLICATIONS, RECOMMENDATIONS, AND LIMITATIONS

6.1 INTRODUCTION

In this study, Chapter 1 introduced the readers to the challenges associated with the management of patients with epilepsy and the fact that a gap exists in the management of patients living with epilepsy in South Africa. The reader was also introduced to the concept of a seizure diary and the need to explore this tool further to determine the possible role it could play in managing patients with epilepsy.

The subsequent Chapters, 2–5, took the form of published articles and manuscripts.

Chapter 6 will conclude the study and intends to summarise the study, reflect on the research process, results, and limitations, and make future recommendations.

6.2 OVERVIEW

This thesis explored the theoretical basis and practical application of a seizure diary for patients with epilepsy. Chapter 1 introduced the seizure diary in its current form and format, as used locally and internationally. It discussed the research questions, aim, objectives, rationale, research paradigm, research design, validity of the study, scope of the study, and ethical considerations, and offered an overview of the processes followed by the study.

Chapter 2 (Article 1) provided an extensive review of current literature, and investigated the standard and international practices associated with using a seizure diary to manage patients with epilepsy. In total 1 152 articles were identified from the database, and 23 articles were reviewed and used to determine the relevance of seizure diaries in current clinical practice and care for patients with epilepsy. The knowledge gained from the articles reviewed was used as a background for further studies on the diary (Articles 2, 3 and 4). Questionnaires 1 and 2 and the modified Delphi study questionnaires were designed from information obtained from the extensive review of literature on the seizure diary.

This study used a quantitative questionnaire-based method to obtain participant data in Phases 2, 3 and 5a. Most of the study participants were selected with convenience sampling.

After an extensive modified Delphi survey, the required contents of a seizure diary were identified. A seizure diary was created based on the expert recommendations, with input based on active patient participation. This diary was introduced to patients and was reviewed after they had used it for six months, and their comments were used to create the final new seizure diary. The new seizure diary will be sent to the Department of Health, so that it can consider using the diary for the management of patients living with epilepsy.

Overall, the goal of this study was to improve seizure management by developing an improved seizure diary to assist in the management of patients with epilepsy in South Africa.

This study investigated four research objectives, that were achieved as described in the next subsections.

6.2.1 Research objective 1

> *To determine and review the current norms and international practices for the use of seizure diaries to manage epilepsy*

Before this study, most literature describing the use of the seizure diary was based in the Western world; little research had been undertaken in Africa. Furthermore, no published scoping or systematic reviews on using a seizure diary to manage patients with epilepsy were found while searching relevant databases. After an extensive search of pertinent literature, this study identified themes, categories, and subcategories relating to a seizure diary. The identified themes were the types of seizure diaries used in clinical practice, the contents and structure of a seizure diary, the use and efficacy of seizure diaries in medicine, and challenges facing the use of seizure diaries for patient management. The categories and subcategories explored more in-depth details about using a seizure diary in clinical practice and research, such as types of dairies, seizure frequency, seizure duration, and so on.

The details provided by this scoping review of the literature were quite extensive. They can be viewed in the publication of Article 1, ***Current norms and practices in using a seizure diary for managing epilepsy: A scoping review*** (*cf.* Chapter 2).

6.2.2 Research objective 2

> *To determine the perceptions and attitudes of patients with epilepsy in South Africa on the use of a seizure diary to manage patients with epilepsy*

In Chapter 3 (Article 2) of this study, patients' perceptions of and attitudes towards the seizure diary were obtained. A structured questionnaire was used to obtain information from the study sample. Relatives and caregivers of patients were allowed to assist in completing the questionnaire. The questionnaire obtained information about the biodata of patients involved in the study. It consisted of open and closed-ended questions about the patient's epilepsy and seizures and the seizure diary, the latter for those who had previous exposure to a seizure diary. Most patients who had had epilepsy for more than 11 years did not know the type of seizures they had, and had an annual seizure frequency of more than once a year.

A few patients who had previous exposure to a seizure diary reported challenges with completing the diary. Almost all the patients were willing to use the seizure diary. These findings are reported in the published article 2, ***The perceptions and attitudes of patients with epilepsy to the use of a seizure diary, South Africa*** *(cf.* Chapter 3).

6.2.3 Research objective 3

> *To develop a new seizure diary that can be used to manage patients with epilepsy in South Africa, based on expert opinions of the members of a Delphi panel, and contributions by patients*

The required contents of a seizure diary were the focus of Chapter 4 (Article 3). The researchers adopted a Delphi survey to meet this objective. For the modified Delphi survey, experts from different specialties who were familiar with managing patients with epilepsy, were recruited. The Delphi consisted of three rounds of deliberations on certain items; experts had the option to make individual suggestions on other items that may be relevant for debate in the study. They suggested 18 items for inclusion; the contents of the seizure diary were selected based on a broad consensus among the expert panel.

The article describing this Delphi study, titled ***A modified Delphi study to determine the contents of a seizure diary for patients living with epilepsy in South Africa,*** are reported in a peer-reviewed journal (*Journal of Public Health in Africa*).

6.2.4 Research objective 4

> *To determine the patients' evaluation of the new seizure diary, and to use the information to revise the diary further and present a final, improved seizure diary*

In Chapter 5 (Article 4), the experience of the diary by patients, relatives, and caregivers responsible for completing the diary was described in detail. The questionnaire used in this study was a follow-up on the initial questionnaire described in Chapter 3. After using the diary for six months, patients were requested to complete a questionnaire. Open and closed-ended questions were used in the questionnaire. The initial biodata of the person completing the diary was obtained, and various questions relating to the use and impact of the diary for the users were asked.

Findings from the study are reported in a peer-reviewed journal. The study is titled ***Experience of the new seizure diary in the Free State and Northern Cape of South Africa.***

The publication incorporated Phases 4, 5a and 5b. Patients and caregivers were asked to comment on what they wanted to change after using the diary for six months. Their recommendations were considered and incorporated into the diary.

A final design of the new seizure diary was created based on these recommendations, and will be available in the different local languages (Afrikaans, English, Setswana and Sesotho).

The researchers will recommend the improved new seizure diary to the Department of Health (Free State and Northern Cape) and they will recommend that it considers using the new diary for epileptic patients.

6.3 IMPLICATIONS OF THE STUDY

6.3.1 Goals and contribution

The goal of this study was to develop a new seizure diary for the management of patients with epilepsy, based on the recommendation of a panel of experts experienced in the management of epilepsy, and a contribution by patients, relatives and caregivers of patients living with epilepsy. To achieve this goal, the researcher addressed the research objectives regarding current international standards, practices and expert opinions on the contents of a seizure diary, and patients' perceptions of and attitudes towards the use of a seizure diary in their management of epilepsy.

The first contribution was a scoping review of the literature on the epilepsy diary. This was published in a peer-reviewed journal (*cf.* Chapter 2). The article reports on the literature on current standards and international practices associated with using a seizure diary. These findings serve as a template that could guide future studies on a seizure diary.

The second contribution is the development of a new seizure diary. The process incorporated the principle of patient-centred care. The manuscript has been accepted for publication in a peer-reviewed journal (*cf.* Chapter 5). The article reports on patients' experience of the new seizure diary. The final version of the seizure diary incorporated recommendations from patients, relatives and caregivers who had first-hand experience of using the diary. The process encouraged their involvement in decision-making and respected their values and preferences.

Implementing the seizure diary as a self-management tool for patients will contribute significantly to better monitoring of seizure frequency, seizure duration, types of seizures and other relevant information relating to patients living with epilepsy. The diary will act as a source of important patient information for healthcare providers, which will help them to make the best treatment decisions for their patients.

6.3.2 Publications

This PhD thesis is structured as publishable articles. All articles presented in Chapters 2, 3, 4, and 5 have already been published. Three articles were submitted to a national journal, while an international journal accepted the other.

6.3.3 Conferences

The study findings have been presented at a national conference. The results reported in Article 2 were presented at the Annual South African Academy of Family Physicians National Congress in 2022.

Findings from the other articles have been submitted for presentation at local and international conferences (Articles 1 and 3), namely the WONCA Australia Conference 2023, the International Neurology Conference Canada 2023, and the 25th annual South African Academy of Family Physicians National Congress 2023, in Johannesburg. Article 1 has been accepted for presentation at WONCA 2023 and the international neurology conference Canada 2023.

In future, the researcher hopes to present the findings from this thesis in the University of the Free States 3-minute thesis and the annual Free State Department of Health research forum. Doing so will improve awareness of using a seizure diary as a tool in epilepsy care.

6.3.4 Study limitations

The following limitations were encountered in this study.

1) There is little literature about seizure diaries. The search criteria used may have led to some relevant literature being missed while searching the relevant databases.
2) Most of the literature cited in this study emanate from high-income nations, such as the United States of America and the United Kingdom. The lack of literature for low-income countries and the rest of Africa makes it difficult to understand how diaries can be used in low-income populations and the rest of Africa.
3) The study was limited to patients with epilepsy in Kimberley and Bloemfontein, and the findings may be difficult to generalise to other African population groups.

4) The small number of international experts recruited for the Delphi study limited our ability to obtain a broader view of the contents of a seizure diary. The panellists were mainly from South Africa; their views are probably more in keeping with what is expected locally. A larger international panel may have had a different finding.
5) The COVID-19 pandemic had a negative impact on the ability of the researcher to track the patients. Clinic appointments for follow-up and medication were changed from monthly to 6 monthly to reduce the contact between health workers and patients. This made it challenging to find the patients in the clinics throughout the duration of the study.

6.4 QUALITY OF THE STUDY

The research was quantitative; it was focused and concise. A questionnaire in which each respondent was exposed to the same set of questions and the same system of coding responses was used. The questionnaires addressed the research problem. Questions were structured to meet the research objectives, they were kept simple and precise, and aimed to reduce response bias.

6.4.1 Internal validity

In the design of the diary, we ensured that the internal validity of the diary was established by carefully planning and ensuring that each phase of the research process was executed as planned. The diary's design process used a panel of local and international experts from various specialities. Face validity of the diary was ensured by lecturers who were knowledgeable about the diary discussing the contents of the diary. A pilot study for the modified Delphi and questionnaires helped to ensure that internal validity was maintained. The effect on patients with epilepsy of using the diary was measured, and the researcher ensured that the outcomes were reported truthfully. Validity was enhanced further by the peer review of the questionnaires by a departmental board comprising three family physicians. The questionnaires were peer-evaluated by the evaluation committee of the Faculty of Health Sciences and were approved after undergoing an ethics review.

6.4.2 External validity

The study's external validity was ensured by sampling patient populations in Kimberley and Bloemfontein. The participants were selected with convenience sampling based on their presentation at their local and specialist clinics. An adequate sample size was selected with the biostatistician’s assistance, to ensure meaningful statistical analysis. This ensured that the study findings could be generalised to other populations in the country with epilepsy.

6.5 VALUE AND SIGNIFICANCE OF THE STUDY

6.5.1 Value of the study

The study may be valuable to the Department of Health, since it developed a tool that can be used to improve the management of patients with epilepsy who being treated across South Africa; this tool can be used to monitor patients’ adherence to their medications.

The tool that was developed by this study could be important to patients, because it could assist in improving the participation of patients in their own care and management. The study helped to get relatives involved in the management of epilepsy patients and to keep track of the frequency of their seizures.

The tool could be valuable to health workers, and would assist in providing relevant patient information that they need to make decisions that will help improve patient management.

6.5.2 Significance of the study

The significance of the study is that it facilitated the development of an improved seizure diary that can be introduced as a monitoring tool for epileptic patients. It also demonstrates the concept of a seizure diary, its feasibility, acceptability, applicability in practice, and its impact on patients with epilepsy, their relatives, and caregivers.

The study demonstrates the practicability of the seizure diary, and that it is an effective tool for monitoring patients with epilepsy.

6.5.3 Reliability

The study's design ensured that its reliability was maintained, and the study could be reproduced in any other country where researchers are interested in performing a similar study. Reliability was enhanced by piloting the questionnaires. Findings from prior studies, online diaries, and documents informed the content of the questionnaires. The questionnaire design followed the principles of good questionnaire design, to enhance its reliability.

6.5.4 Objectivity

The research was objective in its approach; it gathered unbiased data and answered the research questions. The researcher devoted much effort to ensuring the study was precise, open, honest, truthful, and unbiased.

6.6 FINAL CONCLUSION

This study has succeeded in producing a new and improved seizure diary. This diary is an improvement on the basic calendar diary that is distributed by pharmaceutical companies. This new diary was developed with the assistance of experts, patients, relatives, and caregivers. It is more interactive and asks relevant questions, yet it is simple enough to be completed by patients, relatives, or caregivers. Most participants liked the size of the new diary and found it easy to carry around with them. Most participants who had previous exposure to a seizure diary preferred the new and improved seizure diary above the original diary.

We propose that the Department of Health and all other relevant stakeholders encourage the use of this diary in the management of patients living with epilepsy.

6.6.1 Recommendations

A seizure diary is a tool that has been documented to assist in managing patients with epilepsy, despite the challenges associated with its use in clinical practice and research. Further research on the seizure diary should be carried out in the future to improve its usefulness. The researcher recommends the following.

1) Future research on seizure diaries should focus on introducing electronic seizure diaries that have been designed explicitly by Africans for Africans to manage patients living with epilepsy on the African continent. Internet applications with a seizure diary should be developed and be readily available for patients who want to use them.

2) Monitoring of seizure frequencies is important in the management of epilepsy, and future research should be focused on developing non-invasive, culturally acceptable devices that can reliably monitor seizures without any patient inputs, such as wearable wrist devices, bracelets, and other technologies. Such a tool will significantly enhance epilepsy care in Africa.

3) The process of creating a patient retained record to facilitate self-management of a chronic condition can serve as a blueprint or implementation science approach for developing similar interventions targeting other chronic diseases. This method can be easily adapted and replicated while considering specific chronic conditions.

4) The private sector can adopt and integrate the seizure diary into their healthcare systems for patients with epilepsy who are not keen on using commercial or electronic diaries. Doing so will enhance care and support for individuals with epilepsy or seizure-related conditions. Additionally, the diary's adoption can contribute to research and data-driven decision-making, advancing knowledge in epilepsy care in the private sector.

6.7 PERSONAL CHALLENGES

The process and challenges encountered by the researcher in this study were overcome by searching relevant literature and exchanging ideas with experienced researchers in family medicine and neurology. The researcher completed the thesis via the publication route, despite initially lacking research experience. This was done with the hope that the rigorous process would help improve the researchers’ writing skills and confidence in research methodology. Each paper was a tedious learning process and the acceptance by the peer-reviewed journals for publication brought with it a great sense of relief and joy for the researcher and his supervisors.

This PhD study has been a great learning process for the author. It was filled with challenges, and the process taught the author much about patience and perseverance, despite having to face significant obstacles.

6.8 FINAL REMARKS

In this study, the author conducted a scoping review of literature, obtained information about patients’ perceptions of and attitudes to the seizure diary, obtained expert opinions on the contents of a seizure diary via a modified Delphi study, and explored patients' experiences of diary use. With the help of this information and the contribution of study participants, the author developed a new, improved seizure diary to manage patients with epilepsy. This diary will be recommended for use in the Northern Cape and Free State provinces.

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APPENDICES

Appendix A: Ethics approval letter

Appendix B: Ethics amendment letter

Appendix C: Approval Free State Department of Health

Appendix D: Approval Northern Cape Department of Health

Appendix E: Free State Department of Health/Northern Cape Department of Health request letter for permission

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Appendix G: Turnitin report

Appendix H: Language editor’s report

Appendix I: Information document for potential participants

Appendix J: Consent letter to participate in the research

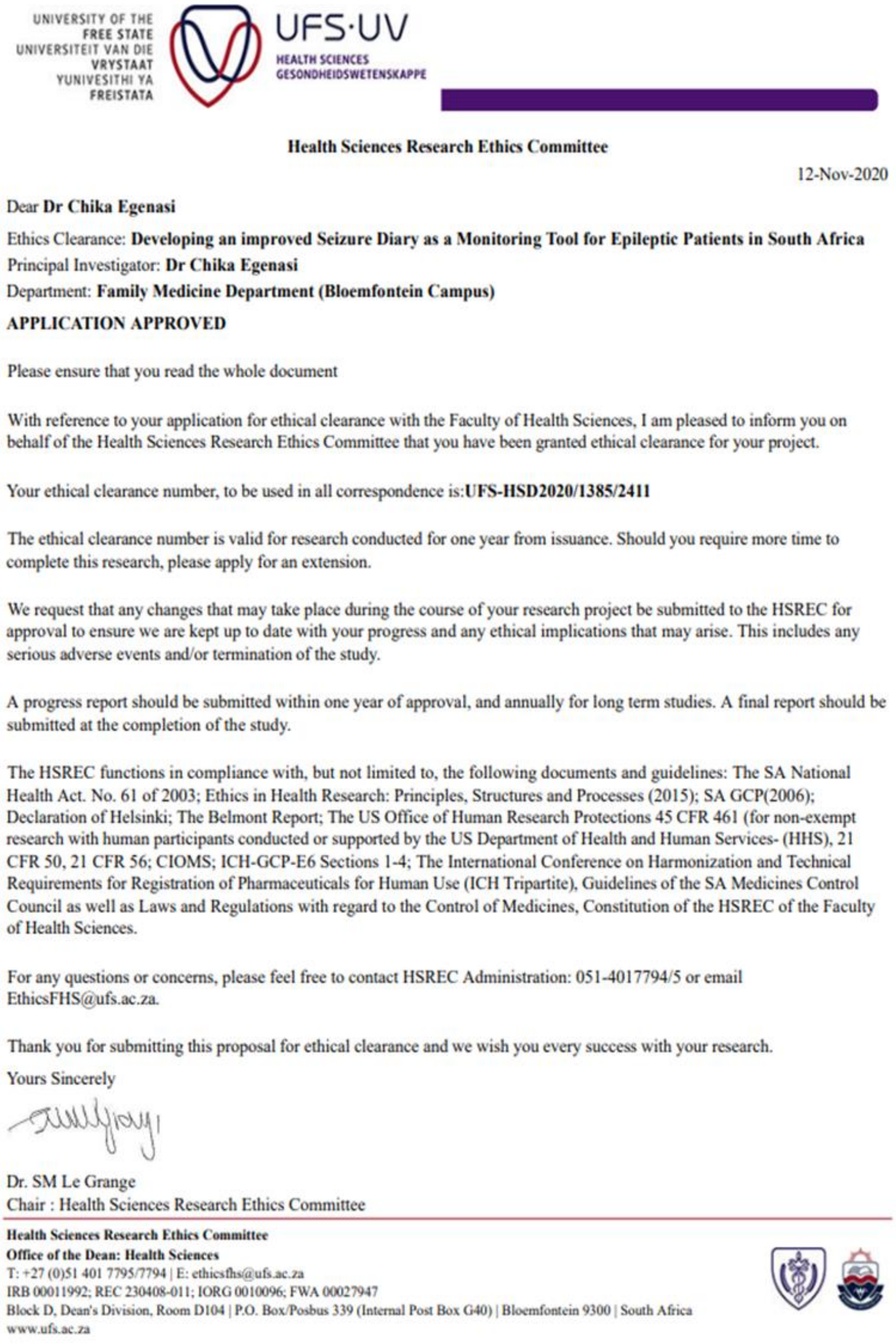
Appendix K: Questionnaire 1: Perception and attitude to the new seizure diary

Appendix L: Questionnaire 2: Experience of the new seizure diary

Appendix M: Letter of request and information document to Delphi participants

Appendix N: Draft Delphi Questionnaire for seizure diary

Appendix A: Ethics approval letter



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Health Sciences Research Ethics Committee

12-Nov-2020

Dear **Dr Chika Egenasi**

Ethics Clearance: **Developing an improved Seizure Diary as a Monitoring Tool for Epileptic Patients in South Africa**
Principal Investigator: **Dr Chika Egenasi**
Department: **Family Medicine Department (Bloemfontein Campus)**

APPLICATION APPROVED

Please ensure that you read the whole document

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance for your project.

Your ethical clearance number, to be used in all correspondence is:**UFS-HSD2020/1385/2411**

The ethical clearance number is valid for research conducted for one year from issuance. Should you require more time to complete this research, please apply for an extension.

We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email EthicsFHS@ufs.ac.za.

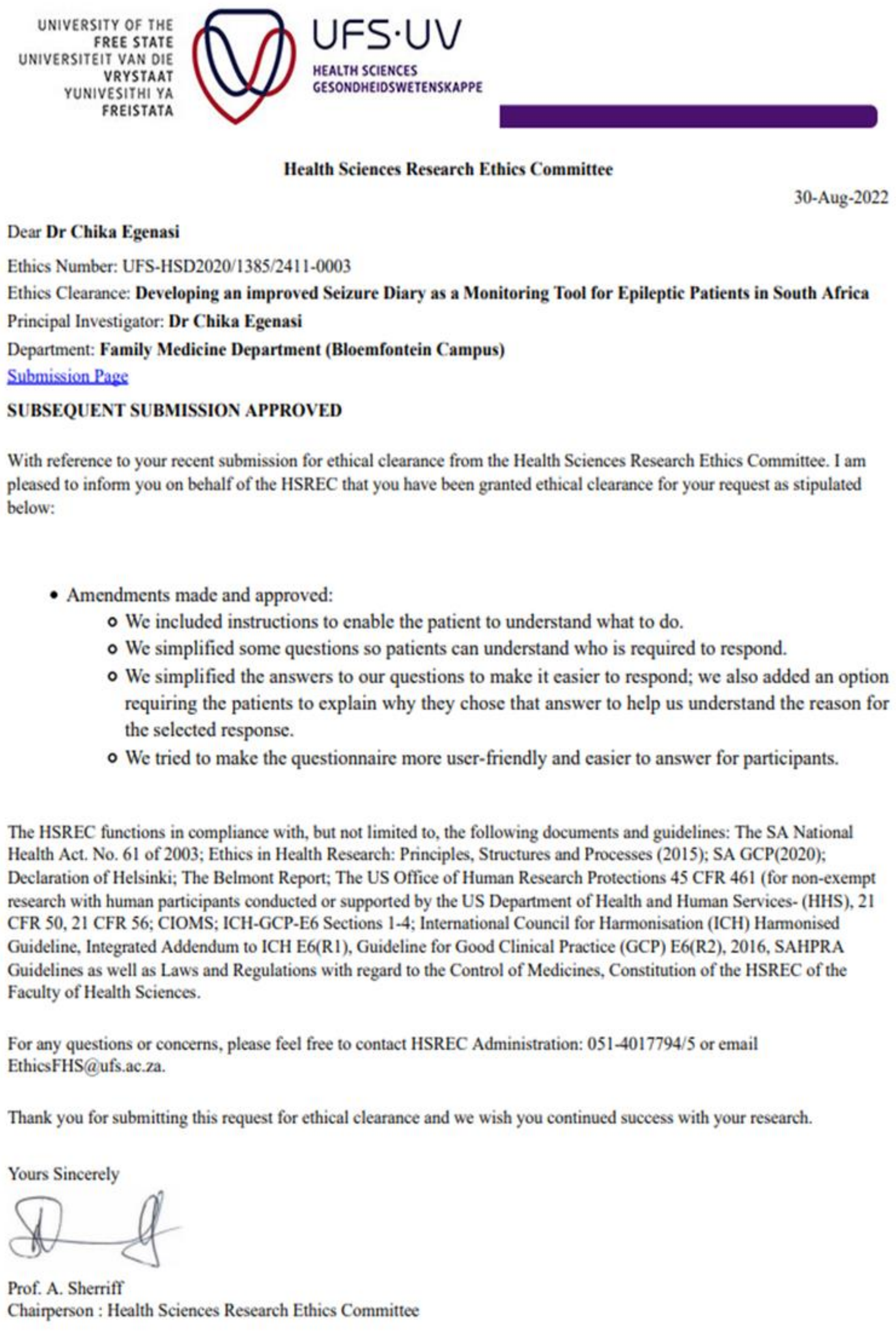
Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours Sincerely

Dr. SM Le Grange
Chair : Health Sciences Research Ethics Committee

Health Sciences Research Ethics Committee
Office of the Dean: Health Sciences
T: +27 (0)51 401 7795/7794 | E: ethicsfhs@ufs.ac.za
IRB 00011992; REC 230408-011; IORG 0010096; FWA 00027947
Block D, Dean's Division, Room D104 | P.O. Box/Posbus 339 (Internal Post Box G40) | Bloemfontein 9300 | South Africa
www.ufs.ac.za

Appendix B: Ethics amendment letter



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Health Sciences Research Ethics Committee

30-Aug-2022

Dear **Dr Chika Egenasi**

Ethics Number: UFS-HSD2020/1385/2411-0003

Ethics Clearance: **Developing an improved Seizure Diary as a Monitoring Tool for Epileptic Patients in South Africa**

Principal Investigator: **Dr Chika Egenasi**

Department: **Family Medicine Department (Bloemfontein Campus)**

Submission Page

SUBSEQUENT SUBMISSION APPROVED

With reference to your recent submission for ethical clearance from the Health Sciences Research Ethics Committee. I am pleased to inform you on behalf of the HSREC that you have been granted ethical clearance for your request as stipulated below:

- Amendments made and approved:
    - We included instructions to enable the patient to understand what to do.
    - We simplified some questions so patients can understand who is required to respond.
    - We simplified the answers to our questions to make it easier to respond; we also added an option requiring the patients to explain why they chose that answer to help us understand the reason for the selected response.
    - We tried to make the questionnaire more user-friendly and easier to answer for participants.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2020); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; International Council for Harmonisation (ICH) Harmonised Guideline, Integrated Addendum to ICH E6(R1), Guideline for Good Clinical Practice (GCP) E6(R2), 2016, SAHPRA Guidelines as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

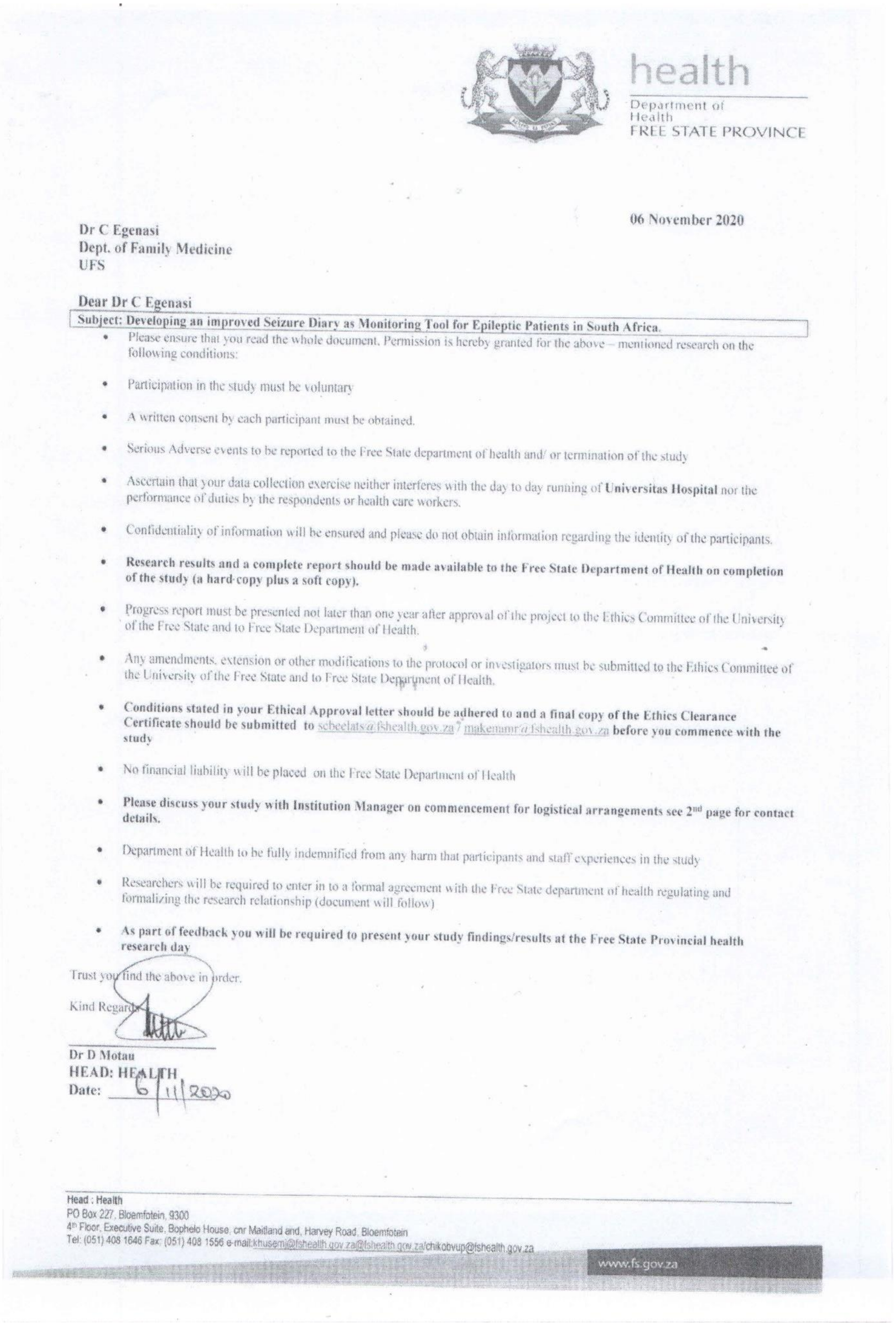
For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email EthicsFHS@ufs.ac.za.

Thank you for submitting this request for ethical clearance and we wish you continued success with your research.

Yours Sincerely

Prof. A. Sherriff
Chairperson : Health Sciences Research Ethics Committee

Appendix C: Approval Free State Department of Health



health
Department of
Health
FREE STATE PROVINCE

06 November 2020

Dr C Egenasi
Dept. of Family Medicine
UFS

Dear Dr C Egenasi

Subject: Developing an improved Seizure Diary as Monitoring Tool for Epileptic Patients in South Africa.

- Please ensure that you read the whole document. Permission is hereby granted for the above – mentioned research on the following conditions:
- Participation in the study must be voluntary
- A written consent by each participant must be obtained.
- Serious Adverse events to be reported to the Free State department of health and/ or termination of the study
- Ascertain that your data collection exercise neither interferes with the day to day running of **Universitas Hospital** nor the performance of duties by the respondents or health care workers.
- Confidentiality of information will be ensured and please do not obtain information regarding the identity of the participants.
- **Research results and a complete report should be made available to the Free State Department of Health on completion of the study (a hard-copy plus a soft copy).**
- Progress report must be presented not later than one year after approval of the project to the Ethics Committee of the University of the Free State and to Free State Department of Health.
- Any amendments, extension or other modifications to the protocol or investigators must be submitted to the Ethics Committee of the University of the Free State and to Free State Department of Health.
- **Conditions stated in your Ethical Approval letter should be adhered to and a final copy of the Ethics Clearance Certificate should be submitted to** scbeelats@fshealth.gov.za / makenamr@fshealth.gov.za **before you commence with the study**
- No financial liability will be placed on the Free State Department of Health
- **Please discuss your study with Institution Manager on commencement for logistical arrangements see 2nd page for contact details.**
- Department of Health to be fully indemnified from any harm that participants and staff experiences in the study
- Researchers will be required to enter in to a formal agreement with the Free State department of health regulating and formalizing the research relationship (document will follow)
- **As part of feedback you will be required to present your study findings/results at the Free State Provincial health research day**

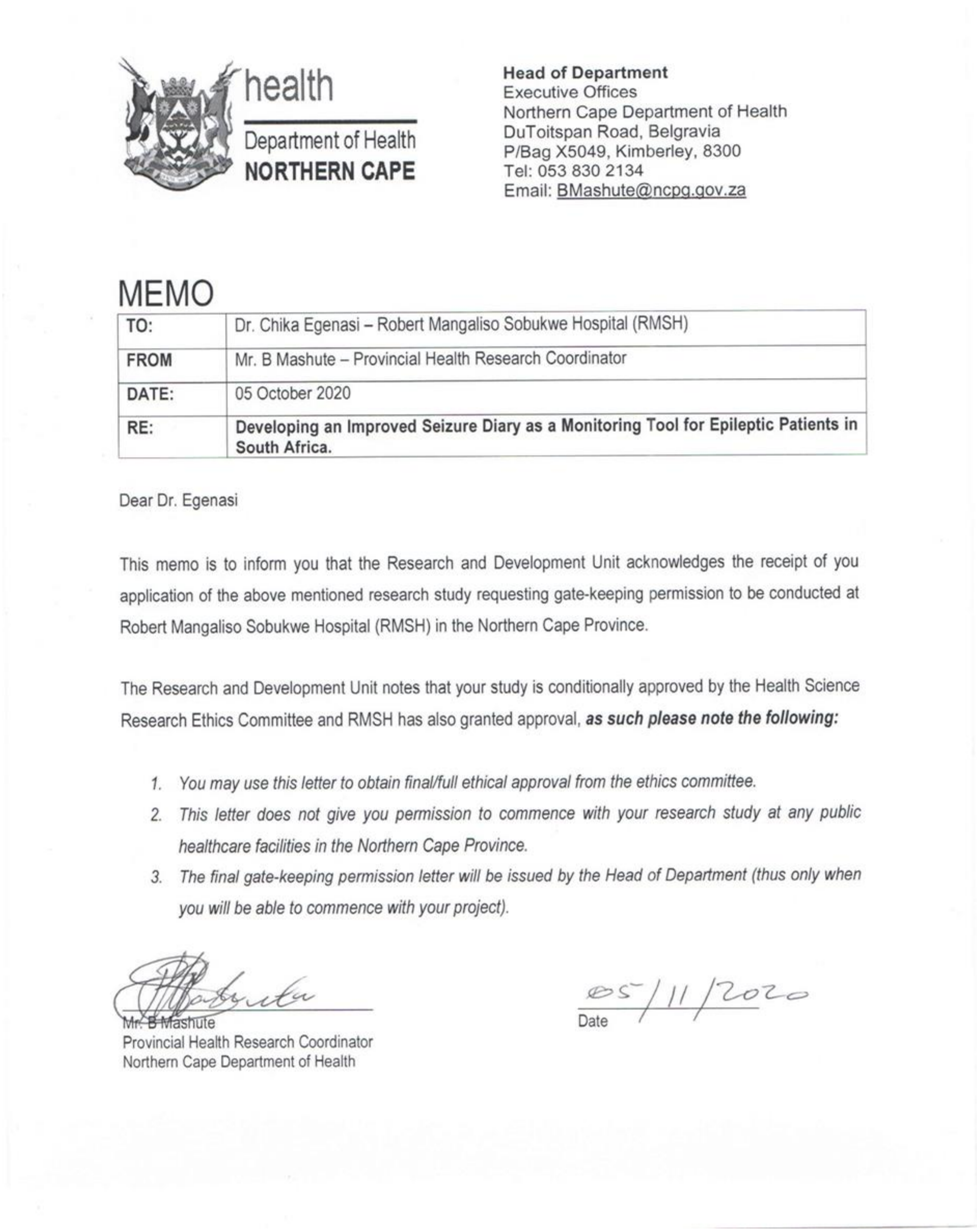
Trust you find the above in order.

Kind Regards

Dr D Motau
HEAD: HEALTH
Date: 6/11/2020

Head : Health
PO Box 227, Bloemfotein, 9300
4th Floor, Executive Suite, Bophelo House, cnr Maitland and, Harvey Road, Bloemfotein
Tel: (051) 408 1646 Fax: (051) 408 1556 e-mail:khusemj@fshealth.gov.za@fshealth.gov.za/chikobvup@fshealth.gov.za
www.fs.gov.za

Appendix D: Approval Northern Cape Department of Health



health
Department of Health
NORTHERN CAPE

Head of Department
Executive Offices
Northern Cape Department of Health
DuToitspan Road, Belgravia
P/Bag X5049, Kimberley, 8300
Tel: 053 830 2134
Email: BMashute@ncpg.gov.za

MEMO

TO:	Dr. Chika Egenasi – Robert Mangaliso Sobukwe Hospital (RMSH)
FROM	Mr. B Mashute – Provincial Health Research Coordinator
DATE:	05 October 2020
RE:	**Developing an Improved Seizure Diary as a Monitoring Tool for Epileptic Patients in South Africa.**

Dear Dr. Egenasi

This memo is to inform you that the Research and Development Unit acknowledges the receipt of you application of the above mentioned research study requesting gate-keeping permission to be conducted at Robert Mangaliso Sobukwe Hospital (RMSH) in the Northern Cape Province.

The Research and Development Unit notes that your study is conditionally approved by the Health Science Research Ethics Committee and RMSH has also granted approval, ***as such please note the following:***

1. *You may use this letter to obtain final/full ethical approval from the ethics committee.*
2. *This letter does not give you permission to commence with your research study at any public healthcare facilities in the Northern Cape Province.*
3. *The final gate-keeping permission letter will be issued by the Head of Department (thus only when you will be able to commence with your project).*

Mr. B Mashute
Provincial Health Research Coordinator
Northern Cape Department of Health

05/11/2020
Date

Appendix E: Free State Department of Health/Northern Cape Department of Health request letter for permission

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To The Department of Health
Free State/Northern Cape
South Africa.

15/03/23

Permission to distribute the new seizure diary to patients living with Epilepsy in the Free State and Northern Cape.

The researcher and his team thank the Department of Health of the Free State and Northern Cape for permitting us to collect data at the Universitas Hospital epilepsy clinic for the study Titled Developing an Improved Seizure Diary as a Monitoring Tool for Epileptic Patients in South Africa. The study aimed to develop an improved new seizure diary to improve seizure management in adult epileptic patients in South Africa.

The study was conducted in Kimberley and Bloemfontein and involved 182 patients with epilepsy. The study consisted of 5 phases which were Phase 1 (Scoping review of literature on epilepsy), Phase 2 (The perceptions and attitudes of patients with epilepsy to the use of a seizure diary in managing patients with epilepsy), and Phase 3 (Delphi study) involving both local and international experts in the field of epilepsy. Phase 4, a longitudinal study (Use of the new, improved seizure diary for six months), 5a, a cross-sectional study (Experience of the new seizure diary) and 5b (The suggested final version of the seizure diary). It was an extensive study. Two of the objectives of this study have been peer-reviewed and published in a reputable journal; the third has been accepted and will soon be published, while the 4th article is still being reviewed for publication.

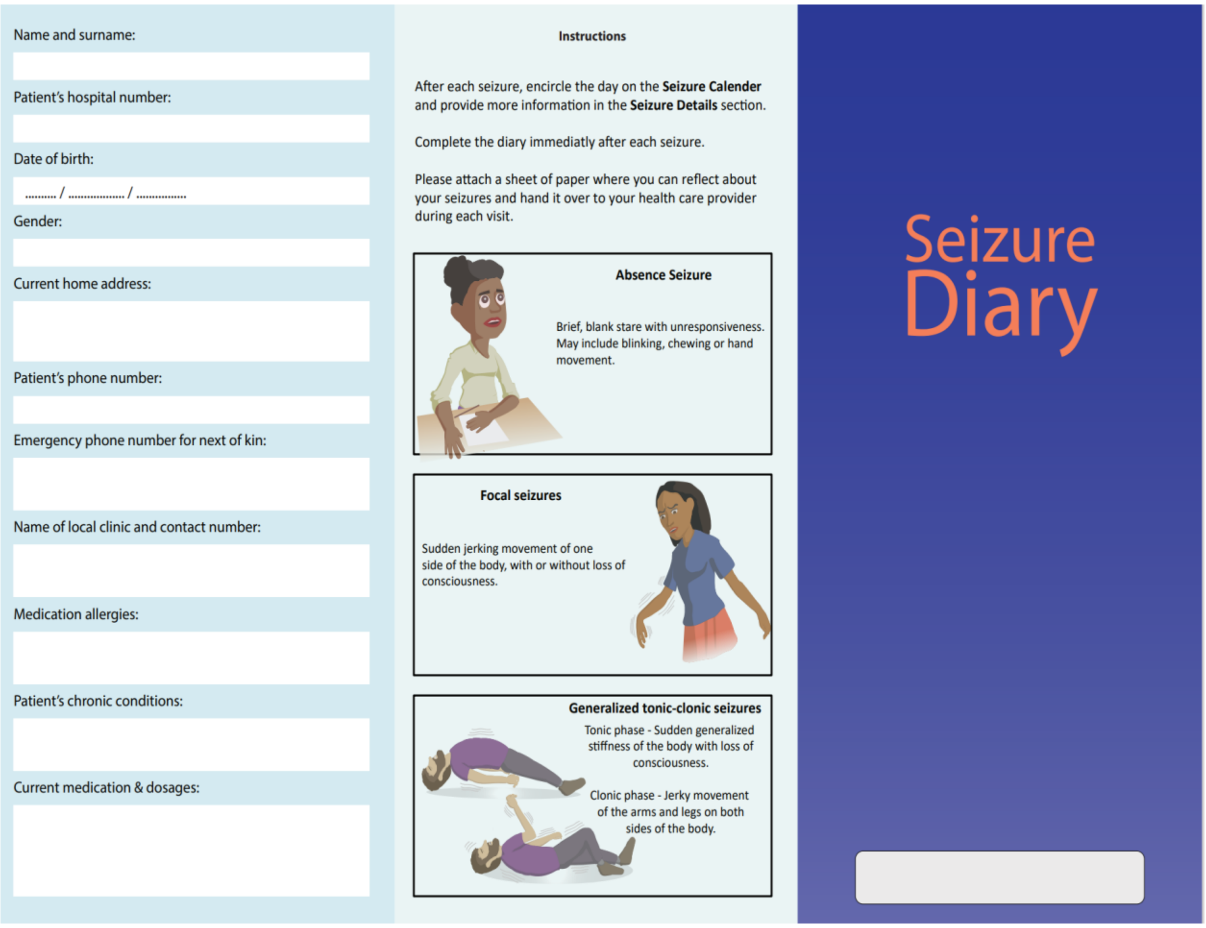
The impact of this study was for the first time, both patients with epilepsy and their caregivers who understand the burden of the disease, along with experts in the field of epilepsy, were actively involved and contributed to the process of the creation of a seizure diary for the use of patients living with epilepsy. They were active partners in creating a tool to improve their health.

The seizure diary, created as the outcome of this study, is attached as an appendix for your perusal. It is a simple diary which we believe will be easy for patients and their caregivers to use. The diary will greatly assist healthcare providers in managing patients with epilepsy by providing important health information that can assist in treatment decisions.

We humbly request that you grant us permission to print and distribute copies of the seizure diary and for healthcare workers to use the seizure diary in the management of patients with epilepsy attending the clinics and hospitals across the Free State and Northern Cape province. If requested, we will provide training and support for healthcare providers, patients and caregivers on how to use the seizure diary.

Thank you for allowing us to embark on and complete this research project. We look forward to a favourable response from your department.

Dr Egenasi Chika and research team
Department of Family Medicine
The University of the Free State.



Name and surname:

Patient's hospital number:

Date of birth:

.... / .... / ....

Gender:

Current home address:

Patient's phone number:

Emergency phone number for next of kin:

Name of local clinic and contact number:

Medication allergies:

Patient's chronic conditions:

Current medication & dosages:

Instructions

After each seizure, encircle the day on the **Seizure Calender** and provide more information in the **Seizure Details** section.

Complete the diary immediatly after each seizure.

Please attach a sheet of paper where you can reflect about your seizures and hand it over to your health care provider during each visit.

Absence Seizure

Brief, blank stare with unresponsiveness. May include blinking, chewing or hand movement.

Focal seizures

Sudden jerking movement of one side of the body, with or without loss of consciousness.

Generalized tonic-clonic seizures

Tonic phase - Sudden generalized stiffness of the body with loss of consciousness.

Clonic phase - Jerky movement of the arms and legs on both sides of the body.

Seizure Diary

Year

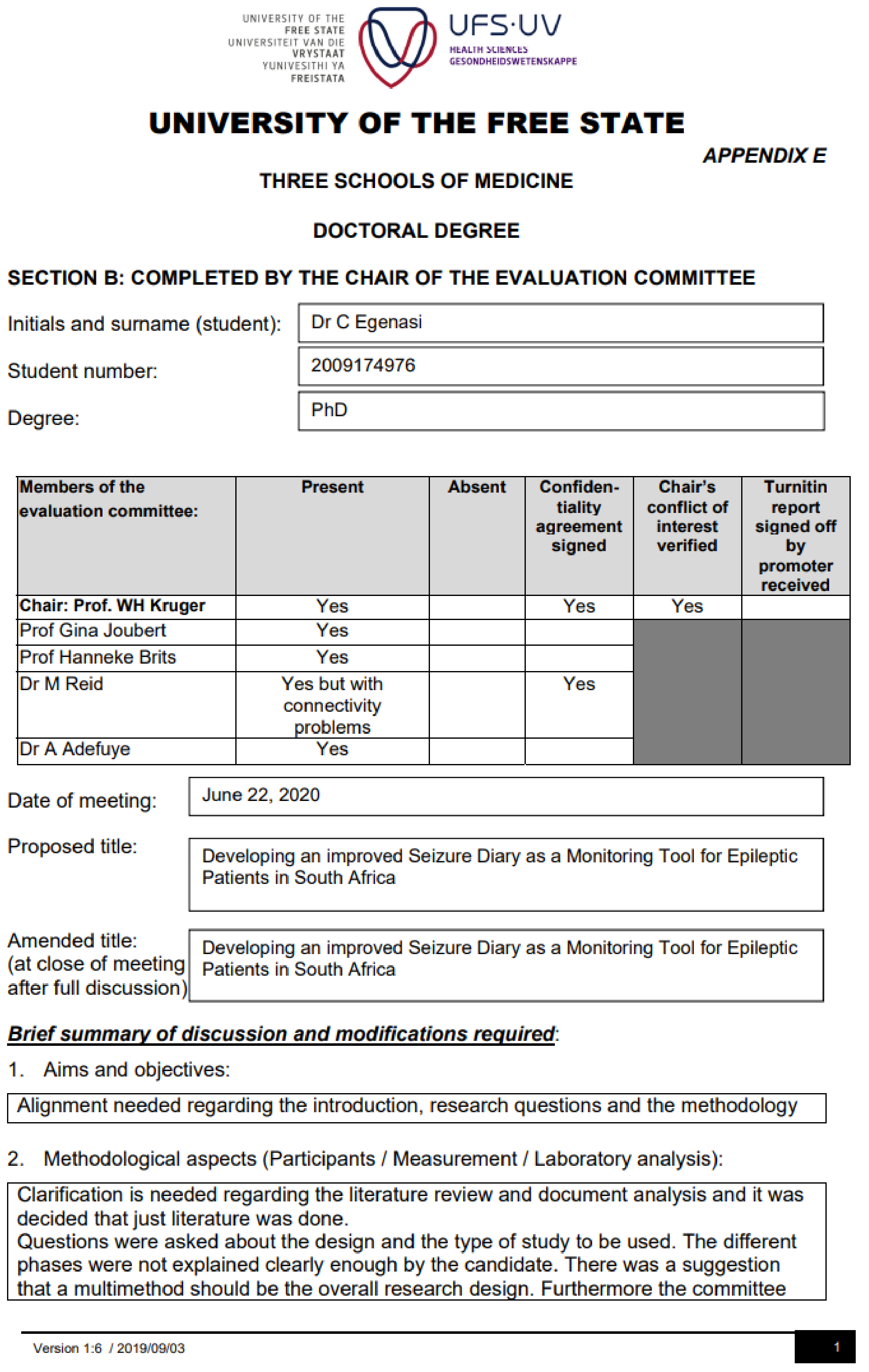
SEIZURE CALENDER

MONTH	DAY																															Total
Jan	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Feb	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29			
Mar	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Apr	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
May	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Jun	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Jul	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Aug	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Sep	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Oct	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Nov	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30		
Dec	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	

SEIZURE DETAILS

Date of Seizure	Time of day	Were you awake?		Type of seizure				Loss of consciousness	Duration
		Asleep	Awake	Focal	Generalised Tonic-Clonic	Absence seizure	Other		

Appendix F: Faculty Board approval letter



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UNIVERSITY OF THE FREE STATE

APPENDIX E

THREE SCHOOLS OF MEDICINE

DOCTORAL DEGREE

SECTION B: COMPLETED BY THE CHAIR OF THE EVALUATION COMMITTEE

Initials and surname (student):	Dr C Egenasi
Student number:	2009174976
Degree:	PhD

Members of the evaluation committee:	**Present**	**Absent**	**Confiden-tiality agreement signed**	**Chair's conflict of interest verified**	**Turnitin report signed off by promoter received**
Chair: Prof. WH Kruger	Yes		Yes	Yes	
Prof Gina Joubert	Yes				
Prof Hanneke Brits	Yes				
Dr M Reid	Yes but with connectivity problems		Yes		
Dr A Adefuye	Yes				

Date of meeting:	June 22, 2020
Proposed title:	Developing an improved Seizure Diary as a Monitoring Tool for Epileptic Patients in South Africa
Amended title: (at close of meeting after full discussion)	Developing an improved Seizure Diary as a Monitoring Tool for Epileptic Patients in South Africa

<u>Brief summary of discussion and modifications required</u>:

1. Aims and objectives:

Alignment needed regarding the introduction, research questions and the methodology

2. Methodological aspects (Participants / Measurement / Laboratory analysis):

Clarification is needed regarding the literature review and document analysis and it was decided that just literature was done.
Questions were asked about the design and the type of study to be used. The different phases were not explained clearly enough by the candidate. There was a suggestion that a multimethod should be the overall research design. Furthermore the committee

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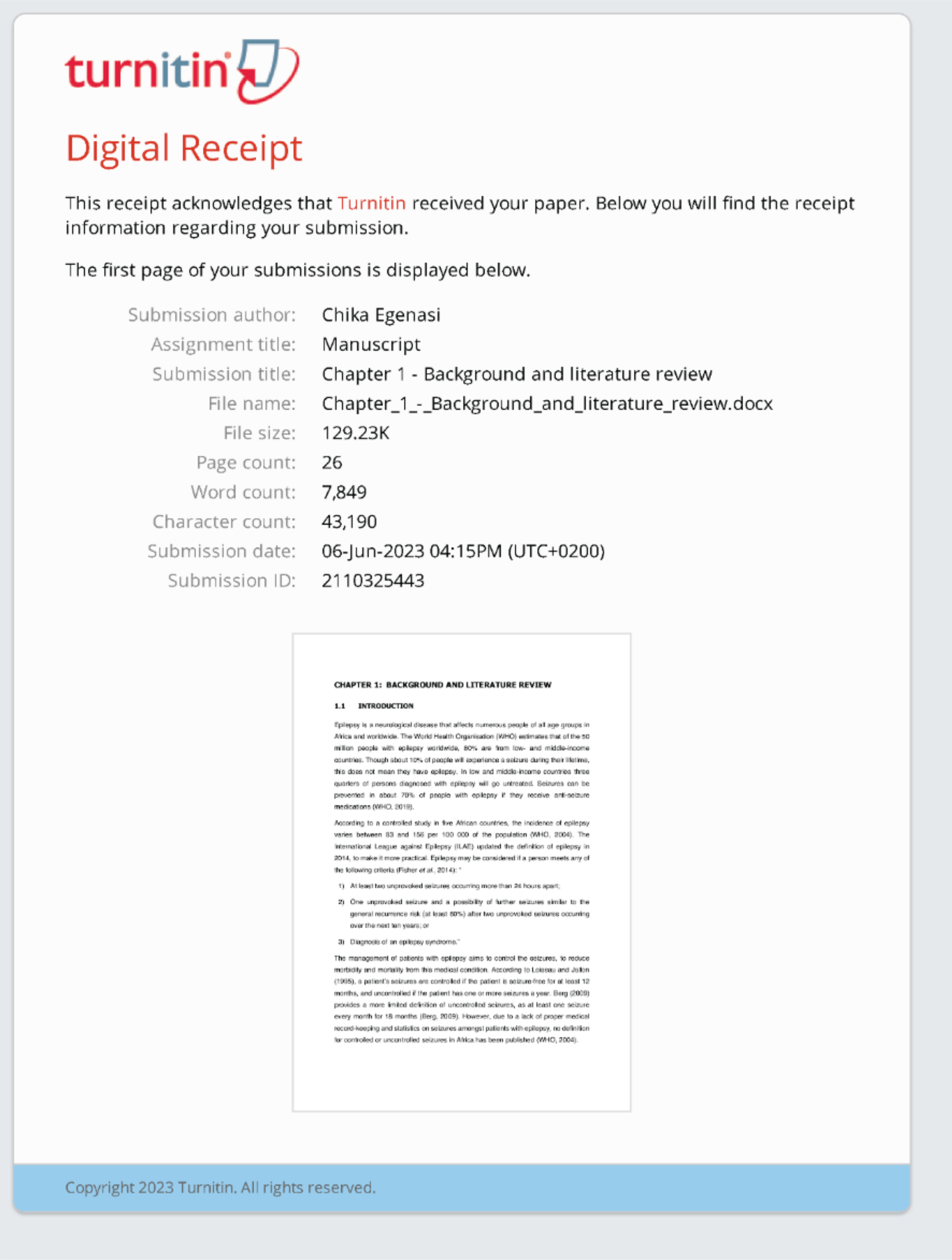
Appendix G: Turnitin report



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Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

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Assignment title:	Manuscript
Submission title:	Chapter 1 - Background and literature review
File name:	Chapter_1_-_Background_and_literature_review.docx
File size:	129.23K
Page count:	26
Word count:	7,849
Character count:	43,190
Submission date:	06-Jun-2023 04:15PM (UTC+0200)
Submission ID:	2110325443

CHAPTER 1: BACKGROUND AND LITERATURE REVIEW

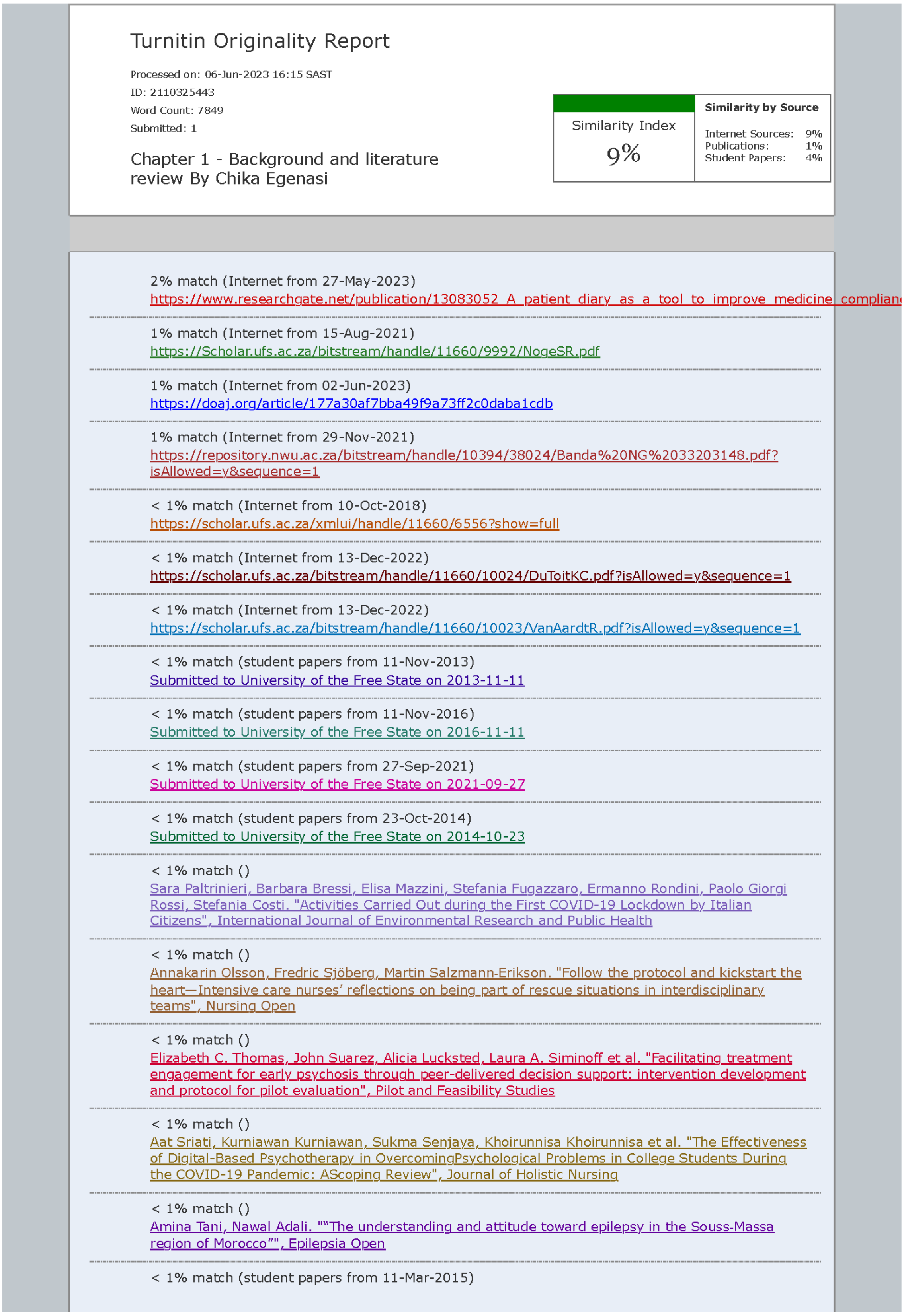
1.1 INTRODUCTION

Epilepsy is a neurological disease that affects numerous people of all age groups in Africa and worldwide. The World Health Organisation (WHO) estimates that of the 50 million people with epilepsy worldwide, 80% are from low- and middle-income countries. Though about 10% of people will experience a seizure during their lifetime, this does not mean they have epilepsy. In low and middle-income countries three quarters of persons diagnosed with epilepsy will go untreated. Seizures can be prevented in about 70% of people with epilepsy if they receive anti-seizure medications (WHO, 2019).

According to a controlled study in five African countries, the incidence of epilepsy varies between 83 and 156 per 100 000 of the population (WHO, 2004). The International League against Epilepsy (ILAE) updated the definition of epilepsy in 2014, to make it more practical. Epilepsy may be considered if a person meets any of the following criteria (Fisher *et al.*, 2014): "

1) At least two unprovoked seizures occurring more than 24 hours apart;
2) One unprovoked seizure and a possibility of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures occurring over the next ten years; or
3) Diagnosis of an epilepsy syndrome."

The management of patients with epilepsy aims to control the seizures, to reduce morbidity and mortality from this medical condition. According to Loiseau and Jallon (1995), a patient's seizures are controlled if the patient is seizure-free for at least 12 months, and uncontrolled if the patient has one or more seizures a year. Berg (2009) provides a more limited definition of uncontrolled seizures, as at least one seizure every month for 18 months (Berg, 2009). However, due to a lack of proper medical record-keeping and statistics on seizures amongst patients with epilepsy, no definition for controlled or uncontrolled seizures in Africa has been published (WHO, 2004).



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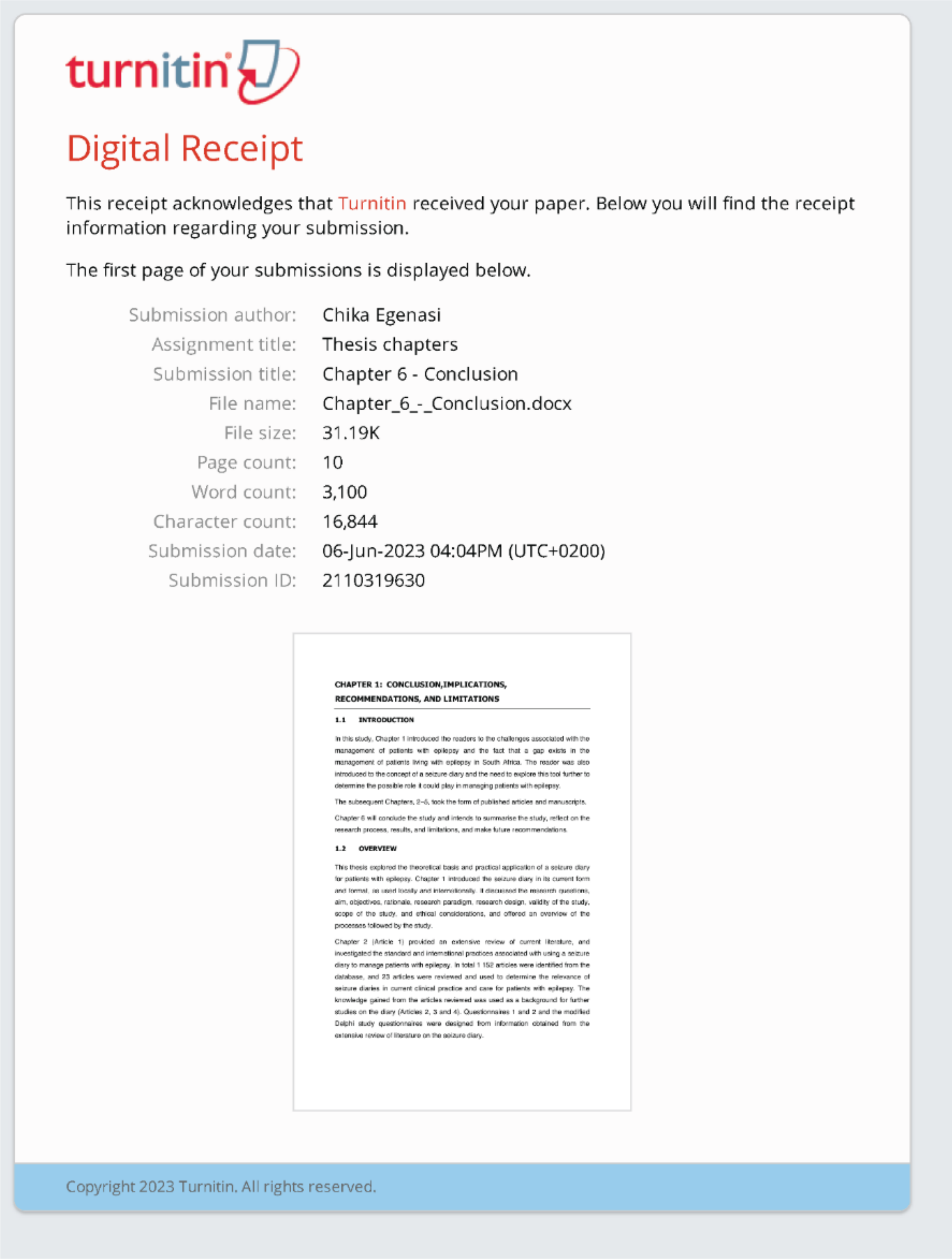

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CHAPTER 1: CONCLUSION,IMPLICATIONS, RECOMMENDATIONS, AND LIMITATIONS

1.1 INTRODUCTION

In this study, Chapter 1 introduced the readers to the challenges associated with the management of patients with epilepsy and the fact that a gap exists in the management of patients living with epilepsy in South Africa. The reader was also introduced to the concept of a seizure diary and the need to explore this tool further to determine the possible role it could play in managing patients with epilepsy.

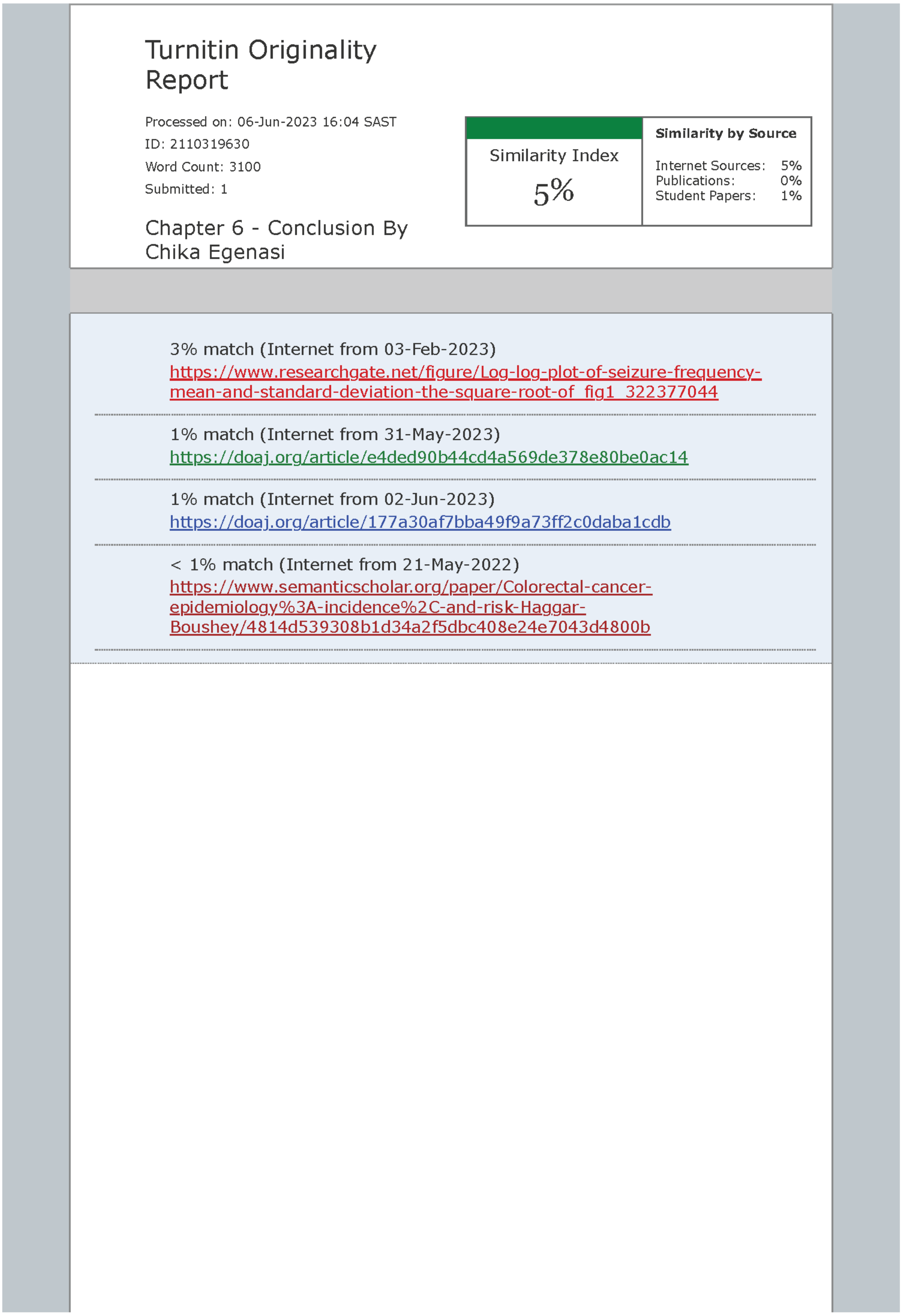
The subsequent Chapters, 2–5, took the form of published articles and manuscripts.

Chapter 6 will conclude the study and intends to summarise the study, reflect on the research process, results, and limitations, and make future recommendations.

1.2 OVERVIEW

This thesis explored the theoretical basis and practical application of a seizure diary for patients with epilepsy. Chapter 1 introduced the seizure diary in its current form and format, as used locally and internationally. It discussed the research questions, aim, objectives, rationale, research paradigm, research design, validity of the study, scope of the study, and ethical considerations, and offered an overview of the processes followed by the study.

Chapter 2 (Article 1) provided an extensive review of current literature, and investigated the standard and international practices associated with using a seizure diary to manage patients with epilepsy. In total 1 152 articles were identified from the database, and 23 articles were reviewed and used to determine the relevance of seizure diaries in current clinical practice and care for patients with epilepsy. The knowledge gained from the articles reviewed was used as a background for further studies on the diary (Articles 2, 3 and 4). Questionnaires 1 and 2 and the modified Delphi study questionnaires were designed from information obtained from the extensive review of literature on the seizure diary.



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Appendix H: Language editor's report

Declaration

30 May 2023

PO Box 4
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+264 813359120
hettie.human@gmail.com

PhD Thesis: Developing an improved seizure diary as a monitoring tool for epileptic patients in South Africa

Student: Egenasi Chika Kennedy

I confirm that I edited Chapters 1 and 6, checked that the reference list contains the references cited, and recommended changes to the text.

HSHuman

MA Language Practice

Hettie Human
WRITER | EDITOR | TRANSLATOR | INTERPRETER
+264 813 359 120 | hettie.human@gmail.com

Appendix I: Information document for potential participants

Request to participate in the PhD study titled:

Developing an improved Seizure Diary as a Monitoring Tool for Epileptic Patients in South Africa.

My name is Dr Egenasi Chika, am a specialist with the department of Family medicine Kimberley hospital. I am in the process of writing a dissertation to obtain A PhD degree in Family Medicine in the Faculty of Health Sciences at the University of the Free State. The title of my research is developing an improved Seizure Diary as a Monitoring Tool for Epileptic Patients in South Africa.

My supervisors are Professor Anandan Moodley from the department of Neurology and Professor WJ Steinberg from the department of Family Medicine both of the University of the Free State.

The study is expected to last for about 2 years; during this period, you will be required to complete 2 questionnaires and use a diary within 12 months . The researcher and his assistants will see you often during the 12 months period.

The study will help provide information required to improve the seizure diary for future use by patients with epilepsy.

The following process will be followed during the period of this study.

- If you accept to participate in this study, you will be required to complete and sign a consent form.
- You will be required to complete a perception and attitude to the diary questionnaire which will take about 15-20 minutes to complete.
- The improved seizure diary will be given to you after 6 months, we will show you how to use it after which you can take it home and use it as instructed.
- The Researcher and his assistants will follow-up with you at your local clinics and specialist clinics for 6 months.
- You will be required to complete another perception about the diary questionnaire after using the diary for 6 months.
- The information you provide will help in the development of a new improved seizure diary for approval by the department of health, intended for use by patients with epilepsy.
- The findings of the study will be made available to the School of Medicine, the University of the Free State, the Free state department of health, the Northern Cape department of health, department of health South Africa, and other relevant organisations that deal with patients with epilepsy through paper presentations at conferences and seminars and by the publishing of articles in applicable journals.
- You will not incur any cost as a result of participation in this study nor will any compensation be offered for participation. Participants will not be exposed to any risks by participating in this study. Participation in this study is voluntary; you may also withdraw from this study at any given time without any penalty. Refusal to participate will not involve any penalty or loss of benefits which you are entitled to by your health care provider.

- Efforts will be made to keep your personal information and answers confidential, however absolute confidentiality cannot be guaranteed, personal information may be disclosed only if required by law.
- Certain organisations may request to inspect and/or copy your records for quality assurance data analysis such as the Ethics committee of Faculty of health science of university of Free State, if results are published; this may lead to individual or cohort identification.

Should you have any specific questions, my contact details are as follows:

DR EGENASI CHIKA

Telephone number: 0538026978

Cellular phone: 0826920040

Email address: ckegens@yahoo.com

Postal address: Kimberley Hospital complex, 144 Du Toit span Road

Kimberley 8301

For any complaints/problems you can contact **the Health Sciences Research Ethics committee (HSREC) of the University of the Free State** telephone number (051) 4052812.

Thank you for taking the time to read this communication and I sincerely hope that you will be willing to contribute to this project.

Yours sincerely

Dr Egenasi Chika. K

Department of Family Medicine Kimberley hospital

Department of Family Medicine, University of the Free State

Bloemfontein

Appendix J: Consent letter to participate in the research

Developing an improved Seizure Diary as a Monitoring Tool for Epileptic Patients in South Africa.

The reasons for the study is to enable us develop an improved seizure diary that can be used as a tool to monitor epileptic patients and improve medication adherence.

You have been asked to participate in a research study.

You have been informed about the study by

____

You may contact Dr Egenasi on 0826920040 anytime if you have questions about the research.

You may contact the secretariat of the health sciences research ethics committee, UFS at telephone number 0514052812 if you have questions about your rights as a research subject.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.

If you agree to participate you will be given a signed copy of this document as well as the participant information sheet which is a written summary of the research.

You may withdraw from this study anytime you wish to do so.

All information gathered in this research project will be kept confidential.

The research study including the above information has been verbally described to me. I understand what my involvement in the study means and voluntarily agree to participate.

____

Signature of participant Date 201__/___/___/

____

Signature of Witness Date201__/___/___/

____

Signature of Translator Date201__/___/___/

Appendix K: Draft Questionnaire 1: Perception and attitude to the seizure diary

---

Instructions: All question refer to the patient. Please tick only one answer per question. Multiple answers can be selected for question 29 and 30. You can add your comments in the space provided.

Section A

1) Study No ……………

2) Have you been diagnosed with epilepsy? ☐ **Yes** **No** ☐

3) Age: …………..years

4) Gender: Male ☐ **Female** ☐

5) Occupation: Student ☐ **Pensioner** ☐ **Employed** ☐ **Unemployed** ☐

6) Highest level of education: Below grade 12 ☐ **Matric** ☐ **University** ☐ **Others** ☐

7) I am; Wife ☐ **Husband** ☐ **Child** ☐ **Relative** ☐ **Caregiver** ☐ **Patient** ☐

8) Which clinic are you attending? Universitas ☐ **City** ☐ **Betty Getsewe** ☐ **Beaconsfield**
Casualty ☐ ☐

SECTION B Questions about patient's epilepsy

9) How long have you (Patient) been diagnosed with epilepsy

Less than 1 year ☐ **1-5 years** ☐ **6-10 years** ☐ **11 years or more** ☐

10) Are you on treatment with anti-epileptic drugs Yes ☐ **No** ☐

SECTION C Questions about seizures

11) How often do you fit in a year? None ☐ **Once** ☐ **More than one** ☐

12) What type of seizures do you have? GTC ☐ **Focal** ☐ **Absence** ☐ **Don't know** ☐

Others (explain) …….

13) Are you able to remember you had a fit after an episode?

Always ☐ **Sometimes** ☐ **Never** ☐

14) Do you need someone to inform you that you had a fit?

Always ☐ **Sometimes** ☐ **Never** ☐

15) Are you able to recall how many seizures you have in a month?

Always ☐ **Sometimes** ☐ **Never** ☐

16) Do you think documenting your fits will help you remember? Yes ☐ No ☐

SECTION D Questions about diary

17) Have you ever heard about the epilepsy diary? Yes ☐ No ☐

18) Have you ever used an epilepsy diary? Yes ☐ No ☐

If your answer to question 18 is Yes please continue with section D, if not move on to section E question 32

19) Are you currently using the epilepsy diary? Yes ☐ No ☐

20) Was it recommended by your doctor? Yes ☐ No ☐

21) Do you understand the diary? Yes ☐ No ☐

22) Do you use the diary every day you fit? Yes ☐ No ☐

23) Do you enjoy using the diary? Yes ☐ No ☐

24) Do you find the diary useful for monitoring your epilepsy? Yes ☐ No ☐

25) Does the diary help you keep track of your seizures? Yes ☐ No ☐

26) Does it help you keep track of how often you fit? Yes ☐ No ☐

27) Using the diary does it help you to take your medication? Yes ☐ No ☐

28) Do you have any challenges with completing the diary? Yes ☐ No ☐

29) What were your challenges with completing the diary?

a) No time to complete it.

b) Not trained to use it.

c) Nobody to help me complete it.

d) Did not find it useful.

e) Don't normally remember to complete.

f) My doctor does not check the diary, so I am not motivated to complete it.

g) It is difficult to complete it.

h) Having to complete a diary makes me tired.

i) It is not important to me.

j) Others……………………………………………………………………………………………

30) What information do you think should be in it? (Can tick multiple options)

Date of seizure ☐ **Frequency of seizure** ☐ **Type of seizure** ☐

Medication & Dosage ☐ **Emergency contact details** ☐ **Doctors details** ☐

Others..

……………………………………………………………………………………………………….

……………………………………………………………………………………………………….

……………………………………………………………………………………………………….

……………………………………………………………………………………………………….

31) Do you feel it is important to hand the diary over to the health care practitioner managing your case at every visit?

Yes ☐ **No** ☐

<u>SECTION E Conclusion</u>

32) Do you know the diary is free? **Yes** ☐ **No** ☐

33) Are you willing to use/continue to use it? **Yes** ☐ **No** ☐

Thank you for your time and willingness to complete this form.

Appendix L: Draft Questionnaire 2: Experience of new seizure diary

---

Instructions: All questions are directed at the person regularly completing the diary. Please tick only one answer per question. You can add your comments in the space provided.

SECTION A

1) Study Number ....

2) Who regularly completes the new seizure diary?

Patient ☐ Wife ☐ Husband ☐ Children ☐ Caregiver ☐ Relatives ☐

3) Age of the person completing the diary. ....years

4) Gender of the person completing the diary. Male ☐ Female ☐

5) Occupation of the person completing the diary. Student ☐ Pensioner ☐ Employed ☐ Unemployed ☐

6) Highest educational level of the person completing the diary? Below grade 12 ☐ Matric ☐ University ☐ Others ☐

7) The person completing the diary with the patient/ the patient attends. Bloemfontein neurology clinic ☐ Casualty ☐ Beaconsfield ☐ City ☐ Betty Gatsewe ☐

SECTION B Questions about the use of the new seizure diary

8) Do you understand the new seizure diary?

Yes ☐ No ☐ Not sure ☐

9) If you don't understand the new diary, which of the options below is the reason?

a) The language was difficult to understand.

b) I don't know what to do with it.

c) How to use it was not explained to me.

d) I find it too difficult to understand.

e) It is too confusing for me.

f) It is too complicated to use.

g) Others ....

10) Do you like the size of the new seizure diary

Yes ☐ No ☐ Not sure ☐

If yes, why…………………………………………..

If no, why not…………………………………….

11) Do you think the new seizure diary is useful?

Yes ☐ **No** ☐ **Not sure** ☐

If yes, why…………………………………………..

If no, why not…………………………………….

12) Do you enjoy completing the new seizure diary?

Yes ☐ **No** ☐ **Not sure** ☐

If yes, why…………………………………………..

If no, why not…………………………………….

13) After a fit, when do you complete the new seizure diary?

Immediately ☐ **1 day later** ☐ **2 days to less than a month** ☐

1 – 2 Months ☐ **3 – 5 Months** ☐ **6 Months or more** ☐

14) Does the new seizure diary help track your/the patients' seizures?

Yes ☐ **No** ☐ **Not sure** ☐

15) Does the new diary help relatives/caregivers keep track of your/the patients' seizures?

Yes ☐ **No** ☐ **Not sure** ☐

16) Do you find the new diary useful in helping to provide information about your/patients' current medications?

Yes ☐ **No** ☐ **Not sure** ☐

17) Does the new diary help to provide information when you meet with your/patient's doctor?

Yes ☐ **No** ☐ **Not sure** ☐

18) Where do you keep the new seizure diary?

In a handbag ☐ **On the fridge** ☐ **In the drawer** ☐ **On the table** ☐ **In the office** ☐

Others ☐ **…………………………………………………………….**

19) Do you want to continue using the new seizure diary in future?

Yes ☐ **No** ☐ **Not sure** ☐

20) Do you think anything should change in order to further improve the new diary?

Yes ☐ No ☐

If Yes, please comment………………………………………………………………………………

……

……

Complete if relevant to you:

21) Did you/the patient previously use a dairy?

Yes ☐ No ☐

If yes, please answer question 22

If no, you have completed the questionnaire.

22) Compared to the former dairy, which do you prefer?

Old seizure diary ☐ New seizure diary ☐

Please give reasons.

……

……

……

……

Thank you for your time and willingness to complete this questionnaire.

Appendix M: Lettter of request and information document to Delphi survey participants

Information Document

Dear Participant,

Request to participate in the PhD study titled:

Developing an improved Seizure Diary as a Monitoring Tool for Epileptic Patients in South Africa.

You have been chosen for this study due to your expertise in the management of patients with epilepsy and knowledge of the seizure diary.

As indicated by the title, the purpose of the study is to develop and use the improved South African seizure diary, as a monitoring tool for patients with epilepsy on treatment and to see if the diary helps to improve participants' medication adherence.

Currently, there is no standardized monitoring tool for epileptic patients on medication. This makes it difficult for healthcare workers to monitor their patients' progress and obtain the necessary information that may help manage the patient better, especially if the patient is without any collateral to provide information. In most instances, ' collaterals cannot remember important information that the health care provider may need to enable them to make important decisions. The currently available paper diaries used in certain clinics lack details that can help healthcare practitioners manage their patients better. That is why we decided to develop a more interactive seizure diary that patients can keep with them at home, enabling them to keep relevant information concerning their seizures, medications and how they take them. Caregivers and other family members can also complete this diary and can be brought along with the participants to the clinics they attend so that the healthcare workers can have this important information when they see the participants.

The aim of the study is to develop and use the improved seizure diary that will help in the management of patients with epilepsy in South Africa.

A Delphi technique is a widely used and accepted method for gathering data from respondents within their domain of expertise (Hsu and Sandford, 2007). It is designed as a group communication process which aims to achieve a convergence of opinion on a specific real-world issue (Hsu and Sandford, 2007).

The study will use the Delphi technique consisting of a panel of both local and international experts from different specialities that work with the diary to gather information on what should be the acceptable content of a seizure diary.

You will be required to voluntarily complete and sign a consent form to indicate your willingness to participate in this study.

The duration of the Delphi process will be 4- 6 months. You will have 4 weeks to respond during each round.

An electronic questionnaire survey using the online EvaSys survey management system of the University of the Free State will be used in sending out questionnaires during each round. The questionnaire consists of a 3- point modified Likert scale; you will be required to choose only one option for each question. Consensus is reached when 70% of responding participants agree on one point; a maximum of 4 rounds will be allowed during this study. You will receive summaries on the outcome of each stage of the process; you will be offered the opportunity to change your judgement on any issue where consensus is not achieved within a 4 weeks' time frame.

The information from the Delphi process will be used in the design of the improved seizure diary that will be made available to the department of health for approval before patient use.

Findings from this study may be presented at conferences or published as articles in journals.

I, therefore, kindly request you to participate in the Delphi survey.

Participation in this study is voluntary, and you can withdraw anytime, should you wish to do so.

Should you have any specific questions, my contact details are as follows:

Dr Egenasi Chika

Telephone number: 0538026978

Cellular phone: 0826920040

Email address: ckegens@yahoo.com

Postal address: Kimberley Hospital complex, 144 Du Toit span Road

Kimberley 8301

For any complaints/problems, you can contact **the Health Sciences Research Ethics Committee** telephone number (051) 4052812

Thank you for taking the time to read this communication, and I sincerely hope that you will be willing to contribute to this project.

Yours sincerely

Dr Egenasi Chika. K

Department of Family Medicine Kimberley hospital

Department of Family Medicine, University of the Free State

Bloemfontein.

Appendix N: Draft Delphi Questionnaire for seizure diary

INSTRUCTIONS

Please complete this aspect concerning your credentials.

1) Gender

Male ☐ Female ☐

2) What is your speciality?

----

3) Current position

----

4) Place of employment

Public Hospital ☐ Private Hospital ☐

5) Years of experience in your speciality?

☐ 0-4 ☐ 5-9 ☐ 10 or more

6) Work with patients with Epilepsy?

YES ☐ NO ☐

7) Are you familiar with the use of the epilepsy diary?

YES ☐ ☐

8) Country where you practice

SA ☐ If other state here ☐

DRAFT DELPHI QUESTIONNAIRE FOR SEIZURE DIARY

Please tick in your opinion what needs to be included in the diary.

No	**Questions**	**Likert scale**		
		Definitely required **1**	**Optional** **2**	**Not required** **3**

INFORMATIONS REQUIRED ONCE

1	Name of patient	1	2	3
2	Date of birth	1	2	3
3	Gender of patient	1	2	3
4	Occupation of patient	1	2	3
5	Highest educational qualifications	1	2	3
6	Current home address	1	2	3
7	Patients phone number	1	2	3
8	Emergency phone number for next of kin	1	2	3
9	Name of local clinic and contact number	1	2	3
10	Doctors name and phone number	1	2	3
11	Medication allergies	1	2	3
12	Local emergency service number	1	2	3

REGULARLY REQUIRED INFORMATION

13	Patients chronic conditions	1	2	3
14	Patients other chronic medications	1	2	3
15	Current epilepsy medications	1	2	3
16	Patients current medication dosages	1	2	3
17	Medication side effects	1	2	3
18	Patients monthly pill counts	1	2	3
19	Used medications dispensing containers	1	2	3
20	Patients epilepsy medications drug levels	1	2	3
21	Availability of medications in Hospital/clinics	1	2	3
22	Frequency of patients seizures	1	2	3
23	Abbreviations depicting patients seizure types	1	2	3
24	Times of the day patient had the seizures	1	2	3
25	Duration of seizures	1	2	3
26	Common ligands for triggers	1	2	3
27	Seizures occurred while Sleeping or awake?	1	2	3
28	Patients known seizure triggers	1	2	3
29	Patients postictal duration	1	2	3
30	History of hospital admission	1	2	3
31	Patients reflections about their seizures	1	2	3
32	How often should the diary be completed?	1	2	3

(A)	Daily regardless if the patient had a seizure or not	1	2	3
(B)	Monthly based on patients recall of seizures	1	2	3
33	Use of the annual calendar with different months of the year inserted into the diary.	1	2	3
34	Use of a monthly calendar received every month by the patients.	1	2	3
35	Instruction to circle days of the months with seizures on the calendar	1	2	3
36	Basic information about epilepsy	1	2	3
37	Epilepsy do's and don'ts for patients	1	2	3
38	Space for comments on EEG reports	1	2	3
39	Doctors comments during visits	1	2	3
40	Current employers number	1	2	3
41	Comments on driving a car	1	2	3
42	Hospital logo on front page of diary only	1	2	3
43	Hospital logo on every page of diary	1	2	3
44	Commercial adverts on every page of diary	1	2	3
45	Commercial adverts on selected pages only	1	2	3
46	Different diary colours for male & females	1	2	3
47	Coloured diary background	1	2	3
48	Background pictures on diary	1	2	3
49	Serial identification numbers for each diary	1	2	3

50	Barcode identification for each diary	1	2	3

Do you have any suggestions for further items to include in the diary?

……

……

……

……