

STUDY PROTOCOL

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# Developing guidelines for nursing management of epilepsy in Ghanaian schools

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## Abstract

**Background** The absence of guidelines for the nursing management of individuals living with epilepsy, who are students in Ghana, has resulted in the high dropout rates of such students. It is our hope, that in the near future, these individuals living with epilepsy will receive the needed attention, experience less stigmatization and discrimination. This, we expect, will result in better retention of such students in schools, improved academic performance and successful graduation. To achieve this, there is the need to develop appropriate guidelines and implement same for their benefit. In line with this, the study aims to develop guidelines for nurses to manage individuals living with epilepsy in Ghanaian schools.

**Methodology** Qualitative approach will be adopted to conduct this study in two phases. In the first phase, a case study design will be deployed in the Twifo Atti-Morkwa District of the Central Region of Ghana. The case is the nursing management of individuals living with epilepsy within the school context, and the sources of information will be the general nurses, psychiatric, or community psychiatric nurses working at the schools. Within the context of the case, parents or guardians of individuals living with epilepsy in the schools as well as their teachers will be included in the study. Data will be collected through individual interviews for nurses and parents while focus group discussions will be used for the teachers. Thematic analysis will be used to analyze the data. In the second phase, guidelines will be developed using the modified e-Delphi Technique. The study will be piloted in the Komenda-Edina-Eguafo-Abrem Municipality of the Central Region of Ghana. Ethics approval for this study has been obtained from the Ethical Review Committee of the University of Pretoria in South Africa. Additionally, Administrative approvals have been obtained from the Ghana Education Service.

**Discussion** The guidelines developed will form the basis for nursing management of individuals living with epilepsy in Ghanaian schools. This will help to improve educational outcomes for the individuals living with epilepsy.

**Keywords** Epilepsy, Ghanaian schools, Management guidelines, Nursing management

## Background

The World Health Organization (WHO), in the year 2019, estimated the global prevalence of epilepsy to be 50 million. According to the organization's estimates, as many as 80% of Individuals Living with Epilepsy (ILWE) are located in low- and middle-income countries of which Ghana is a part [1]. This number is expected to increase as the world's population increases, hence, making epilepsy a huge burden in the near future [2]. In Ghana, one percent of the population lives with epilepsy. In the year 2018, the Ministry of Health

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(MOH-GH) reported the prevalence to be 270 000 out of a population of 27 000 000. Despite being among the top five medical conditions in Ghana, and being considered the oldest and most common neuropsychiatric disorder reported at rural health clinics, a treatment gap as high as 85% exists [3].

WHO rightly describes epilepsy as a chronic non-communicable disease of the brain. Similarly, the International League Against Epilepsy (ILAE) refers to epilepsy as a disorder affecting the brain, in which there is a persistent tendency to experience seizures, accompanied by neurobiological, psychological, cognitive and social consequences [4]. Possible causes of the disorder outlined include structural abnormalities with the brain, genetic factors, infections such as cerebral malaria, metabolic factors, and immune disorders; while, in some cases, the disorder is of unknown origin [1]. Unfortunately, many of the ILWE themselves and society at large erroneously believe that this disorder results from evil spirit activity [4]. For example, epilepsy is thought to be due to witchcraft activity or demonic possession [5, 6] or cannibalism [6]. In Niger, 9.7%, 3.4% and 38.6% of teachers studied considered epilepsy to be caused by witchcraft, possession by jinni (spirits) and impurity, respectively [7]. In a study in Ghana, [8] respondents mentioned bad spirits and witchcraft as causes of epilepsy. Also, a study among teachers in Sudan [9] reported that 21.5% of respondents identified devils and superstitious causality for epilepsy. These myths held by society tend to affect how they relate to people with the condition.

MOH-GH has initiated some efforts to address the epilepsy challenge in Ghana. Notable among them was the fight epilepsy program, which was a 5-year project from 2012 to 2018. However, these efforts have and continue to face many challenges, some of which are inadequate work force, (compounded by the general unpreparedness of the existing workforce) high levels of stigma and discrimination [8], and the absence of policies [3]. Of specific concern to the current study is the absence of management guidelines for epilepsy in schools. It was found in a United States nationwide survey that the implementation of their epilepsy smart school program has improved the lives of ILWE in schools by raising awareness and mitigating stigma [10]. Unfortunately, in Ghana, no such guidelines exist, and this poses a challenge to nurses and school authorities as to what to do with such students. As a result, handling seizures in Ghanaian schools remains a matter of discretion. Due to this, very wide discrepancies exist across schools. These discrepancies range from ILWE being sent home from school to seek treatment, being ignored while they struggle through the seizures on their own in the full view of others or being taken to

hospital. This has led to poor retention of such students in school.

Ghana's Inclusive Educational Policy identifies ILWEs as students with special needs. However, they are not indicated in a category of their own. Rather, they form part of a general category referring to students with special needs; hence, it is difficult to stipulate specific considerations for ILWE. Similarly, school health education program (SHEP) has been in operation in Ghanaian schools since 1992. The objectives of the SHEP are relevant to this study especially those which are concerned with the promotion of student safety and injury prevention in schools, and ensuring student retention through the prevention of illness-related absenteeism. To achieve these objectives, nurses have been assigned to schools to deal with health-related issues through health education and various forms of support to students and staff, including early identification and management or referral of the sick [11]. While the assigned nurses visit their schools periodically, other schools have full-time employed school nurses stationed in their clinics and infirmaries, to care for the health needs of their students.

Mensah [12] found in his study in the Eastern, Western and Central Regions of Ghana that more than half of the schools they studied had school-based healthcare delivery facilities. With this arrangement, ILWE in schools can be managed and retained in school. Unfortunately, it has been noted that the absence of adequate training and guidelines to manage the disorder is affecting outcomes, as well as advocacy and lobbying for resource allocation by nurses in schools [13]. Some nurses assigned to these schools indicated in informal conversations with the researchers that they have difficulty managing ILWE because no guidelines exist to that effect. Other challenges they outlined included social issues related to how staff and students relate to ILWE, seizure management emergencies, difficulty with advocacy to the extent of some school managements asking students to stay home until seizures resolve. Some of the nurses admitted that they have knowledge gaps related to epilepsy management and that additional training will be beneficial. Non-adherence to treatment and non-availability of emergency medication were also cited. Another nurse cited the unfavorable nature of school infrastructure such as desks used by ILWE.

Available evidence makes it clear that clinical practice guidelines have optimized the management of ILWE in health facilities [14] by serving as a basis for management, policy formation and improving quality of care. Service provision and care-giving can be disordered, fragmented and inefficient if no guidelines exist to serve as its basis [15]. There is the need for guidelines in many areas of epilepsy management [14]; one of which is the

school environment. Just as clinical practice guidelines have optimized the management of ILWE in health facilities [14] guidelines to improve management of ILWE in schools will form the basis for nursing management in basic and high schools, hence the need for this current study.

### **Aim**

The aim of this study is to develop guidelines for the management of epilepsy in Ghanaian schools by nurses.

### **Specific objectives**

The study will be conducted in two phases, each with its own objective/s. The immediate topic of the case is the nursing management of ILWE within the school context. However, the immediate topic of the case happens within a broader context, which includes the teachers and parents of ILWE and as they could contribute valuable information regarding the management of epilepsy in the school environment, they will be included in the study.

#### **Phase 1**

1. To explore and describe the experiences of nurses in Ghanaian schools regarding the management of epilepsy among school children
2. To explore and describe the experiences of teachers in Ghanaian schools regarding the management of epilepsy among school children
3. To explore and describe the experiences of parents of ILWE who attend a Ghanaian school regarding the management of epilepsy among school children.

#### **Phase 2**

4. To develop guidelines for nurses regarding the management of epilepsy among school children.

### **Significance of the study**

Sustainable Development Goal (SDG) 3 target 4 encompasses non-communicable diseases with the aim of reducing premature deaths and improving wellbeing. Epilepsy lies at the heart of this SDG and the findings of this study could contribute to its attainment. Novelty in this research is in the development of guidelines for the nursing management of ILWE in Ghanaian schools. Currently, no such guidelines exist. The Ministry of Education could consider making it a policy to incorporate the guidelines developed by this study into Ghanaian schools' set up. Additionally, educational systems of

other countries in Africa and other parts of the world could adopt the guidelines for use in their schools.

Also, the findings of this study can be incorporated into the curricula for the training of healthcare professionals especially nurses. This is particularly important because they will be in the forefront of implementing the guidelines through school health programs. This will increase their understanding and better prepare them for a career in which they are likely to manage such individuals. Nurses already practicing will also benefit from this study findings through workshops, ward conferences and seminars.

Guidelines for the nursing management of epilepsy in schools could ease the challenges encountered by ILWE in school. It might also minimize the stress their families experience while attempting to get them educated. With this, it could be easier to educate ILWE.

Finally, findings from this research will add to the existing pool of knowledge on the nursing management of individuals living with epilepsy in schools. This study's recommendations could serve as a basis for further studies into nursing management of ILWE in schools.

### **Delineation**

This study will be conducted in selected schools in the selected district in Ghana and the nurses assigned to these schools, teachers involved with ILWEs and parents of ILWE in these schools will be requested to participate. The study is not intended to address hospital management of epilepsy. This research will only focus on ILWE of school going age. No other disease conditions will be considered.

### **Literature review**

A scoping review will be carried out as part of this study. This review will allow the researcher to conceptualize the current study within the context of existing literature. The review of literature in this study will be carried out to answer four research questions: what are the experiences of nurses in Ghana regarding the management of epilepsy among school children?, what are the experiences of teachers in Ghana regarding the management of epilepsy among school children?, what experiences do parents of ILWE who attend Ghanaian schools have regarding the management of epilepsy at school?, and how should epilepsy in school going children be managed by nurses in Ghanaian schools?. It is important to answer these questions as the answers found will contribute to improving the management of epilepsy among school children in the school context.

### Theoretical framework

A theoretical framework supports and provides structure for research. It provides structure for the various aspects of research particularly the significance, purpose, problem and research questions. Additionally, the theoretical framework provides a basis for the literature review, methodology and analysis in research [16]. This study will be guided by the Nursing Metaparadigm of Jean Watson's Theory of Human Caring.

The metaparadigm of nursing includes person, health, environment and nursing. These four constitute a framework which encompasses the phenomena of importance to nursing as a profession. The word metaparadigm was introduced into nursing by Margaret Hardy in 1978 and later by Jacqueline Fawcett in 1984 [17]. The four concepts of the metaparadigm are linked by three basic relationships: 'person and health', 'person, environment and health' as well as 'person, health and nursing' [18]. The universality of these four concepts of importance to nursing is confirmed by their reflection in various nursing theories.

The Theory of Human Caring [19] stipulates that "human caring and relationship-centered caring is a foundational ethic for healing practices; it honors the unity of the whole human being, while also attending to creating a healing environment." This theory "places human-to-human caring as central to the professional nursing responsibilities" [19] with the aim of using human caring in preserving dignity, integrity and relationships. This study aims at developing guidelines for the nursing ('nursing') management of epilepsy ('health') among ILWE ('person') in Ghanaian schools ('environment'). Hence, the metaparadigm of nursing as construed by Jean Watson in her Theory of Caring [19] is a suitable framework which will guide this study.

In this study, the person is the ILWE who is a student in a Ghanaian school. These ILWE, by virtue of their disorder, require nursing management while in school in order to successfully complete their studies. Parents and guardians are important part of the social context in which the person exists. Hence, understanding their experiences is imperative to the process of formulating the needed guidelines. This theory recognizes that the person is a whole thus, having spiritual, social, physical and emotional needs [21]. Hence, there is the need to understand the unique needs of each student and these go beyond just the physical, the seizures. In the development of guidelines, psychosocial support should be catered for. This will address the social and emotional needs of the ILWE. Doing this will ensure that care for the ILWE in school is personalized to promote trust, improve self-worth and ensure that both the ILWE and their families are involved in decision making.

The health concept of the nursing metaparadigm refers to the processes involved in life and death [20]. Watson regards health as the unity and harmony between mind, body and soul and it is a subjective experience defined by the individual [19]. ILWE in schools require not just physical wellbeing, but also mental and spiritual wellbeing. To achieve this, nursing management guidelines for ILWE in schools should not just focus on the physical aspects of health. It will combine medical treatment for seizures, and mental health support, which will include stress management, seizure triggers, diet and emotional coping. This focus on comprehensive well-being will help students become seizure free and also have the needed support to thrive in school and improve their academic achievements.

The environment [19] is the physical space in which the caring occasions occur, where nurses and patients come together in human transaction. Spaces have to be created where ILWE will feel valued, supported and safe. In the current study, the school environment, in which the nurses are to care for ILWE, is considered the environment. Teachers are an integral aspect of this environment. By exploring the experiences of teachers who are in constant contact with the ILWE in their classrooms as well as the first to be called upon when seizures occur, a clearer view of the epilepsy management in schools will be presented. While developing guidelines, it is critical to remember that the creation of a supportive environment of key. Teachers and peers require training to improve their understanding of epilepsy and also reduce stigma and curb social isolation. This will ensure that ILWE in school feel accepted. School environments and the activities therein have to be modified to reduce seizure risks and also reduce the tendencies of injury during seizures whenever they occur.

Watson views nursing as an art and science with caring as the essence of nursing [19]. Nurses should assist their patients in finding meaning to illness and suffering, thus promoting patients' health. In this study, nursing will include all the activities carried out by nurses to manage ILWE in schools. By exploring the experiences of nurses in this regard, a better understanding will be obtained regarding the state of epilepsy management in school and the matters arising; which is critical to formulating the guidelines. Guidelines should include the idea of building therapeutic relationships between nurses, ILWE and their families as well as teachers in the schools. If this is done, continues education will be ensured, as well as emotional support and ILWE will be empowered to manage their conditions.



## Methodology

### Study status and timelines

Data collection for the study has not yet commenced. A pilot study commenced on the 3rd of June 2024 and is currently underway at the Komenda-Edina-Aguafo-Abirem District of the Central Region. Two parents of students living with epilepsy and two nurses have been recruited for individual interviews; whilst six teachers have been recruited for a focus group interview. The aim of the pilot study is to assess how the entire case study process will unfold and also fine tune the interview guides if deemed necessary. The data from the pilot will be published and also included in the final thesis report. The main data collection for the study is scheduled to commence on the 16th of June 2024 and continue through the month of July. Data analysis, preparation and presentation of findings is expected to be done in the month of August 2024.

### Ethical considerations

#### Ethics approval

A formal approval for research is required from the institutional review board of the university or organization before the study is carried out [21]. In line with this, ethics approval for this study has been obtained from the Faculty of Health Sciences Research Ethics Committee University of Pretoria (ethical approval number 110/2023), and administrative clearance from the Ghana Education Service.

#### Informed consent

Study participants will be required to provide written consent in order to be allowed to take part in this study. This will be done using the Participant Information and Informed Consent Documents attached as Appendices. This document provides details about the nature of the study, procedures involved, risks and discomforts and possible benefits available as well as information regarding who to contact in case participants require additional information. Again, participants' permission will be sought before audio recordings of interviews and focus group discussions are done. Participants will have the freedom to withdraw from the study at any point they so desire.

#### Avoidance of harm

During the conduct of research, steps must be taken to protect participants from harm [22]. This study participants will be protected from harm. Steps to be taken to achieve this include ensuring that participants receive full disclosure of information regarding the study before they are invited to participate. The researcher will ensure

that the study is transparent. Thus, no lies will be told about the nature of the study. Additionally, no sensitive information which can influence participant's decision to participate or decline will be withheld from them.

#### Privacy and confidentiality

All data collected will be treated with utmost confidentiality and where applicable, anonymity. To ensure this, participants' names will not be required on any of the documents. Both the audio records and transcripts will be stored in secure folders on both laptop and external hard drive. Hard copy documents will be filed and stored in locked metal cabinets. Only the researcher, supervisors and members of the ethics committee, if they request, will have access to these records. It is unethical to put names of participants on a list so that they can be invited to take part in future researches [21]. This practice will also be avoided in this study.

#### Equitable selection of participants

In this study, participants will include parents of ILWE, nurses who are responsible for their care in schools and teachers in the schools they attend. The researcher will ensure that these participants are fairly selected and that none is unfairly included or excluded from the study.

#### Reporting preliminary findings

In order to conduct research ethically, it is important to tolerate contrary views [21]. According to him, this can be achieved through reporting preliminary findings to "critical friends". This will ensure that these individuals offer alternative explanations to the researcher's preliminary findings. Doing this will minimize biases and increase the chances that the final findings of the study will reflect the reality. In line with this recommendation, preliminary findings will be reported to the study supervisors. This will be done during data collection.

#### Study assumptions

This current research will be based on the constructivist research paradigm. In constructivism "reality is believed to have multiple constructions" [23] and knowledge is built from understanding study participants' unique views of a situation and the meaning attached to their views [24]. In this study, the desire to understand nursing management of epilepsy in the school context, which is expected to lead to the development of guidelines, requires this paradigm.

#### Study setting

The study will be conducted in selected schools in the Twifo Atti – Morkwa District, which is one of the twenty-two districts in the Central Region of Ghana. The district

is located on the western part of the Central Region. The district had a population of 100,851 by the end of 2022 [3]. Approximately forty-two percent of the district's population are fourteen years and below; with another 11.2% between fifteen and nineteen years. Only 0.5% of the populace are eighty-five years and above. These statistics portray a very young population.

Before the year 2012, only 97 ILWE were documented as receiving treatment. With the introduction of the "fight against epilepsy", 1389 new cases were also receiving treatment in the year 2013. An additional 678 new cases were identified by December 2016 [3]. According to MOH-GH, these cases which are being managed represent less than half (48.5%) of the cases in the district. This suggests a prevalence of some 4,453 recorded cases in the district. Preliminary assessment information obtained from the psychiatric unit of the Twifo Praso Hospital (district hospital) reveals that currently, about 70 to 75% of cases seen at the unit are people diagnosed with epilepsy. This district is thought to be suitable for this study for a number of reasons. First, the number of cases of epilepsy in the district is quite high. Second, the district has schools spanning from kindergarten to senior high school, which are attended by ILWE. A total of five schools have been contacted for inclusion in the study. These were purposefully selected solely based on the presence of ILWE in those schools.

### Phases of the study

The study will be carried out in two phases, each with its methodology and these are discussed below.

#### Phase 2

##### *Study design - case study*

This study will adopt a qualitative approach with case study design using Yin's method. A case study is a design in which the researcher conducts an in-depth analysis of a case, which can be a program, activity, event, process or an individual [21]. This design is suitable for this study because an in-depth study of the nursing management of epilepsy in Ghanaian schools is required to formulate guidelines. Specifically, a holistic multiple-case design will be adopted. The holistic design is suitable because no subunits exist in the case under study. According to Yin the holistic design involves only one unit of analysis [21]. While studying nursing management of epilepsy in school going children in schools in the Twifo Atti-Morkwa District of the Central Region, community health nurses, general nurses, psychiatric and community psychiatric nurses who have been assigned to the schools, will be involved as units of analysis. The researcher considers it a common case because of its likelihood to portray the circumstances, situation and

challenges encountered by nurses while managing epilepsy in schools in Ghana.

Multiple cases will be studied to provide evidence to strengthen the findings from the initial case; in a fashion which will mimic the phenomenon of replication in experimental designs. A multiple-case approach is deemed suitable because it will allow for the replication of the study in multiple school settings. These multiple settings have been selected to predict similar results. The district is multicultural, reflecting the various Ghanaian subcultures. This will ensure that, to a large extent, the developed guidelines will be applicable in most, if not all other parts of the country. On the whole, the holistic multiple-case study is considered more robust, yielding evidence which is likely to be compelling [21].

##### *The case and its context*

The unit of analysis is the nursing management of ILWE within the school context, and the sources of information will be the general nurses, psychiatric, or community psychiatric nurses working at the schools. There are normally two nurses being community health nurses, general nurses, psychiatric and community psychiatric nurses assigned to each school. They pay periodic visits to the schools, give health talks to staff and students, assess students with health issues and refer where necessary. They also manage minor ailments and assist school authorities as to how to deal with health-related issues. A few schools have a nurse permanently stationed in their infirmaries to help deal with health challenges which might arise.

Within the context, the parents or guardians of ILWE in the schools as well as their teachers will be included in the study. In basic schools, the class teacher system is mostly used. This is the system in which specific teachers are assigned to teach specific classes permanently. In such situations, such teachers are only reshuffled when necessary. To complement the efforts of these class teachers, special subjects such as French are assigned to be taught by teachers with competencies in such areas. This system puts the school children under the direct monitoring of specific class teachers. In the junior high schools however, students are taught by subject teachers. Each subject teacher meets the students within their designated times on the time table. Then, selected teachers, known as: 'form masters' and 'form mistresses', are assigned to the various levels. Such selected teachers are directly responsible for the welfare of their students in the levels assigned to them.

##### *Case binding*

In the conduct of case studies, to ensure that appropriate data is collected and from relevant sources only, it is

important that cases be bound. Binding cases involves identifying and distinguishing the topic of the case study from its context [21]. In order to do this, the immediate topic and context of the case should be clearly identified. In this study, the immediate topic of the case is nursing management of epilepsy in schools. This is so because it is the problem and the main phenomenon under study in this research. Additionally, the context of the case will include the teachers and parents. These are considered the context because they are likely to influence nursing management of epilepsy in the schools. Currently, five basic schools have been identified in the district, which are being attended by ILWE.

### **Study population and sampling**

**Nurses** Since the case is nursing management of epilepsy in Ghanaian schools, nurses assigned to the schools will be contacted for inclusion in the study. Categories of nurses assigned to schools in Ghana include: community health nurses, general nurses, psychiatric and community psychiatric nurses.

**Sampling** Census will be conducted; since there are usually 2 nurses assigned to each school, both of them will be interviewed across the 5 schools to be selected. Where there are more than 2 nurses per school, the first 2 longest serving will be recruited; and if less than 2, the available 1 will be recruited.

**Inclusion and exclusion criteria** In order to be included in the study, nurses must be assigned and working with the selected schools in the selected district. Again, they should provide voluntary consent for participation. Nurses who do not work in schools and those working in schools who fail to provide consent will be excluded from the study.

**Where they will be contacted** The nurses will be contacted in the schools where they work. Administrative clearance for the study has already been obtained from the Ghana Education Service (GES). This clearance letter will be presented to the administrations of the schools in which the nurses work. With permission granted by the administration, the nurses will be contacted. As stated in the informed consent document for nurses, details of the study will be provided and they will be informed that participation is voluntary. They will be told that they are free to withdraw from the study at any point they so desire. Nurses who agree to take part in the study will be required to indicate same by signing the informed consent form. Data will then be obtained from consenting nurses. A sample of the consent form to be administered

to nurses prior to their participation in the study has been attached as Appendix A in the supplementary files.

**Teachers** For the teachers, the children are under their care in the various classrooms. Hence, they hold first-hand information regarding how they fare in school. Again, the implementation of guidelines cannot succeed without the involvement of teachers. So, they will be included in the study so that they can contribute their perspectives to findings.

**Sampling** Purposive sampling technique will be used to select only teachers who have been directly involved in management of ILWE in school. Purposive sampling is employed in research to select participants who have rich information about the phenomenon of interest [25]. Sampling will be done until data saturation is reached. In each school, the selected teachers (between six and twelve) will be organized for a focus group. Data saturation is the point during data collection, where no new information or insight is obtained [26].

**Inclusion and exclusion criteria** In order to be included in the study, teachers should have had an ILWE in their classrooms or should have been directly involved in the management of ILWE at school. The teacher should have also provided voluntary consent for inclusion. Teachers who fail to provide consent and those who have never been involved in managing ILWE at school will be excluded.

**Where they will be contacted** The teachers will be contacted in the schools where they teach. Administrative clearance for the study has already been obtained from the Ghana Education Service (GES). This clearance letter will be presented to the administrations of the schools in which the teachers teach. With permission granted by the administration, the teachers will be contacted. As stated in the informed consent document for teachers, details of the study will be provided and they will be told that participation is voluntary. They will be told that they are free to withdraw from the study at any point they so desire. Teachers who agree to take part in the study will be required to indicate same by signing the informed consent form. Data will then be obtained from consenting teachers through focus group discussions. A sample of the consent form to be administered to teachers prior to their participation in the study has been included in the supplementary files as Appendix B.

**Parents / guardians** Parents / guardians hold the information required to understand the general health, well-being and coping of the ILWE. They are directly involved

in the management of their wards even in school, so they will be included in the study.

**Sampling** Parents of ILWE in school will be purposively sampled for inclusion in the study. Interviews will be conducted until data saturation is reached.

**Inclusion and exclusion criteria** In order to be included in the study, parents / guardians should have children with epilepsy in the selected schools. Additionally, they should be actively involved in the management of the ILWE and also provide voluntary consent for participation. Absentee parents, parents who do not have ILWE in school and those who refuse to give consent will be excluded from the study.

**Where they will be contacted** Parents will be contacted in their homes. This will be done with the help of the wards and arranged with the help of the nurses. Administrative clearance has been obtained from the Ghana Education Service (GES) is applicable to the parents/guardians. The opinion leaders in the immediate communities in which the parents live will be contacted to seek their permission to enter their communities. Copies of the administrative clearance letter will be presented to the opinion leaders who are chiefs, assembly men or other traditional leaders. With permission granted by the opinion leaders and with the lead of the nurses and wards, the parents will be contacted. As stated in the informed consent document for parents, details of the study will be provided and they will be told that participation is voluntary. They will be told that they are free to withdraw from the study at any point they so desire. Parents who agree to take part in the study will be required to indicate same by signing the informed consent form. Data will then be obtained from consenting parents. A sample of the consent form to be administered to parents/guardians prior to their participation in the study has been attached to the supplementary files as Appendix C.

#### **Data collection and management**

Qualitative data plays a critical role in case study research. This study will, hence, involve the collection of qualitative data [21]. A series of steps will be followed to collect and organize data. These can be summarized as followed: development of a case study protocol, conduct of pilot case study, actual data collection and handling of the data [21].

According to Yin, developing a protocol will help keep the research focused on its research questions, hence avoiding the possibilities of mis-matches in the end [21]. Protocols help anticipate the problems to be encountered

in the study process so as to prepare towards dealing with them. The protocol is another important step towards harmonizing data collection activities in this study. This research proposal will serve as the research protocol. It contains details of how the researcher intends to carry out the study. So, it will serve as a guide for the study.

The interview guides for all participants are being piloted. This is expected to help refine plans made towards data collection. The interview guides to be used for data collection as well as the procedures to be followed will be assessed in light of the pilot [21]. A school has been selected in the Komenda-Edina-Eguafo-Abirem District of the Central Region as a pilot case. This school was selected because there are students with epilepsy there and the community in which it is located is similar to that under study. Permission has been granted for all schools that will be included in the study as well as the pilot case. The two nurses in the school as well as two parents of students with epilepsy in the school, as well as 6 teachers in the context will be studied. This pilot study will help the researcher to see if everything works as it should or whether any changes are required. Ethical clearance processes for this study have been completed awaiting the pilot.

Actual data collection will commence after satisfactory resolution of the matters arising from the pilot test. Qualitative data will be collected from the nurses through in-depth interviews. The interviews will take place in the schools to which they have been assigned. With the help of the head teachers, appropriate places will be identified in the schools to serve as venues for the interviews. The interviews will be conducted at the time appropriate for the nurses, as will fit comfortably into their work schedules at the schools and once they have given consent. The interviews will be structured, with open-ended questions. These questions will be directly related to their management of epilepsy in the schools. Responses will be tape recorded for transcription afterwards. A sample of the nurses' interview guide has been attached as Appendix D of the supplementary files.

In the context of this study, data will be collected from teachers using focus group discussions only after they have consented to participate. Since the students progressed from one level of basic education to another, their class teachers will be invited together for focus group discussions. The discussion will be tape recorded with the permission of the participants. Focus group discussion allows for the collection of in-depth data from a purposefully selected group of people rather than individuals [27]. This method is thought to be best because the group nature of the interview is expected to facilitate free expression of views among the teachers. Five focus group discussions will be held in the five schools



selected for the study. One focus group will be held in each school. Membership will comprise of teachers, the head teacher and the researcher as moderator. A group is expected to be made up of six to ten members. The interviews will be held at the convenience of the teachers and at a venue provided by the school. The researcher will moderate as teachers discuss the issues among themselves. The discussions will pertain to how they manage ILWE in their classes. The researcher will also take field notes about what is observed during the focus groups. The researcher will also reflect on his own feelings during the focus group discussions. Audio recordings will be transcribed later. During the focus group discussions, as is usually done in schools, teachers will arrange to have their co-teachers who are national service personnel, to engage their classes. In the process of the focus group, less dominant members will be encouraged to participate to prevent bias. A sample of the teachers' interview guide has been attached as Appendix E of the supplementary files.

Due to the difficulty of getting parents together as is expected in this study, parents will be interviewed individually in their homes after they have provided consent and appropriate dates and times set. Nurses, who are already in contact with these parents, will be requested to help reach out to them to seek their consent and plan for the interviews. Interviews will be audio recorded with the consent of the participants and transcribed afterwards. Field notes will also be taken and reflect on what the researcher observed during the interviews and his own experiences.

In addition to the interviews and the focus group discussions, any records on nursing management of epilepsy preserved in the school by nurses or administrators, will also be reviewed and analyzed. Again, researcher's field notes will also be analyzed. A sample of the parents' interview guide has been attached as Appendix F of the supplementary files. Interviews will be conducted in English language. In cases where parents cannot communicate in the English Language, the interviews will be conducted in their local language and transcribed later. In such cases, interpreters will be employed.

#### **Data analysis**

Data collected in this study will be analyzed using thematic analysis. This will be achieved through the inductive strategy using the codes and coding technique. This technique allows the researcher to work on the data through an analytic path which will lead to the identification of relationships in the data [21]. First, the audio records of the interviews will be transcribed. The transcripts will be read over and over again in order to become familiar with it. Second, various codes which

represent various concepts of interest will be assigned to the data. The inductive technique allows the researcher to link the data back to the research questions of this study. This helps the researcher to work through the data at answering the questions which the study commenced with.

Third, a data repository will be created in Microsoft Access. Microsoft Access is easy to learn and allows for easy creation of relational databases, which this study requires. After this, using ATLAS.ti software for qualitative analysis, codes will be developed and assigned to the various themes which emerge from the data. These codes will then be grouped according to the various themes they address. In order to ensure that there are no duplications of codes, frequency distribution will be developed to rationalize the codes. Then, the coded data will be analyzed based on the themes which emerge, linking the data back to the study's research question. Data from nurses will be grouped and analyzed both within and across school to answer research question 1. Similarly, data from teachers will be analyzed together to answer research question 2 and same for parents to answer research question 3.

#### **Trustworthiness**

Lincoln and Guba outline the test for trustworthiness which can be applied to any qualitative research. This test deals with four main criteria: credibility, transferability, dependability and confirmability [28]. Following these tests is important for ensuring quality in this study and details have been discussed below.

Credibility is the extent to which the findings of a study are equal to reality [14]. Credibility in this study will be ensured by three means. First, multiple data sources will be used. These will include in-depth interviews of nurses, parents or guardians of ILWE; as well as focus group discussions among teachers. Data from these different sources will result in data triangulation, a phenomenon required to ensure case study quality [14]. Secondly, a chain of evidence will be maintained. This will ensure that the findings of the study can be traced back to the initial research question. Finally, where interviews are conducted, the informants will be allowed to confirm the accuracy of the transcripts to ensure that their views were accurately captured [21].

Transferability is analogous to external validity in qualitative studies [14], which refers to as whether or not the findings of a study can be generalized [21], and how the generalization can be done. To achieve this, it is recommended that a thick description of the local situation surrounding the study be given so as to allow readers and other researchers to compare to their own circumstances [14]. Details to be included in this thick narrative are:

methods and time frame for data collection, and the time frame for the entire study. This will serve as suggestion for application to new context.

Dependability refers to the extent to which the process of data collection can be trusted [28]. To them, this can be achieved through an audit by a competent disinterested auditor. Both the actual audit by a professional peer and the researcher's anticipation of the audit, regulate the researcher's conduct and what is recorded as fact [14]. Yin suggests that dependability can be achieved by developing a case study protocol [14]. This protocol will help keep track of the details of data collection processes. This proposal will serve as a case study protocol to guide this study. Research supervisors will serve as auditors to check the dependability of the processes adopted.

Confirmability gets the study as close to objective reality as qualitative research can get [14]. Lincoln and Guba see this fourth criterion as an audit of the product of the study, thus: data and reconstructions [28]. A case study database will be created. This will contain all the data collected from all the various sources. This database will be preserved for reference and auditing.

## Phase 2

### *Design– Delphi technique*

The process of guideline development will be guided by the modified e-Delphi technique. When developing guidelines during health research, the Delphi technique is the best method to use [29]. It involves developing guidelines based on review of reports from multiple rounds of questions sent to a panel of experts.

In the current study, the modified e-Delphi technique will be employed to obtain the opinion of the participants through questionnaire interaction [30]. The modified Delphi is an iterative process with several rounds of questionnaire completion until consensus is reached [31]. Before the actual modified Delphi starts, the researcher should decide what constitutes consensus. In this study, consensus will be gained when  $\geq 75\%$  of the panelists agree on inclusion of the guideline [31]. The modified e-Delphi is suitable for developing guidelines and it is done via the internet [32]. Panelists invited will have the opportunity to provide responses at their own time and in their natural settings. Another benefit of the modified e-Delphi is that it affords panelists anonymity [30] and hence minimizes biases which would have originated from looking into each other's faces in a face-to-face meeting.

To provide sufficient information on the current evidence available elsewhere regarding epilepsy management in schools, a scoping review will be carried out. Scoping reviews examine the body and volume literature available on a subject [33].

### *The process*

The process will take place in four stages. The first stage will involve selection of participants (panelists) who will be people with experience in the area of discussion [31]. These individuals will be selected using purposive sampling and they will provide informed consent before participating in the study. A sample of the informed consent form for panelists has been attached as Appendix G of supplementary files.

### *Population and sampling*

The number of panelists used in a Delphi study varies greatly and between 12 and 15 members seem to be the norm [34]. Firstly, two teachers who have had ILWE in their classrooms will be identified and selected. Their selection will be due to their experience in teaching and handling ILWE in school. Second, two of the nurses who have been involved in managing ILWE in the selected schools will also be invited. In addition, four nurses who are regarded as experts in the field of managing ILWE will be recruited. They will include national and international nurses who have conducted research and published about the nursing management of ILWE in schools in the past five years. The researcher will browse journals such as the *Journal of School Nursing*, an accredited journal. Third, a parent of an ILWE will be included. The selected parent will be literate to enhance their participation on the panel and also have a child with epilepsy currently in school. A parent whose child has been in school for at least one academic year will be preferred. Fourth, the neurologist as well as another doctor in the Neurology Department of the Cape Coast Teaching Hospital will be invited to take part. Being the neurology practitioners who receive and manage referrals from all over the Central Region and beyond, their expertise will be required on the panel. Finally, the Psychiatrist at the Ankaful Psychiatric Hospital be included due to the expertise in managing ILWE. A total of 12 members will form the panel.

During the second stage, the first-round online questionnaire, consisting of three sections: Section A - demographic data, Section B - the preliminary guidelines, and Section C – comments/additional guidelines as suggested by the panelists. A sample of the dummy first-round online questionnaire has been attached to the supplementary files as Appendix H. The process is estimated to last three rounds. However, other rounds will be allowed as deemed enough to finalize the guidelines. Each round of modified e-Delphi is expected to last 2 weeks. Upon completion of the phase 1 of the study and the literature review, the first-round questionnaire will be completed.

The researcher will draft the preliminary guidelines based on the findings of phase one and literature. Panelists will be requested to rate the guidelines and to write

free-text comments to either explain their rating or disagreement with the guideline. The rating will be done according to a 5-point Likert scale with the items ranging from 'strongly disagree' to 'strongly agree' with the panelists selecting a corresponding number e.g. strongly disagree=1 and strongly agree=5. Panelists will be given two weeks to respond; the researcher will provide a reminder after one week and again at the end of the second week to stimulate submission. If there are non-responders who are unable to continue the process, they will be substituted where deemed necessary.

The consensus from the first round will be integrated into the guidelines as a second draft of the guidelines (second questionnaire) and re-circulated during the third stage of the process. Views expressed with the second questionnaire will be collated and integrated to form the third draft of the guidelines, which will be again circulated among panelists. The final stage will involve reaching a consensus on the guidelines and finalizing it. If consensus is not reached on all issues, other rounds will be introduced. However, where it becomes impossible to reach consensus, an external arbitrator, who is an expert in epilepsy management in schools, will be brought to review the unresolved items and provide recommendations to help resolution. To increase the reliability and validity of the modified Delphi, the researcher will ensure all decisions pertaining to the design of the modified Delphi will be made at the beginning of the study [31].

#### **Data analysis**

The data will be analyzed based on the consensus reached about the guidelines. Descriptive statistics such as measures of central tendency, percentages and frequency counts will be used to analyze the quantitative data. If any qualitative data is collected, content analysis will be used for the analysis [34].

#### **Discussion**

The general global trend of epilepsy depicts a continuously increasing prevalence of the disorder. As the population of the world increases, this trend is expected to continue. This trend is making epilepsy a disorder of public health importance. Considerable efforts are required to both prevent the disorder so as to hence reversing the trend, as well as contribute to coping of individuals who have the disorder.

The number of students with epilepsy who enroll in school is increasing and will continue to do so as the population of Ghana increases [3]. This phenomenon is being driven by two forces: the increasing prevalence of the disorder as well as the attempt by governments in various jurisdictions to improve access to education through free compulsory education programs, hence increasing

enrolment in schools [1]. It is important that schools are prepared adequately to help them manage such students in the areas of first aid seizure management, seizure emergency response and enhanced coping of the general school environment with students who have epilepsy.

Unfortunately, interim literature review has demonstrated that there are generally inadequate knowledge levels, negative attitudes and poor first aid practices towards ILWE in schools. This current research has been strategically positioned to add to the global research endeavor to improve the management of school children with epilepsy by nurses in the school context. Additionally, this study will also contribute to the achievement of the non-communicable disease related SDGs. With these, individuals living with epilepsy will enjoy improved social integration especially in school environments, hence boosting their academic achievements.

#### **Strengths of the study**

A critical strength of this study is that it is based on the Yin's case study methodology, which is a robust methodology. Also, protocol has gone through peer review processes leading up to the grant of ethical clearance. These reviews with the constructive feedback provided have all contributed to shaping the study for quality. Finally, the conduct of a pilot adds to the study quality.

#### **Implementation and dissemination**

Findings from this study will be disseminated through a number of channels. Firstly, findings will be published in reputable journals for others to access and read. Secondly, copies will be made available to the participating institutions. Again, the Ministries of Health and Education in Ghana will be given copies. Additionally, conferences will be held at the University of Cape Coast and its affiliate institutions, through the School of Nursing and Midwifery; as well as the participating institutions to discuss findings. If deemed necessary, local radio and television outlets will be used. Findings will also be published on the website of Epilepsy Aid Ghana and shared as short messages through various social media platforms.

#### **Conclusion**

This study will culminate in the development of guidelines for the management of epilepsy in schools. This will help retain ILWE in schools and contribute to enhancing their educational achievements.

#### **Abbreviations**

ILWE	Individuals Living with Epilepsy
MOH-GH	Ministry of Health Ghana
WHO	World Health Organization
SDG	Sustainable Development Goals

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12883-024-03908-5>.

Supplementary Material 1.

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### Authors' contributions

SSD conceived the study; SSD, RL and AVW designed the study and also wrote this protocol. SSD developed the interview guides, which were refined by RL and AVW.

### Funding

Funding for the study will be provided by the University of Cape Coast.

### Data availability

No datasets were generated or analysed during the current study.

### Ethics approval and consent to participate

Ethical clearance for the study has been obtained from the Faculty of Health Sciences Research Ethics Committee of University of Pretoria, South Africa. The ethics reference number for the protocol is 110/2023. Administrative clearance for the study has also been obtained from the Ghana Education Service. Participants will be required to provide written consent in order to be included in the study. Additionally, participants will have the right to withdraw from the study at any time they so desire.

### Consent for publication

Not applicable.

### Competing interests

The authors declare that they have no competing interests.

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