

# **SECTION ONE**

## **BACKGROUND TO THE STUDY**

### **1.1 INTRODUCTION**

In compliance with the demands of the Salamanca Statement, UNESCO (United Nations, Scientific and Cultural Organization, 1994:iii) the Constitution of South Africa and the White Paper 6 (Department of Education, 2001) advocates a plan for human rights in education. The main objective of all these documents is to acknowledge the rights of all learners to basic education by enabling and accommodating a diverse range of learning needs within the general education system. The establishment of inclusive education is seen as determining the nature of the school, the classroom environment, the curriculum and the roles of teachers, parents, and all the role players. In South Africa, the implementation of inclusive education is regarded as an important form of support. This process includes the establishment of partnerships between schools and parents, empowering them to participate in matters concerning the education of their children.

The focus of this research is to investigate the learning support needs of chronically ill learners living with severe epilepsy. In contextualising and orientating this study, Section One will give a brief outline of the study. Thereafter, the research question will be formulated, followed by the aim of the study deriving from the research question. The research methods and design will then be outlined. Finally, the personal assumptions of the researcher will be stated.

### **1.2 ORIENTATION AND MOTIVATION**

In South Africa, between four and five persons per thousand of the population suffer from epilepsy (Kapp, 2000:261), the incidence of children being even higher, at about eight per thousand children (Kapp, 2000:261-262). To put this into perspective, in every school of a few hundred learners there may be at least one sufferer. According to Kapp (2000:261-264), about 50% of all learners with epilepsy experience learning problems. In view of the fact that, in most cases, the initial seizure occurs before the

end of the child's primary school years, about one in every three children with epilepsy does not achieve according to their learning potential (Beaumont, 1987:5-6, as quoted in Kapp, 2000:261).

Severe epilepsy contributes to the learner's absence from school, with hospitalisation being a regular problem for learners. This, in turn, presents a difficult situation for teachers tasked with maintaining the academic progress of all learners. As a result, learners with epilepsy sometimes spend between three to six days per month in hospital, and upon discharge go home to recover. Absence from school breaks the educational continuity, and on returning to the school, the teachers do not know where to fit them into the curriculum, or how to help them catch up with other learners. Teachers are then faced with the problem of reassessing their level of academic competence, a time-consuming exercise in a classroom with a ratio of perhaps one teacher to forty learners. Moreover, re-entry into the school from the hospital largely depends upon proper support, good arrangements, communication and co-operation of classmates, none of which can be guaranteed. Studies (Prugh & Bowlby 1975, as quoted by Kleinberg, 1982:61) support Spitz's research and describe in great detail the deleterious effects that hospitalisation can have on learners.

With the advent of the child advocacy and the consumers' rights movement in the 1960s, there was a development in constituency pressure for changes. Parents and professionals bonded together for the rights of children (Kleinberg, 1982:61). An international multi-disciplinary organization called the Association for the Core of Children's Health (ACCH), made considerable progress, over the last fifteen years, in representing the psychosocial needs of learners in health settings (Kleinberg, 1982:61). The ACCH pressed for change in health settings, proclaiming "... issues of concern today suggesting that specific steps are needed to accomplish the goals of providing an optimal experience for children and families faced with hospitalisation." (Kleinberg, 1982:61).

South Africa's Constitution includes a Bill of Rights aimed at protecting the rights of each individual (Republic of South Africa, 1996:6). Entrenched in the Bill of Rights are the rights of all children to education, irrespective of gender, colour, disability, religion or culture (Republic of South Africa, 1996:7). The Constitution, the Bill of

Rights and the South African Schools Act of 1996 categorically uphold and protect the rights of all children, including learners with severe epilepsy, to a basic education. This is also entrenched in the international trend towards inclusive education (UNESCO, 1994:ix). Effectively, this means that children with severe epilepsy, including those confined to hospital premises, should still receive proper education. Full educational continuity during hospitalisation, whenever possible, should be given.

However, the problem remains in our rural communities, where many children with severe epilepsy are excluded from school, especially in provinces like Limpopo, where there are no hospital schools. These children are excluded without any form of quality instruction, and the social isolation and lack of peer interaction remains a serious negative consequence of hospitalisation. Peers who either isolate or tease the child for their disability or illness often reinforce the resulting fear or hesitancy by the child to engage socially. Kleinberg, (1982:69) discovered that for the chronically ill child with severe epilepsy, educational continuity is of vital concern. Absences from school can add up to a substantial amount of missed schooling, affecting also their welfare, happiness and general well-being. The challenge that now faces teachers, parents and hospital staff in this country is to seek ways of maintaining educational continuity through proper support, including support for learners in hospital.

It is of paramount importance, first, to establish how hospitalisation affects learners living with severe epilepsy. Then steps can be taken to establish ways of supporting educational instruction while in hospital and upon coming back to the school. The ultimate aim would be to close the gap of non-educational instruction during hospitalisation and to use information provided by research, such as this study, to accomplish this.

### **1.3 PROBLEM STATEMENT**

It is necessary to determine the learning support needs of chronically ill children with severe epilepsy and how hospitalisation affects their educational continuity. Consequently this study investigates how schools and hospitals can implement support programs.

### **1.3.1 Research questions**

The problem researched in this study may be formulated in the following research questions:

**What support needs do chronically ill learners living with severe epilepsy need while in hospital and upon coming back to the school?**

**What are the educational effects of hospitalisation on learners living with severe epilepsy?**

### **1.4 THE AIMS OF THE STUDY**

With regard to the problem statement mentioned above, the aim of this study is:

- To identify the support requirements that the learners with severe epilepsy require from the schools, the hospital and other role players.
- To establish the effects that hospitalisation has on learners living with severe epilepsy.

### **1.5 THE RESEARCH DESIGN AND METHODOLOGY**

#### **1.5.1 Research design**

A detailed discussion of the research design and methods of this study will be given in Section Two. In this section, only a brief description of research design and methods will be discussed. This study will use the qualitative approach that is descriptive and contextual. Leedy (1993:142) says that this approach is, in great part, concerned with human beings, interpersonal relationships, personal values, meanings, beliefs, thoughts and feelings. In this regard, the qualitative researcher attempts to attain rich, real, deep and valid data from a rational standpoint. According to Merriam (1988:17) the aim of qualitative research is to gain insight into the meanings that the participants

give to reality. As a result, the participants in this study will provide rich, deep and valid data. They will comprise of learners, teachers, principal and the head nurse attached to the school in the Capricorn region of Limpopo Province. (See Table 2.1 and 2.2 in Section Two for biographical information of participants and Addendum C for the biographical questionnaire administered to teachers, principal and the head nurse.)

### **1.5.2 Research methodology**

In this section, procedures followed with regard to data collection and data analysis will be explored.

#### **1.5.2.1 Literature review**

The literature review in this study will assist the researcher in the formulation of the problem and selection of research methods. A literature review is meant, primarily, to assist the researcher in attacking the problem for research by providing the study the means to "... reveal investigations similar to the researcher's own and to show how the collateral researchers handled those situations, illuminating a method of dealing with a problem situation that may suggest avenues of approach to similar difficulties that the researcher may be facing and further revealing the sources of data that the researcher may not have known existed" (Leedy, 1993:87). According to Merriam (1988:63), the findings of the study are best interpreted in the light of what was previously known about the topic.

#### **1.5.2.2 Interviews**

The purpose of using this method was to get answers to questions and in order to understand the experiences, perceptions, opinions, acts and reactions of the principal, teachers, learners and head nurse as they relate to the ways in which hospitalisation affects learners living with severe epilepsy, and to establish the support requirements and also arrive at potential solutions (Leedy, 1993:192). For this purpose, individual and focus group interviews were conducted. Participants in this study were selected because they currently work with epileptic learners, and, as a result, have certain

characteristics in common that relate to the topic (De Vos, Strydom, Fouche & Delpont 2002:305-306).

The questions posed to the participants are, “What are the support needs of learners living with epilepsy?” and secondly “What are the effects of hospitalisation on learners living with severe epilepsy?” These questions give insight into the participants’ experiences, perceptions and feelings. Furthermore, from these leading questions, communication was encouraged and probing questions were asked in order to gain more insight and knowledge and to clarify information where necessary.

### **1.5.2.3 Data analysis**

Data analysis in this study was done according to methods described by Henning, Gravett and Van Rensburg (2004:102), whereby content analysis was done by reading data sets to form categories and themes to apprehend the context. In Phase Two, the coding, segments of meaning were done by categorizing related codes into groups and seeking relationships between categories to form thematic patterns. Phase Three was the final writing of categories for the set of data and presenting that pattern of related themes. The aim of this data analysis is to identify patterns and draw conclusions in order to generate appropriate recommendations in this study.

### **1.5.2.4 Validity and reliability**

Regardless of the type of research, validity and reliability are concerns that must be approached through careful attention to a study’s conceptualization and the way in which data will be collected, analysed and interpreted (Merriam 1988:163). Various other authors such as Leedy (1997:168), Creswell (1994:157) and Macmillan & Schumacher (1993:385-391) refer to the fact that there is no single, commonly accepted standard for judging or ensuring the reliability and validity of qualitative research. Furthermore, a wide variety of participants will take part in this study to ensure validity and reliability. Refer to page (20) in Section Two for a detailed discussion based on validity and reliability of this study.

## **1.6 ASSUMPTIONS**

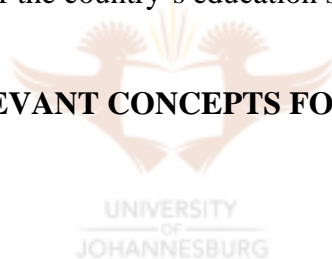
The researcher's assumptions will be discussed briefly below, and for the purpose of this study it is assumed that:

- Hospitalisation has an effect on school effectiveness, which causes educational and instructional discontinuity for learners with severe epilepsy;
- Support is required from schools, families, the hospitals and other role players in order for the learners to cope in their daily lives;
- Lack of instructional continuity is detrimental to the well-being of learners living with severe epilepsy;
- The more instructional continuity is timely, accurate, consistent and meaningfully done the more effective the school and learners become;
- Educational continuity is not only a significant element in the life of the learners, but also a major component of the country's education system.

## **1.7 DEFINITION OF RELEVANT CONCEPTS FOR THE STUDY**

### **School**

According to the Concise Oxford Dictionary (1999:938) a 'school' is defined as an institution for educating children. Van der Westhuizen (1997:41 as quoted in Reber, 1985:65) defines the school as a service organization. In addition, Kruger and Van Schalkwyk (1993:03 as quoted in Reber,1985:66) defines school as a situation or a number of situations in which a number of pupils gather in various learning groups so that they may be taught by an teacher or teachers. For the purpose of this research project, schools will be defined as institutions where teaching and learning takes place.



## **Resources**

According to the Concise Oxford Dictionary, resources are a means of supplying what is needed. For the purpose of this study, resources will be defined as facilities needed by any school to promote effective teaching and learning.

## **Epilepsy**

Epilepsy is a physical condition that occurs as a result of abnormal discharge signals that are part of the functioning of the brain. Epilepsy may take a number of different forms (Kapp, 1991, as quoted by Donald, Lazarus & Lolwana, 2002:35).

## **Chronic illness**

Chronic illness is not a single disease entity but an umbrella term that includes medical conditions such as epilepsy. For the purpose of this study, epilepsy will be referred to as a chronic illness. It is not equivalent to a long-standing physical or neurological handicap; the sufferers can be ill or well, independent of their handicap. It is a set of conditions that affects one or more body organs and represents an active disease process (Kleinberg, 1982:3).

## **Hospitalisation**

The time that the patient spends in the medical arena of the hospital that is in most cases a non-educational setting whereby the business of medicine often intrudes on the teacher's role and schedules (Kleinberg, 1982:73).

## **1.8 ETHICAL CONSIDERATIONS**

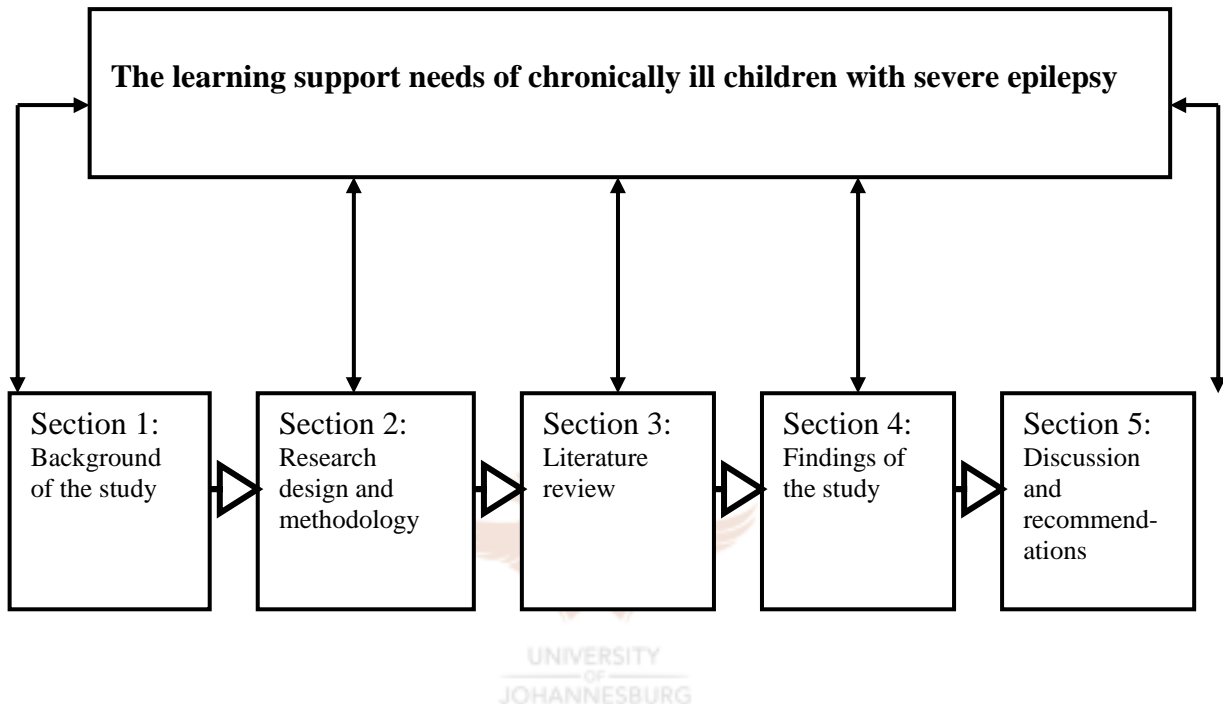
Detailed ethical guidelines and practices will be presented in Section Two. In short, the ethical guidelines that will be considered in this study include anonymity, privacy, confidentiality and the liberty to withdraw from the study. In addition, the participants will be provided with the reports of this investigation and its findings upon the completion of the research.



## 1.9 COURSE OF THE STUDY

In order to inform the reader about the progress of the study, I present a diagram of the following sections:

**Figure 1.1 Course of the study**



## 1.10 CONCLUSION

This investigation deals with the support requirements of the learners living with severe epilepsy and the effects of hospitalisation as a result of their condition. The topic will be investigated in terms of the five sections. In this section, the following aspects have received attention: introduction, problem statement, aims, research design and methodology, assumptions of the study, clarification of relevant concepts for the study and ethical considerations. This section provides the overview of the research and aspects that will receive attention.

## **SECTION TWO**

### **RESEARCH DESIGN AND METHODOLOGY**

#### **2.1 INTRODUCTION**

In this section, the research design for the study will be described, followed by research methods with reference to methods of data collection, data processing, methods of data interpretation and consolidation of data. In addition, reliability, validity and ethical issues will be presented.

#### **2.2 RESEARCH DESIGN**

Leedy (1993:125) refers to research design as planning and the visualisation of the data and problems associated with the employment of data in the entire research project. He further refers to it as the common sense and clear thinking necessary for the management of the entire research endeavor, which is the complete strategy of attack upon the central research problem.

Research design is a matter of thinking, imagining and thinking again through the research study by planning and providing the overall framework. Design is usually developed in order to provide a format for the detailed steps in the study. It is relatively specific consisting of a series of guidelines for systematic gathering which depends upon the statement of the problem (Leedy, 1993:127).

According to Macmillan and Schumacher (1993:31) the purpose of a research design is to provide the most valid, accurate answers possible to the research questions. The research design of this study can be described as qualitative, contextual and descriptive.

## **Qualitative**

Macmillan and Schumacher (1993:372) define qualitative research as naturalistic enquiry, the use of non-interfering data collection strategies to discover the natural flow of events and processes and how participants interpret them. For the purpose of this study, a qualitative paradigm would best suit the aim of gaining greater understanding of the social actions, beliefs, thoughts and perceptions of the participants towards the effects that hospitalisation has on learners with epilepsy, the meaning they attach to epilepsy as a chronic illness and the need they have for support that can be put into place. A qualitative paradigm will also provide a broader version of theory.

Research using the qualitative paradigm describes and analyses people, individual and collective social actions, beliefs, thoughts and perceptions. The aim of qualitative research, according to Morse (1994:03) is the development of theory, description, clarification and comprehension rather than extract testing of a hypothesis. In this study, a systematic and subjective approach will be used to establish the exact educational discontinuity in the educational instruction of learners that are living with epilepsy, its effects upon those learners and their support needs. Miles and Huberman (1994:06) emphasise the importance of the qualitative researcher's ability to gather information on the perceptions of participants from inside, through the process of deep attentiveness and empathetic understanding while suspending preconceptions about the topics under discussion.

The aim of qualitative research is to gain insight into the meaning that people give to the experiences in their lives, and how they structure their worlds according to these meanings (Merriam, 1988:16-17). This is done by means of what Miles and Huberman (1994:10) refer to as thick descriptions that are vivid, nested in real context and has a ring of truth that has a strong impact on the reader. Data in the form of words and pictures, rather than numbers or figures, are gathered and used to convey what the researcher has learned about a particular phenomenon.

## **Contextual**

According to Leedy (1993:141), qualitative research considers the self as an instrument. The self is an instrument that engages the situation and makes sense of it. This is done most often without the aid of an observation schedule; it is not a matter of checking behaviour but rather of perceiving their presence and interpreting their significance.

This study takes place within the context of a special school at Bochum, a semi-urban area in the Capricorn district, where learners living with severe epilepsy as a chronic illness spend a lot of the time in hospital because of their condition, lose out on what is taught at school during their absence and also do not receive proper support upon returning to the school.

## **Descriptive**

Merriam (1988:11) refers to the aim of descriptive research as a method of examining events or phenomena in such a way that there is no manipulation or treatment of the participants and the researcher takes things as they are. The aim is that the researcher should gain understanding of the participant's experiences based on thick and rich descriptions that are vivid and nested in the real context based on the truth that has a strong impact on the reader. As stated previously, the aim of this study is to describe and find out the accurate and true description of the support requirements of learners with severe epilepsy as a result of hospitalisation.

## **2.3 RESEARCH METHODS**

### **2.3.1 Selection of participants**

Qualitative researchers usually work with small samples of people, situated in their context and studied in depth (Miles & Huberman, 1994:27). A purposive sampling method was used in this study. In purposive sampling, the researcher thinks critically about the parameters of the population and then chooses the sample case accordingly. It has been further emphasized by Creswell (1998:118) that clear identification and

formulation of criteria for the selection of participants are of cardinal importance. In this study, a particular case of learners, teachers, nurse and principal was chosen because they are involved with learners living with severe epilepsy (Silverman, 2000:104). Thus the participants in this study consist of secondary school learners with epilepsy, school teachers, the principal, and a nurse attached to the school. This group is considered as “bounded” as they all have a common sense of obviousness, that is, they are all affected by the condition of illness that affects the learners living with severe epilepsy (Kapp, 2000:146).

The purposeful selection of participants in this study represented a key decision point in qualitative study, as a researcher designing qualitative studies needs clear criteria in mind to provide rationales for their decisions. The search for data was guided by processes that provided rich detail to maximize the range of specific information that was obtained from the participants and about the context (De Vos, Strydom, Fouche` & Delpont, 2002:335). The selection of participants for this study was an extremely time-consuming endeavour, especially as, in order to include their children in the study, it was necessary to obtain the consent of parents who reside far from the school.

The selection criteria included the following:

- The learners should have severe epilepsy;
- The teachers and the principal should be working with learners living with epilepsy;
- The head sister should be working at a clinic attached to the school catering for learners with barriers to learning including epilepsy.

Table 2.1 and 2.2 provides biographic information of the participants in this study.

<b>Participant</b>	<b>Gender</b>	<b>Age</b>	<b>Qualifications</b>	<b>Experience at a special school</b>
Participant 1: Teacher	Female	30-40	B.Ed (Special Needs)	11
Participant 2: Teacher.	Female	40-50	Diploma in Remedial Ed.	10
Participant 3: Teacher.	Male	30-40	Senior Teachers Diploma	11
Participant 4: Teacher.	Male	30-40	B.Ed (Special Needs)	11
Participant 5: Teacher.	Female	30-40	BA.Ed	10
Participant 6: Teacher.	Female	30-40	B.Ed (Special Needs)	12
Participant 7: Teacher.	Female	30-40	B.Ed (management)	10
Participant 8: Principal	Female	40-50	B.Ed (Special Needs)	22
Participant 9: Nurse.	Female	40-50	Diploma in Nursing	20

**Table 2.7 Categories and themes**

<b>Participant</b>	<b>Gender</b>	<b>Age</b>	<b>Grade</b>	<b>Nature of disability</b>
Participant 1: learner	Female	18	11	Tonic- Clonic
Participant 2: learner	Female	18	11	Tonic-Clonic
Participant 3: learner	Male	19	11	Clonic convulsions
Participant 4: learner	Female	17	10	Clonic convulsions
Participant 5: learner	Female	17	10	Clonic convulsions
Participant 6: learner	Male	20	12	Myoclonic spasms
Participant 7: learner	Male	22	12	Myoclonic spasms.

**Table 2.2 Learners as participants in the study**

The sample size of the participants was considered to be adequate for this study.

### **2.3.2 Methods of data collection**

The methods of collecting data varied. Each method will briefly be discussed in this section.

### **Literature review**

Primarily, a literature review is meant to assist the researcher in attacking the problem for research by contributing to the study with the following benefits, "... reveal investigations similar to the researcher's own and to show how the collateral researchers handled those situations, illuminating a method of dealing with a problem situation that may suggest avenues of approach to similar difficulties that the researcher may be facing and further revealing the sources of data that the researcher may not have known existed" (Leedy, 1993:87). Without theory there is nothing to

research as theory is used to guide the study in an explanatory way (Silverman, 1993:01). The literature review in this study assisted the researcher in the formulation of the problem and selection of research methods.

### **Individual interviews**

In this study, individual interviews will be conducted with the principal and the head nurse attached to the school in order to determine the support requirements of learners living with epilepsy and the effects that hospitalisation has on their learning.

The purpose of using this method is to get answers to questions and understand the experiences of the principal and nurses in the lives of learners living with severe epilepsy, and their perceptions of the support required. This method was used to determine the principal and nurses perceptions, opinions acts and reactions towards the research problem and also potential solutions. The challenge lay in maintaining flexibility and eliciting individual stories while, at the same time, gathering information with consistency (Leedy, 1993:192).

### **Focus group interviews**

Focus groups are group interviews that amount to better understanding of how people feel or think about an issue. Participants are selected because they have certain characteristics in common that relate to the topic of the focus group. The group is focused, in that it involves some kind of collective activity (De Vos et al., 2002:305-306). The researcher creates a tolerant environment that encourages participants to share perceptions, points of view, experiences and concerns without pressurising participants to vote or reach consensus (Krueger & Casey, 2000: 4).

Macmillan and Schumacher (1993:444) describe the focus group discussion as a discussion on the basis of which information is obtained. In this case, the participants, including the facilitator, conducted it as an open conversation in which each participant commented, asked questions of other participants and responded to comments. The role of the researcher was to direct discussion of topics and encourages the discussion in a fair and unbiased manner.



In this study, two focus group interviews were conducted with seven school teachers whose classes include learners living with severe epilepsy, and with a second focus group consisting of seven secondary school learners, all of whom are living with epilepsy.

### **2.3.3 Data analysis**

According to Marshall and Rossman (1995:114), data analysis is the most difficult, complex, ambiguous, creative and enjoyable phase. The challenge of data analysis is to make sense of the data. This process is initiated by the transformation of verbal data into text. This is achieved by transcribing the interviews (See addendum A). The analytic process demands a heightened awareness of data, a focused attention on the data and openness to the subtle, tacit undercurrents of social life. It involves identifying salient themes, recurring ideas or language and patterns of belief that link people and settings together. This is the most challenging phase of research and one that can integrate the entire endeavour (De Vos et al., 2002: 344).

In this study, the approach followed for data analysis is mainly based upon the content data analysis method suggested by Henning et al. (2004:102-104). Data was reduced by means of coding the categories and themes. The aim of this data analysis method is to identify patterns and draw conclusions in order to generate appropriate recommendations. Miles and Huberman (1994:119) describe qualitative data analysis as "... a continuous interactive enterprise." In this interactive enterprise the researcher acts as the primary instrument of analysis.

These stages of data analysis are illustrated in Table 2.3:

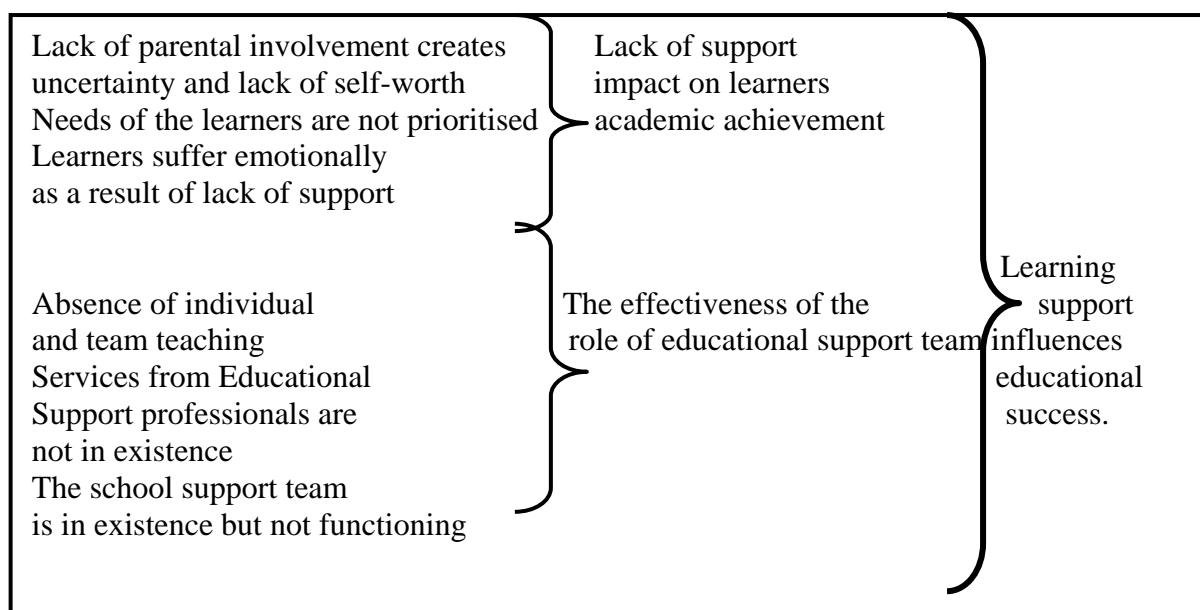
<p><b>STAGE 1</b> <b>Consolidation and data reduction</b> Involves the organisation and reduction of data from interviews, by means of the Content Data Analysis Method, in order to construct categories and themes in the data.</p> <p><b>Step 1:</b> Verbatim transcription of the interviews <b>Step 2:</b> Repeated note making on relevant data and patterns <b>Step 3:</b> Combination of notes made during initial readings <b>Step 4:</b> Merger of different data groupings into themes on one master list <b>Step 5:</b> Development of categories into which groupings or themes are consolidated</p> <p><b>STAGE 2</b> <b>Data interpretation</b> During this stage, data were displayed in order to simplify the interpretation process and drawing of conclusions.</p> <p><b>Step 1:</b> Transference of data into a visual form for comparisons and interpretations to be made <b>Step 2:</b> Interpretation and drawing of tentative conclusions</p> <p><b>STAGE 3</b> <b>Verification</b> Data were integrated in the framework of inclusive education in South Africa with particular reference to epilepsy, in order to gain a greater understanding from the data and to verify emerging categories and themes according to validity criteria.</p> <p><b>Step 1:</b> Interpretation of data in relation to the research question and the literature study <b>Step 2:</b> Assessment of the validity and reliability of the inquiry</p>
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**Table 2.3 Process of content data analysis**

Tables 2.4 and 2.5 provide an illustration of the manner in which the Content Data Analysis Method was employed in the different stages of data analysis. This is followed by Tables 2.6 and 2.7 illustrating the main categories and themes.

<p>Obviously there is a <u>break</u> when the child is hospitalised and when he comes back. He usually may take maybe 2 to 5 days in the hospital and when he comes back you have to <u>start again</u> because the child has <u>forgotten</u> during the absence. You will have to <u>repeat</u> your lesson and this is <u>very frustrating for the teacher</u>. This learner is having <u>learning problems</u> and is <u>stigmatised</u> and does not have self-confidence any more and he is <u>not performing very well</u>. The other thing is the medication. I am a teacher and do not understand why a child must have medication because the <u>nurses do not give any explanations</u>.</p>	<ul style="list-style-type: none"> <li>→ Educational Discontinuity</li> <li>→ Forgetfulness</li> <li>→ Impacts on teachers</li> <li>→ Stigmatisation and labelling</li> <li>→ Develop learning problems</li> <li>→ Collaboration of role players</li> </ul>
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**Table 2.4 Illustration of the Content Data Analysis Method: Phase One**



**Table 2.5 Phase Two: Clustering categories and themes**

<p style="text-align: center;"><b>Main categories:</b></p> <p>Hospitalisation impacts on educational continuity of learners.  Learning support influences educational success.  Institutional operation impacts on the learners with epilepsy.  Hospitalisation impacts on teachers in unique ways.  Collaboration of role players contributes towards adjustment and support.</p>
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**Table 2.6 Main categories**

The main categories were divided into themes as illustrated in Table 2.7.

Hospitalisation impacts on educational continuity of learners.	<ul style="list-style-type: none"> <li>○ Hospitalisation creates educational gap.</li> <li>○ Stigmatisation and labeling.</li> <li>○ Forgetfulness and inability to follow instructions.</li> <li>○ Behavioural problems emanating from epileptic attacks</li> </ul>
Learning support influences educational success.	<ul style="list-style-type: none"> <li>○ Role of educational support professionals</li> <li>○ Parental involvement and support</li> <li>○ Individual teaching and curriculum adaptation</li> </ul>
Institutional operation impacts on the learners with epilepsy.	<ul style="list-style-type: none"> <li>○ Role of teachers and hospital staff in supporting learners</li> <li>○ Assessment and curriculum placement</li> <li>○ Impact of effective team teaching</li> </ul>
Hospitalisation impacts on teachers in unique ways.	<ul style="list-style-type: none"> <li>○ Operation of the school contributing to better adjustment</li> <li>○ Co-ordination of the support services in the school</li> </ul>
Collaboration of role players contributes towards adjustment and support.	<ul style="list-style-type: none"> <li>○ Collaboration and communication</li> <li>○ Need for utilization of resources</li> <li>○ Importance of in-service training</li> </ul>

**Table 2.7 Categories and themes**

### 2.3.4 Validity and reliability

The methods that were used to attain validity and reliability in this study will now be discussed.

## **Internal validity**

This refers to the degree to which the interpretations and concepts have mutual meanings shared by the participants and researcher (Macmillan & Schumacher, 1993:391). In other words, it is essential for the researcher to capture and portray the reality of the world as it appears to the participants. Researcher's self-monitoring, called disciplined and subjectivity, submits all phases of the research process to continuous and rigorous questioning and evaluation.

According to Leedy (1993:41) internal validity is the freedom from bias in forming conclusions in view of the data. The methods suggested by Macmillan and Schumacher (1993:391-392), Leedy (1993:167-169) and Maykut and Morehouse (1994:146) will be mainly used to ensure internal validity of this study. These methods are discussed below:

## **Disciplined subjectivity**

In order to achieve disciplined subjectivity in this study, the researcher wrote out all potential biases about the topic before the beginning of the study, and kept a memo and a reflexive journal. The memo and reflex journal made the researcher alert during the process of formal data analysis (Macmillan & Schumacher, 1993: 392).

## **Peer analysis of data**

The findings of the study were discussed with colleagues by requesting them to make comments upon the findings, and the main categories and themes that emerged (Merriam, 1988:169).

## **Researcher's assumptions and position**

In the first section on the onset of this study, the researchers' beliefs, assumptions and biases were made as a contribution to the validity of these findings. Some of the findings had a close correlation with assumptions that were stated earlier.

Furthermore, the literature review and theory on which the study is based will be discussed in Section Three.

### **Chain of evidence**

A strong chain of evidence flows through this study, in research questions, motivation, methodology, data and findings. These serve to make the validity stronger (Leedy, 1993:169). The reader and other researchers can use this study as an operating manual and as an attempt to establish the chain of evidence.

### **External validity**

This relates to the generalisation of the conclusions reached, as conclusions drawn from one study and are generalised to other situations (Leedy, 1993:41 and Merriam, 1988:173). In other words, in this study the researcher does not aim at generalisation of results but the extension of the understandings and detailed descriptions that can enable others to understand similar situations and extend their understanding in subsequent research. Knowledge is produced not by replication but by preponderance of evidence found in separate studies over time (Macmillan & Schumacher, 1993:394, Guba & Lincoln, 1985 and Merriam, 1988:73). This reaffirms the importance of first establishing internal validity before external validity is discussed. It is therefore important that what the researcher learns from a specific situation can be transferred to another situation, depending on the degree of similarity that fits between the two studies, which will take place in different contexts (Miles & Huberman, 1994:229).

In order to facilitate this process, the following strategies were employed in this study (Merriam, 1998:177). Certain effects of hospitalisation were described and compared with the effects already identified in the study, in order to enable the reader to make a comparison with her own situation (Guba & Lincoln, 1985 as quoted by Merriam 1988:177). Through provision of detailed descriptions, the reader and other researchers interested in transferring information have the base and foundation of information that is reliable (Le Compte, 1993:177).

## **Reliability**

Reliability is the extent to which independent researchers could discover the same phenomenon on which there is agreement on the description of the phenomenon between the researcher and the participants (MacMillan & Schumacher, 1998:385). According to Lincoln and Guba (1985, as quoted by Meriam, 1998:171) reliability and validity are inextricably linked in the conduct of research. They state that "... demonstrations of internal validity amount to a simultaneous demonstration of reliability." Therefore the same methods that will be used to ensure internal validity will consequently ensure reliability. There is a compact disc containing raw data from the interviews attached to the inside back cover of the dissertation to ensure trustworthiness and reliability of the raw data.

### **2.3.5 Ethical considerations**

Merriam (1988:179) refers to the fact that ethical dilemmas are likely to emerge at two points during the study, that is, during the data collection and in the dissemination of findings. Various authors refer to the ethical considerations that the researcher has to bear in mind while doing research (Miles & Huberman, 1994:240, Creswell, 1994:148, Meriam, 1998:179, Macmillan & Schumacher, 1993:182-185 and Leedy, 1993:128). The methods employed to control the ethical standards of this study are briefly discussed below, including the Rand Afrikaans University's ethical clearance letter obtained from the Ethics Committee and a letter from the editor (see letter in Addendum D).

### **Confidentiality and anonymity**

All the participants of the individual and focus group interviews were reassured that their names would not be used in the transcriptions. In order to ensure that they are protected from any possible risks relating to their rights to privacy, the researcher has made certain that data cannot be linked to the names of participants.

## **Informed consent**

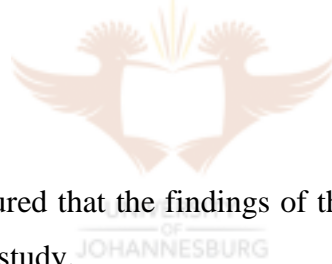
Informed consent of all participants was obtained by asking participants, that is, learners, teachers, principal and nurse, to sign a letter that indicates understanding of the research and consent to participate (see Addendum C). This was done as data gathering at public schools that requires learners' participation beyond normal learners' school times requires parents' permission, as well as that of the school district and the principal.

## **Voluntary participation**

All the participants were also reassured that they were under no obligation to participate and could leave at any time if they felt uncomfortable. They were not in any way coerced into participating. The procedure, time requirements and type of participation expected from them were explained at the onset of the interviews.

## **Feedback**

All the participants were assured that the findings of the study would be shared with them at the conclusion of the study.



## **2.4 CONCLUSION**

In this section, the research design was described. The nature and the unique characteristics of the qualitative research methods were discussed, including the data collection and data analysis. Measures of ensuring validity, reliability and ethical considerations of this study were also discussed.



## **SECTION THREE**

### **LITERATURE REVIEW AND THEORETICAL FRAMEWORK**

#### **3.1 INTRODUCTION**

Literature was consulted and discussed in order to gain further insights into the proposed study. Literature regarding severe epilepsy and support requirements is discussed with reference to historical perspectives and current research, definitions, incidence and support. In the final part of this section, the focus on the effects of hospitalisation will be clarified, focusing on the school system and the components of the support needs resulting from hospitalisation, as well as some research on this topic and how hospitalisation may affect the teaching process.

##### **3.1.1 THE INTERNATIONAL PERSPECTIVE AND CURRENT RESEARCH ON EPILEPSY**

Until the early 1950s, very little research was conducted on the learning support needs of children suffering from chronic and severe epilepsy. Parents were often seen as intruders in the impersonal, routine hospital system. In the late 1940s, (Spitz 1945 as quoted by Kleinberg, 1982:60) described children he had visited in hospital who were suffering from chronic illness. Later studies by (Robertson, 1988 & Bowly 1975 as quoted by Kleinberg, 1982:61) lent support to Spitz's research and described in great detail the deleterious effects that hospitalisation had on children with severe epilepsy (Kleinberg, 1982:61).

With the advent of child advocacy and consumers' rights movements in the 1960s came the development of a constituency to pressure for changes. Parents and other professionals banded together to lobby for the rights of children. The Association for the Care of Children's Health (ACCH), an international multidisciplinary organisation, made great strides in representing the psychosocial needs of children (Kleinberg, 1982:61-62). However, despite much positive change resulting from this over the decade, there is still much work to be done (Kleinberg, 1982: 61).

### **3.1.2 THE SOUTH AFRICAN CONTEXT - PERSPECTIVES AND CURRENT RESEARCH**

Parents of children with barriers to learning started forming groups recently, advocating for the rights of learners with barriers to learning, including those with severe epilepsy in a more normal school environment (Stainback & Stainback, 1995:20). According to the reports of the medical services of the City Council of Pretoria, health disorders were found in 55% of young children in pre-primary schools and crèches, including learners with severe epilepsy. Kapp (2000:256-261) refers to statistical findings, which indicate that an average of 10% of all children experience severe epilepsy before the age of fifteen years.

During the 1950s, learning problems and, more specifically, mental retardation and epilepsy, were mainly ascribed to neurological deficits where medication was usually the basis of treatment (Poplin, 1988:390). Due to these deficits, it was generally felt that these children would not be able to cope in ordinary schools and special and separate schools were often established to deal with their specific problems (Du Toit, 1996:6). However, teachers became aware that the neurological tests were not always successful in identifying children with learning problems. Even children who were not neurologically impaired according to screening tests still appeared unable to master the skills needed to achieve success at schools. The consequent approach was to place these children in a simplified environment, in accordance with their limited psychosocial and perceptual skills. Within this environment, the goal was to assist them in gaining the necessary skills, in order to minimise and remove their deficits and ultimately to place them back into the mainstream when they were ready to cope (Du Toit, 1996:6).

Gradually, the focus has moved from the learning disabled having to overcome their deficits to fit into the system, to the system having to adjust and make allowances to cope with learners with barriers to learning. This coincides with the view that learning problems possibly originate not only from deficits within the children, but also from deficits within the system. This implies that the problems may be caused by the system that has been unable to meet or adapt to the needs of the children (Hegarty,

1994:126). Furthermore, “research shows that because learning is self selected, self motivated and self constructed, the best predictor of what learners will learn next is what they already know and what interests them.” (Poplin, 1988:407). This implies that the system has to create a safe, welcoming environment that meets the needs of all children, wherever they are, and helps them construct meaning out of the world around them. Eventually, in this sphere of their lives, the system of education should adapt to meet the children where they are, joining them in their specific approach to thinking and learning, and assisting them to develop strategies that suit them and are meaningful to them and meet their needs.

Furthermore, White Paper 6 (2001:6), on building an inclusive education and training system, suggests certain principles on which to reconstruct and develop it. These included the provision of education for all learners, placing the emphasis on support through full service schools and introducing strategies and interventions that will assist teachers to cope with diversity of learning and teaching needs so as to ensure that transitory learning difficulties are ameliorated (White Paper 6, 2001:10). The approach to education should be holistic, focusing on the total development of all learners, which will encompass academic and vocational skills as well as on a broad range of psychological, health and social needs (Du Toit, 1996:14).

Donald et al. (1996:76) also emphasise the importance of a holistic approach to educational development, focusing not only on coping curatively with the vast number of learners with barriers to learning who currently exist, but also preventatively, as a long term goal, removing as many as possible of the contributing factors. Depending on the needs of the learners, the system should move to meet the children’s needs whenever possible, be it within a segregated special school, a special class, an aid class, a regular class with some time in a remedial class or full time in a regular class or in a hospital setting (Schoeman, 1996:02).

All the above models have contributed to the education of learners with barriers to learning. Today, the focus has shifted from the children’s deficits to adapting the system to meeting the needs of each individual child (White Paper 6, 2001:06-08). The underlying philosophy of building an inclusive education system is addressing barriers to learning as a belief in the inherent rights of all people to participate

meaningfully in their societies (White Paper 6, 2001:19, Du Toit 1996:07, Naicker 1995:153). An inclusive system offers learners the realistic opportunity to learn from experience and to respect and accept people of varying abilities by means of social interaction with one another. Therefore all learning communities should accept diversity and appreciate and respond to the diverse needs of its members as implied in the Constitution of South Africa (1996:14), and as proposed by the Salamanca Statement (UNESCO 1994:viii) and reaffirmed by White Paper 6 (2001:06).

For the purpose of this study, I will now briefly explore the definition of epilepsy, its incidence, types, symptoms and general considerations. The questions now raised are, with all policies drawn, how can the support needs of learners with severe epilepsy be met, and how can the effects of hospitalisation be lessened for learners living with epilepsy, with particular reference to continuity of educational instruction. In order to do this, one should first look more closely at the characteristics of epilepsy.

### **3.2 DEFINITION**



#### **Epilepsy**

Epilepsy is a sudden disturbance or change in brain function as a result of unusual electrical activity in the brain cells. A seizure is an “attack” of epilepsy. One manifestation of epilepsy is a convulsion, which is characterised by extensive involuntary muscular contraction, mostly occurring rhythmically. Its characteristics include the following (Kapp, 2000:256):

- It is temporary, that is, after the disturbance has passed completely, the individual functions in the same way as before the seizure occurred.
- A lowering or loss of consciousness usually, but not always, occurs. Disturbance in movement, sensation, behaviour and perception may take place.

- Seizures can occur repeatedly, but the intervals between them may vary from minutes to years.

According to the definition above, epilepsy is a clinical condition caused by sudden brain dysrhythms. The neurons or brain cells may be so excessively excited because of various factors, such as irritation through brain lesions, high fever, toxins and external stimuli that an epileptic seizure may follow. In fact, any living brain may be brought to the point of epileptic seizure, depending on the intensity of the stimulus and the natural resistance of the person's brain. In some children, external stimuli such as a flickering light, for example, when driving through a lane of trees with the sun shining from the side, or a poorly functioning television set, may cause a seizure. Physical indispositions such as teething, fever or fatigue may precipitate seizures in children, as may emotional stress (Kapp, 2000:259)

### **3.3 INCIDENCE OF EPILEPSY**

According to Svoboda (1979 as quoted by Kapp, 2000:261), about 50% of all people with epilepsy experience learning problems. Even when a cause of the seizure disorder is not known, the epileptic patient often shows some evidence of a learning deficit. If the cause of the epilepsy is known, this tendency is significantly greater, especially if there is known brain damage (Svoboda 1979 as quoted by Kapp, 2000:263). Barnard (1970 as quoted by Kapp, 2000:264) indicates that between four and five persons per thousand of the South African population suffer from epilepsy. This means that in every school with a few hundred learners there may be one or more epileptic learners.

### **3.4 TYPES OF EPILEPTIC SEIZURES**

#### **3.4.1 Generalised seizures**

Generalised tonic-clonic or grand mal seizures affect all the muscles and motor functioning, causing the learner to lose consciousness, fall, stiffen, and then begin to jerk as the muscles alter and the learner relaxes. Breathing may stop briefly, and the

skin may become bluish. After a minute, the breathing slows down and stops, with normal breathing starting again and the child slowly recovering. The generalised tonic seizure involves the whole brain, and when the electrical disturbance starts in one part of the brain and then spreads, it is called a seizure, which is secondarily generalised clonic. In the school that forms the focus of this study, about 10% of the learners live with this form of epilepsy. As most of them believe that epilepsy originates from evil spirits, it takes time to convince them to take medication. Learners therefore spend most of their time in hospital for medical treatment. Moreover, this condition creates learning problems, as it creates educational discontinuity during the time of hospitalisation.

### **3.4.2 Absence seizures**

Absence seizures, once called *petit mal*, are brief periods of blank staring in which the learner is unaware and unable to respond. They start and end abruptly, often lasting only a few seconds, but happen many times a day, interrupting attention and concentration. A child may start a sentence, stare for a moment or two, and then continue without realising there was a break, sometimes blinking rapidly and making movements with the mouth. These seizures are accompanied by short spells of unconsciousness, sometimes of just a few seconds. Absences may be sporadic or may occur as often as a hundred times a day. Absences occur suddenly without any prior signal or warning and immediately involve both sides of the brain. During the seizure, the child has an empty, glazed expression in the eyes, sometimes turning them upwards and making a sharp sound with the mouth. However, an absence may also occur without any motor symptoms, so that the sudden disruption of the activity, maybe reading, writing and speaking, is the only outwardly observable sign of the seizure. This form of epilepsy exists in the school on which this study focused, but it was difficult to establish the percentage of learners living with this condition as it was regarded as a minor form and this study focuses on severe epilepsy.

### **3.4.3 Atonic seizures**

Atonic seizures cause a sudden loss of muscle tone. In some learners, all that happens is in the head. Other children may fall suddenly to the ground. Both types of the

seizures affect the face and head and children, who have them may have to wear a protective helmet if controlled. Atonic seizures are sometimes called ‘drop attacks’.

### **3.4.4 Tonic-clonic seizures**

Tonic-clonic seizures account for only 10% of all seizures, but when the majority of individuals imagine a typical seizure, the events of a tonic-clonic seizure are considered the classic occurrence. At the onset, the learner will often give a sudden cry. This cry is caused by the abrupt contraction of the diaphragm and chest muscles with the removal of air through the respiratory tract. This is quickly followed by the tonic phase, a fall in a stiff or rigid fashion, rather than being limp or slumped. The eyes roll back, the jaw is clenched and muscles are contracted. The learner may bite his or her tongue or cheek during this stage. The tonic phase will last approximately 30 or 60 seconds.

Clonic movements follow this phase: the repetitive flexion of the body, including the arms, neck and hips. The movements are rhythmic, synchronous and jerky. The clonic movements usually continue for several minutes, but less than five minutes. The learner may produce excessive saliva, exhibit shallow breathing or develop cyanosis. The clonic movements will gradually slow down, then stop. The learner will become flaccid and exhausted. The anal and urinary sphincters may relax, with resulting incontinence. The learner may remain unconscious for several minutes. As consciousness returns, the learner often experiences fatigue, loss of memory, headache and confusion. This period can last from several minutes to hours. The seizures will occur in an unpredictable pattern varying in frequency. This type of epilepsy is rare and accounts for less than 10% of the learners in which the focus of the research was based on.

### **3.5 HOSPITALISATION OF LEARNERS LIVING WITH SEVERE EPILEPSY**

The successful control of epileptic seizures requires regular use of medication. However, the majority of the learners do not take medication earlier, so that a seizure often results in hospitalisation. In the majority of cases, based on the school which this study focused on, medication should be taken for life. Since most learners regard

epilepsy as a form of evil spirit, they first treat it with religious rituals, only taking medication when it is too late and the condition of the learner is severely affected.

Medication, however, sometimes has harmful side effects. Also, some medicines make the learners drowsy and may, among the unenlightened and especially among some teachers, create the impression that the child is lazy. In other cases medication may lead to restlessness, irritability, agitation and even, although in the minority of cases, deviant behaviour. The use of medication, especially prolonged use, sometimes also affects the learner's general health. The learner, who does not feel well and is often unmotivated in the teaching-learning situation, is slow to complete tasks and to achieve, and even offers resistance (Kapp, 2000:266).

Doctors usually treat epilepsy with drugs, referred to as 'anti-epileptic medication'. They are prescribed as tablets, sprinkles or capsules, or in syrup form. They are designed to stop seizures, but some of them control just one or two types of seizure. These drugs do not cure epilepsy. If the medication is given irregularly, the level in the child's blood becomes too low to be effective and seizures become more common, which eventually requires lengthy hospitalisation. That is why it is very important for the learners to continue taking medication regularly. However, there is no question that the medications do have a slowing effect on some aspects of physical co-ordination. Memory may be affected and behaviour changes may become problems as well.

Apart from the need for continued medical supervision, the need for educational continuity remains a central issue in the lives of learners living with epilepsy. Hospitalisation of learners with severe epilepsy, that is, grand mal, usually occurs at time of increased stress, with diagnosis being verified when a child has suffered a severe attack. Weakness often results from the illness or the necessary treatment, leaving the child even more vulnerable. Hospitalisation causes separation between the child and the family, and is painful. The child is thrust into unfamiliar surroundings, bombarded by strange sounds, smells and sights. The normal ability to function may be decreased by weakness, and he or she is uncertain of the varying expectations placed upon him or her (Kleinberg, 1982:61-65).



Depending upon their age, the children's fears may focus on issues of abandonment, punishment or death. Often these fears are realised when parents, classmates and teachers fail to visit. The lack of control over their lives and the lack of the right to make decisions regarding daily schedules or treatment, become other serious consequences of hospitalisation. With or without help, learners' responses to the social stresses resulting from illness are individualised, although few patterns are commonly observed. The psychological defense mechanisms, seen by Mattson (1980, as quoted by Kleinberg, 1982:59), as the unconscious means of making threatening reality more bearable, are withdrawal, depression, denial, acting out and regression.

Some children with epilepsy withdraw from school because of the possible effect of stigmatisation, choosing instead to drop out. Their effect may be poor and they may seem to have little interest in anything and little energy to pursue even simple daily routines. Faced with the loss of a normal future and suffering from illness and depression expressed by loss of interest in school, they may require professional intervention. Occasionally, children with depression resulting from seizures may talk of suicide, or of giving up. Denial is also used as a protection against the devastating emotional effects of epilepsy as chronic illness. At times they may even use coping strategy to refuse further necessary treatments and thus precipitate medical crises (Mattson, 1980 as quoted by Kleinberg, 1982:59).

Learners living with epilepsy often experience feelings of anger and rage that may lead them to act out physically, verbally abusing hospital staff, parents, peers, teachers and siblings. Sarcasm and name-calling are frequently used as they are immobilised for long periods of time. For these children, the fear of being unable to protect themselves from an epileptic seizure and the shame and embarrassment of being helpless combine to produce an overwhelming sense of rage, expressed verbally and physically towards others. As a result, their enforced dependency upon others, and the interference with normal developmental continuity at school, all combine to make regression a common coping strategy. This is because they are attempting to move towards a more independent path but may feel ambivalent about parental control. Often it may be easier to retreat to an early stage, to be pampered and protected, rather than attempt to break away from their parents (Mattson, 1980 as quoted by Kleinberg, 1982:59-61).

There are possible detrimental effects that the regular or irregular use of prescribed medication may have, systematically yet unobtrusively, on the child. Carefully observing not only children with epilepsy but all children who try to conceal their problems, or are unaware of them, requires knowledge of epilepsy and its manifestations. Outcomes can be reached at different rates by different means. The regular use of medication is essential and provision should be made for the child to take it during school hours under the supervision of a health personnel. The nurse attached to the school can supervise the children's taking of medication, according to the doctor's prescription and not at times that suits the teachers best (Kapp, 2002:265-267).

### **3.6 SYMPTOMS OR MANIFESTATIONS OF EPILEPTIC SEIZURES**

Symptoms of epilepsy include:

- Signs of confusion without other symptoms and without any reasonable cause. The children suddenly appear disorientated; it may look as if the familiar environment of the class or playground is strange to them;
- Temper tantrums and fear of danger, sudden and unexpected, without any evident cause or disproportionate to the apparent cause;
- Sudden emotional disturbances, signs of fear and anxiety;
- Sudden disturbed muscular control, awkwardness, clumsiness and lack of coordination, which do not correlate with their usual actions. They may stumble and bump into things, or drop things;
- Wetting of the bed, and incontinence;
- Sometimes, simply difficult behaviour that the person close to them is unaccustomed to, or which periodically occurs while they are totally compliant, including the following, as described by (Kapp, 2000:266).

#### **3.6.1 Behavioural and emotional problems**

Behavioural and emotional problems are common among learners living with epilepsy. As people who need support, these learners are dependent on teachers to

cope with their learning, as they always need reassurance, especially after experiencing a seizure. Their growing up is also influenced by the attitudes and behaviour of friends and others with whom they have contact (Kapp, 2000:265).

Within the social context, epileptic seizures also create problems for the children. The typical absence temporarily but unexpectedly cuts them off from this world, and this arouses feelings of estrangement in the child. As after the seizure, the children become confused, partially paralysed, experiences speech disturbance and difficulty in understanding others. For the bystander, these symptoms usually arouse a feeling that the children are embarrassed and feel hurt, inadequate, and inferior and different from others. To such children, relationships with other people takes on negative connotations (Kapp, 2000:266).

Epileptic seizures are a source of fear for the children. They regard seizures as an embarrassment and, at times, they try to disguise this condition. They can conceal their use of medication, but not the seizures. This frustrates the children and they betray the presence of this frustration and inability to properly control the situation by depression, rebelliousness or aloofness. Epilepsy affects the formation of the children's self-concept, as the recurrence of seizures reinforces the poor self-concept and their defenses become shuttered (Svoboda, 1979:159).

All this is not easy for the parents and errors such as overprotection, pampering or rejection often occur, with unique complications for the development of the child's independence. The child, as a whole, is involved in learning, physically, emotionally and cognitively. A stable emotional life is essential to successful learning. In all that a person undertakes, there is always an underlying feeling evident. Emotions are thus a matter that has a bearing on the children's feeling of safety, self-confidence and risk taking. Johnson and Myklebust (1967:1-25) further state that four aspects of the children's ability are perceiving, paying attention, thinking and learning, and that these should be integrated with one another to make possible a good relationship between their learning, achievement and basic ability, which is related to their sensory ability, motor skills and emotional condition (Kapp, 2000:267).

In addition, the possibility of learners with epilepsy to be successful in an inclusive educational setting depends on various factors. Such children remain in educational need because their health condition needs more purposeful guidance to adjust to and accept their illness in order to live peacefully. Their learning and progress are also influenced by the teacher's attitudes towards them and his or her readiness to work with them.

Learners with severe epilepsy should become involved in the school activities as much as possible, although limitations will have to be placed on their participation in potentially high-risk activities. Restrictions should be realistic and not simply because the child has epilepsy (Kapp, 2002:260-267).

### **3.6.2. Problems regarding physical aspects**

Van Den Berg, (1952:25) and Faber (1956:39) as quoted in Kapp, (2002:273) state that the body becomes an object for the learners with epilepsy, as the body with its illness becomes their enemy due to unexpected attack of seizures. Kapp (2000:176) states that it is through the body that man can be himself and can become himself. It is also through the body that man can orientate himself, can move, explore and conduct dialogue with the world. Kapp further shows that the body offers man a permanent possibility to approach things. According to Van Den Berg, as quoted by (Kapp, 2000:177), normally man feels good about his body. The body is the faithful friend of a healthy man. However, illness resulting in epileptic seizures disturbs this relationship and the body becomes strange and unfaithful.

Nearly every illness offers the possibility of regressive behaviour, especially in children. (Levellin, 1979:315 as quoted by Kapp, 2000:177) point out, however, that regression is often threatening to the child. It is characteristic of children with epilepsy that there is a continual change in the child's body. Langeveld (1964:126 as quoted by Kapp, 2000:177) maintains that a child finds it more difficult than adults to reconcile to a physical problem. They feel insecure, and this leads to poor self-concept as a result of being different from other children.

### **3.6.3 Problems with regard to cognitive aspects**

Throughout the centuries, philosophers and educationists have emphasised the importance of physical development and good health as a framework for optimal cognitive activity. There is, however, also a close association between the effective, physical and cognitive nature of the child. Hafmeyer (1970 as quoted by Kapp, 2000:180) points out that the body of the ill child with epilepsy is no longer used as medium of action, but it binds the body directly to her physical existence. This means that the child no longer feeling safe and secure, but falls back into helplessness and is restricted in the exploration of her world.

When a child is ill with epilepsy, the environment changes for her. It no longer invites her to participate. Illness as a result of epilepsy makes it difficult to learn about things in the world, and to associates with them. Epilepsy therefore has a negative effect on the cognitive level that applies to children (Morrow, 1985 as quoted by Kapp, 2000:180).

Ill children with epilepsy are often absent from school due to hospitalisation. The class continues with the schoolwork while the sick child is absent. Deficiencies and gaps develop in the child's instruction. Consequently, new work is often difficult for these children to understand. Sometimes these children under-achieve (Perrin, 1987: 28 as quoted Kapp, 2000:81) and this is exacerbated by the fact that adults expect them to achieve poorly. Although learners with epilepsy generally under-achieve, there are some who achieve well academically because the time in which they are physically less active is spent reading constructive books in hospital beds or at home. Therefore, some of these children possess a wide general knowledge.

### **3.6.4 Problems with regard to moral issues**

Isaacs and McElroy (1980 as quoted by Kapp, 2000: 179) indicate that children who do not yet have the ability to interpret the cause and affect of their epileptic condition, are inclined to interpret seizures and other symptoms as a punishment for naughtiness committed at some stage of their lives. This is because children are inclined to moralise on the level of punishment and reward. Consequently, they accept that

seizures and other symptoms of epilepsy are controlled by adults and are deliberately meted out to them as punishment.

Epilepsy does affect the moral development of the child, in the sense that they may develop unfounded feelings of guilt, as children with epilepsy often feel that they are perhaps implicated in the origin of illness. They may also feel guilty about the expense and inconvenience that their illness incurs (Kapp, 2000:180).

### **3.7 MANAGING SEIZURES**

A generalised convulsion in a child is something few teachers ever really get used to, no matter how many times they have seen it happen. Moreover, there is no way to shorten the typical generalised seizure, but there are several things that can be done to reduce its impact on the learners. There are, however, do's and don'ts on how to handle the seizures.

Sharp objects have to be out of the way. Even though the children may look as if they are in pain, they are actually having a seizure and they may stop breathing for a few moments, or become pale. This is a natural part of the seizure, caused by a temporary relapse of the blood. Tight clothing should be loosened, especially around the neck. The teacher or other adult should wipe away any saliva and turn the child on his or her side in case there is vomiting during the seizure.

Teachers should not attempt to bring them out of the seizure by using cold water, slapping or shaking, as these methods could be harmful. Restraining their movements is advisable, and no medicine or any other substance should be pushed into the mouth. Nothing else should be put in the mouth in an attempt to prevent the child from biting the tongue, as this could lead to broken teeth.

The teacher should record what happens during the attack and watch and note when the child regains consciousness, writing down the time of day and what the child was doing just before the seizure, even though this may sound like an impossibly unemotional way to approach a seizure. If convulsive seizure lasts longer than five minutes, or if the child has two of the symptoms without regaining consciousness, the

doctor must be called. Epilepsy requires immediate treatment. Managing a complex seizure mostly involves keeping dangerous objects out of the way and making sure the child does nothing to hurt himself during the seizure.

It is always important to remember that there is no conscious behaviour involved within the seizure. A child should never be punished or made to feel guilty over something he cannot control. Older children often get upset if they lose bladder or bowel control during the seizure. Ideally, there is a change of clothes handy to save the child from embarrassment if the seizures occur at school.

### **3.9 CONCLUSION**

In this section, it was evident that hospitalisation has detrimental effects on learners with epilepsy. Measured against the international movement towards inclusion, South Africa is in a relatively advantageous position. With the policy of inclusion that is currently implemented in the country, learners with chronic illnesses, including epilepsy, are more likely to receive support from teachers within the framework of inclusive education policy. The following section will attempt to explain this advantage through focusing on the findings of this investigation.

## **SECTION FOUR**

### **FINDINGS OF THE STUDY**

#### **4.1 INTRODUCTION**

In the previous section, a literature review was presented which focused on the learning support needs of chronically ill learners with severe epilepsy, and the research design of the enquiry was discussed. In this section, the findings of the enquiry are discussed. The aim of this inquiry was to gain a deeper understanding of the learning support needs of chronically ill children with severe epilepsy. As discussed in the previous sections, data for this study was collected by means of focus group interviews and individual interviews. These data were then transcribed and analysed by means of the content data analysis. Throughout the process of analysis, categories and themes emerged.

#### **4.2 FINDINGS**

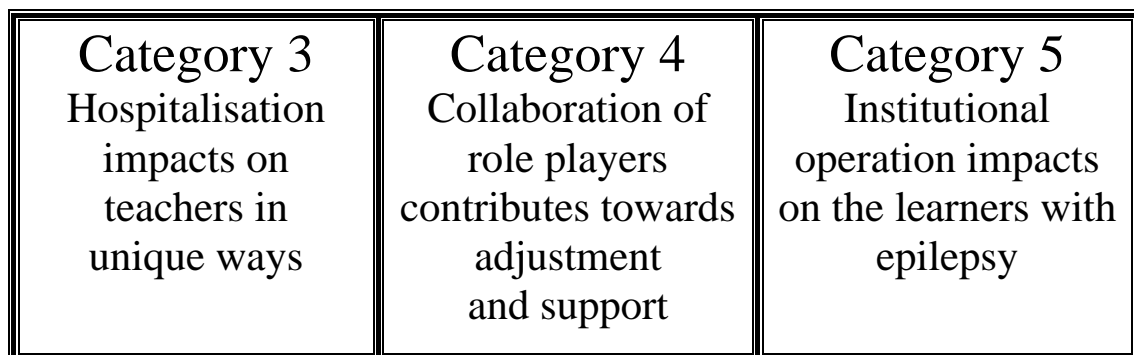
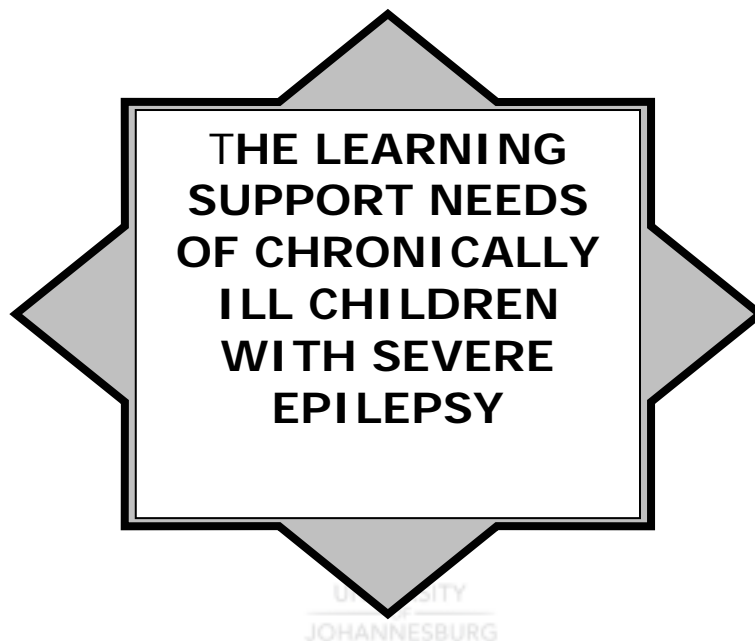
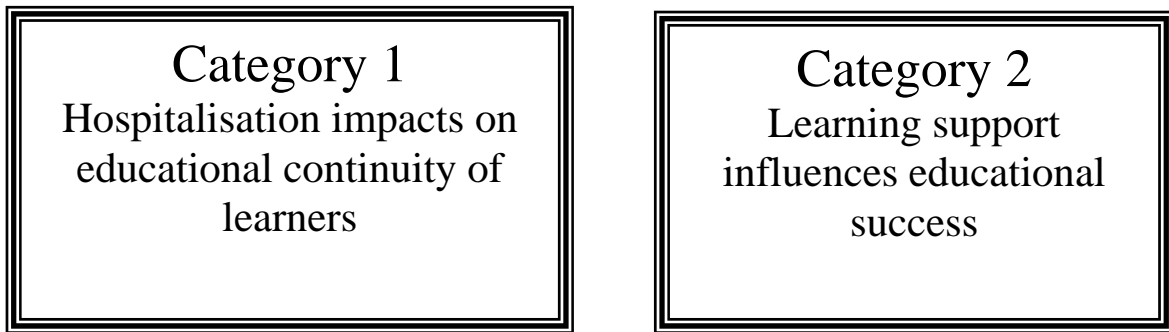
The categories and themes that emerged from the analytic process are discussed in this section. These themes are educational continuity relating to hospitalisation, as viewed by teachers, learners, and the head sister, and, secondly, the learning supports needs of chronically ill learners with epilepsy. In the third category, the theme relates to the challenges and frustrations facing teachers. The fourth category focused on the importance of communication and collaboration of all role players. Lastly, in the fifth category, institutional operation is discussed, as a hindrance to the support needs of the learners.

#### **4.3 MAIN CATEGORIES**

The concept map in 4.3. serves as an advance organiser for the discussion of the categories.



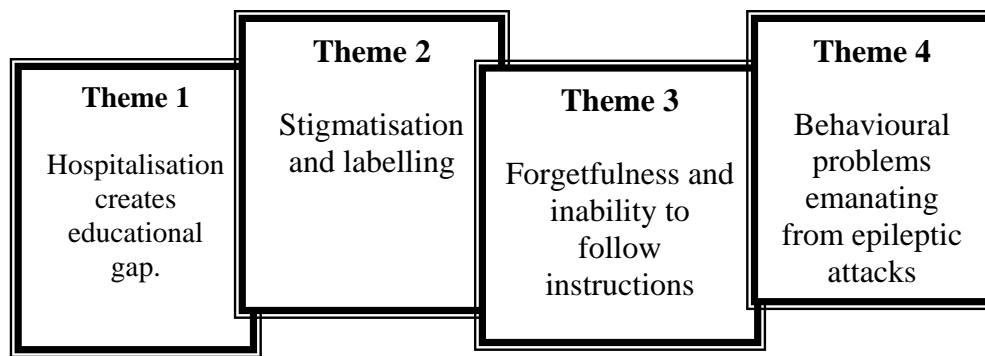
## Main categories



### 4.3.1 Category One

#### **Hospitalisation impacts on educational continuity of learners**

The concept map in 4.3.2 illustrates the constitution of this category and the manner in which it was divided into the four themes.



A significant theme that emerged was the learners' experience of educational discontinuity during the term of hospitalisation. As a result, teachers expressed their desire to continue teaching during the period of hospitalisation. They seemed convinced that continuation of tuition in hospital would also prepare the learners to cope effectively, even upon discharge from hospital and when back at the school. One teacher explained her feelings: "...*I must say hospitalisation causes break in learning, no tuition, teaching in hospital while other learners are proceeding, there is missing out of learning...*" (FG.1, line 306-307, own italics). Teachers realised that hospital environments are unfamiliar to the learners, but continuing with classroom activities should be adequate in helping them not to feel left out and at the same level as their classmates. Teachers were concerned that when learners were left alone at the hospital, they seemed to forget everything they had done at school and teachers were unable to place them correctly when they returned, as they did not know where to start.

It was striking that, for most teachers, the process of hospitalisation involved overwhelming feelings of uncertainty, anxiety, fear and constant worry. Although each child's situation is unique, most teachers were confronted with having to make adjustment decisions on a continuous basis. This is because they had to make sure that learners received proper education and support. Teachers aired their views this way: "...*hospitalisation I'm telling you is really bad for these children with epilepsy because when they are back at school, ... they are really confused children are not performing because of hospitalisation and fear of readmission.*" (FG.1, line 568-570, own italics).

Teachers had to fight for the learner's rights in the face of lack of support from their immediate educational authority, who apparently believed that these learners needed to stay at home as they caused problems in the school. Teachers' experiences of dealing with epileptic children had been ignored or by-passed by the educational authorities on numerous occasions when they sought correct educational advice in terms of the curriculum and classroom practice. Teachers continued to be faced with problems which were a hindrance to helping learners with chronic illness associated with living with severe epilepsy.

Teachers added that educational discontinuity contributed towards the educational backlog of chronically ill learners with epilepsy:

*We always start again from scratch with previous lessons especially in mathematics regarding additions counting and explaining the same thing again and again everything is new to them... Obviously there is a break when the child is hospitalised and when he comes back. They seem to have lost track of what is going on ...* (FG.1, line 308-311, own italicization).

One learner also explained her reason for low performance like this: "...We miss out, we don't have time, and we can't spell well any longer as we have spent a lot of time without writing..." (FG.2, line 661-663).

It appears that the learners had an underlying determination to achieve, but the pressure of their health condition, peer pressure and the demands of the academic work were just too much to bear. Their motivation was therefore undermined by name-calling and stigmatisation by peers and classmates. According to the teachers and the head sister involved in this enquiry, the staff frequently felt a decreasing desire to encourage these children, whilst they themselves felt demoralised and unmotivated.

Another significant concern that emerged was the medical treatment that had to be taken during school hours. It was described by teachers as disturbing the functioning and principle of classroom teaching. The learners left the classroom for the clinic to take medication, and afterwards they suddenly felt drowsy, with a consequent lowering of the concentration span. As a result, they no longer participated in the

activities in the classroom. The following day the teacher would have to start again from what the learner remembered. The learners further emphasised this point by saying: "... *We miss out*, we don't have time, and we *can't spell well* any longer as we have spent a lot of time without writing or not participating in classroom activities ..."

(FG. 2, line 661-663, own italics).

Teachers indicated that they were not sure if they were doing the correct things in their daily performance of duties in trying to help learners. Also, some regarded seizures as 'evil spirits' that have to be treated at home by parents, whereas, according to the learners, some parents had negative feelings about themselves and their children with epilepsy. For instance, they had feelings of self-blame when they discovered that this condition could be hereditary.

Moreover, learners with epilepsy are, in most cases, rejected because of their health conditions. They are isolated socially, which causes deterioration in their health. Uys and Middleton (1999:479) argue that learners with epilepsy tend to view themselves and their condition as threatening, hence they are likely to seek support. They are also threatened if they have previously experienced rejection as a result of their condition. They give up hope of anything good in their lives if no attempts are made to boost their self-concepts. Their negative self-concepts give rise to more problems for these learners as long as they are not accepted in a group. One teacher explained some of the problems she had encountered in class:

They have *learning problems* and are *stigmatised* and do not have *self-confidence* any more and he is not *performing* very well, it's true they get *teased* by friends and the elderly... When you ask them they just say others are teasing them. ... (FG.1, line 351-354, own italics).

One of the learner participant emphasised the point in this manner:

...I think while I am at hospital I felt very much *isolated* - there is no one next to me - all people are far away... I give up sometimes. I just tell myself that if I am in hospital I won't be able to do my studies. Like when I think about this disease when I am in class I won't even concentrate in class because I am

concentrating on the disease or how it affects me... (FG.2, line 604-605, own italics).

As a result, there is a strong belief among teachers and peers that learners with epilepsy are ‘mentally abnormal’, as their behaviour is not similar to the others. According to Kisker (1997:312), it has been discovered that there is more prejudice against people with epilepsy than against those with mental disorders. Uys and Middleton (1999:749) support the view that over two-thirds of people believe that people with epilepsy are ‘abnormal’. More than one-third associate epilepsy with violent crime.

The participants in this project gave other reasons for educational discontinuity. These are related to forgetting what was taught in class prior to hospitalisation, seizures as the cause of forgetting, inability to complete classroom tasks and inability to continue learning after epileptic seizures. It seemed very important to the teachers that learners received tuition during their term of hospitalisation, so that instead of experiencing confusion and frustration upon their discharge, they would be at the same level with their classmates when they returned to school. Another teacher shared her sentiments that: “... You have to address her alone *repeatedly*. Experience some problems because she has *forgotten* what was happening in the classroom they experience a *backlog in their studies...*” (FG.1, line 411-413, own itilicition).

The learners also emphasized this point in this manner:

...the other thing is like when you are going to write a test you have to go to the *beginning* and start reading *afresh alone* you can't *cope* when you have to work all by yourself...

Sometimes when I want to read I think I *may collapse* before I read so I think it is *no longer important to read*, why *must I stress* my self about reading. There is another mind that come and makes you read less and *think about collapse* and when I wake up it start from the beginning as I *have forgotten* what I read about because of this *disease is doing me...* (FG. 2, line 631-634, own italics)

At the same time, teachers wanted the learners to be challenged intellectually in terms of their scholastic work while they were in hospital. This was evident from one teacher when she said that the authorities were ready to offer tuition in hospital: "...we can plan together and *start planning* well for next year..." (FG.1, line 513-515, own italics). All the other teachers were nodding their heads as a sign of agreement.

Teachers were also concerned about the drop-out rate, due to lack of proper support for learners with epilepsy. The learners agreed with teachers regarding the educational backlog that resulted in a high rate of dropping out:

...I felt as though I am hated when I come back to school I found that I *was back*, my work is *very poor* and I have to remain in the same class I can't go to the other class even when others goes ...nurses also give us medication that makes us sleep in the class and teachers do not understand that and they end up blaming us... (FG.2, line 625-627, own italics).

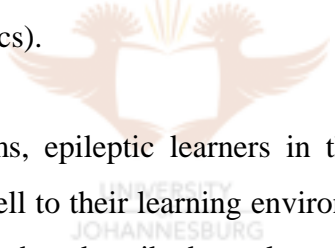
Teachers indicated that they were not only unsure and suspicious about epilepsy, but also about the personalities of these learners, as they were slow in their mental functioning. It appears as though their opinions were fixed and they were excessively concerned about their bodily functions. They were constantly irritable and could become violent at the slightest provocation: "...Many of our learners' behaviour is that of aggression and withdrawal due to low self-esteem, I think because of seizures I tell you... they are frustrated, kids are frustrated..." (FG.1, line 435-437).

In addition, teachers also confirmed that, once the other learners were orientated and informed, they behaved differently towards the epileptic learners. Their love, warmth and concern for learners with epilepsy became very much more evident, with a corresponding improvement in the condition of the epileptic child. This highlights the fact that the responses of others is a crucial factor in determining the behaviour of the epileptic learner. Most of the unacceptable behaviour, especially fighting, is not consciously and intentionally meant and violent behaviour takes place during that time of unconsciousness. Teachers said that if the behaviour of these learners was understood by peers, they could easily be accepted and accommodated. Once they

have peer acceptance, they can accept themselves and their condition. However, one of the learners expressed a different view regarding their behaviour:

...when I go to school they *will tease* me so that I would rather stay at home and pretend as though my parents do not have money. I felt as though I am *hated* when I come back to school I found that I was *back*, ...sometimes when you are hospitalised and thereafter teased we don't come back to the school you remain at home as you are *afraid* to come back to school because of teasing and you become violent... (FG.2, line 620-625, own italics).

Teachers indicated that they experienced situations that they had not been prepared for during their years of training and experience. This serves to highlight the narrowness of the teacher-training curriculum. In an attempt to help learners with epilepsy, they were uncertain what to do due to their lack of knowledge. One of the teachers said: "...workshops and in-serve training are essential to be able to handle seizures, be equipped, first aid training, provision of information is a necessity... (FG.1, line 385-387, own italics).



As a result of these problems, epileptic learners in this study were, according to teachers, not adapting very well to their learning environments and academically they performed very poorly. A teacher described one learner's academic performance in the following terms: "... She *cannot follow instructions*, at times *she just stares blank*, when you repeat the instructions it's *like doom*, and you have to address her *alone repeatedly*..." (FG.1, line 342-345, own italics).

The next theme that I will explore is the critical role of the educational support professionals in meeting the needs of learners with epilepsy.

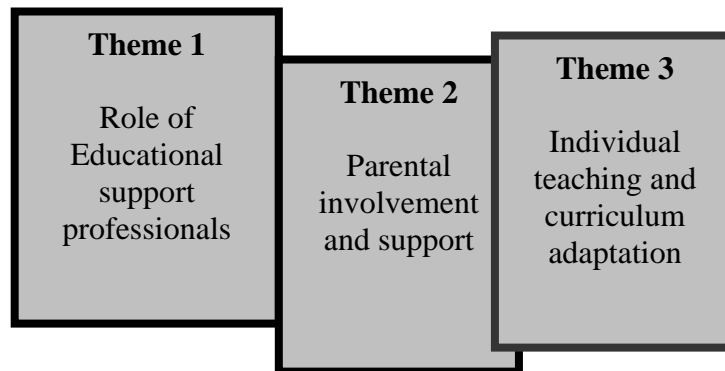
### **4.3.2 Category Two**

This category and its themes will be illustrated in the concept map below.

#### **Learning support influences educational success**

Proper support seemed to depend on the commitment and eagerness of the principal, teachers, parents, peers and other role players. The majority of teachers believed that

the principal working together with other role players could reduce the drop-out rate and level of labelling and stigmatising of learners with severe epilepsy in the school environment. Engelbrecht et al. (2001:50-51) indicate that support would require that intersect oral collaboration be pursued as a priority.



A significant theme that was mentioned by the majority of teachers was that support was not always forthcoming from the teachers and other role-players involved with the learners. Most of these role-players, including teachers, were perceived as unsupportive and uncaring, as failing to nurture the learners or meet their needs, and as not making the effort required to make a difference in the lives of the learners with epilepsy. They simply left them to cope and adjust on their own in the classroom. Another teacher emphasised this point thus:

...We also do not have learning support material to support such type of learners when they come back from the hospital. We are not effective due to the *poor level of operation in the school* but we hope to improve the level to ensure that we address this...I still put the blame on the structure of the school, structure of our school it is totally not ... working according with the special school norm. (FG.1, line 437-439, own italics).

Another teacher specifically mentioned that it was the teacher's attitude that made a difference in the lives of the learners. Instead of taking up the challenge, teachers simply said that they did not have the necessary training, skills or knowledge to work with learners who have epilepsy. Teachers acknowledged that it was important to try



and support the learners, recognise their potential and motivate them to achieve: “...*We are missing a point by neglecting the needs of the learners, leaving them to adjust and cope on their own...*...due to different disabilities that we are having, I think we better try our best even when it’s not possible.” (FG.1, line 408-411, own italics).

Other teachers also felt that teachers could do more by becoming more supportive. Most of the teachers were prepared to make adjustment for the learners in the classroom: “...we are ready to resume our responsibility...” (FG.1, line 417-419). Teachers also said that some of the major barriers to supporting the learners with epilepsy were lack of resources, knowledge and training. It seemed that, without the necessary training, teachers were inclined to feel frustrated with the situation.

Despite the efforts made by the school support team to change the organization and the running of the school, learners with chronic epilepsy still experienced less support and a greater degree of exclusion from their peer groups in the school. The teachers confessed that they were not doing enough: “...Our school is *not addressing the needs of the children with epilepsy...*” (FG.I, line 428-429, own italics).

It was further acknowledged by the participants that the school as a whole could play a very important role in supporting epileptic learners. For the majority of teachers and the hospital staff, the contribution made by the support personnel was perceived as inadequate in creating hope for the learners' futures. The contribution made by the support personnel left teachers and learners with a feeling of hopelessness.

Teachers and learners did not perceive the school as fulfilling an important role in supporting epileptic learners. Most of the teachers who were involved in this study mentioned that there were no relevant support professionals in the school. The school had the services of social workers, a remedial teacher and the clinic nurse, but they were not involved in supporting the epileptic learners. One teacher said:

*...There are no coping strategies in place, no reassurance and help for learning to be fruitful, we are killing these learners indirectly... Unless we can solve ... that problem by using the social workers that we have in our school ... like I said the nurses will tell you that there is confidentiality they do not*

have ...to trust anyone about the diagnoses of another person so we are having that problem... We do have remedial teachers at the school but no, no they are present but *not effective* ... they are not effective due to the poor level of operation in the school.” (FG. 1, line 454-458, own italics).

As a result, learners adjusted on their own as their needs were neglected. It was mentioned during the inquiry that in the school there were two teachers who held further degrees in social work and also teachers who had qualified as remedial teachers. These teachers were unable to support the learners as they had to become full-time teachers in the classroom. They could not fulfil their roles as remedial teachers and social workers and operate on a full-time basis in those roles, as they were afraid they might lose their jobs. They indicated their concerns in this manner: “*We are afraid of loosing our jobs* as a result every teacher does his own things...” (FG.1, line 500-501 own italics).

Teachers continued to refer to the lack of trust between them and their employer, for example, in the process of redeployment that their employer imposed upon them. According to them, this process was hindering other teachers from operating as full-time remedial teachers. Furthermore, the school did not have the services of other professional support specialists, such as psychologists or speech therapists. They were located at the nearby hospital, with very busy schedules, and parents could not afford to involve them privately as the majority were unemployed.

Teachers indicated that it was evident that learners were unable to cope on their own as it took time for them to understand and learn again once they had been hospitalised and after seizures. They failed to catch up on their own, but they eventually had to adjust or drop out of the school, as there was no support structure in place for them. Teachers expressed their feelings in this manner: “He will *adjust or he will fall out because I do not have the time.*” I do not *place a child that comes back from the hospital anywhere...* he will just come into class whether he has just had the attack for 3 hours or five days *I will go on with my work...*” (FG.1, line 315-318, own italics).

All the teachers involved in the enquiry indicated the need to support the learners. They indicated the importance of team-teaching in which all teachers were involved.

They also indicated that introducing individual teaching would be beneficial to the learners, although it was a difficult task. One teacher indicated that "... it was time-consuming and the learners are not very keen on that kind of solitary treatment, especially secondary phase learners, they are rejecting individualisation as they think it labels them as dull ... Once you start this thing of individualisation *the child feels like I am dull it means I am dull...I will obviously go on with the syllabus and forget about that child...*" (FG.1, line 408-411, own italics).

Most of the parents of learners with epilepsy were unemployed and poorly informed. They did not attend parents meetings and academically were not involved in the education of their children. As one teacher reported: "... I worked at the school for more than ten years but I *never consulted with a parent about the learning progress of a learner, I am teaching...*" (FG.1, line 576-577, own italics). Parents seldom visited the school, coming in only to bring their children during the opening or when the school closed for vacations. On numerous occasions they sent the learners' siblings to fetch them, a procedure confirmed by indicating the following:

Problem is that parents in the secondary section, their children will tell them that, they must not attend its not necessary to come to the school, they *rather listen to their children than to the school*. Well, in most cases the parents when they are here for parents meetings they *do not attend meetings* and it's a problem as most of them are staying far from the school..." (FG.1, line 443-445, own italics).

Learners in this way further confirmed this statement: "...We tell our parents not to come because when they come teachers tell them *lies about our behaviour...*" (FG.2, line 659-663, own italics)

It seems that the majority of learners in this study still endured the demanding circumstances of being hospitalised due to their health conditions. Most had poor self-concepts and weak personality traits that make them unable to survive in the school environment and the society at large. They were certainly unlikely to cope in their studies and appeared to possess less perseverance in getting what they wanted in life, as their levels of motivation to achieve were very low. Most of the teachers confirmed

that they were not working towards supporting the learners with epilepsy, for example saying: “But no, no presently I do *not think we do compromise ...*” (FG.1.line 561-564, own italics). Furthermore, perseverance could not be developed and nurtured at home, as some parents associated epilepsy with ‘evil spirits’ and wanted to treat this illness religiously. During the interview it was indicated by teachers that parents consulted with their religious leaders first, and it was only when the learner’s condition became more severe that they sought conventional medical intervention. Parents frequently failed to discipline children for misbehaving, for fear of the onset of seizures. Furthermore, while learners may have come back from hospital eager to resume classes and pick up where they left off, teachers were faced with the challenge of placing them appropriately. During their absence from the school, the academic process of the class moved on, and teachers were faced with the task of reassessing the learners in order to start them off again.

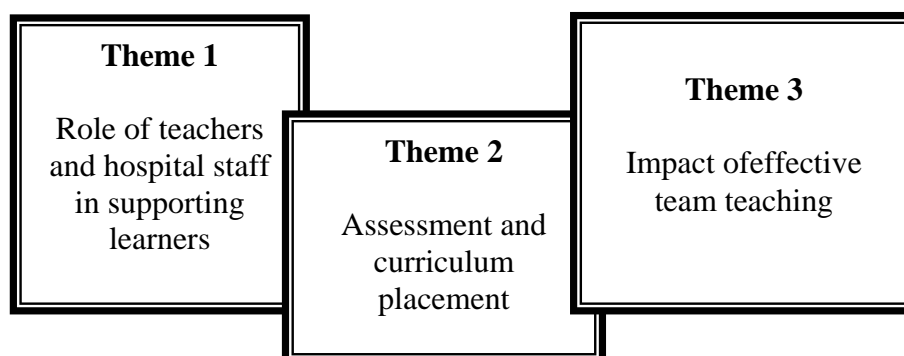
The next category that will be explored is that of the critical challenges facing teachers. The concept map below illustrates the category and its themes.



### 4.3.3 Category Three

#### **Hospitalisation challenges teachers in unique ways**

The themes that emerged during the interview regarding this category are as follows:



Most of the teachers involved in the enquiry were concerned about the problem of confidentiality that existed between them and the hospital. They felt that the hospital staff kept beneficial information from them that would help them understand the

conditions of the learners and help them support these learners with regard to their academic progress. The hospital staff felt that there were limits to the information that they could supply, as confidential information might not be divulged to any other person without the consent of the patient. Eventually, both parties realised the need to work together and to co-ordinate their services for the benefit of the learners. Both the teachers and the hospital staff agreed when it was indicated that:

...If teachers are *told* I think it will be easier for us... (FG 1, line 652-655, own italicisation). It seems the clinic and the school do not work hand in glove...we do not have *access of information* from the clinic there is no correlation between the school and the clinic. ... This thing of medication I am a teacher and I do not understand why a *child must have medication*, because nurses do not usually talk to me... (FG.1 line 357-359, own italics). "...I think working with teachers can be *beneficial*..." (I 1, line 240-243, own italics).

As a result, most of the time, teachers failed to ascertain the level of a learner's competency, so that the learners became frustrated and confused and eventually dropped out of school. Teachers involved in the inquiry referred to reassessment as time-consuming and tiring. They felt that this was the work of the remedial teachers and indicated that they wrote numerous reports to the school management team, but nothing was done. As a result, they had stopped writing reports and were trying their best, under difficult circumstances, to continue with learner assessment where possible, consulting each other for support. Some suggested team-teaching as a solution to their problems, as they regarded it as beneficial. They therefore envisaged starting team-teaching and subject committees. The teachers' frustrations were confirmed when they said:

...You are forced to address the child *alone* after giving instructions just to address whatever in order for the child to *repeat* after you. Always *repeat instruction* and *do individualization* so that you must ... you are sure that every child has followed your instructions..." (FG.1, line 335-337, own italics).

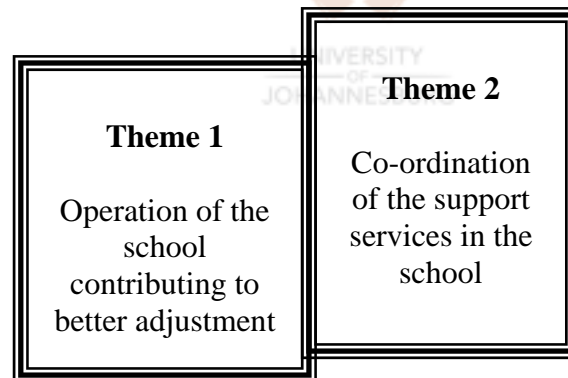
All the teachers involved in the enquiry agreed that the way the school operated had an influence on the support it offered the learners: “We are operating like normal school, whereas we are a special school...” (FG.1, line 420-423). Teachers also agreed that, together with the principal, the other members of the school support team, such as the school governing body and school management team, were all important in supporting the learners with epilepsy in the school.

The fourth category that will be analysed is the institutional operation as it impacts upon learners with severe epilepsy. The concept map showing the categories and themes will be illustrated in section 4.2.4.

#### **4.3.4 Category Four**

##### **Institutional operation impacts on the learners with epilepsy**

The following concept map illustrates the category that deals with the institutional operation that impact on learners with severe epilepsy. The themes in this category are:



It was indicated that the school operated like an ordinary school although it was a special school. One teacher said: “We are *operating like an ordinary school in a special school...*” (FG.1 line 420-423, own italics). By this she meant that the learners’ needs were not prioritised. Teachers were under pressure from the management to do administrative work in the form of completing various pieces of paperwork, as requested by the Department of Education. The quantity of such work was over-emphasised, at the expense of the quality of work. A certain amount of

classwork, homework, such as tests and projects, had to be completed by the end of each month.

Individual teaching and the pace of the learning for each learner were expressed in OBE terms, but they were not adhered to in principle. Furthermore, the completion of the syllabus was seen as more important than supporting the learners in the classroom. Teachers indicated that completion of worksheets and schedules was prioritised and regarded as important, together with the submission of marked worksheets. They also highlighted that, regardless of the learners' performance, what matters was the submission. Despite numerous reports and recommendations that the teachers had forwarded to the management, they had been told that they must proceed according to the instructions of the area management of the district. The teachers' views regarding institutional operation were expressed as follows:

...Because at the end of the month *they need that monthly test* I must just concentrate on those who are in class...this means we are more concerned with *quantity rather than quality of the learners* that we must produce. We are just *running the school normally as if the school we are working at the normal school* where learners do not have barriers whereas *we are killing them...* (FG.1, line 428-430, own italics).

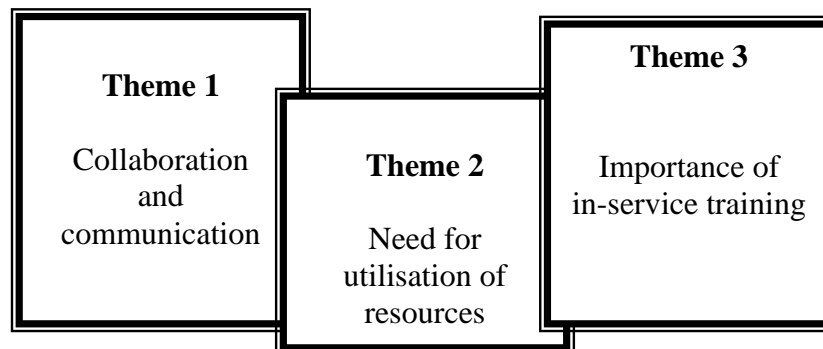
As a result of this emphasis on bureaucracy, teachers were demoralised, losing interest, not given a chance to explore, tired of the boring routine, especially since, whenever they had meetings and wrote recommendations, their recommendations were not implemented: "...we have written many reports and *we are tired...*" (FG.1, line 565-567, own italics). They further indicated that they felt sorry for the learners and hoped that White Paper 6 might bring about changes, as some of its principles were impossible to implement. However, they were doubtful that this would happen. All these problems made it impossible for teachers to co-ordinate and execute their duties, or to offer proper support for learners in the classroom.

The category that deals with the collaboration of stakeholders contributing towards adjustment and support will be discussed next, and the concept map in figure 4.2.5 illustrates the category and the themes.

### 4.3.5 Category Five

#### Collaboration of role players contributing towards adjustment and support

Collaboration and communication, the need for utilisation of resources and the importance of in-service training are the themes that discussed under this category.



Not only the teachers, the principal and the learners, but also the hospital staff, stressed the importance of a communicative relationship between teachers, parents and the hospital, and all the role-players who contributed to the successful support of learners with epilepsy. They wished to establish a working relationship between the teachers, parents, hospital and the entire support system. They also indicated the importance of establishing structures for effective communication between the nurses, teachers and parents. They realised that the school support team could make a difference, as its role was to support the whole of the school community. As a result of the poor communication by parents with the teachers, there were no links between home and school:

...Parents have to support a lot as they are the ones that are withdrawn... we normally organise sessions for them but they send the learners sisters and brothers who are too small that when we talk to them they do not even *listen* as they want to go home...parents have to support a lot, as they are the ones that are withdrawn due to their children's condition..." (FG.1, line 463-467, own italics).

One other important theme that emerged was the need to train housemothers in the school. The housemothers could also be trained about various diseases and conditions,



including epilepsy. The teachers indicated that "...housemothers need to *understand what epilepsy is*, what signs are there and what is it that they are supposed to do when the child is attacked, especially at night in the hostels..." (FG.1, line 398-400, own italics). Housemothers need to collaborate with teachers, the school management team and the entire school in order to help the learners. It was also indicated that it was very important for housemothers of various schools to interact and to share information and discuss the experience they had acquired at their individual schools. They occupy a very important role in acting as guardians when the children's parents are at home, and are responsible for look after the learners and supporting them by collaborating with other role-players. Their main responsibility is to ensure that learners get assistance when required. The following statements supported the above:

*...Not forgetting that we are a residential school... I think its very much necessary to for the housemother to be included in the school support team. I am not sure if there is any ongoing communication between clinic and parents because the nurses only do those things in the clinic it does not involve us. I do not have any communication with the nurses and I do not know what is happening in the hospital and it is about 500 meters away from the school. Unless we can solve ... that problem by using the social workers that we have in our school to lessen communication problem.* (FG.1, line 442-444, own italics).

It was also indicated that the clinic staff had an important role to play by giving learners medication. In other words, they could alleviate problems that would otherwise lead to the hospitalisation of some learners with epilepsy. In addition, the information provided by the clinic staff could enable the teachers to understand their epileptic learners better and to deal with them more effectively in the classroom situation.

The community and the school governing body were also seen as important role players in the school. Their main role is to support the staff and principal, so that the school runs properly, all learners are supported and everyone benefits from what the school has to offer. The community is also very important, as it can help make ordinary people understand what is going on in a special school. When the community

is involved in the school governing body, they can encourage their neighbours who have children with barriers to learning to come and register them at school, including children with epilepsy. Almost all the participants were in agreement with this:

We need to *improve relations* with all the *role players* in the school and the nurses ...for the sake of these learners. It's a pity as you find the school understaffed no one can go to hospital to give exercises to learners at the hospital education should continue. Like I said those people like remedial teachers, the SST must be of support to the learners I don't think they get support from the system... (FG.1, line 541-543, own italics. )

In addition, the teachers indicated that the Learners' Representative Council (LRC) could assist the school by helping to build up the confidence of the learners with epilepsy. The principal, teachers and the housemothers could not have their eyes on everyone in the school at all times, but the LRC could assist, especially during the weekend when teachers had gone home and there were a limited number of staff members on duty. It was also indicated that workshops should be organised for the LRC so that the leaders were knowledgeable about a variety of things.

#### **4.4 Conclusion**

In this section, I described the findings by means of content data analysis. I constructed and discussed five categories. The different categories were: the impact of hospitalisation on the educational continuity of learners, educational support needs, the impact of hospitalisation on teachers in various ways, the collaboration of role players and their contribution towards adjustment and support and institutional operation impacts on the learners with epilepsy.

Section Five will focus on the discussion of the findings, in terms of the aim of the study, namely to determine levels of support for learners with epilepsy in hospital and on returning to school. It will make recommendations for practice and further research in this topic.

## **SECTION 5**

### **DISCUSSION AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

In the concluding section of this study, I will focus on the discussion and interpretation of its findings, as they relate to the existing literature based on the hospitalisation of chronically ill learners living with severe epilepsy. I will briefly make recommendations based on the support needs of the learners and the partnerships of all the role players. I will conclude with recommendations for further research.

#### **5.2 DISCUSSION**

The findings in this study will add to the contextual understanding of the support needs of learners with severe epilepsy.

##### **5.2.1 Hospitalisation and educational continuity through the perspectives of the participants**

This study focused on the hospitalisation of learners living with severe epilepsy and their support needs. It aimed to add to the contextual understanding of the topic. The results of this study indicated that, for the learners living with severe epilepsy, educational continuity is of vital importance, as hospitalisation causes separation between the learner, the school, and the family, a separation that is painful for all. The learners are thrown into unfamiliar surroundings, bombarded by strange sounds, smells and sights. They are often confronted by a variety of caregivers whose methods of child-care may be very different from those of the parents. Specific cultural rituals or foods that the child is accustomed to may be missing. The concern of the participants that learners' normal way of living changes during hospitalisation seems to correlate with what Kleinberg (1982:59) refers to as "the learner's normality of functions" that may be decreased by weakness, pain or forced immobility as a result of hospitalisation. They are uncertain of the varying expectations placed upon them.

Participants view hospitalisation as causing absences from class that are often frequent and recurrent. While often short-term, these absences can add up to a substantial amount of missed school time. Good communication between the teachers, parents, school personnel, health professionals and child is also enhanced by such continuity. According to Kleinberg (1982:70-71), teachers need to be open and respectful to a number of people in developing the teacher-learner relationship; often they must strive to meet their professional objectives while supporting the needs of the learner, parents and other health professionals. Vital therapeutic treatments may need to take precedence over the school assignment. The learner's depression or sense of futility may interfere with concentration and motivation; as such, the parents may look to the teachers for comfort and support.

It was indicated that there are many learners with epilepsy in general education. Furthermore, it was argued that, for them to be successful, they need education, because their medical condition make them more vulnerable to frustration and tension than healthy learners, and they need more purposeful guidance in order to adjust and to accept their illness in order to live well. Kapp (2000:267) further argues that the learning process of these learners is influenced by the teacher's readiness to see them reach educational heights within larger context of the society. This means that the teacher should look at the subtle and indirect manifestations of epilepsy.

Mindful of the possible detrimental effects that the irregular use of prescribed medication may have, systematic yet unobtrusive observation of the learner is of importance. By carefully observing the learner in the class, the teacher can also identify the one who tries to conceal his or her problems, or is even unaware of them. This requires the knowledge of epilepsy and its manifestations by the teacher (Kapp, 2000:268).

In the participants' view, most chronically ill learners with epilepsy spend the majority of their time at the hospital and at home, rather than at the school. Hospitalisation often occurs at a time of increased stress pain and weakness, often resulting from non-compliance with the prescribed treatment, leaving the learner even

more vulnerable. Kleinberg (1982:58-59) emphasised this when he stated that for most learners with chronic illness, periods of hospitalisation are traumatic.

According to the participants, families and schools are also vulnerable to the trauma of hospitalisation of ill learners, with separation that is painful for them as well. They may even suffer from a sense of guilt about what they have or have not done, blaming themselves for having precipitated the admission. As a result, frequent hospitalisation of a learner implies loss of control by the teachers over the progress of the learners and a sense of failure in not being able to provide educational instruction.

### **5.2.2 Adapting instructional activities**

In addition to minimising the effects of hospitalisation through educational continuity, it is necessary to adapt the instructional activities and procedures to the level of the learners' potential. Lewis and Doorlag (1995:409–410) further indicate that learners require adaptation of instruction in order to keep pace with the general education. When learners miss school because of illness or medical treatment, extra instruction should be provided so that they do not fall behind. For those who work slowly, the teachers can alter requirements for assignments or amount of work and exams, more time can be allowed or the amount of work can be reduced. Lewis and Doorlag (1995:409) maintain that by adapting instruction in these ways, the general education teacher creates a learning environment in which learners have a chance of success. Planning the learner's return to school also requires a team approach, which requires collaboration between the hospital staff, school personnel, the learner and his family (Lewis & Doorlag, 1995:409–410).

In this regard the participants argued that the teacher has to be a member of a team of professionals concerned about the development and growth of the learners. Members of the team include the special education teacher, occupational therapist, speech therapist, physiotherapists, the school nurse, the doctor, the social work, regular educational teacher and parents. As a result, the inclusion of therapy procedures in the classroom encourages a close relationship between the therapists and the teacher, and reduces the fragmentation of goals, treatment and teaching for the individual learner (Bullock & Lyndal, 1992: 412-414).

### **5.2.3 Medical treatment and the academic performance**

For many participants, although the regular use of medication is essential, it was indicated that it disturbs the normal functioning of the learner in the classroom. Therefore, someone at the school needs to supervise the learners' taking of medication according to the doctor's prescription, at a time that suits the teacher. This finding is also borne out by Kapp (2000:267) who maintains that it is usually advisable for the teacher to inform classmates and other learners in the school about the medication that learners with epilepsy are supposed to take, as this information contributes to the unconditional acceptance of epileptic learners as equals by their fellow learners and helps them to reach their potential.

According to Kleinberg (1982:269), this approach relates directly to the successful re-entry of the learner into the school program, and often depends upon the support and co-operation of the learner's schoolmates. Social isolation and lack of peer interaction remain a serious negative consequence of epilepsy in schools. These negative reactions to the learners have their roots in a number of sources: lack of knowledge as to the causes of illness often leads to fear and misconceptions. Other learners, and even adults, may mistakenly assume that the illness is contagious. Epilepsy has long been erroneously associated with 'evil spirits', 'mental retardation' or 'craziness', and its victims may consequently be avoided or teased. Mostly, differentness in any form is suspect, and weakness is often ridiculed. Kleinberg (1982:269) maintains that the classroom teacher needs to address these concerns directly in order to affect attitude changes. This can be done by increasing learners' general knowledge about the illness and its effects and by helping them to explore and clarify their attitude towards the illness.

The meaning that the participants attached to the hospital routines are regarded as intrusive and disruptive to a learner's normal routine. Kleinberg (1982:59) found that learners placed in such unnatural surroundings would be fearful and anxious. Their fear may focus on the issue of abandonment or punishment. Often these fears are realised when parents, teachers and classmates failed to visit, injections are given or body parts are disturbed (Kleinberg, 1982:59). A participant learner indicated how

frightening hospitalisation is by drawing a picture that illustrated her fears (See Addendum E).

#### **5.2.4 Behavioural and emotional disturbances**

From the participants' view, behaviour and emotional indicators such as worry, stress and anxiety problems are common among epileptic learners. These learners are dependent on their teachers and parents for support, and their conduct and attitudes towards them influence the development of their personalities to a large extent. Kapp (2000:265) supports this view when he maintains that their growing up is also influenced greatly by the attitude and behaviour of friends and others in a society with whom they have contact.

Epileptic seizures overwhelm the learner with fear. They regard seizures as an embarrassment and sometimes try to disguise their condition. This frustrates the learner and s/he betrays the presence of the frustrations and inability to control the situation by rebelliousness and aloofness. Epilepsy therefore affects the learner's self concept and the defences are shattered. Kapp (2000:265) maintains that the child's epileptic condition permeates his or her whole existence and life revolves around it. All this is not easy for the child or the parents and educational errors such as overprotection, pampering and even rejection often occur, with unique complications for the development of the learner's independence. Emotionally, it is therefore a matter which has a bearing on the learner's feeling of safety, self-confidence and risk taking. Tension, anxiety, aggression, uncertainty and feelings of inferiority are types of experience that restrict the learner's ability to perceive, pay attention, think and learn (Kapp, 2000:266).

#### **5.2.5 Support needs as a requirement for success**

The importance of supportive relationships between teachers, parents, principal and the hospital staff became clear during the course of the study. The relationship between the teachers, parents and the hospital staff appears to be very important towards supporting learners living with epilepsy. A good relationship is essential for minimising the anxiety during the learner's hospitalisation by explaining the

diagnostic and treatment plan to the child at the hospital in a manner that s/he can understand. The child should be allowed as much normal activity as possible. Brunner and Suddarth (1986:1434) maintain that the most gratifying feeling was when teachers and nurses stayed with the learner after the seizure to reassure them and the parents that they would be alright, and help the learner to adjust to reality if they had a problem remembering the episode. Older children may require intervention to deal with guilt and embarrassment resulting from incontinence and other loss of physical control. Diversions appropriate to the child's age can be provided and play equipment should be such that it will not cause injury during seizure (Brunner & Suddarth, 1986: 1434).

The provision of emotional support for the child's parents is essential, by preparing them for the fact that it may take several months of regulated medication before adequate control is obtained and also referring them to the appropriate community resources and services of social workers, community health nurses, school nurse and other available services. Assurance and praise for achievement in dealing with the child is essential at all times, as parents' reaction has to be observed for evidence of rejection or over protection. All the examinations and evaluations that the child receives have to be described, for example, the blood studies and medications. Parents have to be informed about the disease, assured that epilepsy it is not contagious, is seldom dangerous and does not indicate insanity or mental retardation (Brunner & Suddarth, 1986:1436).

In addition, approaches to learning that involve learner-to-learner support can be effective in creating a classroom that encourages the participation of all learners. In such approaches, learners work collaboratively within the classroom and are encouraged to help each other with their work. Strategies may include group work, peer tutoring, mediated learning and co-operative learning. Engelbrecht, et al. (2001:50-51) furthermore indicate that a community-based approach to support would require that intersectoral oral collaboration be pursued as a priority. It is important to understand that barriers to learning and the health and social needs of a learner, rather than his academic needs, should form the basis for the working partnership. The aim is to bring together as many resources, perspectives and types of expertise as possible



to support centres of learning and communities in meeting the needs of the learners (Engelbrecht & Green, 2001:51).

The data in this study highlighted the importance of the school-based support team, which has to build partnership with the community in order to work together to support learners with barriers to learning. In terms of the ecological and systems theory, relevant subsystems cannot function in isolation, but exist in a unified relationship and influence each other (Donald et al., 2002:47). In order to promote a comprehensive, whole-school development, an approach involving all aspects of the school as organisation is needed. The need for education support services within this framework is obvious. Teachers can play an important role in building a positive teaching and learning environment and a responsive curriculum to minimise and address the support needs of learners with epilepsy and to promote their well-being. The reorientation of support services necessitates a major emphasis on intersectoral, interdisciplinary collaboration, bringing together different systems and co-ordinating support within the eco-systemic framework (Engelbrecht & Green, 2001:51).

#### **5.2.6 Meeting the learners health needs**

At the same time, learners with epilepsy may require special diets, have restrictions placed on their physical activities or take medication during school day. Swart and Pettipher (2002) propose that teachers 'break down walls' in their classrooms, that is minimise isolation and work collaboratively as equal partners with other professionals in order to effectively support learners with severe epilepsy. The teacher's first step in meeting the special health needs is to learn as much as possible about each learner's limitation and capabilities. Medical personnel, such as the school nurse, and even the physician concerned, can be the source of information which can help the teacher interpret the medical reports and translate medical findings into educationally relevant information. The nurse can explain to the teacher why certain learners have activities that should be restricted, how different medications affect the learner's classroom behaviour and what the reasons are for medical treatment and procedures.

The nurse can also help the teacher learn to deal with unusual medical situations, such as coping with an epileptic seizure in the classroom. If teachers are aware of the

proper procedures to follow when seizures occur, they will face such situations more calmly and be of more assistance to the affected learners and their peers. Information about the health needs of learners should be presented factually, with emphasis not only on the learner's problem, but also on his or her abilities. The sharing of information is particularly important for the affected learner (Lewis & Doorlag, 1995:397-398).

### **5.2.7 Communication and collaboration**

Collaboration is at the heart of a more preventative, health orientated and developmental approach to professional educational support. Collaboration is a critical issue for success. Collaboration has to be inclusive, encompassing teachers, principal, administrators, parents, learners, nurse and professional support personnel (Engelbrecht et al., 2001:22-23).

It is clear that reaching consensus regarding the collaboration of services and professionals in a school is essential. Collaboration is not an end in itself, but a catalytic process used in interactive relationships among individuals working together towards a mutually defined concrete outcome that must be an ongoing process. At school the collaborating team must share ideas and work together across a variety of settings, within an atmosphere of mutual respect, support, trust and open communication, consensual decision-making and joint ownership.

Based on the interpretation of the findings, the following recommendations can be made regarding the hospitalisation of learners with epilepsy and their support needs.

## **5.3 RECOMMENDATIONS**

As I have already discussed the findings of the study, I now proceed to make recommendations based on the findings.

- 'Wraparound' support, through a range of social, emotional, behavioural and educational support, can be offered to learners with epilepsy and their families.

This service aims to stabilise the current living situation, whether the child is residing at school or at home. Interventions help re-educate the child and family with skills for living safely and successfully ([www.mentalhealth.samha.gov/](http://www.mentalhealth.samha.gov/)). Program lengths can range from a one-time engagement to long-term support matched with a specially trained service provider; each child receives one-to-one attention and an individualised treatment plan that may incorporate vocational and education services, life skill enhancement and family support services as well as activity therapy ([www.pennfoundation.org/](http://www.pennfoundation.org/)).

- The Department of Education is urged to speed up the process of implementing the policy on curriculum adaptation, particularly for the benefit of learners with barriers. It is essential to point out that the adaptation need not by any means compromise the standard of the curriculum. An attempt has been made here to provide the teacher with practical hints and guidelines that will assist her in the classroom in order to address curriculum needs for learners with epilepsy ([www.education.pmv.gov.za](http://www.education.pmv.gov.za)).
- Collaborative working relationships between parents, teachers, learners, house-mothers, hospital staff and all other role-players must be characterized by warmth, love, perseverance, tolerance, acceptance and understanding. This working relationship should, at all times, make provision for support necessary to enable learners to cope in the classroom.
- Parents, as partners in the education of learners, should be involved at all times as classroom aides, and can be requested to visit learners who are hospitalised to offer support. The establishment of this commitment is a key in supporting learners with chronic illness living with epilepsy.
- The education of these learners always requires collaboration and communication among all role players at all levels of all systems and sub-systems involved. This implies mutual support, acceptance, involvement and willingness to work together and learn from each other.

- The house-mothers, as learners' guardians, have to be trained to help learners with homework after school so that they are further empowered to support, help and accept of the learner's health condition.
- Furthermore, the Education Department and the district support teams must work together with school support teams, taking an active role in supporting the learners with epilepsy during school re-entry from the hospital, so that learning can take place effectively in a conducive environment.
- Various policies in the department of education such as White Paper 6, Curriculum Adaptation and many others that make provision for the support requirements of learners with barriers to learning should be explained to parents and teachers for empowerment purpose.
- The findings of the enquiry showed the importance of the ecosystematic approach to learning, in which all systems are involved. This approach should be used to enhance collaboration and communication among role players.
- Regular meetings should be held to in order to communicate problems encountered in the school with the parents and also seek alternative methods of involving parents, as it was indicated that parents do not avail themselves of the opportunities offered during the parents meetings.
- Finally, all role players, including members of the community, should be trained, as some of them do not have prior knowledge in working with learners with epilepsy.

## **5.4 RECOMMENDATIONS FOR FURTHER RESEARCH**

The findings of this enquiry have emphasised the need for further research on the type of support that other role-players can offer in helping learners with epilepsy to cope well in the classroom environment. It became evident that learners who are frequently

hospitalised require certain kinds of support, and the specific impact that hospitalisation has on learners with epilepsy has not yet been investigated satisfactorily.

In addition, a study on the effects that hospitalisation of learners with epilepsy has on their classmates and family systems would also contribute to enlarging the scope of research in South Africa regarding this topic. The classmates and the family system, including consultation with siblings and parents are often neglected during research enquires. Research enquiries that focus on this topic should include investigations of the impact of hospitalisation on the classmates, the family as a whole, and even how it impacts on the teachers and the other learners' performance in the classroom.

Moreover, the research investigations should effectively examine the way nursing staff, housemothers, teachers and support personnel should be trained in further supporting the learners. The study should further examine the way in which parents, teachers, house-mothers and other role players can be trained to work together with each other in order to successfully contribute to the support needs of learners with epilepsy.

The following questions make provision for further research enquires.

- How are classmates of learners with epilepsy affected by their frequent hospitalisation?
- What are the support needs that the classmates have?
- How does the family system of learners with epilepsy respond to their frequent hospitalisation?
- What is the impact of the support structures for hospitalised learners living with epilepsy in the school?

## **5.5 LIMITATIONS OF THE STUDY**

This enquiry was done in order to be able to understand the impact that hospitalisation has on learners with epilepsy and their support needs. Thus the findings are only

representative of the views of a specific group of teachers, learners, nurses and the principal of one school. These views may not represent all learners, teachers, principals and the nursing staff. All the participants in this enquiry were from Bochum area in the Capricorn district of Polokwane in Limpopo province. All the participants in this enquiry voluntarily agreed to participate, as they are actively involved in the education of the learners with epilepsy. All these limitations are mainly related to the qualitative nature of case selection.

All the data that was collected from the participants was done by means of individual and focus-group interviews. To verify data that was collected, the main categories and themes that emerged from the study were taken back to the participants for verification purposes. Data was also verified through the means of peer verification. A colleague was asked to go through the interview and the categories and themes that emerged in order to verify the information. Thus the enquiry's limitations are directly related to the research design, which is a qualitative sampling and data collection method.



## **5.6 CONCLUSION**

In this study, I investigated the hospitalisation of chronically ill learners living with epilepsy and their support needs. The aim of this enquiry was to provide a way to achieve deeper comprehension of the impact that hospitalisation has on learners with epilepsy and their support needs at school. The study was positioned in the qualitative research design.

At the beginning of the enquiry, I presented the background to the investigation, the research problem, assumptions, and research questions. Then the literature review was presented, followed by the theoretical framework relevant to the study. This framework focused on the ecological and systems theory. Then the research design was constructed, data was presented and the findings were explored. Using the content data analysis and interpretation, the categories and themes were discussed. Finally the recommendations for further research were stated.

In South Africa, against the background of inclusive education, the advances in support for learners have been considerable, but this study has shown that there are still areas where improvements can be made. The main requirements are the adaptation of the main curriculum to the needs of the learners with severe epilepsy. In addition, it is necessary to ensure that learners are supported from hospital back into the school sector. From my findings, this does not generally take place. Professional support teams are needed to help the teachers to recognise and cope with the daily demands of meeting the specialised needs of learners with severe forms of epilepsy.



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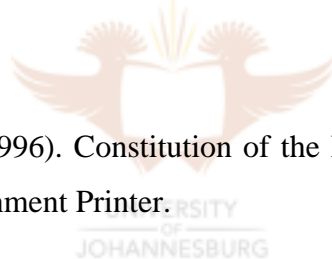
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## ADDENDUM A

### MATRIX OF RAW DATA FROM INTERVIEWS

#### THEME 1: HOSPITALISATION IMPACTS ON EDUCATIONAL CONTINUITY OF LEARNERS.

	<b>Stigmatization and labelling.</b>	<b>Behavioural problems.</b>	<b>Forgetfulness.</b>	<b>Educational discontinuity.</b>
<b>Participant 1 Teacher</b>	“They have learning problems and are stigmatized and do not have self confidence any more and he is not performing very well.”	“Many of our learners’ behaviour are that of aggression and withdrawal due to low esteem I think because of seizures.”	“We always start again from scratch with previous lessons...”	“I must say hospitalisation cause break in learning, no tuition, teaching in hospital while other learners are proceeding...”
<b>Participant 2 Teacher</b>	“Once you start this thing of individualisation the child feels like I am dull it means I am dull.”	“I tell you madam they are frustrated, our kids are frustrated, and it’s pathetic my dear...”	“She cannot follow instructions, at times she just stares blank, when you repeat the instructions its like doom...”	“Hospitalisation I’m telling you is really bad for these children with epilepsy because when they are back at school they are really confused.”
<b>Participant 3 Teacher</b>	“Its true they get teased by friends and the elderly you know people are merciless and they will also get these attacks some day too.”	“Many of our learners behaviour is that of aggression and withdrawal due to low esteem I think because of seizures”	“...explaining the same thing again and again everything is new to them...”	“Children are not performing because of hospitalisation and fear of readmission.”
<b>Participant 4 Teacher</b>	“Instructions like when you have a child with petit mal epilepsy it is usually not visible but they still get teased.”		“...and you have to address her alone repeatedly.” “Experience some problems because she has forgotten what was happening in the classroom.”	
<b>Participant 5 Teacher</b>	“I am only allowed to say to the child it is now twelve o’clock go and have medication.”	“He will sometimes just have a blank stare and you will not be realizing it.”	“When the child comes back you have to start again from the scratch with your lesson.”	“There is no more tuition in the hospital.”
<b>Participant 6 Teacher</b>	“Children are not performing because of hospitalisation and fear of readmission.”		“The other thing is forgetting during the absence or his absence the child might forget what was happening in the	“Obviously there is a break when the child is hospitalised and when he comes back.”

			classroom.”	
<b>Participant 7 Teacher</b>	“When you ask them they just say others are teasing them.”	“Depression that they may experience  ...though our learners are very naughty”	“Teacher are going to experience some problems because she has forgotten what was happening in the classroom”	“...the learner will feel not just thrown around the hospital and the school.”
<b>Participant 8 Teacher</b>	“When you ask them they just say others are teasing them.”  “As you can also have it any time so it forms a stigma.”	“...always remarking many things when they are from home they are always depressed”	“They seem to have lost track of what is going on.” “I do not think we can expect such children to perform well if you can ask that learner a question she has forgotten she has forgotten where what is was happening.”	“They experience a backlog in their studies...”
<b>Participant L1</b>	“I think while am at hospital I felt very much isolated there is no one next to me all people are far away.”	“Those other learners in lower grade are learning this teasing from us and they grow up with it to be like us, beating each other, smoking and drinking.”	“We miss out, we don’t have time, and we can’t spell well any longer as we have spent a lot of time without writing.”	“Nurses give us medication that makes us sleep in the class and teachers do not understand that and they end up blaming us.”
<b>Participant L2</b>	“...this thing is not good its going to stress him up when teacher is not around the learner won’t be able to analyse the work alone without the teacher.”	“Myself I give up sometimes I just tell myself that if I am in hospital I won’t be able to do my studies.”	“Work it means I won’t cope as they are already ahead of me because I wasn’t available.”	“I felt as though I am hated when I come back to school I found that I was back, my work is very poor and I have to remain in the same class I can’t go to the other class even when others goes.”
<b>Participant L3</b>	“You are not even free to show them your marks you are unable to ask for help because they gossip and tease you.”	“ I think that is important is to tell the learner what they have done during school hours,”	“You were not available so at least if they can do the revision if with us then we will be able to continue with our work.”	“When I go to school they will tease me so that I would rather stay at home and pretend as though my parents do not have money.”
<b>Participant L4</b>	“Most of us fail because of this thing and as learners we don’t work together but tease each other.”	“Like myself I am having epilepsy and I am epileptic and sometimes when I want to read I think I may collapse before I read so I think it is no longer important to read, why must I stress my self about reading.”	“There is another mind that come and makes you read less and think about collapse and when I wake up it start from the beginning as I have forgotten what I read about because of this decease is doing me.”	“Sometimes when you are hospitalised and thereafter teased we don’t come back to the school you remain at home as you are afraid to come back to school because of teasing.”
<b>Participant L5</b>	“You can’t even be with other learners you think if I can be with them they will start teasing me you	“Like when I think about this desease when I am in class I wont even concentrates in class	“: When other children are writing it would be good if you were send work from school for you to	“. Our work is not well done because we are not available during school hours.”

	can't do your work with them."	because I am concentrating on the decrease or how it affects me."	complete while you are in hospital so that you don't remain behind."	
<b>Participant L6</b>	"You know they will tease you so it is better to be away from them and be alone."	". Sometimes u feel like beating a person who teased you and it seems as if now you are fighting with them."	"I won't even concentrate in class because I am concentrating on the decrease or how it affects me."	"The other thing is like when you are going to write a test you have to go to the beginning and start reading afresh alone you can't cope when you have to work all by yourself and things like that."
<b>Participant L7</b>	"They have done things it seems like you are so stupid that you are unable to answer questions."	"Your behaviour is changed you have to go to the beginning and start reading afresh alone you can't cope when you have to work all by yourself."	"And you find that you are not around and have done things it seems like you are stupid and are unable to answer questions."	"I am down cause I am not at school."

## THEME 2: EDUCATIONAL SUPPORT NEEDS.

	<b>Role of support professionals.</b>	<b>Parental Support</b>	<b>Individualisation</b>	<b>Curriculum adaptation.</b>
<b>Participant 1 Teacher</b>	"Our school is not addressing the needs of the children."	"Problem is that parents in the secondary section, their children will tell them that, they must not attend its not necessary to come to the school, they rather listen to their children than to the school."	"For now I say there are no support structures to support learners as If I'm looking at the quantity of my work that I must submit to the office after a month therefore I don't have time for individualisation"	"...but if you can practice individualization it is then that you can realize everything that this learner needs help."
<b>Participant 2 Teacher</b>	"I still put the blame on the structure of the school, structure of our school it is totally not eh...eh... working according with the special school norms."	"Well, in most cases the parents when they are here for parents meetings they do not attend meetings and it's a problem as most of them are staying far from the school."	"Once you start this thing of individualisation the child feels like I am dull it means I am dull."	"...due to different disabilities that we are having, I think we better try our level best even when it's not possible."
<b>Participant 3 Teacher</b>	"It seems the clinic and the school do not work hand in glove because in the school we do not have access from information from the clinic there is no correlation between the school and the clinic at our school."	"Not forgetting that we are a residential school eh I think its very much necessary..."	"We are operating like normal school whereas we are a special school we must treat we must treat these learners individually because they are not like those learners normal schools."	"...where the management needs the syllabi to be completed and a number of so many class works, so many tests, I will obviously go on with the syllabus and forget about

				that child because I ...”
<b>Participant 4 Teacher</b>	“We also do not have learning support material to support such type of learners when they come back from the hospital.”	“...most of them are staying far from the school.”	“Yes only if I give myself time to tell the child why I am doing this individualisation thing because when he comes back from the hospital it is like his first day at school.”	“I think we must just compromise.”
<b>Participant 5 Teacher</b>	“He will adjust or he will or he will fall out because I do not have the time.”	“Other problem is that children in the secondary section,... they must not attend its not necessary to come to the school, they rather listen to their children than to the school.”	“No, no its not possible for individualisation but due to different disabilities that we are having.”	“But no, no presently I do not think we do compromise as long as we are operating like a normal school as she said ...I will obviously go on with the syllabus and forget about that child.”
<b>Participant 6 Teacher</b>	“I do not place a child that comes back from the hospital anywhere my dear, he will just come into class whether he has just had the attack for 3 hours or five days I will go on with my work.”	“...for the housemother to be included in the school support team as a guardian.”	“Well another thing that can prevent us from individualisation is the structure that we are operating.”	“No we are not addressing the needs of those learning that are experiencing the having barriers to their learning.”
<b>Participant 1 Nurse</b>		“Parents have to support a lot, as they are the ones that are withdrawn due to their children’s condition.”	“I do not know from the teachers view but at the hospital for 24hours teachers are free to go there for 24 hours.”	
<b>Participant 2 Teacher</b>	“... They are not effective due to the poor level of operation in the school but we hope to improve the level to ensure that we address this...”	“Moral of parents should also be lifted parents should not feel as being punished by God.”  “Parents must provide the school with all the full information about the child.”	“I think if upon their coming back from the hospital if they can be refereed to remedial classes.”	“The money that we receive from the department is not enough to ensure that we have necessary resources eh... for curriculum adaptation.”  “One of the problems we have with the curriculum adaptation is funding.”



**THEME 3: HOSPITALISATION IMPACTS ON TEACHERS IN UNIQUE WAYS.**

	<b>Role of teachers and hospital staff in supporting learners.</b>	<b>Coordination and placement.</b>	<b>Commitment.</b>	<b>Effective team teaching.</b>
<b>Participant 1 Teacher</b>	“You are forced to address that child alone after giving instructions just to address whatever in order for the child to repeat after you.”		“We have to be committed really...”	“What is needed in the office I do not have any communication with the nurses or other teachers and I do not know what is happening in the hospital and it is about 500 metres away from the school.”
<b>Participant 2 Teacher</b>	“To add on that I think teachers need training on such issues like epilepsy on how do they handle seizure.”	“Because at the end of the months they need that monthly test I must just concentrate on those who are in class...”	“I think we better try our level best even when it’s not possible.”	“Unless we can solve ...eh.... that problem by using the social workers that we have in our school “... like I said the nurses will tell you that there is this thing of confidentiality they do not have to ...to...to trust anyone about the diagnoses of another person so we are having that problem.””
<b>Participant 3 Teacher</b>	“if teacher are trained I think it will be easier for us as teachers how to handle the seizure because its not everyone who knows”	“This means we are more concerned with quantity rather than quality of the learners that we must produce.”	“only if I give myself time”	“Because those things are only done in the clinic by the nurses it does not involve us.
<b>Participant 4 Teacher</b>		“No we are not addressing the needs of those learning that are experiencing the having barriers to their learning”	“I think we must just compromise	“It seems the clinic and the school do not work hand in clove.”

<b>Participant 5 Teacher</b>	“I will be the first to be redeployed. ...this fear is creating a lot of problems and I think this fear is created by our system we are ready to work even harder.”	“Yes it can be possible if we all sit down as a team and convince one another that we are all operating on...”	“But we are have two social workers one speaker said they are non-functional something like that.”	“We do not have access from information from the clinic there its no correlation between the school and the clinic.”
<b>Participant 6 Teacher</b>	“Maybe those teachers did not want to be in the remedial classes because they feared that maybe they will loose their jobs.”	“We are just running the school normally as if the school we are working at the learners do not have barriers whereas we are killing them.”	“I think they are ready they can not just go on with the course if they were not interested in working with these things that is helping the kids.”	“We are afraid of loosing our jobs as a result every teacher does his own things.”
<b>Participant 1 Principal</b>	“... if there were enough teachers in the school, once the child is admitted then the school should make sure that on regular basis they visit the hospital and provide with teaching.”	“I think if arrangements can be made teachers can be able to teach during hospital stay.”	“For instance, in case of epilepsy for teachers to understand the biological background of learners’ conditions teachers need to be able to know how to teach that child in class.”	“We do have remedial teachers at the school but no, no they are present but not effective.”

#### **THEME 4: COLLABORATION OF STAKEHOLDERS.**

	<b>Ethos of the school contributing to better adjustment.</b>	<b>Implementation of policies.</b>	<b>Coordination of services.</b>
<b>Participant: 1 Teacher</b>	“Always repeat instruction and do individualization so that you must .eh... you are sure that every child has followed your instructions and at that stage.”	“Maybe white paper and inclusion may save this situation to be better of than it is now people...”	“I think consulting the school support team can solve that one...”
<b>Participant: 2 Teacher</b>	“Children are always eh guarding against the symptoms and each time they realize he is about to have a seizure they call me.”		“I think... ok I think the school support team includes the teachers and the nurses; even the nurses are in the school support team they must be included.”
<b>Participant: 3 Teacher</b>	“Yes I cannot divulge that to another learner but to another teacher I can divulge.”	“...if our system was addressing the needs of the learners and we had confidence in them I think we will not be having such kind of problems.”	“Not forgetting that we are a residential school eh I think its very much necessary to for the housemother to be included in the school support team.”
<b>Participant: 4 Teacher</b>	“For now I say there are no support structures to support	“There was a lot of fear because they don’t have	“I am not sure if there is any ongoing communication

	learners.”	trust in the system.”	between clinic and parents because those things are only done in the clinic by the nurses it does not involve us.”
<b>Participant: 5 Teacher</b>	“Like I said those people like remedial teachers, the SST must be of support to the learners I don’t think they get support from the system.”	“...the implementation is a problem like this thing of remedial teachers the SST set down and recommended that there should remedial teaching and classes but the when classified or identified a remedial class there was a problem people didn’t want to go there.”	“We have social workers, we have remedial teachers, are we utilising them, no we are not, if one teacher can say lets give this social worker an office the others will say no no no they are teachers and they must also teach but why if we put that aside and use them maybe there will be organised.”
<b>Participant: 6 Teacher</b>	“We need to improve relations with all the stakeholders in the school and the nurses ...eh ...for the sake of these learners.”		“if the child can get an attack in class I may not know.”
<b>Participant: 1 Principal</b>	“It’s a pity as you find the school understaffed no one can go to hospital to give exercises to learners at the hospital education should continue.”	“You see these days they say governance of the school is the government of the school that is the structure that can take decisions after the principal has made recommendations then the SGB will look into the coffers to see if they have money in case they have to find a project needs money, parental involvement and any other thing and implement all the good things.”	“It’s very difficult but we hope with proper mechanisms people can ensure that the community around them understand it’s necessary.”

**THEME 5: INSTITUTIONAL OPERATION IMPACTS ON THE LEARNERS WITH EPILEPSY.**

	<b>Collaboration and communication</b>	<b>Utilization of resources</b>	<b>Workshops and in-service training</b>	<b>Communication.</b>
<b>Participant: 1 Teacher</b>	“This thing of medication I am a teacher and I do not understand why a child must have medication, because nurses do not usually talk to me.”	“But we are have two social workers one speaker said they are non-functional something like that.”	“To add on that I think teachers need training on such issues like epilepsy on how do they handle seizure.”	“The other problem is the problem of confidentiality... like I said the nurses will tell you that there is this thing of confidentiality they do not have to ...to...to trust anyone about the diagnoses of another person so we are having that problem.”

<b>Participant: 2 Principal</b>	“... I think consulting the school support team can solve that one.”	“Not forgetting that we are a residential school eh I think its very much necessary to for the housemother to be included in the school support team.”	“I think training in a form of workshops or any kind of training to be able to handle learners”	“I think its necessary its not a question of that I think we must talk about that so that we might be able to help...Unless we can solve ...eh... that problem by using the social workers that we have in our school, yes, yes to lessen communication problem.”
<b>Participant: 3 Teacher</b>	“You are not allowed, only the school support team to go to the clinic.”	“We do have remedial teachers at the school but no, no they are present but not effective eh... they are not effective due to the poor level of operation in the school.”	“if we can get anybody to offer us training any kind regardless of how the training is done just information”	“Unless we can solve ...eh... that problem by using the social workers that we have in our school, yes, yes to lessen communication problem.”
<b>Participant: 4 Teacher</b>	“We are operating like normal school whereas we are a special school.”	“It seems the clinic and the school do not work hand in glove because in the school we do not have access from information from the clinic there its no correlation between the school and the clinic.”		“I sometimes see those nurses from the clinic looking for the parents’ phone numbers so that the children of such that are suffering from epilepsy.”
<b>Participant: 5 Teacher</b>	“But no, no presently I do not think we can compromise as long as we are operating like a normal school as she said.”		“People that have expertise are not given a chance.”	“This means we are more concerned with quantity rather than quality of the learners that we must produce.”
<b>Participant: 6 Teacher</b>	“he will adjust or he will or he will fall out because I do not have the time, I must submit.”	“We also do not have learning support material to support such type of learners when they come back from the hospital.”	“OK... to add on that during the past years we had such type of training by the late...”	“I do not have any communication with the nurses and I do not know what is happening in the hospital and it is about 500 metres away from the school.”
<b>Participant: 1</b>	“I think the school		“Yes, some are	“I am not sure if

<b>Principal</b>	has to talk to parents so that if the child is admitted the parents must provide the school with all the full information about the child.”		given such an opportunities to attend workshops as the school affiliates to various organizations and when the school has got money we send teachers...”	there is any ongoing communication between clinic and parents because those things are only done in the clinic by the nurses it does not involve us.”
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**ADDENDUM B**

**BIOGRAPHICAL QUESTIONNAIRE FOR THE TEACHERS,  
PRINCIPAL AND THE SCHOOL NURSRE.**

**HOSPITALISATION OF EPILEPTIC LEARNERS PROJECT**

**BIOGRAPHICAL INFORMATION**

**Participant’s biographic questionnaire**



**1. Particulars of teacher/ principal**

Full name:.....

Name of the School:.....

Address of the school:.....

.....  
.....  
.....

Gender:.....

Age: 20-30/ 30-40/ 40-50/50-60/60-70.

School standard completed:.....

Highest qualifications:.....

Years in special school:.....

Years in mainstream school:.....

Latest workshop attended:.....

Latest training attended:.....

## ADDENDUM C

### LETTERS OF CONSENT

<p>The principal .....</p> <p><b>REQUESTING YOUR PARTICIPATION IN THE RESEARCH PROJECT.</b></p> <p>I Chuma A.M, hereby request your participation in the research study that concerns hospitalisation of chronically ill children and the support requirements.</p> <p>I am presently a final year student at RAU University studying towards the degree of Masters in learning support. In the course of the project I will request you to assist me by providing information through interviews. During these interview sessions your rights will be respected and confidentiality and anonymity will be maintained which means that the source of information will not be disclosed without your permission. During this study you have the right to withdraw at any time.</p> <p>As a participant you will also benefit form this research, as you will gain new knowledge about hospitalisation of children and the support they require. Concurrently you will benefit from the recommendations that will be made and be able to assume responsibility for proactively embracing those recommendations.</p> <p>I.....on the day of .....month.....year of.....hereby declare to participate in this research project.</p>	<p>Chuma A.M. 200313119 Bochum 0790</p>
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<p>Dear participant The Nurse.....</p> <p><b>REQUESTING YOUR PARTICIPATION IN THE RESEARCH PROJECT.</b></p> <p>I Chuma A.M, hereby request your participation in the research study that concerns hospitalisation of chronically ill children and the support requirements.</p> <p>I am presently a final year student at RAU University studying towards the degree of Masters in learning support. In the course of the project I will request you to assist me by providing information through interviews. During these interview sessions your rights will be respected and confidentiality and anonymity will be maintained which means that the source of information will not be disclosed without your permission. During this study you have the right to withdraw at any time.</p> <p>As a participant you will also benefit form this research, as you will gain new knowledge about hospitalisation of children and the support they require. Concurrently you will benefit from the recommendations that will be made and be able to assume responsibility for proactively embracing those recommendations.</p>	<p>Chuma A.M. 200313119 Bochum 0790</p>
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I.....on the day of .....month.....year of.....hereby declare to participate in this research project.

Chuma A.M. 200313119  
Bochum  
0790

Dear participant  
The parent of.....

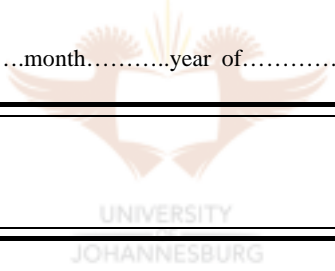
**REQUESTING YOUR CONSENT FOR THE PARTICIPATION OF YOUR CHILD IN THE RESEARCH PROJECT.**

I Chuma A.M, hereby request your child's participation in the research study that concerns hospitalisation of chronically ill children and the support requirements.

I am presently a final year student at RAU University studying towards the degree of Masters in learning support. In the course of the project I will request your child to assist me by providing information through interviews. During these interview sessions your child's rights will be respected and confidentiality and anonymity will be maintained which means that the source of information will not be disclosed without your permission. During this study the child has the right to withdraw at any time.

As a participant the child will also benefit form this research, as s/he will gain new knowledge about hospitalisation of children and the support they require. Concurrently s/he will benefit from the recommendations that will be made and be able to assume responsibility for proactively embracing those recommendations.

I.....on the day of .....month.....year of.....hereby declare to participate in this research project.



Chuma A.M. 200313119  
Bochum  
0790

Dear participant  
The teacher.....

**REQUESTING YOUR PARTICIPATION IN THE RESEARCH PROJECT.**

I Chuma A.M, hereby request your participation in the research study that concerns hospitalisation of chronically ill children and the support requirements.

I am presently a final year student at RAU University studying towards the degree of Masters in learning support. In the course of the project I will request you to assist me by providing information through interviews. During these interview sessions your rights will be respected and confidentiality and anonymity will be maintained which means that the source of information will not be disclosed without your permission. During this study you have the right to withdraw at any time.

As a participant you will also benefit form this research, as you will gain new knowledge about hospitalisation of children and the support they require. Concurrently you will benefit from the recommendations that will be made and be able to assume responsibility for proactively embracing those recommendations.

I.....on the day of .....month.....year of.....hereby declare to participate in this research project.

Chuma A.M. 200313119  
Bochum  
0790

Department of Education

**REQUESTING YOUR PERMISSION TO CONDUCT RESEARCH PROJECT.**

I Chuma A.M, hereby request your permission to conduct a research study that concerns hospitalisation of chronically ill children and the support requirements.

I am presently a final year student at RAU University studying towards the degree of Masters in learning support. In the course of the project I will request teachers, nurses, principal and learners of Helene Franz School to assist me by providing information through interviews. During these interview sessions their rights will be respected and confidentiality and anonymity will be maintained which means that the source of information will not be disclosed without their permission. During this study they have the right to withdraw at any time.

The Department of Education will also benefit from this research, as new knowledge about hospitalisation will be gained of children and the support they require. Concurrently both the school and the parents will benefit from the recommendations that will be made and be able to assume responsibility for proactively embracing those recommendations.

Hoping for your positive response.  
Yours sincerely  
Chuma A.M.

