A psycho-educational approach towards adolescents suffering from epilepsy

by

Isaac Kadi Ntlhane

MINI-DISSERTATION

Submitted in partial fulfilment of the requirements

for the degree

MAGISTER EDUCATIONIS

in

PSYCHO-EDUCATIONAL PROGRAMME DEVELOPMENT

in the

FACULTY OF EDUCATION AND NURSING

at the

RAND AFRIKAANS UNIVERSITY

Supervisor: Prof CPH Myburgh

Co-Supervisor: Prof M Poggenpoel

May 2002

ACKNOWLEDGEMENTS

I would like to extend my gratitude and thanks to the following:

I DEDICATE THIS RESEARCH STUDY

TO

ALL

FAMILIES,

HEALTH -

AND

EDUCATIONAL

SERVICES

TABLE OF CONTENTS

ABSTRACT

The primary purpose of this research study is to provide information to improve the health education of adolescents suffering from epilepsy, by giving them support through acceptance and involvement. The objective of this study has been successfully achieved. The adolescents who were interviewed and workshopped showed an emotional, educational and behavioural improvements. They are accepted by the educators and peers at their schools. The methods used in this psycho-educational approach are observation, interviews, workshops and discussions. The researcher followed a qualitative, explorative, descriptive and contextual research method.

In the second chapter the researcher described the way in which the sample has been selected and the method used to collect data. In the third chapter central themes have been identified and categorised. The fourth chapter indicates the programme development, implementation and evaluation. The fifth chapter deals with conclusions, limitations and the recommendations on what needs to be investigated by other researchers of the same interest in this topic. In this chapter the researcher also made certain recommendations to curriculum developers and other authorities regarding the transformation process in education, research and practice.

The researcher found that the lack of adequate knowledge of educators and parents is the factor that contributes most towards rejection of adolescents suffering from epilepsy. This precipitates the illness of such people. Superstitious ideas should be set aside in the management of this illness (Maddison, 1993:276). These guidelines are mainly based on the structure that reflects the description on how adolescents suffering from epilepsy should be supported, so that they accept themselves and are accepted by others. Their mental health can therefore be improved if their feelings, perceptions and thoughts of regarding themselves are positive and if they experience the same positivity of other people. If this is the case they might get the feeling that they belong to the society in a normal and healthy way, without doubting themselves and other people around them.

KAKARETŠO

Maikemišetšo a magolo a dinyakišišo tše ke go kaonafatša thuta-maphelo ya baswa bao ba swerego ke bolwetši bja go wa ka go ba fa thekgo yeo e ka tlišwago ka go ikamogela le go tšea karolo. Monyakišiši o kgonne go tšwelela go fihlela maikemišetšo a thuto ye ka ge ba botšišwa le bahlahliwa ba baswa ba bontšhitše diphetogo mabapi le maikutlo, thuto le mekgwa go dithaka tša bona dikolong. Mekgwa yeo e šomišitšwego mahlalethutong ke ye e latelago: Go tsinkela dilo, go botšiša le go ba hlhlelela tsebo le ka go ahlaahla. Monyakišiši o šomišitše mekgwa ya makgonthe, mekgwa ya go nyakolla le ya tlhaloso ge a nyakišiša.

Kgaolo ya bobedi e tšweletša mokgwa woo sampolo e kgethilwego le mokgwa wo o šomišitšwego go hwetša dilo tše di nyakegago. Kgwekgwe ya taba e hwetšwa kgaolong ya boraro. Kgaolo ya bone e na le thumo yeo e bontšhago gore monyakišiši o fihletše maikemišetšo-magolo a thuto ye nngwe ya tšeo di hlokwago go banyakišiši ba bangweba go ba le kgahlego ya go swana le mo hlogwaneng ye. Kgaolo ye, gape, e na le dikakanyo go tlhabollo ya lenaneo-thuto le go ba bagolo bao ba nago le maatla a go thoma diphetogo thutong, dinyakišišong le ditlwaelong.

Monyakišiši o hweditše gore mabofokodi a barutiši le batswadi ke ona ao a nago letšhušumetšo mo go ganweng ga baswa bao ba fokolang ka bolwetši bja go wa, gomme ka go dira bjalo bolwetši bo gakala le go feta go batho ba bjalo. Taba ya tumelwana go melekwana (superstitions) e swanetše go beelwa thoko gore bolwetši bjo bo laolege. Tsinkelo e kgolo go mananeo-thuto e agilwe godimo ga sebopego seo se bontšhago ditlhaloso ka fao baswa bao ba fokolago bolwetši bja go wa ba ka thekgwago, gore ba hwetše kamogelo ya maemo a godimo, go tšwa go bona balwetši le go tšwa bathong bao ba ba dukulogilego. Se se tla kaonafatša megopolo ya bana gabotse. Ge e le maikutlo, ka fao ba bonago dilo ka gona le go ba le dikgopolo tše

viii

botse, gona dikgopolo tše di tla kaonafala kudukudu gomme tša kgona go dula setšhabeng ka boitshepo.

CHAPTER 1

RATIONALE AND OVERVIEW

1.1   RATIONALE

Epileptic disability is a problem experienced by many Africans. Epilepsy manifests itself with seizures or fits. The patient loses consciousness, falls down and jerks. Some people become frightened by such a patient when witnessing seizures. This is due to ignorance. Most people do not know how to assist in such a situation and these patients are in most cases rejected. Uys and Middleton (1999:479) mention that people with epilepsy are more likely to evaluate their condition as threatening if they have previously experienced rejection as a result of their condition. "People with epilepsy tend to view themselves and their condition as unacceptable to themselves and to others and are thus less likely to seek support" (Uys and Middleton, 1999:479).

It is furthermore alleged that epilepsy is emanating from stress-related problems. Some people argue that the disability is inherited from parents or ancestors. Epilepsy has disadvantageous implications to learners as these learners are not able to attend lessons regularly. Many adolescents have to terminate their schooling very early due to their suffering from epilepsy. Many gifted brains are thrown away due to ignorance. Superstitious beliefs also play a role in this regard. Maddison and Kellehear (1983:266) also emphasise that primitive superstitions about the nature of a person suffering from epilepsy may cause other people to shun him to some extent.

It is alleged that spiritual-, social-, economic-, and physical related stress, as well as the abuse of substances, especially alcohol, are the factors that contribute mostly towards epileptic seizures. According to Freedman, Kaplan and Sadock (1978:2068) it is well known that emotional disturbances such as excitement, fear, frustration, tension and

anxiety are common precipitants of true epileptic seizures in many patients, particularly in older children and adolescents.

1.2   PROBLEM STATEMENT

Many useful and gifted people of this country are being ignored due to lack of adequate knowledge. Epileptic disability is a natural disability and a condition which can be controlled. There are strong allegations that epilepsy is inherited or that it originates from brain damage. After all, epilepsy is a symptom rather than a disease and it has a variety of causes.

Little or no help is provided to such people and most of them lose hope of a better life very early in their lives. This can aggravate the problem on an emotional as well as a behavioural level. The potential of the sufferers of epilepsy has in most cases never developed due to early termination of schooling because of the discouragement of parents and even educators.

In many African cultures, parents first go to the traditional healers for rescue. It may be true that the traditional healer may be of assistance with regard to witchcraft issues. Some people are of the opinion that it is not easy to ignore advice from these people, due to the philosophy and psychology applied by them. Some patients were advised that epilepsy emanates from tiredness for having been overused physically by witches during the night. Regarding female adolescents suffering from epilepsy there is a myth that there is a merciless baboon which has sex with them during the night, hence tiredness which gives rise to seizures. This may lead to a negative self-image. Maddison and Kellehear (1983:276) advise that a nurse should assist in the creation of a supportive, sensible atmosphere in which the patient can be treated. They further say that there is no place for out of date superstitions in the management of this condition.

It is observed by the schools that adolescents who are suffering from epilepsy are encountering problems in their learning process.

The research questions that can be asked are:

⇒ How does the life world of adolescents who are suffering from epilepsy look like?

⇒ How do co-learners, educators and parents view adolescents suffering from epilepsy?

⇒ How can educators and parents be assisted to support adolescents suffering from epilepsy?

1.3   OBJECTIVES

The objectives of this study are:

⇒ To explore and describe the life world of adolescents suffering from epilepsy.

⇒ To explore and describe co-learners' views on adolescents suffering from epilepsy.

⇒ To explore and describe the views of educators and parents on how adolescents suffering from epilepsy can be supported.

⇒ To develop, implement and evaluate a psycho-educational programme on adolescents suffering from epilepsy.

1.4   PARADIGMATIC PERSPECTIVE

The paradigmatic perspective is discussed under the metatheoretical, theoretical and methodological assumptions.

1.4.1   Metatheoretical assumptions

Adolescents suffering from epilepsy have painful problems regarding their self-concept. Due to this problem within them, they sometimes have a negative self-image. They are mainly worried by the fact that they do not know what is happening to them during seizure attacks due to unconsciousness, more especially when they are at school or even when they are mixing with other adolescents. After such an attack self-identity problems follow and adolescents suffering from epilepsy will keep on asking themselves questions which mostly do not arrive at answers:

⇒ What do people say when they see me?

⇒ What happens to me during seizure attacks?

⇒ Why should this happen to me?

⇒ How can I get out of this problem?

⇒ How can I become fully accepted by the community?

All these questions without answers can create more and more behavioural and emotional problems. This is why it is alleged that people suffering from epilepsy are short-tempered. They seem to be bored in most situations and they are mostly not participating in discussions or debates. The present educator in outcomes based education should have a good knowledge of such behaviour. Learners with epilepsy should therefore not be disadvantaged for little or no participation. They should be assessed in another way. Such learners have a very slow pace in writing. As such, class works, tests and examinations are never completed. The examination-oriented education system has been disadvantaging these people for a long time.

1.4.2   Theoretical assumptions

According to Farrel (1987:62) epilepsy is a condition in which the affected person tends to have recurrent seizures (fits) because of an altered state in the brain. The chemical imbalance leads to excessive electrical discharges in nerve cells, which in turn is just a symptom and not a disease. According to Reynolds and Mann (1986:620) epilepsy is the most common neurological disease. They further explain that the term "seizure" refers to the syndrome and is mostly used to refer to recurring seizures. This again has periodic or permanent cerebral dysfunctions which lead to abnormal electrical activity or discharge of cerebral neurones.

Brain (1995 in Reynolds and Mann, 1986:620) defines epilepsy as a paroxysmal and transitory disturbance of the function of the brain which develops suddenly, ceases spontaneously and exhibits a conspicuous tendency to recurrence.

According to Hughes and Corsini (1994:3) a seizure is described as an excessive, disorderly neuronal discharge, characterised by discreet attacks, tending to be recurrent, in which there is a disturbance of movement, sensation, perception, behaviour, mood or consciousness. The assumption is that all people inherit seizure threshold.

Vlok (1996:723) describes epilepsy as a fleeting, periodic, excessive neuronal discharge of energy by groups of brain cells and the brief interruption of function being known as a "fit, ictus, or a seizure". The brain disturbance develops suddenly and ceases spontaneously.

According to Freedman, Kaplan and Sadock (1973:302) epilepsy is that state of impaired brain function characterised by a recurrent, periodic, paroxysmal disturbance in mental function with concomitant alterations in behaviour or thought processes.

Epileptic conditions in most adolescents develop before the age of 20 years and never in people over 20 years. It can occur at any age between 17 years and 20 years, and these years are the most delicate years in the age of an adolescent. In most cases learners, suffering from epilepsy are underachieving due to lack of full participation to lessons or even studies. Sometimes the learner is experiencing a temporary loss of attention, and learning is therefore inhibited. Freedman, Kaplan and Sadock (1973:307) are of the opinion that feelings of depersonalisation and derealisation may last for some seconds. Related to these feelings are the sudden feelings of intense familiarity, the phenomenon of "dejá vu" (the illusion of visual recognition in which a new situation is incorrectly regarded as a repetition of a previous experience). The reciprocal experience of "jamais vu" (false feeling of unfamiliarity with a real situation that one has experienced) is also seen in the subjects. This is entirely new and strange. The frustration created by the low attainment or the failure to attend lessons regularly, are alleged to create emotional and behavioural difficulties which in turn give rise to depression and anxiety. This contributes to a low self-concept and self-identity.

1.4.3 Methodological assumptions

Methodological assumptions are based on a functional approach which Botes (1991:19) describes in her research model. This functional approach acknowledges the fact that the knowledge that has been gathered in this research project must be of value in all educational practices. This involves people and institutions such as learners, educators and parents, in places such as schools, homes and churches. This functional approach will be utilised in the derivation of findings and results of adolescents suffering from epilepsy in their everyday life and their need for support.

1.5 RESEARCH DESIGN AND METHOD

According to Creswell (1994:148) the idea of qualitative research is to purposefully select informants that will best answer the research question. The research design is mainly

programme evaluative, qualitative, descriptive, explorative and contextual in nature.
Marshall and Rossman (1995:39) illustrate Thomas's (1949) proposition that in the study
of human experience, it is essential to know how people define their situation.

Creswell (1994:152) further says that the primary material is that information which has
been obtained directly from the people or situation being studied. The researcher will
therefore collect data from the adolescents suffering from epilepsy, their co-learners, their
educators and their parents. Data shall be collected by writing essays (naïve sketches),
interviews and observations. Learners suffering from epilepsy will write on "Tell your life
story as a learner suffering from epilepsy." Co-learners will write on "How do you view
the adolescents who suffer from epilepsy?" Parents and educators, because of their
supportive role, will write on "What can be done to assist adolescents who suffer from
epilepsy?" The data collected from this situation analysis will be utilised to develop a
psycho-educational programme. The programme will be implemented and evaluated. Data
will be analysed by utilising open coding. The results will then be recontextualised in the
literature by means of literature control.

1.6   ETHICAL MEASURES

According to Holloway and Wheeler (1996:39-50) the researcher will apply principles that
protect participants in the research from any kind of harm or risk. The following aspects
will be considered:

⇒ Voluntary participation
⇒ Freedom to withdraw without discrimination
⇒ Benefits
⇒ Freedom from harm
⇒ Informed consent
⇒ Feedback

These aspects will be described in depth in chapter 2.

1.7 MEASURES TO ENSURE TRUSTWORTHINESS

Guba's (Lincoln and Guba, 1985:39-43 and 209-307) measures of ensuring trustworthiness will be adhered to. Four criteria will be utilised, namely truth value, applicability, consistency and neutrality. The application of these criteria will be discussed in depth in chapter 2.

1.8 DIVISION OF CHAPTERS

Chapter 2 : Research design and method.

Chapter 3: Description of results and literature control.

Chapter 4: Programme development, implementation and evaluation.

Chapter 5: Conclusions, limitations and recommendations.

1.9 SUMMARY

In this chapter the rationale and overview of this research was discussed. In chapter 2 the research design and method will be discussed.

CHAPTER 2

RESEARCH DESIGN AND METHODS

2.1 INTRODUCTION

This chapter will deal mainly on :

⇒ How to play a supportive role towards adolescents suffering from epilepsy.

⇒ What can be done to enable such adolescents to accept themselves.

⇒ Why epilepsy is so fearful among many people.

⇒ Why it is a problem to many educators to accept learners who suffer from epilepsy.

This chapter will also address the following:

⇒ The objectives of research

⇒ The research design

⇒ The research method

⇒ Ethical measures

⇒ Measures to ensure trustworthiness

2.2 OBJECTIVES OF THE RESEARCH

The objectives of this research are:

⇒ To explore and describe the life world of adolescents suffering from epilepsy.

⇒ To explore and describe co-learners' views on adolescents suffering from epilepsy.

⇒ To explore and describe the views of parents and educators on how adolescents suffering from epilepsy can be supported.

⇒ To develop, implement and evaluate a psycho-educational programme on adolescents suffering from epilepsy.

2.3   RESEARCH DESIGN

This research is programme evaluative, qualitative, explorative, descriptive and contextual in nature, as it is based on a set of guidelines and instructions to be followed in addressing the research problem as reflected in Mouton (1996:107).

2.3.1   Programme evaluative

This research is programme evaluative as it provides the situation analysis on how and where data is to be collected. It also provides the programme development, implementation and evaluation. The programme evaluative design is illustrated in figure 2.1 below:

Figure 2.1

Situation analysis, programme development, implementation and evaluation

Step 1: Situation analysis

⇒   Fieldwork

⇒   Adolescents write essays

⇒   Peers, educators and parents are interviewed

Results

Step 2: Developing a programme

⇒   Content

⇒   Approach

            Results

Step 3: Implementing it by workshopping

            Results

Step 4: Evaluating the programme

2.3.2   Qualitative

"In qualitative research, the researcher stresses the socially constructed nature of reality; of how participants make sense of their lives and how they experience their structure of the world" (Creswell, 1994:145). According to Burns and Grove (1993:94-108), a qualitative design is an approach in research that focuses on understanding of the phenomenon as a whole. This research will attempt to discover the experiences and needs of adolescents suffering from epilepsy in depth.

According to Kvale (1996:1) "if you want to know how people understand their world and their life, why not talk with them?" It is therefore of the utmost importance that participants should be encouraged to use their own language, so that they can be listened to and be observed comprehensively.

2.3.3   Explorative

According to Pilot and Hungler (1993:1), "qualitative researchers engage in explorative studies to get a richer understanding of the phenomenon of interest." In this research the phenomenon of interest is basically on exploring the experiences and needs of adolescents suffering from epilepsy.

According to Mouton and Marais (1990:49) the research departs from a position of "not knowing" and the researcher is willing to explore these unknown areas of interviews and workshops on adolescents suffering from epilepsy.

2.3.4 Descriptive

According to Creswell (1994:145) qualitative research is descriptive in that the researcher is interested in process, meaning and understanding gained through words. This research describes the behavioural pattern of adolescents at school and even at their homes through interviews and workshops, in a qualitative and explorative observation process. The participants are expected to describe in depth and as precisely as possible what they experience, how they feel and how they will react (Kvale, 1996:32). The researcher will try by all means not to force any prior knowledge to the participants in order to get the new unexpected phenomenon. Brink (1993:32) says that the researcher will develop an awareness of the lived experience without forcing any prior expectations or knowledge in the process.

2.3.5 Contextual

According to Mouton and Marais (1995 in Mouton, 1996:133) contextual research studies a phenomenon because of its intrinsic and immediate contextual significance. The main aim of this research is to uncover some hidden problems of adolescents suffering from epilepsy in their specific context. The researcher will never forget the time when he did the preliminary research and the cultural and socio-political background in which the participants found themselves. It is not correct to view the cultural background of participants as naïve or superstitious as meaning is shaped by the unique circumstance in which it occurs.

2.4 RESEARCH METHODS

2.4.1 Step 1: Situation analysis

In the situation analysis phase the researcher shall dwell on the life world of adolescents suffering from epilepsy and their experienced needs in their lives. Their emotional, spiritual and psychological needs as people suffering from epilepsy will also be addressed. The researcher will conduct interviews and workshops to explore the needs and experiences of such people. This research study will go deeper into the unique type of health condition of adolescents suffering from epilepsy.

It should not be ignored that the participants themselves cannot actually explain anything that is happening to them during the period of seizure. However, they can describe their post-seizure experiences and emotional feelings. To some participants the "aura" (first stage of a seizure) is highly significant. It is therefore important to the interviewer when framing his questions, to take such factors into consideration. The peers, educators and parents of these adolescents will also be interviewed.

2.4.2 Population and sampling

According to Talbot (1995:241), a population is a group whose members possess specific attributes that the researcher is interested in studying. In this study the adolescents suffering from epilepsy are sampled, together with their peers, their educators and their parents. According to Marshall and Rossman (1995:150) a researcher will determine a sampling strategy that is purposeful. In this research study the adolescents suffering from epilepsy will be sampled purposefully. De Vos (1998:191) views a sample as a subset of measurements drawn from a population in which the researcher is interested. The selection of participants will be based on grade level and age (see paragraph 2.5.3f)

2.4.3   Data collection

In phase 1 of the research study, data will be gathered from the chosen adolescents. The researcher will observe adolescents with epilepsy during workshops and interviews. They shall be requested to describe their life world and their emotional needs. In phase 2 the samples of those living with adolescents suffering from epilepsy, being parents, educators and co-learners will also be described and explored on their views of such people and the possible means and ways of giving them support. They shall write essays on the identified themes as indicated in table 2.1. Such essays will be collected by the researcher for gathering information. This is in line with what Talbot (1995:479) suggests, namely, that field notes are detailed recordings of a variety of information collected in the field of study that the researcher will write as part of the data collection process.

Adolescents write essays on: "My life world as an adolescent suffering from epilepsy."
The peers to these adolescents write on: "My view on a peer suffering from epilepsy." The educators and parents write on: "How an adolescent suffering from epilepsy can be supported."

Interviews will be conducted at schools for adolescents suffering from epilepsy, their peers and educators. Parents will be interviewed at their respective homes.

The adolescents suffering from epilepsy will be observed by the researcher twice a month. Field notes will be recoded and be kept for any further reference.

Data will be collected from the following:

⇒ six adolescents suffering from epilepsy;
⇒ three peers of these adolescents;
⇒ three educators of the adolescents; and
⇒ six parents of the adolescents.

The table below illustrates how data will be collected:

Table 2.1

Collection of data from adolescents with epilepsy, their peers, educators and parents

PARTICIPANTS	INFORMATION REQUIRED FROM RESPONDENTS
Adolescents with epilepsy	My life world as an adolescent suffering from epilepsy
Peers	How do you view adolescents suffering from epilepsy? What is the best way of assisting your peer with epilepsy? Why are you fearful of seizure attacks?
Educators	What are the possible means of assisting adolescents suffering from epilepsy? Why are you fearful of learners with epilepsy?
Parents	How can your daughter or son suffering from epilepsy be supported? What is epilepsy according to your view?

2.4.4   The role of the researcher as an interviewer

The researcher will be an equipped and experienced interviewer in qualitative research methods and he will conduct the interviews.

The interviewer will:

⇒ settle the nervousness of interviewees by assuring them that they are competent and that the interviewer is interested and sees value in what they are to say;

⇒ ascertain that participants' answers are accurately representative of their experiences;

⇒ ensure a positive interview relationship. His emotional tone and intensity of the interaction will guide the conversation. It is not only the question asked and flow of topic at hand that determine the interview relationship;

⇒ act as a facilitator. He shall not be over-talkative; instead the interviewee should be more talkative; and

⇒ indicate to the interviewees when the interview is being concluded (Denzin and Lincoln, 1994:366).

2.4.5   Data analysis

According to Creswell (1994:153) qualitative data analysis will be conducted as an activity occurring simultaneously with data collection. De Vos (1998:266) further expands that data collection, analysis and theory stand in reciprocal relationship with each other. In this research study the analysis will be based on reduction and interpretation of data.

According to De Vos (1998:271) the first basic analytical step is open coding. Data will be broken down into segments, closely examined and compared for similarities and differences. At this stage questions about emotional needs and experiences as reflected in the data will emerge. The researcher has chosen Tesch's (Creswell, 1994:155) method for data analysis. The following eight steps will be taken into account, setting a sense of the whole by reading through all the transcriptions carefully and jotting down some ideas as they come to mind:

⇒ The shortest, and most interesting document will be picked and the researcher will peruse it, thinking about its underlying meaning.

⇒ Thoughts will be written in the margin.

⇒ Having completed all documents, the researcher will then make a list of all necessary topics, putting similar ones together and arranging them in major topics and unique topics.

⇒ The researcher will then take the list and consult with the data. Topics will be abbreviated as codes written next to the appropriate segments of the text.

⇒ The most descriptive wording for the topics will be found and turned into categories. Topics that appear to relate to each other will then be grouped together. Lines may also be drawn between categories to show the interrelationship.

⇒ A final decision on the abbreviated categories will be made and codes will be alphabetised.

⇒ Data material belonging to each category will be gathered and be put in one place and the preliminary analysis will be done.

⇒ The transcribed data will be given to an independent coder who is a specialist in psycho-educational guidance. The researcher and independent coder will meet for consensus discussions.

2.4.6   Literature control

Literature will be used to describe the assumptions and values which the researcher brings to the research enterprise. Literature will be used as frame of reference from previous researchers and specialists with special reference to epilepsy. The literature will demonstrate that the researcher is well-equipped with the knowledge of the topic at hand, and that he has enough knowledge of the related research and the intellectual traditions that surround and support the study.

Existing literature is leaving some gaps due to cultural traditions and beliefs. The researcher will therefore have to fill in such gaps in this study. Smit (1995:22 in De Vos, 1998:104) states that a researcher is able to plan a project in a meaningful and scientifically valid manner only if he has made a thorough study of the literature relevant to the research theme. This study will therefore abide by the above assumption..

2.4.7   Step 2: Programme development

The data from the situation analysis will be utilised to form the framework of reference for the development of a programme.

2.4.8   Step 3: Programme implementation

The developed programme will be implemented with regard to all research participants. Workshops will be used to implement the research study.

2.4.9   Step 4: Programme evaluation

Evaluation in this research study will be used to weigh or assess the value of the study. The research will be evaluated whether it brought some changes or not. The research study will be successful only if changes are realised but where no change can be reported the study will be seen as unsuccessful.

2.5   MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness will be established by the utilisation of Guba's model (Lincoln and Guba, 1985:219) to ensure trustworthiness of qualitative research. The qualitative research in its trustworthiness will ensure the audience that the findings thereof are worth listening to and that they should have confidence in it. The model addresses ways to clean biases in the results of qualitative analysis.

The following four criteria must all be applied by using research strategies:

⇒ Credibility will ensure truth value
⇒ Transferability will ensure applicability

⇒ Dependability will ensure consistency

⇒ Confirmability will ensure neutrality

2.5.1 Credibility

Credibility will be obtained by presenting descriptions and interpretations of participants on experience, needs and emotional feelings of adolescents suffering from epilepsy through interviews and observations. The phenomena are therefore accurately identified and described. Techniques by Lincoln and Guba (1995:301) make it more likely that credible findings and interpretations will be addressed to in the following pattern:

⇒ Criteria: Prolonged field experience and observation.

⇒ Application: The researcher will take time in observing the participants and in the taking of field notes. The literature control, data analysis and description of the findings by the researcher.

⇒ Triangulation: The researcher will use six individuals in an interview but will use groups of two for workshops. Field notes and literature control will be performed.

⇒ Peer group discussion: The researcher will analytically discuss the findings of the steps followed during this research study with colleagues and two professors.

⇒ Reference adequacy: Written life stories and field notes from educators and co-learners will be provided.

⇒ Member checking: This will be based on taking the identified themes back to the respondents.

⇒ Interview technique: The interview will involve open-ended questions.

2.5.2 Transferability

The applicability of one set of findings to another context should be demonstrated. The findings of the adolescents will match the findings of the educators, peers and parents. The demonstration from one context will not deviate from the demonstration from another

context. If contexts are viewed as school, home, or church, the applicability of one set of findings from one place to another shall also be demonstrated. According to De Vos (1998:351) the burden of demonstrating the applicability of one set of findings to another context, rests more on the researcher who would make that transfer than with the original investigator.

2.5.3 Dependability

Following Robson (1993 in Holloway and Wheeler, 1996:56) a qualitative research study that establishes credibility will also be dependable. The study will prove to be dependable through dense description (Lincoln and Guba, 1985:301) of interviews and workshops of adolescents suffering from epilepsy's experiential needs and emotional feelings.

The researcher will be audited continuously by two research supervisors and two professors in the field of study. The product of the study together with new data, findings, interpretation and recommendations will be examined. The coder and recoder for this research will be an experienced qualitative researcher and an expert education specialist.

A group analytical discussion of the findings will take place. This discussion will involve the researcher, some of his colleagues and two professors. The research project will always depend on the circumstances and changes in design as the understanding of the topic at hand increases.

2.5.4 Confirmability

According to Holloway and Wheeler (1996:168) confirmability means that the gathered data are linked to their sources. The reader should establish that the conclusions and interpretations arise directly from them. All records stemming from this research study will be kept so that a trail of events can be followed. A MEd Psycho-educational programme development panel and two professors will be part of the audit team. The results of the

research should be confirmed by all stakeholders. The whole procedure of the research study up to the evaluation of data should be confirmed.

2.6 ETHICAL MEASURES

According to Holloway and Wheeler (1996:39-50) the researcher will apply principles that protect participants in the research from any kind of harm or risk. The researcher's effort to protect the research participants' rights and decisions will be done in an effort to adhere to the ethics of research (Burns and Grove, 1993:95-108).

The researcher will cover the following:

2.6.1 Relationship with participants

Following De Vos (1998:301) the participants will be informed of the particulars that attest to the researcher's credentials to reassure them that they are working with a bona fide researcher. The researcher must therefore present himself in such a way that participants will be open and interested in working with him.

The researcher will make himself known to participants by providing them with his address and telephone numbers so that they may contact him if they have additional information or if they wish to make changes. They will also be able to contact him if they have questions or queries about the research process.

2.6.2 Voluntary participation

The participants' voluntary participation will be encouraged by the researcher. The participants' freedom and flexibility will also be encouraged by the researcher.

2.6.3   Informed consent

It is not enough to get permission from participants. The participants should also know why they are asked to participate and for what reason.

Participants will be informed of:

⇒ Fair treatment

⇒ Privacy

⇒ Confidentiality and anonymity

⇒ Feedback

⇒ Benefits

⇒ Withdrawal

⇒ Procedures to be followed

⇒ Type of participation expected from them

⇒ Sample selection

(a)   Fair treatment

It is very important to inform participants that they have the right to remain or withdraw from the project. The researcher will only collect the necessary data which meet the objectives of the research.

(b)   Privacy

Participants will be assured that there is no possibility of unveiling their privacy, either physically or psychologically, which may lead to embarrassment or even demeaning them.

(c)   **Confidentiality and anonymity**

Participants will need certainty that the information provided by them will not, under any circumstances, be publicly divulged. If such a promise cannot be met, this will threaten their anonymity. It is not the intention of the researcher to threaten the anonymity of participants.

(d)   **Feedback**

The researcher will give feedback to participants. They will know the outcomes of the research openly and honestly.

(e)   **Benefits**

Participants will not only serve in the research study; they will benefit from it as they will increase their self-concept and self-identity.

(f)   **Withdrawal**

There is nothing stopping the participants from withdrawing from the project. This may happen if a participant experiences no benefit out of the project.

(g)   **Procedures to be followed**

Participants will be informed that they will be interviewed. The interviewer will expect them to answer objectively and in depth. They will further be informed that they will have workshops and that their full participation will be of value to the researcher. Field notes will be taken where participants will have to write essays on the identified themes.

(h)   Type of participation expected from participants

Participants will be informed that they are competent and that it is expected of them to give as much information as possible in the interviews and workshops. They are again expected to be honest to the researcher.

(i)   Sample selection

Participants will be informed that they have been purposefully selected as they have the potential of providing the researcher with the most comprehensive understanding of the phenomenon being studied. Participants will be piloted from secondary school boys and girls aged 17 to 20 years. They will be allowed to freely express their needs, their emotional feelings and their experiences as adolescent sufferers of epilepsy. Their peers and educators as well as their parents will also be sampled.

2.7   CONCLUSION

The researcher will now have the data at hand. At this level the programme can be developed, implemented and evaluated.

CHAPTER 3

DESCRIPTION OF RESULTS AND LITERATURE CONTROL

3.1 DESCRIPTION OF THE SAMPLE

The sample is comprised of three peers, three educators, six parents and six adolescents suffering from epilepsy, four of whom are females and two of whom are males. These adolescents are all at secondary school level. All respondents were free to talk or write in a language of their choice. Educators preferred to use English while the rest of the respondents used Sepedi during the interviews. The main focus was to get the central theme of each group of respondents.

3.2 RESULTS

The discussion of the findings is based on the identified central themes, categories and subcategories in the life world of adolescents suffering from epilepsy, as well as the views of peers, educators and parents. A central theme for adolescents suffering from epilepsy is **"Rejection related to disillusionment".** The central theme for peers is **"Fear and sympathy related to mistrust".** The central theme for educators is **"Fearfulness that epilepsy is infectious related to feeling of lack of proper training".** The central theme for parents is **"Hopefulness related to self-hatred for producing children with epilepsy".**

The literature is supporting information collected from the respondents and direct codlings are given. The following graphic representation will determine the discussion of the findings (Refer to the table 3.1).

Table 3.1

**An overview of life stories and views of respondents,
central themes, categories and subcategories**

RESPONDENTS	CENTRAL THEMES	CATEGORIES AND SUBCATEGORIES
A. Adolescents with epilepsy	Rejection related to disillusionment	1. Social isolation related to loneliness ⇒ Threatening situations ⇒ Social embarrassment ⇒ The idea of self-hatred 2. Negative self-concept related to interpersonal conflict ⇒ Feeling of self-pity ⇒ Negative self-image ⇒ Dependence 3. Stigma attached to mental illness related to hostility . ⇒ Frustration ⇒ Anxiety ⇒ Aggressive behaviour

B. Peers	Fear and sympathy related to mistrust	1. Feelings of insecurity ⇒ Misinterpretations ⇒ Violence on slight provocation 2. Sympathy towards the adolescent ⇒ Love ⇒ Warmth ⇒ Concern 3. Fearfulness towards seizure attacks ⇒ Mistrust ⇒ Insecurity ⇒ Lack of proper information
C. Educators	Fearfulness that epilepsy is infectious related to feelings of lack of proper training	1. Awareness of insufficient knowledge ⇒ Hysteric fit as compared to epileptic fit ⇒ Superstitious beliefs 2. Need to be workshopped towards knowledge of epilepsy ⇒ Reality about the condition ⇒ Cry for proper knowledge 3. Fearfulness and feelings of insecurity ⇒ Embarrassment ⇒ Insufficient knowledge

D. Parents	Hopefulness related to self-hatred	1. Empathy and tolerance
		⇒ Feelings of encouragement
		⇒ Readiness to accept guidelines
		⇒ Despair
		2. Feelings of self-blame
		⇒ Epilepsy originates from heredity
		⇒ Faulty beliefs
		⇒ Need for more knowledge
		3. Having concern with self-motivation
		⇒ Preparedness for improvement
		⇒ Playing a parental role

The following discussions are based on table 3.1.

3.2.1 Adolescents with epilepsy

The central theme for adolescents with epilepsy is **"Rejection related to disillusionment."** This theme is discussed under the following:

3.2.1.1 Social isolation related to loneliness

Adolescents suffering from epilepsy are in most cases rejected due to their condition of health. They are socially isolated and this gives rise to deterioration in their health as they become emotionally disturbed. One respondent said: *"Ga ke tsebe gore ke tlo feletša kae ka bolwetši bjo"* (I do not know where I shall end up with this illness.). Another one said: *"Ge ba roma ba bangwe toropong, ba re nna ke šale ka gae ka gore ke tla thulwa ke dikoloi"* (When others are sent to town, I am ordered to remain at home because I shall

be knocked down by motor cars.). Yet another one said: *"Ge ba eya go raloka ga ke kgone go ya le bona"* (When they are going to play, I cannot go with them.). Kisker (1997:312) reports that the social rejection of the individual suffering from epilepsy occurs on a world-wide basis. The loneliness that this adolescent is experiencing creates even more emotional and social problems which in turn give rise to seizure attacks. Man is born a social being and these adolescents should have normal social relations to be able to improve their health.

3.2.1.2   *Negative self-concept related to interpersonal conflict*

One adolescent said: *"Ke hweditše bokaone e le go ineela bjalwa gore ge ke ewa ke se ke ka ikwa, gore moya wa ka o se ke wa tshwenyega"* (I found the best solution is to resort to alcohol so that I may not be spiritually harmed when I experience seizure attacks.). Uys and Middleton (1999:479) are also in line with the problem of these adolescents when they say that people with epilepsy tend to view themselves and their condition as threatening and are thus likely to seek support. They added that people with epilepsy are more likely to evaluate their condition as threatening if they have previously experienced rejection as a result of their condition.

Freedman, Kaplan and Sadock (1973:303) indicate the initial cause of such frustration when they say that on recovery from seizure the adolescent usually complains of muscular aches and often of severe headache. Even with complete recovery there may be feelings of depression and despair, often in reaction to the reality aspects of the seizure and social embarrassment. Uys and Middleton (1999:483) are of the opinion that people with a negative self-image tend to label all situations as threatening. One adolescent said: *"Nna ke lapišitšwe ke bophelo. Ga ke na mohola bathong, ke dula ke le morwalo wa ba ba ntlhokometšego"* (I am tired of living. What's more, I am of no value to other people, and I am always a burden to those who care for me.). Such adolescents are likely to give up hope of anything good in their lives if no attempts are made to uplift their self-concept. Some may even commit suicide as they are always striving towards the betterment of their

situation. The negative self-image gives rise to more problems to adolescents with epilepsy as long as they are not accepted in the group. These adolescents will always experience emotional problems which mostly result in epileptic seizures.

3.2.1.3 Stigma attached to mental illness related to hostility

There is a strong belief that adolescents with epilepsy have an element of abnormality. Their condition is in most cases misinterpreted. One adolescent girl said: *"Dithaka tša rena tša bašimane di boditšwe gore ga se ra felela mogopolong, ka lebaka leo ga ba na le kganyogo go rena"* (Our peer boys have been told that we are mentally abnormal, as such they cannot even propose love to us.). According to Kisker (1997:312) it has also been found that there is more prejudice against people with epilepsy than against those with mental disorders. Uys and Middleton (1999:749) also support this statement when they say that over two thirds of people believe that people with epilepsy are abnormal and more than one third associate epilepsy with violent crime.

Once assured that they are normal beings without any sickness but just a condition, an adolescents with epilepsy experience themselves just like any other people and are likely to progress very well in their lives.

3.2.2 Peers

The central theme for peers is: **Fear and sympathy related to mistrust**. This theme is discussed under the following:

3.2.2.1 Feeling of insecurity

There is a wide range of misinterpretation by peers of adolescents suffering from epilepsy, due to lack of proper education and exposure. One peer said: *"Ge o ka mo kgoma goba wa hema moya wo o tšwago go yena mola a wele, o tlile go fetelwa ke bolwetši bja go*

wa" (Once you can touch him or inhale the breath from him while he is unconscious, you will be infected with epilepsy.).

Peers are not only unsure and suspicious about the illness, but also about the personality of adolescents with epilepsy. The views of Maddison and Kellehear (1983:271) on the personality of a person suffering from epilepsy are that these people show certain personality characteristics with great frequency. They tend to be slow in their mental reactions, they are fixed in their opinions and they are excessively concerned about their bodily functions. They may be constantly irritable and even violent on slight provocation. One adolescent girl had differences with her educators for her ill-treatment towards her classmates. This adolescent with epilepsy said: *"Bana ba ba a nnyatša, ga ba ntšee bjalo ka motho. Ke tla ba lokiša"* (These children are undermining me. They do not consider me to be a human being. I shall fix them up.).

3.2.2.2 *Sympathy towards the adolescent*

Once they are oriented and informed, the peers become different in behaviour and attitude towards adolescents with epilepsy. Their love, warmth and concern towards such adolescents become very much increased. Within two months educators at three schools reported a remarkable change in relationships. Peers could assist the adolescents during epileptic seizures in the absence of educators. At one school there was a report that the peers helped an adolescent with epilepsy on the way between school and home. After they have observed their circumstances they have much concern of their fellow peers suffering from epilepsy. One peer said: *"Ke ngwana wa bo rena. Re tla leka ka maatla go mo thuša"* (She is our sister. We shall try by all means to help her.).

3.2.2.3 *Fearfulness towards seizure attacks*

One peer reported: *"Nna ge a thoma go wa ke a tšhoga"* (When he starts falling, I personally become fearful.). People suffering from epilepsy should be understood and

correctly interpreted. The nature of the condition changes the behaviour of such adolescents. Violent behaviour takes place during the time of unconsciousness. Most of the unacceptable behaviour, especially fighting, are not consciously and intentionally meant by these people. If the behaviours of adolescents with epilepsy is well understood, peers easily accept and accommodate such adolescents. Once they have their peers' acceptance they accept themselves and their condition.

3.2.3   Educators

The educators' central theme is **"Fearfulness that epilepsy is infectious related to the feeling of lack of proper training."** This theme is discussed under the following:

3.2.3.1   *Awareness of insufficient knowledge*

Educators experience situations which they never knew or learnt about before during their years of teaching including their training. This goes back to the narrow curriculum which they received. In an attempt to help, they are always operating on trial and error methods. One educator said: "We are not sure as to whether we are doing the correct thing, or whether we are worsening the situation." She further said that they were not sure whether the condition was infectious. Another educator said: "During such a situation of seizure attacks, we as educators have a problem of how to help these adolescents suffering from epilepsy."

3.2.3.2   *Need to be workshopped towards knowledge of epilepsy*

One educator said: "We cannot do anything with such deeds of evil spirits. What we can do is to send a message home so that parents may come to fetch their ill child." She further indicated that such problems belong to the parents and not to the school. Maddison (1983:276) advises that the nurse should be assisted in the creation of a supportive, sensible atmosphere in which adolescents suffering from epilepsy can be treated. He

further indicates that there is no place for out of date superstitions in the management of this condition. This is very important for educators as nurses of learners on a daily basis. This is contrary to schools in South Africa, where educators are nowhere supported or assisted with regard to the management of epilepsy.

Sometimes educators confuse fits with exhaustion. This is due to insufficient knowledge about epilepsy. If workshopped, educators deal with each and every situation happily and without confusion. Ironbar and Hooper (1991:365) clarify these differences by saying that unlike hysterical fit which responds to painful stimuli, epileptic fit has no response. Sensation slowly returns as sufferers recover from seizure. They further say that a person with hysterical fit is usually well orientated, but the one with epileptic fit may be confused and exhausted afterwards.

3.2.3.3   *Fearfulness and feeling of insecurity*

Educators, just like peers believe that epilepsy is infectious. They are not free to touch an adolescent with epilepsy. Some adolescents suffering from epilepsy were ordered by educators to remain at home or to go to special schools, which are not existing. Educators also associate epilepsy with violent crime as mentioned in paragraph 3.2.1.3.

Educators who have been educated and who are accepting the condition, are improving the circumstances of their epileptic learners. They are mutually accepting that epilepsy is nothing else but a condition.

3.2.4   Parents

Their central theme is: **"Hopefulness related to self-hatred."** This theme is discussed under the following:

3.2.4.1 *Empathy and tolerance*

Parents have certain feelings regarding the condition of their children and some of them do not seem to lose hope. One parent said: *"Na ke bolwetši bja mohuta mang bjo bja go se alafege? Feela ke tla tshela meedi le meetšana go fihlela ke felelwa ke lešaka"* (What type of illness is this which is incurable? But I will go up and down until I remain without a cent.). On the contrary another parent said: *"Ge dithaka tša gagwe di reka dikoloi yena o tla dula e le mokgopedi"* (When his peers buy motorcars of their own, he will remain a beggar.). Hallas, Fraser and MacGillivray (1982:226) clarify this misconception by pointing out that it is important to remember that a person suffering from epilepsy who has been free of day-time seizures for a period of three years is not debarred from holding a driving licence. Hallas, Fraser and MacGillivray (1982:227) say: "In the care of mentally-handicapped person suffering from epilepsy a certain degree of risk must also be accepted in a attempt to ensure a reasonable quality of living."

3.2.4.2 *Feelings of self-blame*

Some parents, if not all of them, have negative feelings about themselves and their children with epilepsy. They even develop feelings of self-blame when they discover that this condition originated from heredity. One parent said: *"Ngwana wa ka o segwa ke batho, e ntše e se molato wa gagwe"* (My daughter is laughed at by people, even though it is not her fault). Another parent mentioned: *"Ke gona gore madimabe ga a hlapiwe"* (There is a saying that bad luck cannot be washed off). Kisker (1977:313) illustrates this by saying that there is evidence that heredity plays an important, if not completely clear role in the aetiology of convulsive disorders of the idiopathic type.

3.2.4.3   *Having concern with self-motivation*

Parents are positive regarding their self-motivation. They accept guidelines happily and in a hopeful mood. One parent mentioned with a deep concern: *"Nna ke tshepha go feletše gore re nyakile go dira phošo ka go hloboga ngwana yo. Le yena ke motho wo a feletšeng"* (I personally fully believe that we nearly committed a mistake by losing hope of this child. He is also a complete human being.). At their homes adolescents with epilepsy are improving very fast due to the acceptance they experience from their parents.

3.3   APPOINTMENTS

The principals of schools targeted were free and accommodative towards this research study. Due consideration, however, was given to avoid loss of valuable school time by learners and educators. The school has been the only common place to get samples. The best time has been during breaks and after school.

Parents alone were met at their homes on the agreed-upon times. Parents together with their children suffering from epilepsy were met during weekends at their respective homes.

3.4   FIELD NOTES

Interviews were held at schools where adolescents with such a disability were identified. Field notes were kept for further references. Peers and educators were also interviewed at their schools. Due to supportive measures taken, the interviews were accepted with gratitude by learners, educators and parents. Parents were interviewed at their respective homes. As researcher used psychological methods, they were able to relieve their painful emotional outbursts. The researcher is presently visited by more adolescents and their parents, even those who are already out of school due to epilepsy. The visits are made at

the researcher's home after the parents have learned from those who were involved in the research project. The community therefore benefits from this research project.

3.5 CONCLUSION

It is very important to have the ability to encourage and support those adolescents with epilepsy, particularly in a psycho-educational approach. The desired impression must be created during communication. The adolescents should be influenced in the way it is intended. Communication with the adolescents must create an impression one wishes, and influence the adolescents in the way one intended. This gives one the ability to identify emotions and to be to resolve conflict. Whenever one communicates with other people, whether they are adolescents, strangers, relatives or elderly people, it is necessary and important to make them feel at home. The adolescents with epilepsy might feel very depressed due to previous rejection of others. This may lead to mental illness if they are continually socially isolated and rejected. They should also be accepted as people of worth in the community.

CHAPTER 4

PROGRAMME DEVELOPMENT, IMPLEMENTATION AND EVALUATION

4.1   PROGRAMME DEVELOPMENT

4.1.1   Components of the programme development

These components are based on the following:

⇒ Encouragement

⇒ Supporting role

⇒ Self-concept

⇒ Self-esteem

⇒ Interpersonal communication and relationship

4.1.1.1   *Encouragement as a component*

According to Fisher (1991:749) it is very important and encouraging to identify people who have found a modus operandi and can even overcome their handicap. This will do much to restore a healthy self-concept and to enhance confidence of people with disabilities.

Fisher (1991:749) further mentions that people suffering from epilepsy and their families can be helped to become active and even renowned individuals who suffered from epilepsy but have lived full, illustrious lives. According to Fisher (1991:749) St Paul, Abram Lincoln, Julius Caesar and many other people were epileptics.

From these examples it can be concluded that epilepsy is not only disadvantageous. It may stimulate or disinhibit energy, releasing the drive required for great accomplishment in oratory, creativity and leadership. If energy is stimulated, one may not feel the pain of being an individual suffering from epilepsy but this will take time and needs encouragement.

4.1.1.2 Support role as a component

The closest people that can provide support are parents, educators and fellow learners. According to Fisher (1991:749) educators should know how to explain seizures and the learner's needs to his fellow learners who are then usually surprisingly tolerant and supportive.

4.1.1.3 Self-concept as a component

According to Stuart and Sundeen (1991:372) self-concept can be defined as the motions, beliefs and convictions that constitute an individual's knowledge of himself and influences his relationship with others. Human behaviour reacts to the world in terms of the way a person perceives it. Self-concept emerges as a result of each person's experience within himself (Stuart and Sundeen (1991:373). Body image during adolescence is a crucial element in shaping the person's self-concept and in facilitating or retarding attainment of status and adequate social relations. People living with someone suffering from epilepsy must treat them in such a way that his self-concept is raised.

4.1.4 Self-esteem as a component

According to Stuart and Sundeen (1991:376) self-esteem is human beings' personal judgement of their own worth, obtained by analysing how well their behaviour conforms to their self-ideal. Self-esteem is lowered when love is lost and when one fails to receive

approval from others. When one is loved and applauded and is praised, the person's self-esteem is raised. According to Perko and Kneigh (1988:339) an individual's self-worth, self-esteem and integrity are enhanced by acceptance, respect and concern for his well-being. The self-esteem of these adolescents should be promoted to re-examine negative feelings about themselves to identify their positive attributes (Wilson and Kneisl 1992:478). To accept, respect and to have concern for people with epilepsy promote their self-esteem, their self-acceptance and their self-worth.

4.1.5 Interpersonal communication and relationship as a component

According to Johnson (1997:105) to live is to communicate. All life creatures communicate in some or other way. Johnson states that communication is the foundation for interpersonal relationships and people's daily lives are filled with one communication experience after another. Human beings are able to reach some understanding of each other, to learn to like, to influence, and to trust each other and to begin and to end relationships. They are able to learn more about themselves and how others perceive them.

Johnson (1997:106) defines interpersonal communication as a message sent by a person to a receiver with the conscious intent of affecting the receiver's behaviour. It takes two to communicate. Through communication with another person human beings begin or maintain relationships. Isolation of people from others will result in lack of communication and this may lower the self-concept of such people.

Johnson (1997:6) further mentions that relationships are the key to personal development, productivity, identity and career success, quality of life, physical health, psychological health, coping with stress, self-actualisation and humanness. A happy life is synonimous with good social relationships.

4.1.6 Guidelines on the approach to programme development

The basic guidelines will be objectives, experiential learning, the role of the facilitator and supportive measures.

4.1.6.1 Objectives

⇒ The objectives of the programme should make a person aware of those aspects that create negative impacts on epilepsy.

⇒ The format of the programme should be structured in such a way that it reveals that self-esteem begins when people are assured that they are worthy of good health and that they are valuable to others.

⇒ Being open to another person enhances one's relationships which will promote one's self-esteem.

⇒ The programme can develop exercises that encourage positive attitudes towards one another irrespective of illness.

⇒ A successful programme provides helpful listening and responding skills, constructive problem solving, constructive communication skills and constructive interpersonal skills.

⇒ A planned and developed programme helps adolescents and parents in building and maintaining interpersonal trust.

4.1.6.2 Experiential learning

According to Johnson (1997:21) all people learn from their experiences. Many things relating to other people can be learned only by experience.

Experiential learning is based on three assumptions:

⇒ People learn best when they are personally involved in the learning experience.

⇒ Knowledge should be discovered to mean anything or to make a difference in behaviour.

⇒ Commitment is highest when people are free to set their own learning goals and actively pursue them within a given framework.

Reading on how to support and assist other people is not enough to make one skilful in giving others support in case of epilepsy. A programme that provides exercises that involve adolescents and parents to practice and experience good supporting roles is the best therapeutic programme to promote health supportive measures.

4.1.6.3   *Role of the facilitator*

The role of the facilitator is to be able to:

⇒ identify causes of negative attitudes towards others;

⇒ create means and ways of changing such attitudes;

⇒ encourage positive attitudes among adolescents, educators and parents; and

⇒ highlight the importance of viewing all people as created by God with a specific aim.

4.1.6.4   *Supportive measures*

The developed programme is supportive when its activities and exercises help to develop and bring about positive attitudes in the lives of adolescents, educators and parents. The following are seen as therapeutic measures in a developed programme:

⇒ constructive interpersonal skills;

⇒ constructive communication skills;

⇒ interpersonal effectiveness;

⇒ constructive conflict management skills; and

⇒ development of appropriate trust.

4.2   PROGRAMME IMPLEMENTATION

The programme will be implemented by means of workshops.

4.2.1   Workshopping adolescents suffering from epilepsy

Appointments have been made via school principals with these learners. The learners were collected and brought to one centre for workshops. The most appropriate times were during break times in order to meet the needs of the schools. Two workshops have been conducted. These adolescents were divided into three groups of two. Their main topic during the group discussions was "epilepsy" and the group came up with different opinions. The first group was concerned about their future occupations, the second group was mainly concerned about rejection by others and the third group was concerned about the means of curing or controlling epilepsy.

During discussions certain solutions were given. These solutions include acceptance of oneself as a person suffering from epilepsy. A person who experiences acceptance by other people will reach maximal potential without any fear of illness. These adolescents are gradually learning and understanding the individual signs or indicatives towards the on-coming seizure. They also understand that they must report to an immediate and nearby person during such signs and indicatives.

During these workshops one got the feeling that these adolescents viewed themselves differently from the past. Each one described his "aura" (first stage of the seizure). This is also seen as an "eye-opener stage". These adolescents are finally referred to the Johannesburg Hospital for medication by specialists.

4.2.2 Workshopping peers

The peers are the classmates of adolescents suffering from epilepsy. The workshops of these peers were conducted at different schools. The main issue was the feelings of peers towards adolescents suffering from epilepsy. Issues raised mostly were sympathy, fearfulness and mistrust. It is important that peers should understand what epilepsy sufferers go through. It is also necessary to rectify all false information given to them through cultural beliefs, to accept sufferers of epilepsy and to avoid the social isolation of adolescents suffering from epilepsy. These adolescents are children of God, like any other person, and they should not be rejected so that they also can reach their full potential.

Another important contribution of the peers is the intention of assistance of their classmates suffering from epilepsy when witnessing seizures. This involves providing first aid without running to educators. Learners had a dramatic play to illustrate first aid and the indications of the three stages of a seizure attack, namely the "aura", the seizure self and the post-seizure stages.

4.2.3 Workshopping educators

The workshops for educators were conducted at different schools. Two workshops for each centre were conducted. Workshops were mainly aimed at equipping educators with knowledge of epilepsy. These workshops were aimed at helping educators to give assistance to their learners with epilepsy and to make the educators understand why these learners must attend normal schools and not special schools.

Educators also conducted their workshop through a dramatic play. They discussed different ways about the "how to assist" aspect. They ended up knowing that nothing should be given to these learners to drink while they are still unconscious. They should avoid any attempt of awakening these learners by calling them by name. They should not

interfere with the jerking of muscles but should only make them lie on their side and remove any obstacles which may harm them. They should await the recovery of such learners and they should not attempt to make them recall past events upon recovery. Educators should not give signs of sympathy towards the recovered learners but they should rather discuss any other event with them.

Educators should keep on meeting with the peers of these adolescents to expand the knowledge of the peers as far as epilepsy is concerned. Educators should also have contact with the parents of such learners.

4.2.4 Workshopping the parents

The parents have been visited at their respective homes as identified by learners and educators. Parents were encouraged to have closer contact with the educators at the respective schools. They also attended workshops on how to accept their children with epilepsy and to rectify the misinformation by the ill-informed about epilepsy. They have also been workshopped on the proper way of handling an adolescent with a seizure attack. They got information about the three stages of the seizure attack and how to handle each stage. A network of educators has been created towards the upliftment of better treatment of adolescents suffering from epilepsy.

It was brought under the attention of the parents that these adolescents should always be under medical control. The researcher also gave them directives to specialists in epilepsy. The researcher accompanied parents and adolescents suffering from epilepsy to the local doctor, who provided letters of referral to the Johannesburg Hospital so that specialists in epilepsy could attend to adolescents. *Samples of the letters are attached* (appendices 1,2 and 3).

4.3 PROGRAMME EVALUATION

The programme was evaluated after four months of observation and motivation.

4.3.1 Evaluation of adolescents suffering from epilepsy

One adolescent mentioned: "B*arutiši le bana ba mpha mafolofolo le nakong ya ka ya mathata. Ke hwetša ke le motho yo mongwe. Ke na le bagwera bao ba nkamogelago, le ge ke wele ba a nthuša. Bothata bjaka bo kaonafetše kudu. Ke ikhwetša ke swana le ngwana yo mongwe le yo mongwe"* (My educators and co-learners are encouraging me even in my difficult times. I am a different person from what I used to be. I have friends who are accepting me, who help me during seizure attacks. My problem is minimised greatly. I am just like any other learner.).

One other learner who was alcohol-addicted due to frustration said: *"Nka se sa nwa bjala. Ke ikhwetša ke dula ke thabile. Batswadi ba ka ba eleditšwe gore ke motho yo bohlokwa kudu. Ba nkišitše bookelong bja Johannesburg go alafišwa. Ke leboga kudu"* (I shall never again take liquor. I am now always happy. My parents have been advised that I am an important person. They therefore took me to the Johannesburg Hospital for treatment. I am very thankful.).

The third learner, who had experienced social isolation said: *"Bana le barutiši ba nthuša ge ke na le bothata. Barutiši ba mpha mafolofolo gomme ke ikhwetša ke thabile. Ke šetše ke hwetša kalafo sepetleleng sa Johannesburg. Le ge go le bjalo ke sa nyaka thekgo go tšwa bathong"* (Learners and educators are assisting me when I have attacks. Educators are encouraging me and I am now a happy person. I am already having treatment from the Johannesburg Hospital. I still need support from other people.). This is also the opinion of two other adolescents. The sixth adolescent, who had experienced rejection from peers, said: *"Bana le barutiši ga ba sa ntšhaba. Ke ikwa ke amogetšwe setšhabeng. Ke kaone*

kudu " (Learners and educators do not reject me anymore. I feel accepted in the community. I have improved very much).

4.3.2 Evaluation of peers

Peers are are having a better understanding now of what epilepsy entails. They are no longer frightened by seizure attacks. They are free to touch and handle their peers when they are attacked by seizures. They got rid of the belief that epilepsy is infectious. They are now accepting these adolescents with love. They reported that they understand the "aura" (warning or first stage of a seizure) of their peers very well, and as such they attend to it before the actual seizure.

The peers are now accepting that hostility during seizure attacks is not done deliberately but that it is a consequence of seizure attacks. They have tolerance of their peers suffering from epilepsy. They are now also assisting them in times of need without reporting to the educator.

4.3.3 Evaluation of educators

Most educators have enjoyed this education and they are applying it fruitfully. There are still some educators who do not want to move away from their past beliefs about epilepsy. There is still a need of involvement from higher authorities in education and welfare. On the average adolescents suffering from epilepsy are being welcomed by educators and more encouragement has been observed. As in the case of the peers, the educators also gained valuable knowledge and understanding of the "aura" stage.

4.3.4 Evaluation of parents

The parents are the most positive group. They gained a different perspective of their beloved children. Self-hatred has been replaced by self-acceptance as people who are also

covered by the love of God. There is closer contact between parents and educators, unlike when they used to be under the impression that educators were undermining them due to their offspring's condition of epilepsy.

4.4 FEEDBACK ON RESULTS AND BENEFITS

The adolescents suffering from epilepsy are now accepting themselves because they are now understanding that epilepsy is just a condition and not a disease. Their condition has improved much, both psychologically and medically. They do not feel rejected by others anymore, even if there is still a need for further education to others to learn to accept them completely. Only a few are still experiencing social isolation by others as the workshops did not involve the whole community. There are still many people who need information. This has been brought under the attention of the Department of Welfare.

Workshopped peers are enjoying it to be with adolescents suffering from epilepsy. They are able to assist them in times of seizure attacks, even before reporting to the educators. They have accepted that epilepsy is not in the least infectious.

Educators and parents of learners suffering from epilepsy also have closer relationships. They all give full support to such adolescents. Even those educators who thought that adolescents with epilepsy should not attend "normal" schools are now accepting that this was a misunderstanding due to lack of proper education. Parents also got rid of their self-blame. However it seems as though the wider community still needs some information about epilepsy.

4.5 SUMMARY

In this chapter the programme has been developed, implemented and evaluated. All stakeholders who have been workshopped are more knowledgeable about epilepsy.

According to the researcher, the government should try to reach the wider community to help the neglected and rejected sufferers of epilepsy in South Africa.

The next chapter will dwell on the conclusion, where the direct quotations are given, the limitations about the shortcomings throughout the research and the recommendations to the future researchers of the same interest.

CHAPTER 5

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1   CONCLUSIONS

The objectives of this research study have been successfully achieved as they have yielded positive results. All participants were thankful towards this project.

Step 1: Adolescents with epilepsy

The adolescents suffering form epilepsy have improved their lived experiences of suffering from epilepsy. They accept themselves completely and their condition has relatively improved. The words of gratitude of some of these adolescents are quoted as follows. One adolescent said: *"Bjalo ke na le bagwera, barutiši le bona ba a nkamogela"* (Now I have friends. Educators, too, are accepting me.). Another one said: *"Batswadi ba ka ba eleditšwe gore le nna ke motho yo bohlokwa kudu"* (My parents have been advised that I am also an important person.). Yet another one said: *"Ga go na le se ke itumelang ka sona go feta go ba le batho ba bangwe"* (There is nothing I enjoy more than to be in company with other people.).

Step 2: Peers

The attitude of the peers also improved very much. They are accepting their co-learners with epilepsy. One peer said: *"Ga re sa tšhošwa ke bolwetši bja gagwe, re kgona go mo thuša le ge barutiši ba se gona"* (We are no more frightened by his condition, we are able to help him even during the absence of educators.).

Step 3: Educators

Educators commonly declared that they have done disservice to the community in the past due to lack of proper education. One educator said: "We apologise to parents for having done so much injustice by rejecting their children, as such tempering with their psychological and social life."

Step 4: Parents

Parents seem to be the most assisted people. One parent said: *"Ruri, ge bana ba rena ba bonwa e le batho, le rena re tla ka ra ba batho mahlong a ba bangwe"* (Surely, if our children are viewed as human beings, we shall also be viewed as human beings in the eyes of others.).

5.2   LIMITATIONS

The research study had some inconveniences and disadvantages. There could be one or two adolescents suffering from epilepsy in a school and those identified schools are far apart from one another. It was relatively not an easy task to get them together for workshops. One other limitation has been the time frame. It could be more favourable if longer times than breaks could have been used for the research.

Peers had been workshopped. They accepted and accommodated their co-learners with epilepsy. However, there is still some ignorance in the wider community because these people did not have any exposure to the research project. Another limitation to peers was that their parents kept on warning them not to touch the adolescents suffering from epilepsy whilst witnessing seizures. They still insist that epilepsy is infectious because the research study could not cover all parents of the peers for workshops.

The researcher is encouraging more support from officials of the Department of Education. Many people in communities are therefore still in the dark as far as epilepsy is concerned. The wider community is still isolating such adolescents socially and all these adolescents' circumstances could therefore not be improved.

5.3   RECOMMENDATIONS

Recommendations are discussed under "education", "research" and "practice".

5.3.1   Education

It is recommended that the education curriculum should be expanded. Education itself is meant to free people. The curriculum in South Africa is very narrow in the sense that people may be deprived by it. An educator should be an educated person and someone you can rely on for help, but in this case the opposite is applicable. This can be observed in the analysis of the findings of the results of the research. Centres for epileptic conditions should be developed where the communities will be given relevant education regarding epilepsy.

5.3.2   Research

Researchers are encouraged to do some more research on this topic so that future orators, leaders and creationists could be educated in a proper way. From the outcomes of this research it is clear that due to lack of proper education most adolescents suffering from epilepsy lose direction and therefore never realise their full potential. Research also disclosed fearful advice from traditional healers and the danger of superstitious beliefs when managing such a condition. The researcher recommends that the South African Government should address the disability legislation as in countries like the United States of America. The people with epilepsy need support from the government as they are in most cases ignored and not catered for.

5.3.3   Practice

It is recommended that all people should accept epilepsy as a condition and not as a disease. People should do away with superstitious beliefs regarding epilepsy. Adolescents suffering from epilepsy should not be socially isolated or rejected. In schools, learners with epilepsy should be identified so that they can be supported. Educators should be free to accommodate adolescents suffering from epilepsy at schools for normal children. Educators should do away with the idea of referring adolescents with epilepsy to special schools which are actually not existing.

Adolescents suffering from epilepsy should accept themselves firstly and they should feel fully accommodated in the community. They should, however, accept that they cannot be involved in certain activities such as motor vehicle driving, cooking on open fires and swimming in deep dams or pools. Adolescents suffering from epilepsy who have learned to be positive and to accept themselves will avoid accidents which may terminate their lives prematurely.

BIBLIOGRAPHY

BOTES, AC 1991: A functional approach in nursing. Johannesburg: Rand Afrikaans University.

BRINK, H 1993: Validity and reliability in qualitative research. Curations. Vol 16 (2) 33-38.

BURNS, N & GROVE, SK 1993: The practice of research, conduct, critique and utilisation. Philadelphia: Sage.

CORSINI, RJ 1994: Encyclopaedia of Psychology. Toronto: John Wiley.

CRESWELL, J 1994: Research design. Qualitative and quantitative approaches. London: Sage.

DENZIN, N & LINCOLN, YS 1994: Handbook of qualitative research. London: Sage.

DE VOS, A S; 1998: Research at grass roots. A primer for the caring professions. Pretoria: Van Schaik.

FARREL, M 1987: The special education handbook. London: David Fulton.

FISHER, EE 1991: Psychology for nurses and the health team. Kenwyn: Juta.

FREEDMAN, AM; KAPLAN, HT & SADOCK, BJ. 1973: Modern synopsis of psychiatry. Baltimore: Williams and Wilkins.

FREEDMAN, AM; KAPLAN, HT & SADOCK, BJ 1978: Comprehensive textbook of

psychiatry. Baltimore: Williams and Wilkins.

HALLAS, CH; FRASER, II & MACGILLIVRAY, RC 1982: the care and training of the mentally handicapped. Bristol: John Wright.

HOLLOWAY, J & WHEELER, S 1996: Qualitative research for nurses. London: Blackwell.

IRONBAR, NO & HOOPER, A 1991: Self-instruction in mental health nursing. London: Baillierre Tindal.

JOHNSON, DW 1997: Researching out. Interpersonal effectiveness and self-actualisation (6th edition) Washington: Library of Congress Cataloguing in Publication data.

KAPLAN, HI & SADOCK, BJ 1991: Synopsis of Psychiatry, Washington: Williams and Wilkins.

KISKER, GW 1977: The disorganised personality. New York: Mc Graw-Hill.

KVALE, S 1996: Interviews. An introduction to qualitative research interviewing. London: Sage.

LINCOLN, YS & GUBA, EG 1985: Naturalistic enquiry. Los Angelis: Sage.

MADDISON, D & KELLEHEAR, KJ 1983: Psychiatric nursing. London: William Clowes.

MARSHALL, C & ROSSMAN, GB 1995: Designing qualitative research. Newbury Park: Sage.

MOUTON, J & MARAIS, HC 1990: Basic concepts in the methodology of social sciences. Pretoria: Human Science Research Council.

PERKO, JE & KNEIGH, HZ 1988: Psychiatric and mental health nursing. Toronto: Prentice Hall.

PILOT, DF & HUNGLER, BP 1993: Study guide for essentials of nursing. Research methods, appraisal and utilization. New York: Human Analytic.

REYNOLDS, CR & MANN, L 1996: Encyclopaedia of special education. New York: John Wiley.

STUART, GW & SUNDEEN, SJ 1991: Principles and practice of psychiatric nursing. Washington: Mosby.

TALBOT, LT 1995: Principles and practice of nursing research. St Louis: Mosby.

UYS, L & MIDDLETON, L 1999: Mental health nursing, Kenwyn: Juta.

VLOK, ME 1996: Manual of community nursing and communicable diseases. Johannesburg: Juta.

WILSON, HS & KNEISL, CR 1992: Psychiatric nursing. Los Angeles: Addison Wesley.

APPENDIX 1

DR. C. P. GIEZING
DR. E. W. TURTON

M.B. Ch.B. (U.O.F.S)
M.B. Ch.B. (U.O.F.S)

Shop 11
Metropolitan Plaza
Lebowakgomo
0737

TUDOX MED
PR. 1456520

Tel/Fax No.
Surgery : (015) 633 5803
Admin Office: (015) 291-4959
Accounts: (015) 633 7542

P O Box 12495
Bendor 0699

First hospital colleague

Francinah Lekawa   DOB 28/10/1985   11/6/2001

c/o. Epilepsy, since ± 9 yrs ago, on Dr Groothoek hospital
Tegretol twice ⊤ more ⊤ 12/12. ⊤ made po Convulsions
continue. No special investigations done no CT's no EEG;
explain as if recurrence seizures with among medication,

A. Uncontrolled Epilepsy
please exclude other etiology. convulsions, CT, EEG etc.
add on treatment

(signatures)

(M.B.B)

DR. C. P. GIEZING   M.B. Ch.B. (U.O.F.S)
DR. E. W. TURTON   M.B. Ch.B. (U.O.F.S)

Shop 11
Metropolitan Plaza
Lebowakgomo
0737

TUDOX MED
PR. 1456520

Tel/Fax No.
Surgery: (015) 633 5803
Admin Office: (015) 291-4959
Accounts: (015) 295-4602

P O Box 12495
Bendor 0699

---

14 - 11 - 2001

To whom it may concern

Re Ms Agnes Tjale

Abovementioned young lady c̄ grand mal epilepsy

Currently on Tegranol 200mg tds
Still attacks but only ± 2x per year
Could you kindly evaluate + R̄ further

Thank you

[signature]

DR C GIEZING & DR E W TURTON
GENERAL PRACTITIONERS
11 Metropolitan Life Plaza
LEBOWAKGOMO 0737
Tel (015) 633 5803

APPENDIX 3

TUDOX MED
PR. 1456520

Shop 11
Metropolitan Plaza
Lebowakgomo
0737

Tel/Fax No.
Surgery: (015) 633 5803
Admin Office: (015) 297 8811
Accounts: (015) 633 7542

P.O. Box 12495
Bendor 0699

---

11 - 03 - 2002

Dear Colleague

Re Abraham Mokgolane

Abovementioned young man — 9yr old
Past 4 years episodes of convulsions - general
tonic clonic. Afterwards - memory loss of
episode. No trauma / No birth injuries etc
Attacks ± 1/month

Δ Epilepsy
Could you kindly evaluate

Regards