

**Testing the effectiveness and/or
appropriateness of the information
material in *The Alliance Programme*
used for Tswana speaking patients
suffering from schizophrenia in the
South African context**

by

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the degree

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DECLARATION

I hereby declare that the dissertation entitled:

Testing the effectiveness and/or appropriateness of existing schizophrenia information material (*The Alliance Programme*) for patients suffering from schizophrenia in the South African context

- Is my own work
- That all the resources consulted and quoted from have been acknowledged and referenced
- Has not been previously submitted for any degree at any university

Ncamsile N. Dlamini

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ABSTRACT

South Africa is a heterogeneous society. It is a multilingual, multicultural country with more than eleven official languages. It is a country that also has big educational and economic inequalities. These differences are pertinent barriers that often obstruct communication, also and especially in health communication. This study addresses such a problem, by first exploring the effectiveness and/or appropriateness of existing schizophrenia information material *The Alliance Programme* which was produced in the USA for universal consumption and is currently used in the South African context. In the study the externally produced schizophrenia information material is adapted to fulfil in the specific needs and preferences of the audience targeted in this study.

The study was conducted based on the assumption that people need to access information that is relevant, easy to understand and appropriate to them in order to make informed decisions about their health. This study was conducted at the Weskoppies hospital in Pretoria (South Africa) among Tswana-speaking patients suffering from schizophrenia. The specific aim of this study was to communicate the information in such a way that this group could use it optimally.

Since this empirical study's main aim was to evaluate and adapt *the Alliance Programme* to make it more suitable for the South African context, a formative research design was implemented. Usability testing was chosen as the research method. Literature review, individual semi-structured interviews, focus group interviews and participant observation were employed as data collection methods. The data was analysed by means of qualitative content analysis.

The findings of this study indicated that the adapted messages or information about schizophrenia did improve the patients' reception of the information. It was then concluded in this study that messages or information should either be adapted or created to suit the needs of a specific audience. This study also recommended that in order to make sure information (about schizophrenia) is communicated effectively and/or appropriately to any group (of patients suffering from schizophrenia), a participatory communication design should be used.

Keywords: Acceptability, Appropriate, Communication Media, Comprehension, Effective, Empirical Qualitative Research, Formative Research, Health Communication, Participatory Communication, Psycho-education, Schizophrenia, *The Alliance Programme*, Usability Testing, Weskoppies Hospital

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Chapter 1

BACKGROUND TO THE STUDY

1.1 INTRODUCTION

Information is one of the resources that can be used to reduce uncertainty and/or increase the number of possibilities for addressing a situation (McGarry, 1975: 22). It is a resource that is needed in order to make informed decisions. Every human being needs effective and/or appropriate information in order to survive. Information plays major roles in the solution of economic, health, social and political problems in communities. It is regarded as a central factor in the solution of any society's aforementioned problems, and is considered as the most basic of all human needs (Mchombu, 1995:99). Society depends on it. It is therefore important that people in communities are provided with relevant, accessible, and easy to understand information, so that they can use it more effectively to solve problems.

One common problem that often occurs when information is provided to people (target audience) is that, in most cases, it is not communicated effectively. The target audience is often not involved from the planning stages through to the evaluation stages of the information communication campaign. This results in an ineffective information communication campaign. To a great extent, this failure is ascribed to the lack of audience participation in the development and production of these campaigns (Snyman & Penzhorn, 2004). The literature indicates that effective communication processes are those that include and invite audience participation (Mody, 1991; Morris, 2001; Snyman & Penzhorn, 2004). This process is referred to by Mody (1991) as a method of incorporating audience participation in the design of communication messages. Effective information campaigns should start with the assumption that people know best what their problems are and what they need in order to cope with them, and should therefore be directly involved in setting the agendas for creating and delivering information messages (WHO, 1997).

This problem is often more entrenched in heterogeneous societies where there are differences with regard to culture, language, education levels, economic status, etc. Such heterogeneous societies are found all over the world: Europe, Africa etc, wherever the need exists for audience segmentation in order to communicate information effectively. South Africa is one of these heterogeneous societies. It is a multilingual, multicultural country with more than eleven official languages and substantial educational and economic inequalities. These differences are significant barriers that often obstruct communication within the country. Overcoming these barriers also complicates the communication of health information in South Africa, as can be seen in the struggle to curb the HIV/AIDS epidemic in this country. Under these circumstances, the communication of health messages to mentally ill patients is an even bigger challenge.

This problem also exists, however, where people from “developed” communities aim to “develop” (inform) people from developing communities. This process of communicating information to developing communities in order to contribute towards the success of their development is referred to by Nair & White (1993:120) as development communication. Agunga (1998) defines development communication as a systematic utilisation of appropriate communication channels and techniques to increase people’s participation in development and to inform, motivate and train rural populations at the grassroots level. It is “a total process that includes the understanding of audience and its needs, communication planning around selected strategies, message production, dissemination reception and feedback” (Nair & White, 1993: 120).

Information is a vital component of development (Leach, 1999: 73). Thus, it is very important that information is communicated effectively to the target audience (developing communities). Effective communication is important if development efforts are to succeed (Agunga, 1998). According to the literature, effective information communication (development communication) is the two-way sharing of information, ideas and experiences with the objective of arriving at a common understanding on issues and possible solutions (Mody, 1991; Ayee, 1993; Seavaes, 1995; Bessette, 1996; Steyn & Nunes, 2001). If there are differences between the receivers and the communicators with regard to culture, language, educational level, economic status etc, these differences could be negative barriers to the effective communication of information. It is also known

that features of developing communities such as culture, language, educational level, economic status etc do not match those of developed communities. Thus, most of the communication campaigns of “developed” communities with respect to “developing” communities are ineffective.

This study addresses such a situation -where material (*The Alliance Programme*) developed in the USA was unchanged and used to inform an audience in a multilingual and multicultural developing country such as South Africa, better known for its rainbow nation. In this study, a specific target audience (well-functioning Tswana-speaking patients suffering from schizophrenia in the Weskoppies hospital) was used. The reason that this target audience was chosen for this study is because an externally produced information material¹ that contains information about schizophrenia (*The Alliance Programme*) is currently being used at the Weskoppies hospital to disseminate or communicate information about schizophrenia to patients suffering from this illness in the hospital. Thus, this study aimed mainly to:

- explore the effectiveness and/or appropriateness of the communication of information about schizophrenia through this material in the South African context; and also to
- determine whether or not this material needs to be adapted in order to suit the South African context, or if it can be used as it currently is.

Health promotion and education is as important in South Africa as it is in any other country. In this study, the complicated issue of how health information (specifically information about schizophrenia) could be effectively communicated to patients suffering from schizophrenia in the Weskoppies hospital is being tackled. By supporting what Servaes has called “the myth of homogeneity”, this study focuses specifically on how the existing material (*The Alliance Programme*) was adapted with regard to:

- content,
- language, and
- design

¹An information material is an information resource in any form of communication media that contains messages on a certain topic.

in order to render it culturally compatible with patients suffering from schizophrenia at the Weskoppies psychiatric hospital. The specific aim was to communicate the information about schizophrenia in such a way that patients could fully assimilate it.

1.2 THE RESEARCH PROBLEM

It is important in the communication of health information to provide relevant content that is supported by an appropriate presentation format, in order for information messages to have the desired impact. According to Leach (1999), “content might be right but if the presentation is inappropriate, then the communication process will not be successful”. On the other hand, the presentation of information to the target audience might be appropriate, but if the content is not relevant, then the communication process will not be successful. This means that the information will not be understood by the target audience for whom it is intended. Therefore, the most important question that health communicators always need to ask themselves is whether or not the intended audience understands the information, and whether or not the information material used to disseminate the health information successfully communicates the message that is intended.

Based on the above problem, the main research question of this study can be formulated as follows: Does the information about schizophrenia contained in *The Alliance Programme* effectively communicate appropriate information to patients suffering from schizophrenia in the South African context?

The main research question can be broken down into the following sub-questions:

- How does the target audience understand the information presented in *The Alliance Programme*? (comprehension)
- How does the target audience feel about the information contained in *The Alliance Programme* that was communicated to them? In other words, what is their attitude towards *The Alliance Programme*?
- How does the target audience feel about the value and/or relevance (usability) of the information communicated by *The Alliance Programme*?

- Do demographic and socio-economic factors play a role in the effective communication of this information?
- How can *The Alliance Programme* be improved so as to suit the South African context?

1.3 AIM OF THE STUDY

The purpose of this study is to test the appropriateness and/or effectiveness of existing, externally developed information material that contains information about schizophrenia (*The Alliance Programme*) to South African patients (context). *The Alliance Programme* will actually be tested at the Weskoppies hospital in Pretoria, using Tswana-speaking schizophrenic patients.

The sub-aims of this study are:

- to find out whether or not *The Alliance Programme* meets the information needs and profile of the target audience and if not, to determine the reasons for this.
- to adapt *The Alliance Programme* according to the information needs and profile of the target audience.
- to test the effectiveness of the adapted version of *The Alliance Programme* and compare it to that of the original.
- to determine the reasons why *The Alliance programme* is (in)effective in the South African context
- to provide guidelines for the production of future schizophrenia information material.

1.4 RESEARCH HYPOTHESIS

Existing externally produced information materials containing information about schizophrenia, such as *The Alliance Programme*, are not appropriate and/or effective for schizophrenic patients in South Africa. These externally produced information materials first need to be adapted to the South African context, in order to be effective and/or appropriate to South African schizophrenic patients.

1.5 DEFINITION OF TERMS

Concepts such as information, communication, information dissemination, psycho-education, *The Alliance Programme*, health communication, participatory communication, usability and effectiveness will be used. To clarify what is meant by these terms, working definitions are provided below:

- **Information** is data that has been processed into an organised, usable form (Szymanski et al., 1999: 117). It is an entity aimed at solving communication problems (McGarry, 1975:23). In this study, information is regarded as an entity that needs to be disseminated in a format that the target audience will understand and can use effectively to solve problems and make decisions.
- **Communication** is defined as a “process in which a source makes data available to a recipient by means of a channel, signs and symbols with the intention of letting the recipient process the data into information with meaning intended by the source” (Marchant, 1988:53). It is a process of negotiation and exchange of meaning, in which messages, ‘people-in-cultures’ and ‘reality’ interact so as to enable meaning to be produced or understanding to occur (O’Sullivan et al, 1994: 50).
- **Information dissemination** also includes information repackaging, which is the practice that attempts to convert the available information into an acceptable and usable format (Stillwell, 1999:42). Authors such as Leach (1999) and Meyer (2000) also refer to this process by the term ‘information dissemination’.

- **Psycho-education** is “a specific or specialised form of education aimed at helping people with mental illnesses or anyone with an interest in mental illnesses to access facts about a broad range of mental illnesses in a clear or concise manner” (*What is Psycho-education*, 2001). It is a way of accessing and learning strategies to deal with mental illness or its effects. According to Pekkala & Merinder (2005), psycho-education involves communicating to people/patients information about their problems/illnesses, how to treat them, and how to recognise signs of relapse, so that they receive treatment before the problem worsens or reoccurs.
- ***The Alliance Programme*** is an existing resource developed to facilitate and support the implementation of psycho-educational programmes (e.g. discussion classes to discuss information about schizophrenia) to patients across different care settings. This resource was developed in the USA and approved by international experts in schizophrenia care. Its development was funded by Pfizer Inc, the world’s largest global pharmaceutical research and development organisation. It is currently being used at the Weskoppies hospital in Pretoria (South Africa) to communicate information about schizophrenia to patients suffering from schizophrenia in the hospital.
- **Health communication** is, according to Vignault (2000)’s definition, “the art and technique of informing, influencing and motivating individual, institutional & public audiences about important health issues”. This author further states that the scope of health communication includes disease prevention, health promotion, health care policy and the business of health care, as well as the enhancement of the quality of life and health of individuals within the community.
- **Participatory communication** is a “process of raising consciousness and deep understanding about social reality, problems and solutions; rather than persuasion for short-term behavioural changes that are only sustainable with continuous campaigns” (Dragon, 2001). This process is not a linear/one-way

process for transmission of information and persuasive messages, but rather favours decentralisation, democracy, people's involvement, dialogue, bottom-up and horizontal communication (Agunga, 1996). According to Dragon (2001), this process creates an environment that empowers individuals and groups, and gives them the freedom to voice their perceptions of reality and to act on these realities.

- **Usability** is the extent to which information materials are used by specific users to achieve goals with effectiveness, efficiency and satisfaction in a specific context of use (Quesenbery, 2001: 1). It is “the degree to which information materials can be effectively used by the target audience in the performance of tasks under environment requirements and constraints” (Guillemette, 1989:217).

In this study, usability will refer to the ease of use of information materials by a target audience in order to perform tasks.

- **Effectiveness** is defined in terms of receiver performance when the information material is used, and acceptability of these materials for the receiver. Basic human performance dimensions include efficiency (speed) and bias (accuracy) in performing tasks. The target audience or receivers themselves are the primary source for reporting perceptions of tiredness, comfort, boredom, frustration or excessive personal effort in using the information material (Guillemette, 1989: 218).

1.6 RESEARCH DESIGN

An empirical qualitative research method will be adopted in this study. This method allows the researchers to “approach the world of the subjects they are investigating with the minimum of preconceived ideas and that they look at the phenomenon under discussion in its natural setting” (Berg, 1998). This type of research has a predominantly descriptive nature, and its aim is to get an in-depth picture of perceptions and the quality of human conduct - the focus is not on quantitatively

measurable behaviour, but on the significance and meaning that people attach to social situations or phenomena, and the intentions that underlie everyday human actions.

Since this study's main aim is to adapt *The Alliance Programme* (developed in the USA) and make it more suitable for the South African context, a formative research design using usability testing is adopted in this research. "Formative research is a kind of development research or action research intended to improve design theory for designing instructional practices and processes" (Reigeluth & Frick, 1999). This type of research is, according to Reigeluth & Frick (1999), sometimes called field testing or usability testing. The aim of usability testing is to ensure that information materials are understood and beneficial to users (Schramm, 1964).

"There are three kinds of usability testing methods for information materials" (Schrivver, 1997), namely:

1. *Text-focused methods*: assess text quality by means of more or less general principles or guidelines, based on ideas or research about how readers respond to texts.
2. *Expert-focused methods*: use feedback by professionals who have expert knowledge about the subject, audience or genre.
3. *Reader focused methods*: use feedback from potential readers in the target audience.

In this study, all three abovementioned methods of usability testing were used to test the effectiveness and/or appropriateness of the communication of schizophrenia information based on the specific information material (*The Alliance Programme*). Reader-focused methods were used because they give direct information about how the audience responded to the different aspects of text quality.

1.7 RESEARCH METHODS

The following data collection methods were used in this research:

- **Literature review**

A literature review was conducted to provide a theoretical background for the study, and a foundation for discussion of the topic. It was also conducted in order to examine how other authors/scientists have already thought about and researched the topic, so as to create a context in which research questions can be answered.

- **Empirical research**

An empirical qualitative research method was adopted in this study. This method allows for researchers to “approach the world of the subjects they are investigating with the minimum of preconceived ideas and that they look at the phenomenon under discussion in its natural setting” (Berg, 1998). This type of research has a predominantly descriptive nature, and its aim is to get an in-depth picture of perceptions and quality of human conduct - the focus is not on quantitatively measurable behaviour, but on the significance and meaning that people attach to social situations or phenomena, and the intentions that underlie everyday human actions.

The empirical research conducted in this study used the following data collection methods:

- **Interviews**

Two types of interviews were conducted in this study: semi-structured individual interviews and focus group discussions.

- **Semi-structured individual interviews**

Semi-structured individual interviews using an interview schedule were conducted during different stages of the research and for different purposes, such as:

- *the screening interviews,*
- *usability testing interviews, and*
- *knowledge retention testing interviews.*

Kritzing (1995) defines semi-structured interviews as “informal interviews that are based on a set of basic questions that you would like to understand better for your informal analysis”. These interviews are conducted with a fairly open framework which allows for focused, conversational, two-way communication (Kvale, 1996). In this study, guided conversations (semi-structured interviews) were mainly used to ask broad questions that did not constrain the conversation. New questions were allowed in order to deepen the level of these discussions.

▪ **Focus group discussions**

Focus group discussions were used to obtain in-depth information on the topic. Focus group discussions combine the advantages of the two main methods of collecting data in qualitative research, the individual interviews and participant observation (Morgan, 1993). The discussion is relaxed and comfortable, as the participants share ideas. Group members stimulate each other by responding to ideas and comments during the discussion. The focus group discussions took place after the individual interviews had been conducted, as a way to validate the data collected during individual interviews. The same participants who were interviewed individually took part as respondents in the focus group discussions.

○ **Participant observation**

Participant observation was used to enrich and consolidate the data obtained from the interviews. Participants were observed in their natural setting. This method helped the researcher to get a clear picture of the behavioural patterns of the participants. It also helped the researchers of this study to collect data without having to rely on the willingness or ability of participants in the study to supply them with information (Struwig & Stead, 2001:96).

1.8 SAMPLING

The sample for this study was chosen on the basis of purposive sampling, which is a non-probability sample consisting of selected and information-rich research participants who are available (Neuman, 1997).

1.9 RESPONDENTS

A group of in/out-patients at Weskoppies hospital with Tshwana as their first or second language was selected as research participants in this study.

Criteria used to include research participants were:

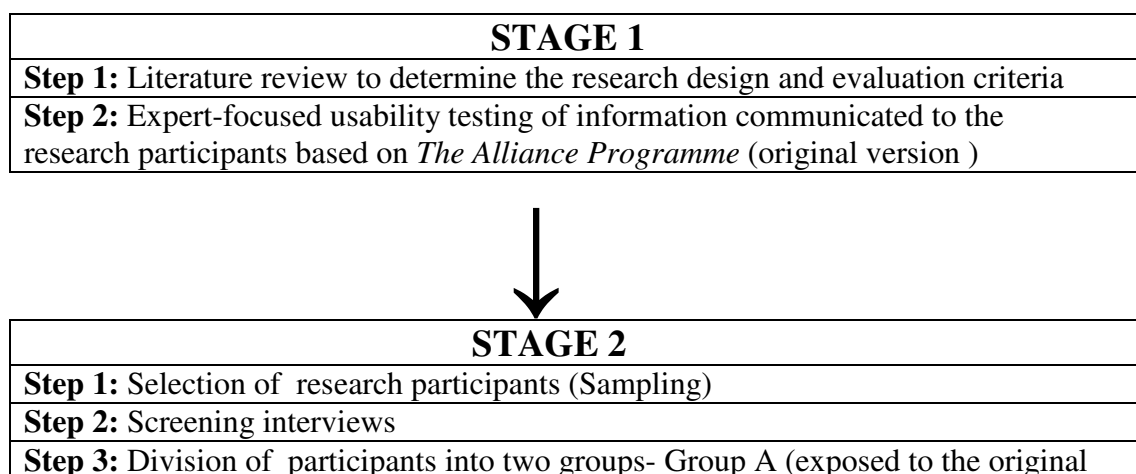
- Individuals aged 18 – 60
- DSM–IV diagnosis of schizophrenia or schizo-affective for more than six months
- Tshwana-speaking individuals
- Individuals able to give their informed consent
- Literate and able to read
- No previous exposure to *The Alliance Programme*

Criteria used to exclude research participants were:

- Current active psychosis
- Recent history of violence or self-injurious behaviour
- Patients with a diagnosis of mental retardation
- Active substance abuse

1.10 RESEARCH PROCEDURE

The following is a diagrammatical representation of the (formative) research procedure that was adopted for this study.



version of *The Alliance Programme*) and Group B (exposed to the adapted version of *The Alliance Programme*)



STAGE 3

Step 1: Exposure of research participants in Group A to information about schizophrenia communicated to them based on *The Alliance Programme* (original version)

Step 2: Receiver-focused usability testing of *The Alliance Programme* (Group A)

Step 3: Analysis of data obtained in Step 2 of this stage



STAGE 4

Adaptation of *The Alliance Programme* based on evidence from:

- literature
- results of expert and text-focused evaluation of *The Alliance programme* (Stage1)
- Linda's adaptation of *The Alliance Programme*
- Findings of receiver-focused usability testing (Stage 3)



STAGE 5

Step 1: Exposure of research participants in Group B to information about schizophrenia based on *The Alliance Programme* (adapted version)

Step 2: Receiver-focused usability testing of *The Alliance Programme* (Group B)

Step 3: Analysis of data obtained in Step 2 of this stage



STAGE 6

Comparison of findings obtained from Group A and Group B usability testing results



STAGE 7

Comparison of findings obtained from Group A and Group B knowledge retention results (after 3 months)

1.11 DATA ANALYSIS

The collected data was analysed using the inductive qualitative content analysis method. The researchers separately analysed the data using pre-determined criteria. They then discussed the findings by comparing common themes and categories that were identified.

1.12 LIMITATION AND DEMARCATION OF THE STUDY

This project would be a limited pilot study (the sample to be used focuses only on Tswana-speaking schizophrenic patients in the Tshwane area). The findings therefore have obvious limitations. The results cannot therefore be applied to all communities in South Africa, as it is known that South Africa has a culturally diverse public. Other cultural groups in other centres may perceive and experience schizophrenia information communication processes differently. Some generic recommendations with regard to information dissemination among psychiatric patients could however be made.

1.13 VALUE OF THE STUDY/MOTIVATION

Very little research about the effectiveness of material used in the communication of information about schizophrenia to patients suffering from this illness has been conducted in the South African context. The result is that materials used in South Africa's mental health services have not been adapted to the South African context (Motlana et al., 2003). The effectiveness and/or appropriateness of schizophrenia information material in the South African context have also not been evaluated. It is for this reason that *The Alliance programme*, an existing schizophrenia information material, was tested at Weskoppies Hospital using Tswana-speaking patients suffering from schizophrenia. It is envisaged that this process will help to improve ways of communicating information to patients suffering from schizophrenia in the immediate context, and all mentally ill patients in the wider South African context.

Evaluating existing schizophrenia information materials in terms of their effectiveness and/or appropriateness will expand our knowledge on the content and format of

Chapter 2

LITERATURE REVIEW

2.1 INTRODUCTION

In this chapter, literature related to the topic of the study will be reviewed. First, the role of information in our everyday lives will be examined. The relationship between information provision and information communication will then be explained. The evolution of general communication models/theories will be discussed, culminating in an explanation of the participatory communication approach. Literature on health communication, focusing on the evolution of health communication theories and the appropriate communication media for health communication, will be reviewed. In conclusion, the researcher will explain the relationship between mental health communication and psycho-education, and then discuss which of these two concepts will be used in this study and why.

2.2 INFORMATION

2.2.1 Information as a vital resource/tool in our everyday lives

Information is vital to empowerment and is an essential resource for building knowledge, training, and engaging in dialogue and decision-making (Burton, 1998:94). Information means different things to different people under different circumstances. Many authors define information as data that has been processed into an organised, usable form (Faibisoff & Ely, 1978; Mchombu, 1995; Kaniki, 1999; Leach, 1999; Szymanski, 1999; Morris, 2001). An awareness of these organised data or facts can lead a person to knowing (Kaniki, 1999: 191; Szymanski, 1999: 117), can reduce uncertainty and/or increase the number of ways that can be used to address a situation (McGarry, 1975: 22). This means that information helps individuals to make informed decisions.

Information is extremely important in our everyday lives, because people act or make decisions based on the type of information they have (Doyle, 1988: 10). Its use is implicit to the existence of man, and the fulfillment of his everyday needs (Stonier, 1996:21). Every human being needs information in order to survive, and the type of information each person

needs depends on his or her individual needs, level of education, type of occupation, culture, etc. (Iwe, 2003:171). “Information plays major roles in the solution of the economical, health, social and political problems in communities. It is regarded as a central factor in the solution of any society’s economic, health and social problems and is considered as the most basic of all human needs” (Mchombu, 1995:99). Society depends on it. According to Rasmussen (2001:14), information can be regarded as an important factor in ensuring that a society functions effectively.

Considering the important role of information, it is clear that without information, living standards will deteriorate. It is therefore important for everyone to have access to relevant information that they can easily understand and absorb, in order to function efficiently and effectively. This applies to communities as well. In order for communities to function effectively and productively and to grow economically, socially and politically, they need to be supplied with relevant information that they can easily understand and absorb (Mchombu, 1998:50). People being provided with the right information at the right time in the most appropriate format leads to development (Mchombu, 1995), since usable information is a vital source of social power (Hargie & Dickson, 2004:204).

2.2.2 Information needs

The main aim and function of providing people with relevant, easy to understand information is to meet or satisfy their needs. A need is a state that arises within a person, suggesting some kind of gap that requires filling (Dervin, 1980). According to this author, a general need may be physiological, psychological, social or economic. “Living organisms survive not just by ingesting energy in the form of food, water and air, but also by ingesting information necessary for enabling them to adjust to their changing environments” (Ascroft & Masilela, 1994:286). Thus, the concept ‘information need’ implies a basic need similar to other basic human needs such as food, water, oxygen, etc. (Wilson, 1981:7).

The term ‘information need’ is difficult to define. The difficulty in defining this term is further compounded by the fact that information itself is an abstract concept (Kaniki, 1999:191). As in the case of many other terms, an overview of literature produces a variety of ways in which ‘information needs’ can be defined and/or described. Kaniki (1999:192) states that an information need is the lack or absence of information required in order to

accomplish a task or necessary to deal with a situation. Other early scholars such as Faibisoff & Ely (1978) and Krikelas (1983) define an information need as a state of uncertainty. This state of uncertainty requires information as a stimulus in order to create a change in a person's level or degree of uncertainty.

A need for information arises when the amount of know-how possessed by an individual is inadequate to cope with problems arising from situations (Morris, 2001: 4). According to this author, the individual may or may not be aware of such an inadequacy. However, whether or not the individual is aware or unaware of such an inadequacy, the provision and/or communication of appropriate information reduces the degree of inadequacy to cope with problems, and/or the degree of uncertainty, thus satisfying the information needs of the individual. The two concepts of information provision and information communication are explained in detail in the next section.

2.2.3 Information provision and information communication

As explained above, people need information for decision making and problem solving. There is no field of human activity in which information is not a component. The satisfaction of people's needs cannot be achieved without adequate communication and provision of needed information (Penzhorn, 2001:63). The two concepts "information provision" and "information communication" are similar, and in most cases these concepts are used interchangeably. Yet, it seems as if information communication extends beyond information provision. Stilwell (1999) defines information communication as the process of providing/disseminating information in appropriate formats and/or channels for the receiver's use. Information communication therefore involves more than just the provision of information. While the term "information provision" is associated with, by authors such as Leach (1999) & Meyer (2000), information dissemination and information transmission respectively, Stilwell (1999:42) relates information provision to information repackaging. This refers to the practice which attempts to provide available information in a usable format.

Information communication does not merely involve the one-way provision of information, as communication is defined as a process of creating meaning, "a process by which two or more people share knowledge so to arrive at a common meaning" (Agunga, 1998:35). It is "a

process of negotiating and exchange of meaning, in which messages, people-in-cultures and reality interact so as to enable meaning to be produced or understanding to occur” (O’Sullivan et al, 1994: 50). The aim of the communication of information is to allow the receiver to share and communicate information or messages effectively.

It is obvious that there is a relationship between information and communication. Although more than information (e.g. feelings) can be communicated, discussions on communication always contain some reference to information. Information is regarded as an important factor in the communication process. Although any communication event involves information provision, information often means little if it is not communicated (Steinberg, 1994).

A relationship also exists between the repackaging of information and information communication or information provision. In order to provide or communicate information effectively, information first needs to be appropriately packaged. This is also explained by Stilwell (1999), when she states that communication involves disseminating information in appropriate formats and channels for use. The reason behind repackaging information is to ensure easy access in suitable formats and channels for recipient(s).

In this study, information communication will be used, since it implies more than the repackaging of information into a new format (message): it also includes the suggestion/condition that effective information communication in some way or other involves a negotiation process, a sharing of commonalities of aims and needs between communicators and receivers.

2.3 COMMUNICATION THEORIES

2.3.1 The evolution of general communication models/theories

As indicated in the above paragraph, effective information communication constitutes more than a linear and causal process between communicators and receivers. Many academic fields and/or theories have contributed to or proposed an increasing focus on participation in information communication programmes. Some of these academic fields will be discussed in this section.

In the 1930s, the positivistic approach towards communication theory was established by scholars in the USA. According to this approach, individuals were regarded as empty vessels to be filled and directed by media content. In the post-First World War era, transmission models were popular. It had its roots in engineering, with formulations such as the Shannon Weaver model, which showed “simple linear information flow from mass media to individuals” (Bowes, 1997). These linear communication models dominated during the modernisation paradigm from about 1945 to 1965 (O’Sullivan et al, 1994). Communication was seen as a process by which A sends a message to B, upon whom it has an effect. “Communication was pictured as one-way message flow from a source, passed through media channels, “decoded” (semantically) by audiences and applied to daily life” (Bowes, 1997).

In opposition to the positivistic approach, the critical research tradition considered the role of ideology in the research of mass media, and acknowledged the influence of context (Servaes, 1995; Servaes & Lie, 1996; Bowes, 1997; Snyman & Penzhorn, 2004). This approach investigates communication by asking how audiences actively construct meaning from mass media communication. Consequently, the later transactional communication models (Steinberg, 2001; Verdeber, 1990) highlight the fact that the meaning of the information or message exchanged during a communication event is influenced by participants’ values, culture, background, occupation, knowledge, and so forth. Meaning is created through a process of negotiation between communicator and receiver. Far from being passive recipients, people are actively involved in the construction of meaning around the media they consume (Servaes & Lie, 1996). The fact that the receiver’s construction of meaning is often different from the meaning intended by the communicator (White, 1994) is expanded on by views formulated in reception theory (Servaes, 1995; Bowes, 1997; Snyman, 2001; Snyman & Penzhorn, 2004).

In order to ensure the effective flow of communication, a communicator and receiver should share a “common codal system” (Petersen, 1992). Reception study postulates that the greater the correspondence between the receiver’s codal system and norms of interpretation and the

sender's codal system and norms of interpretation, the more effective the communication will be (Hansson, 1992). This theory is especially relevant when cultural and other social and/or personal barriers exist between the communicator and the receiver.

This relationship between the communicator and the receiver is also evident in the evolution of what came to be known as Development Communication. In the next section, the history and/or evolution of development communication, which resulted in participatory communication, is discussed in more detail.

2.3.1.1 The history of development communication ending with participatory communication

The early stages of development communication (DC) were primarily based on the transmission of information or transfer of knowledge. It was a one-way process that neglected the role of communication in development. The mass media used in the development communication model was hierarchical, centrally controlled, and a one-way, top-down channel for information dissemination (Mody, 1991: 48). Development communication was seen to take place between a developer (a facilitator or change agent) and a community, who were the recipients of the development project – therefore, between a benefactor and a beneficiary, and mostly in the rural context (Malan, 1998:51). It could be said that most projects undertaken were *for* the people, rather than *by* the people (Servaes, 1995).

According to Servaes (1995:42), growing critique from scholars all over the world, combined with evidence of the massive failure of development initiatives in the Third World, as well as the break-down of the demarcation of the First, Second and Third worlds, gave birth to what is referred to as “another development” or the multiplicity approach to development. The multiplicity approach stresses democratisation and participation at local, national and international levels. Melkote (1991:270) refers to this as “another development”, in which communication models allow for knowledge-sharing on a co-equal basis, rather than the top-down transmission of information and persuasion. “It is a strategy of reaching specific groups of people with new ideas, information and technologies to get rural communities to participate in the development of programmes to act as the implementers” (Agunga, 1997).

In order for development to be appropriate and sustainable, local communities must be integrally involved in development initiatives, which include all the stages of development communication. This means that the people should be involved in any process that is aimed at empowering them. The participatory communication approach to community development places a high premium on listening to people and enabling them to actively participate in development initiatives. People's values, beliefs, attitudes, opinions and societal needs are also considered to be components of development (Lent in Ayee, 1993: 170). The essence of involving local people in the process is the sharing of information in order to build a common understanding, which is essential for effective action (Ayee, 1993: iii).

The participatory communication approach was conceived more than two decades ago. Since then, its principles have enjoyed increasing influence in the work of development communicators (Yoon, 1996). The roots of participatory approaches in development communication can be found in the early 1970s, when many people in development communication began to question the top-down approach that had been dominant in previous decades, which targeted the economic growth of countries as its main aim. This reaction gave birth to the implementation of approaches of a more participatory nature.

“The modernisation and dependency theories in community development and the emergence of participatory communication paved the way for a new paradigm” (Penzhorn, 2001). In this study, the participatory communication approach will be discussed in detail since, according to the literature, it is regarded as the most effective communication approach to information dissemination and communication (Mody, 1991; Snyman, 2004; Servaes, 1995; Phillips et al, 1993).

2.3.2 Participatory communication approach

Communicators in the general communication field also responded to the shift towards participation in the communication process by echoing new approaches in their work (Yoon, 1996), and participatory communication was thus born. The term ‘participatory communication’ is used to describe a process of two-way communication that encourages dialogue centred on problem analysis; people communicating with one another to search for solutions to their problems; and bottom-up communication that raises the awareness of decision-makers of these problems (Bessette, 1996:7; Richardson, 1997:1). Participatory

communication theory argues that the point of departure should be the community or target audience. An audience participatory approach to communication implies making the audience the sender of information, as well as the receiver. The communication process then becomes a circular dialogue. In this dialogue, the audience provides the basis for the information communicated, and how it should be communicated (Mody, 1991).

This approach attempts to move away from a one-way transmission of information to a two-way sharing of information, ideas, and experiences, with the objective of arriving at a common understanding on issues and possible solutions. It is characterised by an emphasis on self-reliance, people's participation and faith in people's ability to learn to change (Ayee, 1993: 170). Engaging the participation of stakeholders in any intervention by sharing information, knowledge, trust and commitment will lead to an appropriate attitude (Seavaes, 1995:45). The essence is the sharing of information in order to build a common understanding, which is essential for effective action (Steyn & Nunes, 2001:31). Participation should not be "the privilege of a few men, but the right of every man" (Servaes, 1995:45). All people should be given opportunities to openly express their views, without being forced to accept what others say.

Participatory communication recognises the importance of feedback and dialogue in the communication process. It encourages individuals and groups to voice their perceptions of reality. "As a process based on dialogue, participatory communication, supported by group media, mass media, or interpersonal interactions, may come to respond to the needs of non-formal, grassroots, or basic education".

There is, however, no recipe for a (successful) participatory communication approach. These approaches will vary according to different geographical conditions, societies, cultures and environmental conditions (Richardson, 1997). Different participatory communication approaches can be used for different purposes. The only prerequisites are that when these approaches are used for communicating, the messages they contain should be needed and understood by audiences.

This challenge of placing community members or receivers at the centre of any communication intervention aimed at empowering them caused the linear approach to communication to make way for a more participatory one (Snyman & Penzhorn, 2004). The

gradual shift towards participatory communication has changed and influenced the practice of and/or approach to communication processes in different disciplines. In this study, the focus will be on participatory communication and how it has influenced health communication.

2.3.3 Audience participatory message design

The ineffectiveness of mass media communication campaigns and the general shift towards participatory communication has significantly changed the practice of and/or approach to communication. The focus of (effective) communication approaches has moved away from the medium and product to the process of dialogue and discussion.

Even though the participatory approach inherently advocates interpersonal communication, other types of communication media can potentially distribute more information effectively to people, provided that the target audience is carefully researched and consulted in the development and production of the messages that are being communicated to them. According to Mody (1991: 20), any communication media can play a role in national transformation and development if they promote “mass participation as a means and as an end”. The successful use of communication media in communication thus depends on a sustained dialogue between the communicator and the audience, whereby the individual is no longer regarded as a target, but rather as a critical participant (Jacobson, 1997).

Maximum information transfer depends on the processes used to develop and produce mass media communication messages. Research indicates that effective communication processes are those that include and invite audience participation (Mody, 1991; Morris, 2001; Snyman & Penzhorn, 2004). Maibach & Parrot (1995) refer to these as communication processes that adopt an audience-centred perspective. Effective information campaigns should start with the assumption that people know best what their problems are, and what they need in order to cope with them, and they therefore should be directly involved in setting the agendas in creating and delivering the information messages (WHO, 1997). This process is, according to Mody (1991), a method of incorporating audience participation into the design of communication messages.

In a participatory communication approach, the use of an information material or information message should therefore be subjected to audience involvement from the planning stages of the communication campaign through to its evaluation stage. The realisation that audiences have different ways of thinking, different vocabularies, and even different interpretations of drawings and photographs, to the experts who initiate communication programmes, leaves message producers with no choice but to base messages on information obtained from the audience. Continuously listening to and obtaining feedback from the audience should be built into each step of the programme development process (Phyllis, Lawrence & Jose, 1997; FHI, 2002).

Since meaningful communication depends on a dialogue between the communicator and receiver, the everyday lives, practices, attitudes, beliefs and lifestyles of the audience should be reflected in the design of the message (Snyman & Penzhorn, 2004). Communication media developers of information messages therefore need to gain knowledge and insight into the lifestyles of the target audience. This implies a formative production process of communication media messages, in which the target audience is involved in some of the phases of the process (Doak, Doak & Root, 1996). Communication media developers should always keep in mind that a “lack of participation or involvement of the target audience in the process used to develop information messages is often suggested as an important reason for the failure to communicate information messages effectively” (Maibach & Parrot, 1995; Doak, Doak & Root, 1996; Panford, 1997; Leach, 1999).

2.4 HEALTH COMMUNICATION

2.4.1 What is health communication?

In paragraph 2.3.2, it has been indicated that this study will focus on participatory communication and how it influences health communication. Firstly, an explanation of what health communication is all about will be provided.

People need relevant and reliable information about how to cope with and/or avoid diseases. “When behavioral or psychological difficulties arise, people need specific information about

what is happening: the diagnosis, the meaning of specific symptoms, what is known about causes, effects, and the implications of the problem in question” (Pekkala & Merinder, 2005). “We depend on relevant health information to promote our own health and health of others: we need relevant health information to make best decisions about avoiding health risks, detecting and diagnosing health problems and seeking health care services” (Parker & Kreps, 2005). It is thus very important to effectively disseminate/communicate health information to the public, so that they have access to relevant, timely and appropriate health information that will help them to take the correct steps. Communication is consequently a care issue in health awareness and/or health promotion (Vignault, 2000). The process of communicating with individuals and communities about health issues is called health communication.

Health communication can therefore be described as the process of providing information that may positively influence people’s choices to safeguard themselves from the most common cause(s) of diseases (Vignault, 2000). Just like the term “communication”, “health communication” has many definitions. In general, health communication is defined as a process for the diffusion of messages to specific audiences in order to influence their knowledge, attitudes and beliefs in favour of healthy behavioural choices (Northhouse et al, 1998). The degree to which the right message reaches the right audience at the right time so as to increase the likelihood of desired outcomes is, according to Ratzan (1994), indicative of high-quality or effective health communication. Effective communication is the backbone of health promotion and disease prevention (Plimpton & Root, 2000). It is a crucial factor in the delivery of high-quality health care. “Health communication encompasses the study and use of communication strategies to inform and influence the decisions of individuals that enhance health. It links the domains of communication and health and is increasingly recognized as a necessary element in efforts to improve personal and public health” (Piotrow et al, 1997). According to Plimpton & Root (2000), the practice of health communication has contributed and can still contribute even more to health promotion and disease prevention in several areas.

Health communication can be considered as one of the sub-fields of development communication. Colle (2002) states that development communication can take place in different real-life development sectors such as agriculture, health and community development. According to Nair and White (1993: 104), development communication is the use of media in the process of motivating, communicating and mobilising a target population

to respond to planned programmes of changes in health, education, agriculture, nutrition, family planning and other sectors of development. The two authors define development communication as “the way in which information is made accessible and disseminated through media in different formats, in order to solve problems and to make decisions to improve the standard of living in a development context”. According to Nair & White (1993)’s definition, health communication then refers to the way in which health information is made accessible and disseminated through media in different formats, in order to solve problems and make decisions to improve the standard of living in development, health and/or other contexts. Through health communication, health information is made accessible and communicated to solve health-related problems, so that people can make informed decisions that will improve their standard of living in a health promotion context.

2.4.2 Models for a health communication approach

2.4.2.1 Evolution of health communication models

“Historically, communication for development has gone through a transition from modernization, dependency, multiplicity, diffusion theories to mention but a few” (Servaes, 1995). Since health communication is one of the sub-fields of development communication (as explained in paragraph 2.4.1), health communication has gone through the same process of evolution that communication for development has (Servaes, 1995).

Most of the early approaches to health communication were based on the transmission model of communication, in which information was seen to pass from senders to receivers. “Communication materials used in the past, to educate patients and caregivers were produced without the active participation of the very patients for whom they were intended” (Motlana et al, 2003). The consequences of such a process are that patients may end up not understanding the message disseminated to them about their illness. In turn, this may impact negatively on their recovery. Communication processes that exclude audience participation are deemed ineffective, because they view communication as a message sent from sender to receiver while in practice, these communication processes exclude the target audience from the design and production of the message, leading to a one-way form of communication.

The gradual shift from this hierarchical, top-down view of communication to a deeper understanding of communication as a two-way process that is interactive and participatory has also influenced and changed the environment of health communication (National Centre for Health Statistics, 2003). As with general communication research, the focus of health communication moved away from the medium and product to the process of dialogue and discussion (Snyman & Penzhorn, 2004). The participatory communication approach is now considered by many authors to be the most effective health communication approach, since it includes audience participation (National Cancer Institute, 1989; Ratzan, 1994; Snyman & Penzhorn, 2004).

2.4.2.2 Models for an audience participatory message design

It has already been argued in 2.3.3 that meaningful communication depends on a dialogue between communicator and receiver, and that the everyday lives, practices, attitudes, beliefs and lifestyles of the audience should be reflected in the design of the message. Producers of health information messages therefore also need to gain knowledge and insight into the lifestyle of the target audience. This implies a formative production process of mediated information messages, in which the target audience is involved in some of the phases of the process (Doak, Doak & Root, 1996). In order to develop effective (health) information materials for any target audience, they should be involved from medium selection right through to concept formulation, production, testing, implementation, monitoring and evaluation (Servaes, 1999). This audience-centred approach is also considered to be the most effective and/or appropriate approach for developing health information messages.

There are many models that advocate and/or demonstrate the audience-centred approach in the development of health messages. These models are also referred to as models of audience participatory message design in health communication. According to Mody (1991: 54), these models involve specific and explicit sequential steps for audience participation. Similar steps to those that Mody (1991) identified in her writing entitled “Systematic steps of audience involvement in message design” are found in, among others, the Communication Wheel of the Centre for Disease Control (Centre for Disease Control, 2001), the Consumer-Based Health Communication Model (Sutton, Balch & Lefebvre, 1995) and HEALTHCOM’s 5-step methodology (Healthcom, 2003). The method of presentation of all these models is different,

and the specific production processes suggested by these models vary. However, their basic aim is to deliver messages to the target audience, and they all emphasise the involvement of the audience in the communication of information. Thus, they are all based on the participatory approach, starting with an assessment of the audience's needs, realities and resources, and ending with an evaluation phase to determine the feedback of the audience.

In essence, the various steps presented in these models can be consolidated into four main phases (Snyman & Penzhorn, 2004), namely:

- Defining, involving and researching the audience. In this phase, information about the target audience is collected using both primary and secondary research techniques.
- Determining the objectives. In this phase, the content and nature of the message should be set according to the information obtained in phase one.
- Production phase. In this phase, the message is developed and produced through a formative process in which the target audience is consulted- including a pre-testing of the message.
- Quality assurance and distribution. The last phase consists of steps to determine whether or not the message has accomplished its purpose through measuring effective distribution and behavioural change, as well as feedback from the target audience.

In any communication process (e.g. health communication), media play an important role in conveying information messages to the target audience. There are many types of communication media, and these are appropriate for different situations. In the next section, communication media appropriate for a health communication event will be discussed in more detail.

2.5 COMMUNICATION MEDIA FOR HEALTH COMMUNICATION

2.5.1 Choosing appropriate media for health communication

One of the important steps in any communication event is to choose the most appropriate medium or media. A medium is, according to Steinberg (1994:15), the physical means by which messages are transmitted or transported between people (the communicator and the receiver) in a communication event. “Medium” and “media” are the same thing, the only difference being that media is the plural form of medium. The terms “medium” and “media” are often used interchangeably with the term “channel”. Steinberg (1994:15) defines the term “channel” as the route by which messages travel. Both a medium and a channel can be regarded as links between the communicator and recipient. In this study, the term ‘communication media’ will be used, since it implies channel(s) through which information is communicated to people (Schramm, 1964: 180)

In order to ensure that information disseminated is understood, appropriate media of communication must be used. There is no difference between deciding on an appropriate medium in the health context and doing so in any other communication situation. The type of information one wants to disseminate often determines how it will be disseminated, and which communication media will be used. Selecting the most appropriate medium depends on the communicator’s goal, resources and the type of audience (Khouri, 1999: 2).

The target audience should be involved when deciding on the type of media to be used. It is important to take the target audience into consideration, because every target group (audience) is unique and has its own needs. According to Panford (1997: 336), it has been established that the single most important factor when selecting a medium for any communication event is to know the audience well. Information about a target audience can be collected by compiling a comprehensive profile of the target audience’s information requirements (Morris, 2001). This means that effective promotion and communication initiatives reflect the audience’s preferred formats, channels and content. Research indicates that effective health promotion and communication initiatives adopt an audience-centred perspective (Maibach & Parrot, 1995).

Selecting the appropriate media for any type of communication campaign is extremely important, since it is assumed that using suitable media will improve the effectiveness of the communication process. Sturges & Neill (1988:206) state that “the nature of the packages into which information is placed is crucial in the provision of information services to the whole community”. In order for messages to be well understood by receivers, the medium used to communicate the message is as important as its content. The target audience can also help to determine the content of the message, if they are allowed to express their needs.

2.5.2 Different types of communication media

There are a variety of communication media through which (health-related) information can be communicated to the receiver. According to several authors (Steinberg, 1994; Yoon, 1996; Mersham & Skinner, 2001; Haggie & Dickson, 2004), one can distinguish between interpersonal communication media and mediated communication media. Mediated communication is when a message reaches recipients through a mechanical or electronic medium, e.g. print, radio, television etc. (Steinberg, 1994). Since this study focuses on interpersonal communication and print-based communication media, these two types of media will be discussed in more detail in the next two sections.

2.5.2.1 Interpersonal communication media

Interpersonal communication is the type of communication that occurs between two or more people in a face-to-face situation (Steinberg, 1994: 37). This type of communication is also referred to as face-to-face communication. “It is an interactional process between two people either face-to-face or through mediated forms” (Daniel et al, 2000). According to these authors, types of interpersonal communication vary from verbal to non-verbal, and from situation to situation. Interpersonal communication can either be on a one-to-one basis or in a group setting (to an audience of two to six people). According to Spitzberg & Cupach (1984), interpersonal communication is not interpersonal if it involves many people. When the number of people exceeds a certain amount, it is no longer interpersonal communication, but then becomes mass communication (communication to large masses of people).

Interpersonal communication in general has an interactive nature when used for information provision (Leach, 1999). It is a two-way process, in which both communicators and receivers share information (interact) so as to reach a common understanding. In this way, skills, experiences and learning are shared (Leach, 1999:77). Thus, this type of communication is a very powerful forum for information exchange. The most common functions of interpersonal communication are listening, talking and conflict resolution (Daniel et al, 2000).

Interpersonal communication allows receivers to obtain both verbal and non-verbal communication cues given by communicators. Communicators are also able to get immediate feedback from their target audience. Interpersonal communication on a one-to-one basis is, according to Spitzberg & Cupach (1984), a very effective way of communicating information to people who are too shy to ask questions in group situations, but by talking to them individually/personally, they feel free to ask questions.

The interpersonal communication approach can be an effective communication tool, but it may not always be an appropriate technique, as it has disadvantages just like any other communication media. One of the main disadvantages of this type of communication is that, in order for it to take place, both the communicator and recipient should be available at the same time. They would probably have to be in the same place if the interpersonal communication process occurred orally, but if it is mediated (e.g. a telephone is used), the communicator and receiver need not be in the same place. Leach (1999)'s view on the provision of information on an individual basis is that it is regarded as time-consuming and has an inability to "cover many people". Interpersonal communication requires spontaneous thinking and can be difficult to terminate (Spitzberg & Cupach, 1984).

2.5.2.2 Print-based communication media

Print-based communication media are one of the types of mediated communication media. As it has already been indicated in paragraph 2.5.2, mediated communication media occurs when messages reach receivers through a mechanical or electronic medium, e.g. radio, print, television etc. (Steinberg, 1994). Print-based media are still by far the most widely used media in information services, despite inroads made by electronic media, e.g. television, internet, etc. (Morris, 2001:12). According to this author, they are media of communication that disseminate information through texts, pictures or a combination of both, e.g. books,

newspapers, pamphlets, magazines etc. Print-based media are popular communication media used to disseminate health information to the South African population (Snyman, 2004).

Print-based media play an important role in the communication of information (Carstens & Snyman, 2003). They are portable media, hardly dependent on technology for their use (Sturges & Neill, 1998: 206). According to Snyman, (2001), this type of communication media requires relatively simple and cheap methodology to produce. They are handy reference sources, easily stored and allowing for accuracy of content and precision of expression (Snyman, 2001; Carstens & Snyman, 2003).

However, the use of print-based media in information provision is inextricably linked to literacy skills (Leach, 1999). Printed information messages are of limited use in reaching illiterate people. They are in fact an “inappropriate extension medium for use in low-literacy communities” (Sturges & Neill, 1998: 206). “When high rates of illiteracy are present, print-based systems are definite unsuitable” (Correa et al, 1997:7). Apart from the question of illiteracy, the inability of print-based media to allow for a two-way [interactive] process could also be viewed as a disadvantage (Leach, 1999:77). Print-based information messages cannot be given without explanation if an effective information communication process is the goal. In this way, print-based media cannot be used alone as a mean of providing information, but should always be used in conjunction with interpersonal communication, so as to allow for a two-way communication process. Printed information messages are very different from interpersonal communications, which occur in face-to-face situations. They do not have audio elements. Print-based communication media have been described as an encounter with a print medium and a message – rather than a relationship with another person, as in interpersonal communication.

In print-based communication media, the communicator who would like to transmit a message to a target audience cannot reach the latter directly in face-to-face situations. The communicator first needs to encode and transmit the message using print-based media. A similar process occurs when the target audience wants to provide feedback to the communicator. Therefore, feedback is delayed. According to Mersham & Skinner (2001:7), there is also relatively little or no interaction or feedback from the audience to the communicator in a print-based communication process, because the audience members are unable to use the same medium to reply to the communicator. Print-based media are less

personal (Spitzberg & Cupach, 1984). Since communicators using print-based media are not exactly sure of who their audience (readers) are, they may direct the message at groups of people who may not have very much in common. Therefore, they (communicators) cannot personally address messages to particular individuals.

One extreme argument is that use of print-based information materials are inseparably linked to a ‘top-down’ information provision approach, in which scientific information is literally fed to recipients. However, print-based media can be used in such a way that information is shared and not imposed on people. An example is sharing information through locally generated print-based information materials. Here, the development of print-based information materials usually involves an extensive consultation of and participation by intended users during the design, development and testing of the information materials.

2.5.3 Different types of media used for health communication

2.5.3.1 Using interpersonal media for health communication

As has been seen in the previous discussion, the participatory communication approach inherently advocates interpersonal communication (e.g. community meetings, demonstrations, etc.) and the utilisation of small media (community radio and video). In paragraph 2.5.2.1, it has been indicated that interpersonal communication could either take place in face-to-face situations or through mediated forms. The main issue is not that the interpersonal health communication process occurs through mediated forms or on a face-to-face basis, but whether or not appropriate health information messages are effectively communicated to the target audience. “The appropriateness of information directed to the audience depends on the appropriate information from the audience” (Schramm, 1964: 177). It is thus important for health information packagers or designers to know their target audience very well e.g. their demographic information, information needs, communication media preferences etc. This is because the successful use of any communication media in health communication depends on sustained dialogue between communicator and audience. “The individual is no longer a target, but a critical participant” (Jacobson, 1997).

However, according to Valente & Poppe (1996), several research studies have found that any mediated communication media used alone in a health information campaign do not bring about a massive shift in public opinion, but when used in combination with interpersonal networks, rapid behavioural change is achieved. Interpersonal communication is therefore effective in changing behaviour in health promotion campaigns.

2.5.3.2 Using print media for health communication

In spite of the fact that the illiterate population (especially in developing countries) is rising (Sisulu, 2004), print-based media are often preferred in health communication campaigns (Leach, 1999; Snyman, 2001; Morris & Stillwell, 2003). Swanepoel (2003), in his comprehensive review on printed mass media communication, which aims to contain the spread of HIV/AIDS, postulates that most health communication campaigns that use print-based media are ineffective. One of the problems is caused by the ineffective processes used to conceptualise and implement these campaigns. In order to create an effective print-based communication process, audience participation should be included and invited. A lack of participation or involvement of the target audience in the process used to develop health information messages is often suggested as an important reason for the failure to effectively communicate health information messages (Doak, Doak & Root, 1996; Leach, 1999). Carefully designed print materials can be used to support the interaction between health workers and clients (Zimmerman et al, 1996).

According to Zimmerman et al (1996), there are many advantages to using print-based information materials in the information, education and communication components of health programs. These advantages include the following:

- Print materials come in many forms, such as booklets, package inserts, posters, fliers, colouring books, comic books and flip charts. This means that health communicators have a wide variety of print-based formats to choose from for health information campaigns.
- Print materials are easy to store and can be used without any special equipment.
- Print materials can be used as reference materials, should the health information provider or clients forget any important messages.

- Print materials provide a means for transmitting standardised information to an audience beyond the initial recipient, since clients often share their print materials with friends, relatives or neighbours.
- Print materials may serve as a motivator for those who wish to improve their literacy skills.

2.5.3.3 Using a mixed media approach for health communication

Interpersonal and print-based media are not the only two types of communication media that are used to disseminate health information to target audiences. Other types of communication media can be used for health communication campaigns. Multiple media could perhaps be used for a single health communication approach.

The literature clearly indicates that the same medium of communication can be used for different situations, and that different groups of audiences will need different types of media. Each medium has its own characteristics (advantages and disadvantages), and it could be effective and/or appropriate for certain circumstances, while not necessarily the best for all circumstances. Nyirenda (1998:26) contends that there is no single medium that is likely to have properties that make it the best for all situations. There are certain messages that can be better understood when a certain communication medium is used, compared to when other communication media are used. One or more media might be necessary in order for each common objective to be achieved.

A single, appropriate communication medium for a target audience can potentially distribute health information to the target audience by using a multiple media approach (using different forms of media) to disseminate the same health information, which leads to more effective health information campaigns, since different individuals within a certain target audience have different preferences in terms of communication media. If each individual could receive health information messages through his or her preferred communication medium, then more individuals would accept the communicated health information, and increased behavioural changes would thus occur.

In this case, it is again advisable to carefully research and consult the target audience in the development and production of the messages communicated to them, by involving the target

audience in choosing the communication media that they prefer. The effective use of communication media in health communication thus also depends on a sustained dialogue between communicator and audience, whereby the individual is no longer regarded as a target, but as a critical participant (Jacobson, 1997).

2.6 MENTAL HEALTH COMMUNICATION (PSYCHO-EDUCATION)

The two concepts “health communication” and “health education” are similar and often used interchangeably in literature. The main aim of health education is to teach and/or provide a target audience with health information. The aim is to help the audience understand the information and use it effectively, so as to live a healthy lifestyle (Green, 1999). The aim of health communication is also to make health information accessible, by disseminating it to an audience to enable them to solve health-related problems and make informed decisions that will improve their standard of living in a health promotion context (Piotrow et al, 1997). In both health communication and health education, information is disseminated and negotiated in order to create meaning.

Health education is however much broader than health communication. According to Goodstadt (2007), health education contains many sub-fields (e.g. advocacy, health public policy, organisational change and development, health communication, intersectoral collaboration, mutual aid and support etc.) which are all concerned with health promotion. Green (1999) states that health communication is not only concerned with the communication of information, but also with fostering the motivation, skills and confidence (self-efficacy) necessary to take actions to improve health. In short, health communication is one of the sub-fields of health education.

The provision of mental health-related information that may help a mentally ill person to make informed decisions about living with a mental illness can be called mental health communication. Mental health communication refers to the process of providing mentally ill patients, their caregivers and families with important information on a specific mental illness and its treatment. In psychiatry, this process is often called psycho-education. The aim of psycho-education is to help patients who suffer from a mental illness (such as schizophrenia), their families and caregivers to:

- learn what they need to know about the mental illness; master new ways to manage it; reduce tension and stress in the family;
- provide social support and encouragement;
- focus on the future (instead of the past); and
- find ways for families and supporters to help consumers in their discovery (What is Psycho-education, 2001).

In medical research, psycho-education “has been associated with a variety of significant gains for mentally ill patients, including: less frequent relapses, reduced psychiatric symptoms, reduced re-admission rates, improved patient’s ability and willingness to stay in long-term treatment, and also improved social functioning of the patient” (McFarlane et al, 1993).

In this study, the term “psycho-education” will encompass the term “mental health communication”, since psycho-education aims in essence to communicate information about mental illnesses to a selected target audience in order to help them take better decisions that will improve the quality of their lives.

2.7 CONCLUSION

The literature clearly indicates that effective communication approaches should allow the sender and receiver to share the same set of skills, use the same language, and use words and signs in the same way (Morgan & Welton, 1992: 10). The communicator and receiver should share a common and/or clear message in order to achieve the aim of the communication. Although the message could be disseminated in many different ways, in the end, the receivers and senders should have one common understanding. Effective communication approaches are those that allow the two parties of a communication process (senders and receivers) to reach a common understanding of the meaning of the message. This approach is generally referred to as the participatory communication approach (Mody, 1991; Snyman & Penzhorn, 2004; Searves, 1995; Phillips et al, 1993). This approach emphasises the participation of the audience in the communication of information. This approach depicts communication as a dynamic process in which both participants are actively engaged in encoding, transmitting, receiving and decoding the message (Steinberg, 1994: 19). It

emphasises the dialectical and interactive nature of both the communication and participation processes (Nair & White, 1993:53).

Effective communication campaigns should start with the assumption that people know best what their problems are and what they need in order to cope with them. They should be directly involved in setting the agendas in the creation and delivering of information messages (WHO, 1997). The only way to involve people (target audience) is through participatory communication, which is a two-way communication process between the communicator and the audience that can provide relevant and timely information to satisfy the audience's information needs. Target audiences and potential users of communication material (e.g. psycho-educational material) should play an important role in the development of the communication material.

Several message design guidelines were identified, in which the common factor is the need to work with the audience from the beginning of the process. Assessing audience's needs came out clearly as the most important factor in the process of designing messages in a health context. The role of the message designer is therefore to elicit information needs from the target audience, interpret and analyse responses, and on this basis, conceptualise and create materials that will best suit the audience's information needs (Zimmerman & Perkin, 1982: 121).

As stated earlier, the aim of this study is to determine the appropriateness and/or effectiveness of psycho-educational information contained in *The Alliance Programme* for patients with schizophrenia in the South African context. It is assumed that in order to ensure that this information is understood and accepted by the South African target audience, a participatory communication approach is most appropriate. In the research that will be described in the rest of the study, it will be investigated whether or not the logic, language and experiences in the mental health information material (*The Alliance Programme*) match the target audience's logic, language and experiences (Doak, Doak & Root, 1996: 66). If the logic, language and experiences of the healthcare instruction (information material) match the logic, language and experiences of the patient (target audience), then understanding, acceptance and behavioural change are more likely to occur.

2.8 SUMMARY

In this chapter, a literature review with regard to aspects related to the study was conducted. Different concepts that relate to health communication were highlighted and discussed. Models for designing and producing effective information campaigns emphasise the involvement of the audience in the creation and delivering of information messages. This process was referred to as the audience-centred approach/participatory communication approach, and this was discussed in this chapter. The evolution of general communication theories was explored, in order to identify some of the trends that converged to contribute to the emergence of the practice of participatory research. The relationship between psycho-education and mental health communication was explained.

The next chapter will describe the research methodology used in this study.

schizophrenia information materials for the South African context, in that it gives one an idea of what kind of schizophrenia information materials are suitable for South Africa. It also gives people an idea of the appropriate ways of communicating schizophrenia information to patients in a South African setting.

1.14 DIVISION OF CHAPTERS

The study is divided into five chapters.

- **Chapter 1** -*Background to the study*

This chapter is the general introduction to the research topic. It includes the aims and objectives, hypothesis and research questions, the scope of the research, definition of technical terms, methodology, value, assumptions and limitations of the study.

- **Chapter 2**- *Literature Review*

A review of relevant literature on the research topic is conducted in this chapter. It also deals with what has already been written on the topic of this study. It analyses these writings and relates them to the topic of this study. The role of information and communication, as well as the evolution of general communication models/theories, ending with participatory communication, are discussed. The importance of the audience in the communication of health information, and the guidelines for choosing appropriate media for health communication campaigns are also discussed.

- **Chapter 3**- *Research Methodology*

This chapter discusses the methodology used in this research. The methodology includes the design used in this study. The choice of, and motivation for, the data collection methods used, as well as the procedures followed to obtain and collect the data, are provided. This chapter describes the step-by-step implementation of the research process, and also describes the data analysis of data obtained in this study.

- **Chapter 4**- *Research findings and discussion*

This chapter discusses the findings of the research process, the problems encountered and the analysis of the interviews and focus group discussions.

○ **Chapter 5- *Conclusion and Recommendations***

This chapter provides the conclusion reached on the basis of research findings, as well as the recommendations that can be used to effectively communicate information about schizophrenia, which incorporates proposed guidelines for an effective psycho-education process in South African settings.

1.15 SUMMARY

In chapter 1, the research problem, objectives and design were briefly addressed in order to serve as a background to the rest of the study. The next chapter discusses the literature review conducted for this study.

Chapter 3

RESEARCH PROCESS

3.1 INTRODUCTION

This study is aimed at determining the usability of the schizophrenia information disseminated partly via the information material (*The Alliance Programme*). This study also aims to:

- explore the effectiveness and/or appropriateness of the communication of schizophrenia information through this information material in the South African context; and
- determine whether or not this material needs to be adapted so as to suit the South African context, or if it can be used as is.

This chapter discusses the research design, research methodology, data collection methods, research process and data analysis undertaken in order to accomplish the aims of this study.

3.2 RESEARCH PROJECT

This is Phase 2 of an ongoing project aimed at designing appropriate information messages about schizophrenia using the audience-based media production approach. The ongoing project consists of the following phases:

- *Phase 1:* Researching the target audience
- *Phase 2:* Testing the effectiveness and/or appropriateness of an existing schizophrenia information material to the target audience
- *Phase 3:* Designing appropriate schizophrenia information material for the South African context, based on the findings of phase 1 and phase 2 of the study.
- *Phase 4:* Producing appropriate schizophrenia information material(s), including pre-testing and modification.

In the first phase of this study, the target audience was researched, and their information needs, perceptions and knowledge of their illness (schizophrenia) were explained. The findings of the first phase of the research project indicated that the information needs of patients suffering from schizophrenia are to a large extent determined by their context and cultural orientation (Motlana et al, 2003).

In the second phase of the study, the findings of the first phase of the study were applied and more research was conducted to test the effectiveness and/or appropriateness of the information contained in *The Alliance Programme*. This programme was developed in the USA by international experts in schizophrenia care, and is currently used to disseminate information about schizophrenia in the South African context at the Weskoppies hospital in Pretoria. This study (Phase 2) is aimed at determining the usability of the information about schizophrenia disseminated via *The Alliance Programme* designed for patients suffering from schizophrenia, and to explore whether or not effective communication of health information takes place. It is foreseen that this study, if necessary, would also provide guidelines as to how *The Alliance Programme* (existing schizophrenia information material) can be improved – preventing the waste of money and time, as is often the case when using externally developed programmes in South Africa.

3.3 WHAT IS *THE ALLIANCE PROGRAMME*?

The Alliance Programme contains information about schizophrenia. It was developed in the USA and approved by international experts in schizophrenia care. It is used for facilitating and supporting the implementation of schizophrenia information discussion classes (psycho-education programmes) with patients suffering from schizophrenia across different settings (*The Alliance Programme: Workbook for health professionals*). The development of this material was funded by Pfizer Inc, the worlds' largest global research-based pharmaceutical organisation.

The Alliance Programme consists of two workbooks: the mental health professionals' workbook and the patients' and caregivers' workbook. Each of these workbooks comprises eleven sections addressing a spectrum of topics relevant to patients with schizophrenia and/or their caregivers. The content includes signs, symptoms and treatment-related issues of the disease. Just like any other mental health information material, the main purpose of *The*

Alliance Programme is to provide patients suffering from schizophrenia with information and advice regarding schizophrenia (their illness), its treatment, and how to cope with it. It is argued that once patients are provided with information about their illness, they become aware of important facts about their illness, and are therefore in a better position to make informed decisions and to cope with their illness.

The effective communication of information about schizophrenia is needed in order to empower patients. In the previous chapter, in paragraph 2.6, it is indicated that “communication of information about schizophrenia” and “psycho-education” are similar concepts, and are used interchangeably in the literature. Therefore, effective communication of schizophrenia information or psycho-education takes place when the target audience understands the information communicated to them, and is able to use this information to make informed decisions that will improve their standard of living in a health promotion context.

3.3.1 Using *The Alliance Programme* at the Weskoppies Hospital

Currently, *The Alliance Programme* is used at the Weskoppies hospital in Pretoria (South Africa) to facilitate psycho-educational classes, with the aim of informing patients at the hospital suffering from schizophrenia about their illness. The Weskoppies Hospital is a psychiatric hospital situated in Pretoria (South Africa), which treat patients with psychiatric disorders e.g. patients suffering from schizophrenia. This hospital offers treatment for a spectrum of patients, ranging from the elderly to the very young, and from severe to mild behavioural disturbances. It has approximately 1400 beds, and approximately 5000 patients are admitted annually.

Due to the high level of illiteracy among patients at the Weskoppies Hospital (target audience/research participants), *The Alliance Programme* was considered to be too complex to be used for the target audience of this study. It is currently being delivered orally to the research participants. A social worker, Linda Booysen, who has seven years’ experience in teaching low- literate patients suffering from schizophrenia about their mental illness, acts as a facilitator in this regard. A Tswana-speaking social worker (Sylvia Pitse) is an interpreter involved in the presentation of information about schizophrenia to patients based on *The Alliance Programme*. She assists Linda by translating everything that she says from English to

Tshwana, in order to ensure that the research participants understand, since they are all Tshwana speakers.

With the experience she has had in this field of disseminating information about schizophrenia to low-literate patients suffering from schizophrenia, the presenter realised that *The Alliance Programme* would be too complex for the target audience of this study. She thus adapted it in her own way the very first time she presented the schizophrenia information based on this programme to the target audience.

3.3.2 An adapted version of *The Alliance Programme*

In this section, a summary of how Linda adapted *The Alliance Programme* is presented. She adapted it in the following ways:

3.3.2.1 Printed text

Research participants were never issued with the printed *Alliance Programme* before or during the schizophrenia information discussion classes to read in class or at home. The research participants just came and listened to Linda's presentations, but they never saw the book (*The Alliance Programme*).

3.3.2.2 Content reduction

Linda tried to reduce the content provided in *The Alliance Programme* by summarising the different topics on schizophrenia, then presenting the information about schizophrenia to the research participants in a short, simplified manner.

3.3.2.3 Contextualisation and personalisation of information

The presenter tried to contextualise and personalise the schizophrenia information she presented to the research participants. During the classes, she would ask all research participants about their personal experiences with schizophrenia, relating these to each topic about schizophrenia that she discussed. She would also explain the content by means of simpler examples that all research participants were familiar with, or use one of the research participant's personal experiences with schizophrenia to further explain a particular theme/lesson on schizophrenia.

3.3.2.4 Local language

In the schizophrenia information discussion classes presented by Linda, another social worker, Sylvia, who spoke Tshwana fluently, was also present. Sylvia translated everything that Linda said in English to Tshwana, in order to ensure that the research participants clearly understood all the information about schizophrenia presented to them in these classes, since they all understood Tshwana.

3.3.2.5 Interactions

Linda tried to present the schizophrenia information discussion classes in an interactive manner. As explained earlier, she would try to involve each and every research participant by asking them about their personal experiences with schizophrenia in relation to a specific topic. She also asked them questions on a particular topic that she would be explaining at that particular time, just to keep them focused and ensure that they understood the information or message being communicated.

3.3.2.6 Difficult words or scientific terms

Linda explained all the words or terms she thought would be difficult in *The Alliance Programme* in simpler terms that the target audience were more likely to understand. Sometimes, she would even use examples to explain these terms further, before she started using them frequently in her presentations.

3.3.2.7 Illustrations

Linda never used any form of illustrations e.g. diagrams, pictures, photographs etc. in her presentations during the schizophrenia information discussion classes. She did however write notes in point format on the board while presenting the schizophrenia information to the research participants, in order for them to read and understand better.

3.3.3 Researching *The Alliance Programme*

Chapter one of *The Alliance Programme*, which focuses on signs, symptoms (including early warning signs), frequency, course and prognosis of schizophrenia, was selected and used for this study. This part of the text, used for evaluation in this study, was selected due to limited time constraints, as it was not going to be possible to evaluate the whole

contents (all the chapters) of *The Alliance Programme*. Hence, not the whole *Alliance Programme* but only a portion thereof was researched.

Chapter one was also the only chapter that was communicated and/or disseminated to the research participants in this study and which was adapted for those in Group B.

3.4 RESEARCH PROCESS

3.4.1 Research approach

Every research project requires a research approach or philosophy on which the research methodology is based. Different people view the world from different perspectives. They take up different positions in the world with regard to the subject of their research. In terms of scientific research, there are three main positions that express markedly different views of the world (Henning, 2004: 15). Firstly, the researcher and the researched are mutually exclusive entities, working independently of each other. The assumption, in this instance, is that each constitutes a separate, discrete world that can be studied in uncontaminated isolation. This is the positivistic framework, which is all about finding the truth and expressing it through empirical means. Secondly, the researcher and the researched work in an interrelated, dialogical fashion - the one trying to understand how the others live, and being part of their world as well. This is the interpretivist framework, which is mostly descriptive, trying to present the reality of participants from their own point of view. And thirdly, the researcher and researched have a mutual aim in mind in terms of the research. "They are both committed to a mutual form of emancipation in a world that creates, maintains and reproduces unequal power relations" (Henning, 2004:15). This is the critical framework which, according to Henning (2004:15), aims at promoting critical consciousness and breaking down the institutional structures and arrangements that reproduce oppressive ideologies, and the social inequalities that are produced, maintained and reproduced by social structures and ideologies.

A methodology is the exact plan and procedure for carrying out research and obtaining valid information (Chardwick et al, 1984: 36). It is concerned with the specific ways or methods that can be used to try to better understand our world (Henning, 2004: 15). The methodological approach undertaken in this project is broadly qualitative, which belongs, according to Henning (2004:15), to the interpretivist framework. The qualitative method is primarily concerned with

an in-depth study of human phenomena, in order to understand its nature. These methods are “useful for researches that are poorly understood, ill-defined and for which control groups cannot be easily devised” (Motlana et al, 2004). According to Charles (1995: 21), qualitative research explores traits of individuals and settings that cannot easily be described numerically.

In order to be more exact or specific, an empirical, qualitative research method was used in this study. This method allows the researchers to “approach the world of the subjects they are investigating with the minimum of preconceived ideas and that they look at the phenomenon under discussion in its natural setting” (Berg, 1998). This type of research has a predominantly descriptive nature, and its aim is to get an in-depth picture of perceptions and the quality of human conduct - the focus is not on quantitatively measurable behaviour, but on the significance and meaning that people attach to social situations or phenomena, and the intentions that underlie everyday human actions. The researchers attempt to discover and describe the respondents’ opinions and how they perceive the world.

3.4.2 Research design

“Research design includes the plan, structure and strategy of research. The main objective of a research design is to control the answer to the research question and to eliminate out variances that have a differential effect on the research results” (Chadwick et al, 1984:26). According to Struwig and Stead (2001), the plan includes a clear specification of the question that one wants to answer, the procedure one will use in collecting data relevant to the question, and the approach to be used in analysing and interpreting the data, so as to shed light on the answer to the question.

Since this study’s main aim to evaluate and adapt *The Alliance Programme* (developed in the USA), in order to make it more suitable for the South African context, a formative research design was implemented, and usability testing was chosen as the practical technique to be used.

3.4.2.1 Formative research

Formative research is an assessment tool to modify and improve products or programs during their planning, development and implementation (Reigeluth, 2006). It is “a kind of research method that holds much promise for generating the kind of knowledge that is most useful to educators-guidelines for practice, which help us decide how best to accomplish our goals, as opposed to descriptive knowledge, which help us understand ‘what is’. Formative research is a kind of development research or action research intended to improve design theory for designing instructional practices and processes” (Reigeluth & Frick, 1999). Toure (2003) refers to this research method as a process-oriented assessment tool that can be adapted for macro-analysis of complex processes, in order to support systematic change. According to this author, this research method draws on case study approaches and uses qualitative research methods.

Formative research entails asking questions such as “What is working?”, “What needs to be improved?”, and “How can it be improved?” (Reinking & Watkins, 2000). This type of research allows researchers to become actively engaged with research participants and institutions in the research, in order to encourage change (Jimenez, 1997). It provides a mechanism for regular and methodical reflection and dialogue throughout implementation, generates knowledge, builds competencies and confidence, and can improve the results of the systemic change process (Toure, 2003). This research method, according to Toure (2003), has been extensively used in the health sector, and is newer to education. Formative research can be useful for all kinds of functional texts varying from manuals to advertisements, and from leaflets to forms (De Jong & Schellens, 1997: 402). General principles guide the development of formative research, and guidelines are usually created or identified (Reigeluth, 2006). For example, a course (schizophrenia information discussion classes) might be developed based solely on guidelines, using as little intuition as possible. According to Reigeluth & Frick (1999), formative research is sometimes called field testing or usability testing.

3.4.2.2 Usability testing

It has been indicated that when choosing information materials¹ for information dissemination and/or information communication, the audience should be taken into consideration. To ensure that the message conveyed is suitable for and understandable by the target audience, usability testing of the message should be conducted. According to Chaka (2003), the aim of usability testing is to ensure that information materials are understood by and beneficial to users.

Usability testing is one of the many different kinds of formative text evaluation (De Jong & Schellens, 1997: 402).

Usability refers to the degree to which documentation² can be effectively used by the target audience in the performance of tasks (Guillemette, 1989: 217). Long (in Guillemette, 1989: 59) distinguishes between three general usability requirements in order for documentation (information material) to be usable:

- for particular readers (receivers);
- to perform specific tasks; and
- in a certain physical and social environment.

An information material is reader (receiver)-usable if it can be effectively used by alternate groups of readers (receivers) possessing expected competencies, skills and knowledge. It is task-usable if readers (receivers) are able to retrieve and process needed information quickly, with minimal physical or mental effort. The document is environmentl-usable if it is accessible when and where it is needed, and is also used within the existing time and economic constraints (Guillemette, 1989:218).

Usability is essentially concerned with the process of using information material. One important aspect is readability, or the degree to which target readers are able to understand the documentation, are able to read quickly, and find it interesting. Readability testing is necessary but an inadequate instrument for assessing usability of information material, because the reader or receiver may face difficulty in locating needed information or establishing links between documented material and the task situation. The assessment of readability involves a

¹ Information materials are information resources in any form of communication media that contain messages on a certain topic.

² Documentation refers to any print media type of information resources (e.g. booklets, pamphlets, brochures etc) which are used to communicate formally with the public.

consideration of various aspects of the reading situation, such as content, organisation, format and style, documentation, reader background, skills and motivation, and certain environmental variables (Guillemette, 1989).

The utilisation of documentation or information materials is a function of its usability and functionality. Functionality refers to the technical capabilities of the documentation. What readers can do with the documentation depends on the degree of its technical design, such as coverage of relevant topics and the presence of access structures (Chaka, 2003: 25).

According to Quesenbery's (2001: 1) definition, usability is the extent to which specific receivers can use information materials with effectiveness, efficiency and satisfaction in a specified context of use. Chaka (2003:26) outlines four key requirements of usability. These are:

- *Usability means thinking about how and why people use a product:* good technical writing, like good interactional design, focuses on the user's goals.
- *Usability means evaluation:* usability relies on user-feedback through evaluation, rather than simply trusting the experiences and expertise of the designer.
- *Usability means more than just "ease of use":* usability also means effective, efficient, engaging, error tolerance, and easy to learn. Interfaces such as information booklets should be evaluated against the combination of these characteristics that best describe the user's requirements for success and satisfaction.
- *Usability means user-centred design:* users are satisfied when an interface is user-centred. This is when their goals, mental models, tasks and requirements are all being met.

In paragraph 3.2, it has already been indicated that the main aim of this study is to test the effectiveness and/or appropriateness of information contained in the schizophrenia information material (*The Alliance Programme*). Due to the high level of illiteracy among patients at the Weskoppies Hospital (target audience/research participants), *The Alliance Programme* was considered to be too complex for these patients, and was thus delivered orally to them.

A literature survey was conducted by the researcher of this study, in order to find out about the usability testing methods for evaluating orally communicated messages. It was discovered that

very little research/literature about the usability testing methods for evaluating orally communicated messages is available. It was then decided that usability testing methods for print-based messages will be used to evaluate or test both orally communicated and print-based information about schizophrenia, which is contained in *The Alliance Programme*.

3.4.2.2.1 Text evaluation methods

In order to look at the suitability and value of a print-based (or orally communicated) information message, it is important to evaluate it. “The purpose of evaluating the information materials is to assess the attitude and performances of readers or receivers, judging the overall quality and various features of documentation activities and diagnosing physical and organizational factors which have an impact on the reading performance” (Guillemette, 1989: 22). In an earlier overview of text evaluation, Schriver (1989:238) distinguished between three types of evaluation methods for evaluating (printed) text quality, namely: text-focused, expert-focused and reader-focused text evaluation. Schriver (1997) refers to these methods as usability testing methods, which are methods of accessing the quality of the texts.

- *Text-focused text evaluation*

This is an evaluation of one or more texts by an expert or writer in document design, according to predetermined criteria (Schriver, 1997). The main objective is to evaluate textual characteristics, namely: content, structure, style and layout, in relation to the criteria determined for the text type in question, and with a clear view to the needs of a particular user group.

- *Expert-focused text evaluation*

This is an evaluation of the text by professionals with expert knowledge of audience, subject matter or text (De Jong & Schellens, 1997). This evaluation is aimed at subject field specialists and possibly document designers.

- *Reader-focused text evaluation*

Reader-focused (or receiver-focused) evaluations are “procedures which rely on feedback from the intended audience” (Schriver, 1989). It is an evaluation of texts by receivers from the target audience. The importance of feedback from target audiences is a consideration that cannot be ignored, also “because of the increasing

shift towards participatory communication among health interventions” (Servaes, 1999). Receiver-focused methods are generally preferred because they give direct information about how the audience may respond to different aspects of text quality (Schriver, 1997). Unlike many traditional evaluation activities, reader/receiver focused evaluation methods concentrate explicitly on the reader-text or receiver-text relationship- in particular, on a complex of text features often referred to as usability or effectiveness (De Jong & Schellens, 1997:404). Such general terms, though, are capable of many different interpretations, depending on, for instance, the purpose of the text.

Even though text-focused and expert-focused methods may provide valuable feedback on messages, De Jong & Schellens (1997: 403) state that these two text evaluation methods cannot replace receiver-focused evaluations. As a result, these authors also state that presenting text-focused and expert-focused methods as genuine rivals of receiver feedback does not seem realistic. It is preferred to view the three kinds of methods as complementary.

In this study, all three usability testing methods explained above will be used to test the effectiveness and/or appropriateness of the text-based and orally communicated information contained in *The Alliance Programme*. The expert-focused and text-focused evaluation methods will be used in this study to evaluate the text-based *Alliance Programme*. Two expert reviewers (one from the Department of Psychiatry and one from the Department of Information Science) evaluated the print or text-based *Alliance Programme* by applying the proposed checklist (See Appendix D). These two evaluation methods are related to each other, since they both use a set of evaluation guidelines. The receiver-focused evaluation method was used to evaluate both the text-based and oral-based information communicated to the target audience, based on *The Alliance Programme*.

3.4.2.2.1 Text characteristics that can be included in receiver-focused text evaluation

In this section, the kinds of text characteristics that can be included in a receiver-focused evaluation of a document are discussed. According to De Jong and Schellens (1997: 404), a productive way of doing this is to break down the overall concept of effectiveness into a series of conditions for effectiveness. The following are the conditions that these two authors listed as useful conditions for differentiating between the focal points of various usability testing methods:

- *Comprehension*

Receivers must correctly understand given information. When major comprehension problems arise, the wrong message or no message is communicated

- *Application*

This condition can be seen as an extension of the preceding one, particularly in the case of instructional documents, such as user manuals, in which comprehension alone is insufficient. In addition to being able to understand the information provided, receivers must also be able to apply it in a productive way and in a realistic setting.

- *Acceptance*

The intended receiver should find the statements in the message to be as acceptable and credible as possible. Behavioural advice must be seen to be relevant and realistic, factual statements must be considered true, company policy must come across as fair and reasonable, and value judgements in the message must be endorsed.

- *Appreciation*

The receiver must appreciate the way in which the information is presented. These conditions cover various aspects such as the tone of the communication-receiver relationship, the familiarity or the aesthetic quality of the formulation. It also includes the receiver's assessment of figures, illustrations and layout.

- *Relevance and completeness*

Finally, a message must contain the right information for its intended recipients.

The information that is given must be new and relevant to the receiver, and it must also be complete - receivers should not be left with unanswered questions.

These conditions suggest the broad spectrum of questions one can ask about a message (De Jong & Schellens, 1997:405). Not all conditions are equally important for all kinds of messages. In practice, one must choose or prioritise the topics on which an evaluation will focus. This study focused on how patients suffering from schizophrenia understand, accept and appreciate the effective usage of messages on schizophrenia communicated to them orally, based on the printed version of *The Alliance Programme*.

3.4.2.3 Sampling

“Sampling is a process of systematically selecting cases for inclusion in a research study” (Neuman, 1997). There are two types of sampling: probability sampling, which is “a method in which each person of a population has the same probability of being selected” (De Vos, 1998) and non-probability sampling, where the probability of including each element of the population in a sample is unknown (Neuman, 1997).

The sample of this study was chosen on the basis of purposive sampling, which is a non-probability sampling method consisting of selected and information-rich respondents who are available (Neuman, 1997). Within the context of this study, the researcher(s) used non-probability sampling because it was not possible to include all patients suffering from schizophrenia at the Weskoppies Hospital. Only a selected number of the desired research participants who were available during the time of the research were included. Purposive sampling includes subjects selected on the basis of specific characteristics or qualities, and eliminates those who fail to meet these criteria (Struwig & Stead, 2001:122). This was done by virtue of the fact that only highly functional Tswana-speaking patients suffering from schizophrenia at the Weskoppies Hospital in Pretoria, South Africa, could be used.

Two sample groups of individuals from the target audience (highly functional Tswana-speaking schizophrenic patients) were randomly selected by means of purposive sampling at the Weskoppies Hospital, Pretoria, South Africa. These groups of participants were referred to as Group A and Group B. These two groups (A & B) were comparable and homogeneous, so as to enable a comparison of the data collected. The two groups did not share respondents. Both groups comprised both in-patients and out-patients from the Weskoppies Hospital.

The inclusion and exclusion criteria that were used to select research participants for this study were:

Inclusion criteria:

- Individuals aged 18 – 60
- DSM–IV diagnosis of schizophrenia or schizo-affective for more than six months
- Tswana-speaking individuals
- Individuals able to give their informed consent
- Literate and able to read
- No previous exposure to *The Alliance Programme*

Exclusion criteria:

- Current, active psychosis
- Recent history of violence or self-injurious behaviour.
- Patients with a diagnosis of mental retardation
- Active substance abuse

3.4.2.4 Data collection methods

In this study, data was gathered through a literature review, semi-structure individual interviews, focus group interviews and participant observation. These data collection methods were used for the different usability testing methods that were used in this study. The literature review was used as a basis for the expert-focused and text-focused evaluation method, and the semi-structured individual interviews, focus group interviews and participant observation were used to perform the receiver-focused evaluation. These data sets were then analysed and

interpreted. In this section, all the abovementioned data collection methods that were used to collect data in this study will be discussed in more detail.

- Literature review and previous research

A literature review is a body of text that aims to review the critical points of current knowledge on a particular topic, serving as an account of what has been published on a topic by accredited scholars and researchers (Dena, 2006). The literature review is here defined as an evaluative report of information found in the literature related to a selected area of study, which provides a theoretical basis for the research, and helps the author to determine the nature of the research. “In writing the literature review, the purpose is to convey to the reader what knowledge and ideas have been established on a topic, and what their strengths and weaknesses are. It is not just a descriptive list of the material available or a set of summaries” (Dena, 2006). According to Muskal (2000; *The literature review*, 2000; Dena, 2006; and other authors), the form of the literature review varies with different types of studies, but the basic purposes remain the same:

In this study, a literature review (including literature from the previous study) was conducted to:

- provide a theoretical background for the study and a foundation for the discussion about the nature of the topic
- justify the research
- ensure that the research has not been done before (or if it is repeated, it is called a "replication study")
- show that the work is adding to the understanding and knowledge of this research field.

As explained in the introductory part of this section, the literature review in this study was used as a basis for the expert and text-focused evaluation methods that were used. Based on the literature review, a checklist that was used to evaluate *The Alliance Programme* by expert-reviewers in this study was composed. Findings from the previous study (phase one) were considered when adapting *The Alliance Programme* to suit the target audience (research participants) of this study.

- Interviews

Interviews are methods of data collection that can generate substantial in-depth qualitative information. According to Baker (1994), an interview is a specialised form of communication between the interviewer (researcher) and the interviewee (research participant) for the purpose of finding out what is on someone else's mind in terms of some agreed subject matter.

It has already been stated in the introductory part of this section that the interviews in this study were conducted in order to perform the receiver-focused evaluation methods that took place in this study. All interviews conducted in this study were recorded using a tape recorder. Tape recordings were transcribed and translated into English by the facilitator (main interviewer). As an extra quality control measure, the transcriptions were checked against the original tapes by another researcher.

There are different types of interviews, but in this study, structured individual interviews and focus group interviews were chosen. These two types of interviews will be discussed in more detail in the next two sections.

- Semi-structured individual interviews

Semi-structured interviews are also referred to as “moderately-scheduled interviews”. This means that these interviews are not highly structured, nor are they unstructured. They are, according to Zorn (1997), the most useful interview format for conducting qualitative research. Semi-structured interviews are “informal interviews that are based on a set of basic questions that you would like to understand better for your informal analysis” (Kitzinger, 1995). This type of interview uses a schedule of questions very much like a questionnaire (Kvale, 1996). “The process of a semi-structured interview involves the interviewer presenting the context of the study and its objectives to the interviewee or interview group. The set of questions are prepared but open, allowing the interviewees to express opinions through discussions” (Kitzinger, 1995). Semi-structured interviews are conducted with a fairly open framework which allows for focused, conversational, two-way communication (Kvale, 1996).

These guided conversations (semi-structured interviews) were used in this study, in order to ask broad questions that did not constrain the conversation, and new questions were allowed to arise as a result of these discussions.

Three sets of interviews took place in this study:

1. *Screening interviews* were conducted to find what the basic knowledge of participants regarding their mental illness (schizophrenia) was before being exposed to *The Alliance Programme*. These interviews were also conducted to obtain informed consent from the participants of this study, as well as the demographic information of research participants.
2. *Usability testing interviews* for evaluating *The Alliance Programme* using the criteria of comprehension, acceptability and usability were conducted. These interviews were conducted to determine the research participants' understanding of the mental illness from which they suffer, after attending the discussion classes on schizophrenia based on *The Alliance Programme*.
3. *Knowledge retention testing interviews*, which were conducted to find out how much knowledge the participants retained after three months of exposure to *The Alliance Programme*.

In all three sets of interviews, semi-structured individual interviews were conducted. Two interview schedules were used: one was only used for the screening interviews (See Appendix A). The other interview schedule was used for both the individual interviews and the focus group discussions that were conducted for the interviews to evaluate *The Alliance Programme* and determine knowledge retention (See Appendix B). The questions in both interview schedules were compiled with regard to the messages about schizophrenia communicated, based on *The Alliance Programme*.

○ Focus group discussions

Apart from the data collected via semi-structured individual interviews, focus group discussions were also used to obtain richer data.

Focus group discussions combine the advantages of the two main methods of collecting data in qualitative research, namely individual interviews and participant observation (Morgan, 1993). Focus group discussions are “carefully planned discussions designed to elicit perceptions on a defined area of interest in a permissive, non-threatening environment” (Krueger, 1988:18). The

discussion is relaxed and comfortable, while the participants share ideas. Group members influence each other by responding to ideas and comments during the discussion. Morgan (1993) defines focus group discussions as exploratory research tools used for the purpose of exploring people's thoughts and feelings and obtaining detailed information about a particular topic or issue. According to DeVos (1998:314), these discussions take place with between eight to ten individuals with similar backgrounds or common interests, under the guidance of a moderator. The main purpose of focus group discussions is to obtain information about how people think and feel, and to understand the underlying reasons for their behaviour.

The focus group interviews were conducted in this study as an open discussion, where the research participants made comments, asked questions of other participants and responded to comments by others. The respondents were encouraged to explain their understanding of the message about schizophrenia.

These discussions were also conducted in this study to add value to the research process in three ways:

- To allow the researchers to “obtain deeper levels of meaning, make important connections and identify subtle nuances in expression and meaning” (Stewart & Shamdassai, 1990: 47); and
- To use the spontaneous interaction between participants in an informal group discussion to reveal information that was not disclosed in the structured, open-ended interview.
- To validate the data collected during the individual interviews. This is because the same participants who were interviewed individually took part as respondents in the focus group discussions.

The interview schedule that was used for the semi-structured individual interviews was also used for focus group interviews, so as to guide focus group discussions. A period of 45-60 minutes was allocated for each focus group session. The focus group discussions were facilitated by two researchers – one with a medical background and one with a background in Information Science. During the focus group discussions, the facilitators divided themselves into:

- *the main interviewer* - one who poses questions from the interview schedule and facilitates discussions; and
- *scribe* - one who takes note of verbal responses and non-verbal cues.

Both facilitators live or work in the Tshwane area, and are thus familiar with local cultures and the most popular language (Tswana) of the Tshwane area. Questions for the interviews were drawn up in a simple language (English) that could be understood by respondents. However, some research participants could not understand the questions, so the main interviewer translated the questions into the audience's local language (Tswana), in order for the participants to understand.

- Participant observation

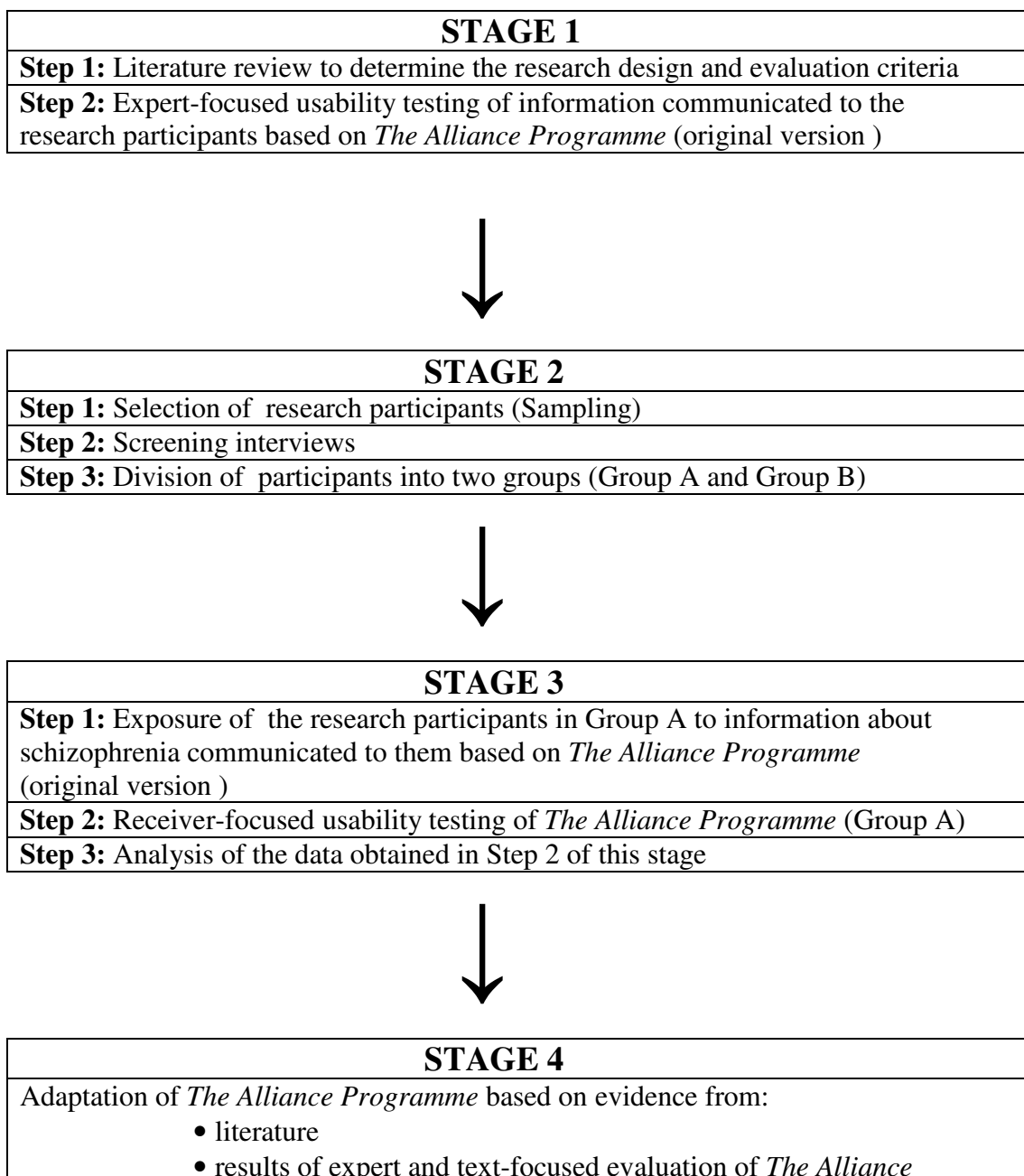
To enrich the data obtained from the interviews (receiver-focused evaluation method), participant observation was also employed in this study. According to Berg (1998), participant observation is the most basic method of obtaining information about the world around us, and it also helps the researcher to get a clear picture of behavioural patterns of research participants. This data collection method also helped researchers in this study to collect data without having to rely on the willingness or ability of research participants in the study to supply them with information (Struwig & Stead, 2001:96). In this study, the observation took place simultaneously with the interviews (semi-structured individual interviews and the focus group discussions). In other words, the research participants were observed during the interviews, where the researchers collected data by observing and recording the research participants' behaviour.

Participant observation has an added advantage of using various instruments for collecting information. The researcher may use notes, cameras, tape recorders, videos or the observation can be conducted without any technological assistance (Struwig & Stead, 2001:101). In this study, field notes were taken and kept for analysis processes.

3.4.3 The research procedure

The procedure according to which the research was undertaken is discussed in this section. The research procedure is discussed according to stages and/or steps that were undertaken in the formative research conducted. First, a diagrammatical representation of all the stages and steps is provided and followed by a detailed description of these stages and steps. In this detailed description of the stages and steps of the research process, all the processes and/or events that were undertaken by different people will be discussed in detail.

3.4.3.1 Diagrammatical representation of the formative research procedure



programme (Stages 1)

- Linda's adaptation of *The Alliance Programme*
- Findings of receiver-focused usability testing (Stages 3)



STAGE 5

Step 1: Exposure of the research participants in Group B to information about schizophrenia based on *The Alliance Programme* (adapted version)

Step 2: Receiver-focused usability testing of *The Alliance Programme* (Group B)

Step 3: Analysis of data obtained in Step 2 of this stages



STAGE 6

Comparison of findings obtained from Group A and Group B usability test results



STAGE 7

Comparison of findings obtained from Group A and Group B knowledge retention results (after 3 months)

3.4.3.2 Step-by-step description of the formative research procedure

STAGE: 1

Step 1: Literature review to determine the evaluation criteria

A literature review was conducted to provide a theoretical background of guidelines that could be used to evaluate an information material. The main aim was to find out what is considered to be effective criteria for evaluating information material. Using this information, criteria for evaluating *The Alliance Programme* were determined

Based on the literature, a checklist for evaluating various aspects of *The Alliance Programme* was composed. The checklist was divided into two sections in which issues pertaining to content and comprehension were used to determine the effectiveness of *The Alliance Programme*. “A checklist is a list of features according to which text is evaluated” (De Jong & Schellens, 1997). It is used as a reminder for issues to consider or use as criteria that text reviewers should work through when reviewing texts (Schrivver, 1989). Evaluating text quality by applying principles or guidelines that have been developed from ideas and sometimes research is, according to De Jong & Schellens (1997), the text-focused evaluation method.

Step 2: Expert-focused usability testing of the information communicated to the research participants based on the original version of *The Alliance Programme*

Two expert-reviewers (one from the Department of Psychiatry; and one from the Department of Information Science) evaluated *The Alliance Programme* by applying the checklist (See Appendix D) that was composed. The text features mentioned above were evaluated on a scale of three:

- 1 indicating “yes” for effective practice
- 2 indicating “not always” or “not sure”
- 3 indicating “no” for ineffective practice

Thus, this evaluation process applied to both text-focused and expert-focused evaluation methods, as these two evaluation methods are related to each other, and are both widely used as a set of evaluation guidelines/procedures. With the aid of the checklist, both reviewers were

able to give an opinion of whether the original version of *The Alliance Programme* was effective and/or appropriate for use in the South African context.

STAGE: 2

Step 1: Selection of participants

A registrar of the Weskoppies Hospital selected research participants by screening the hospital files/records, looking for patients who met the inclusion and exclusion criteria of the desired research participants for this research. The following information was obtained:

- demographic profile of patients,
- patients' diagnosis, and
- patients' level of functioning.

Step 2: Screening interviews

The recruits were then invited to a screening interview. The purpose was to:

- assess the patients' level of functioning;
- verify their personal details;
- verify their language; and
- determine their highest level of education.

First, the patients (participants) were introduced to the study and were given written consent forms on which the study was explained in detail. Those who agreed to take part in the study were informed that they could withdraw from the study at any given time. Individual interviews with the use of an interview schedule were then conducted with research participants, in order to determine the baseline knowledge of the research participants in terms of their mental illness (schizophrenia), before the information based on *The Alliance Programme* was communicated to them

Step 3: Divide participants into two groups

The research participants were then grouped into two separate groups (Group A and Group B). Both groups comprised in-patients and out-patients of the Weskoppies Hospital. These two

groups were comparable “to enable them to relate to each other and to stimulate self-disclosure” (Morgan, 1993).

STAGE: 3

Step 1: Messages in the original version of *The Alliance Programme* communicated to Group A

On the 12th, 19th and 26th of April 2007, discussion classes on the information about schizophrenia with research participants in Group A were conducted. Due to the high level of illiteracy among the research participants, the information in the original version of *The Alliance Programme* was communicated and/or disseminated orally to research participants in Group A by Linda Booysens. All research participants, both researchers and social workers (the presenter of the schizophrenia information discussion classes and the interpreter) attended all three schizophrenia information discussion classes.

These discussion classes on the information about schizophrenia with research participants in Group A were presented in English. All research participants in Group A understood English to a certain degree, but spoke Tshwana fluently. As it has already been indicated in paragraph 3.3, in order to ensure that the research participants understood the information presented in these classes, a Tshwana-speaking social worker (Sylvia), who is an interpreter, assisted Linda by translating everything Linda said in English to Tshwana.

Research participants were never issued *The Alliance Programme* before or during the schizophrenia information discussion classes to read in class or at home. The research participants just came and listened to Linda’s presentations - they never saw the book (*The Alliance Programme*). Linda adapted *The Alliance Programme* when presenting the information to the research participants in Group A. She used the same procedure explained in paragraph 3.3.1.

Step 2: Perform the receiver-focused usability testing with research participants in Group A

On the 3rd of May 2007, the receiver-focused evaluation of the original version of *The Alliance Programme* among the research participants in Group A took place. The research participants in Group A were first interviewed individually, and then in a focus group using an interview schedule with questions designed to elicit opinions about the use of information communicated to them, based on the original version of *The Alliance Programme*, in terms of dimensions such as comprehension, acceptability, selection and application. Only one research participant from Group A could not attend the interviews on this day (3rd of May 2007), due to medical reasons.

Step 3: Analysing Group A's data

After collecting the data from research participants in Group A by semi-structured interviews, focus group discussion interviews and participant observation, it was analysed using inductive qualitative content analysis, in which the research participants' answers were examined question by question in order to determine common themes. The researchers of this study coded and utilised the data by allocating numbers to research participants. They then discussed the findings by comparing the common themes and categories that had been identified.

STAGE: 4

Adaptation of *The Alliance Programme*

The original printed version of *The Alliance Programme* was adapted based on the evidence from:

- Summary of how Linda adapted *The Alliance Programme*
- Literature
- Results from the expert-focused and text-focused evaluations of *The Alliance Programme* (original version)
- Findings from the receiver-focused usability testing performed on research participants in Group A.

The summary and/or conclusions of all the proceedings of adapting *The Alliance Programme* were based on the following themes. In fact, the following principles for creating more effective printed messages were identified and used in the adaptation of *The Alliance Programme*.

Printed text

Printed-text is not necessarily appropriate for an audience with a high level of illiteracy, like the target audience of this study. Printed messages are an inappropriate extension medium to be used to communicate information to low-literate communities (Sturges & Neill, 1998: 206). However, the findings of the interviews of research participants in Group A indicated that all the research participants would like to be issued with booklets in class to be used in both class and at home. Group B was consequently issued with the adapted version³ of *The Alliance Programme* booklet (See Appendix D) to read in class and at home.

This means that in the classes based on the adapted version of *The Alliance Programme*, the information about schizophrenia was communicated orally and also through print-based media. This was done in order to enable the target audience to have access to the information about schizophrenia that was discussed in these classes at any time they wanted or needed the information. Since print-based media is something receivers could leave behind and refer back to anytime, they needed the information contained in it (Leach, 1999: 77). This (having access to the information at anytime) could help receivers to not easily forget the information.

Content reduction

Literature, the findings from the expert-focused evaluation method, as well as the findings from the interviews of research participants in Group A, are both in favour of reducing content. In both cases, it is evident that reduced content is the best way to design effective information materials. Information materials' content should be short and simple, without losing meaning (Bembridge, 1991). In fact, content should only include what the reader absolutely needs to know (and why) about a topic. Unnecessary words should be avoided, as they reduce clarity (Morris & Stillwell, 2003). The content of the adapted version of *The Alliance Programme* was therefore further reduced. Linda also tried to present the different topics about schizophrenia in a very short and simplified manner.

For example, the causes of schizophrenia in the original version of *The Alliance Programme* are explained or discussed in scientific terms and more detail. There is a whole chapter in the original version of *The Alliance Programme* booklet (chapter 2) focusing on the subject of the causes of schizophrenia. Yet, in the adapted version of *The Alliance Programme* booklet, this

³ The adapted version of *The Alliance Programme* is attached in Appendix D

subject is summarised and/or reduced to one page. This page is presented next page of this research report.

Ke go reng batho ba tshwere ke bolwetsi jwa Schizophrenia?⁴



Batho bangwe ba bo bona mo batswading kgotsa lesika. Ba a bo neelwa

Some people get it from parents or relatives. They inherit it.

Tiriso e e sa siamang ya nnotagi kgotsa diritibatsi di etsa gore go nne bonolo go tshwara ke bolwetsi jwa Schizophrenia.

The use of illegal drugs and alcohol can make some people ill



Ka makgetlo a le mantsii ga go se o ka se dirang ge o tsena ke bolwetsi jo. Go

Usually you can't help it if you get schizophrenia. It is like catching the flu.

Contextualisation and personalisation of information

It is evident that contextualised/personalised information is more effective and appropriate for communicating information to low literates such as the target audience of this study. This was proven by the literature, results from the expert-focused evaluation method, and what was noticed in the discussion classes on information about schizophrenia, which were presented to

⁴ Why do people suffer from schizophrenia?

the research participants in Group A. Content should always be accurate, credible, appropriate and relevant to the intended user (Morris, 2001: 29). Contextualising and personalising information for a target audience could, for example, be done by using examples or scenarios that all receivers or research participants are familiar with. Examples or scenarios of or in the Weskoppies Hospital could be used to clarify the information communicated to research participants in this study. The information about schizophrenia discussion classes was presented to research participants in Group B in a more contextualised and/or personalised manner.

For instance, in the adapted version of *The Alliance Programme* booklet, a picture of a thief stealing certain goods was incorporated to serve as an example of how schizophrenia steals certain functions from a person suffering from this illness. All the research participants are familiar with what a thief is and what he/she does. Thus, using an example of a thief to explain the information or message was done in order to help all research participants to understand the information/message better. This example used in the adapted version of *The Alliance Programme* booklet is presented below.

Schizophrenia se dira eng mo mothong?⁵



Schizophrenia se tshwana le
legodu. Se utswa boleng ba rona.

*Schizophrenia is like a thief. It steals
who we are from us*

⁵ What does schizophrenia do to a person?



Se utswa⁶

- menagano ya rona(bokgoni ba rona ba go gopoa dilo)⁷
- go tsea dilo tsia(go kgona ga rona go tsepama le nagana sentle)⁸
- maikemisetso a rona a a siameng a botshelo⁹
- maatla a rona¹⁰
- kitso ya rona ya go ngwala le go buisa¹¹

Local language

Literature, the results from Linda's first adaptation of *The Alliance Programme*, results from the expert-focused evaluation method and findings from the interviews of Group A, all indicate that in order to disseminate information effectively to any audience, information should be translated into the target audience's local language. The audience understands their local language much better than any other language. Content developed should be culturally and linguistically appropriate for the audience (Smith, 1998). Information providers should translate materials into

⁶ It steals

⁷ our memory (our ability to remember things)

⁸ our concentration (our ability to focus and think clearly)

⁹ our good plans for life

¹⁰ our strength and energy

¹¹ our ability to read and write

a language best understood by the target audience (Robinson, 1997:1). Consequently, the adapted version of *The Alliance Programme* presented to research participants in Group B was translated into Tshwana.

It has already been indicated in paragraph 3.3 that a Tshwana-speaking social worker (Sylvia), who is also an interpreter, was involved in the presentation of information about schizophrenia in the discussion classes based on *The Alliance Programme*. She assisted Linda by translating everything Linda said from English to Tshwana, in order to ensure that the research participants understood the information communicated to them, since they are all Tshwana speakers.

Interactions

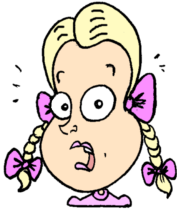
All evidence indicated that information communicated in an interactive manner is the most effective communication method that could be used to communicate information to low-literate audiences like the target audience of this study. According to Bembridge (1991:24), information providers, when creating effective information materials for any target audience, should write the way they talk. This entails writing in a personal, conversational, respectful and friendly style. For effective dissemination of information, the active voice is much preferred, unless there is a good reason for using the passive voice (Cutts, 1995). An interactive question and answer style allow the reader to think, and provides opportunities for immediate learning (Morris, 2001: 39).

In the adapted version of *The Alliance Programme*, care was taken to ensure that information about schizophrenia was presented in an interactive manner. Linda involved research participants by asking them about their personal experiences with schizophrenia in terms of the specific topic. The information about schizophrenia in the print-based adapted version of *The Alliance Programme* was presented in an interactive question and answer style. A comic information presentation format or style was used for communicating the information to research participants, where the different cartoon characters would voice the important information about the particular schizophrenia topic that was being discussed. A question was asked and then the answers relating to that question were provided by different cartoon characters.

This is illustrated in the following page from the adapted version of *The Alliance Programme* booklet.

Schizophrenia ke eng?¹²

Schizophrenia ke eng?¹²



A Schizophrenia ke ge motho a gafa?

It is when someone is mad

Nyaa,ke bolwetse jwa tlhogo

No, schizophrenia is a mental illness



Motho yo a tshwereng ke bolwetse ba tlhogo o itshwara ka ka mokgwa o o sa tlwaelegang.

Someone who has schizophrenia sometimes acts strangely and unusually. This is called psychosis.

Difficult words or scientific terms

With the evidence obtained from Linda's first adaptation of *The Alliance Programme*, literature, results from the expert-focused evaluation method, and findings from the interview of research participants in Group A, it was obvious that in order to ensure that information is disseminated effectively to the target audience, it is important to clearly explain all scientific terms before using them frequently in information material. In order to disseminate information effectively, the best thing is to write in a simple, clear and concise way (Velasco et al, 1996). Choose words that will suit the background of the audience (Plimpton & Root, 2000), those words that your

¹² What is Schizophrenia?

readers are likely to understand. Unfamiliar words should be avoided, especially if used infrequently and not explained. Technical terms and jargon should not be used, unless well understood and commonly used by the target audience, or else defined in the text (Morris, 2001: 39).

In the adapted version of *The Alliance Programme*, all scientific words were clearly explained. In the schizophrenia information discussion classes, Linda explained all the words that she thought were difficult terms in *The Alliance Programme* in simpler terms which the readers were more likely to understand.

The following is a page from the adapted version of *The Alliance programme* booklet, to illustrate that difficult or scientific terms were defined so that research participants would better understand the information or messages communicated to them.

Go kaya eng go runyegelwa ke bolwetse?¹³



Go kaa gore motho o a lwala mo a sa tlhaloganyeng maemo a gagwe mabapi le bonnete. Ga a tlhaloganye ebile o kopane tlhogo.

It means a patient is in the sick phase and has lost contact with reality.

Illustrations

Both the literature and findings from the interview of research participants in Group A show that diagrams, photos, pictures etc. are important inclusions in information material for low-literates, so as to enhance the understanding of the information delivered to them. Illustrations such as photos, diagrams, pictures etc. are commonly included in information materials in order to

¹³ What does it mean to be psychotic?

complement and reinforce the message. Such illustrations are considered to be especially important for audiences with a low-literacy component, who might struggle to understand the text without explanatory pictures (Morris, 2001). Photos, diagrams, pictures, etc. add appeal and can enhance the understanding of the information presented in the information material (Price & Everest, 1995).

In the adapted version of *The Alliance Programme*, illustrations were incorporated in order to ensure that receivers better understood the information communicated to them. With the help of a multimedia expert from the Department of Information Science (Willem-Jan Olwagen), pictures and cartoons were incorporated into the adapted *Alliance Programme* booklet for illustration of the information communicated.

The following is one of the diagrams or illustrations that were incorporated into the adapted version of *The Alliance Programme* booklet in order to reinforce the message or information communicated to research participants.

GOPOLA¹⁴

O tshwanetse go dirisa melemo ya gago jaaka o laetswe ke dingaka kgotsa baaki.¹⁵



¹⁴ Remember

¹⁵ You must take your medicine exactly as the doctors or nurses tell you to

STAGE: 5

Step 1: Messages in the adapted version of *The Alliance Programme* communicated to Group B

On the 14th, 21st and 28th of June 2007, schizophrenia information discussion classes with research participants in Group B were conducted again at the Weskoppies Hospital in Pretoria, South Africa. Due to the high level of illiteracy among participants, the information in the adapted version of *The Alliance Programme* was communicated and/or disseminated orally to research participants in Group B by Linda. She used the same procedure illustrated in paragraph 3.3.1 (The summary of how Linda adapted *The Alliance Programme*). However, research participants were issued with the adapted version of *The Alliance Programme* booklet to read during psycho-education classes or at home.

Step 2: Perform receiver-focused usability testing on research participants in Group B

On the 5th of July 2007, the receiver-focused evaluation of the adapted version of *The Alliance Programme* among research participants in Group B took place. The research participants in Group B were first interviewed individually, then in a focus group, using an interview schedule with questions designed to elicit opinions about the use of information communicated to them, based on the adapted version of *The Alliance Programme*, in terms of dimensions such as comprehension, acceptability, selection and application. The interview schedule that was used for the interviews with research participants in Group A was used. All research participants from Group B attended the interviews on this day (5th of July 2007). However, responses of one research participant were not considered, due to the fact that it was discovered that his functional level was deteriorating and had become psychotic.

Step 3: Analysing Group B's data

After collecting the data from research participants in Group B using the individual, semi-structured interviews, focus group discussions and participant observations, it was analysed using inductive qualitative content analysis, whereby research participants answers were examined question by question to determine common themes. Again, the researchers coded and utilised the data by allocating numbers to research participants. They then discussed findings by comparing common themes and categories that had been identified.

STAGE: 6

Comparison of Group A and Group B findings

Findings of both groups (A & B) were compared, so as to find out whether or not the adapted version of *The Alliance Programme* was more effective and/or appropriate for disseminating information on schizophrenia to patients suffering from this illness in South Africa.

STAGE: 7

Comparison of Group A and Group B knowledge retention findings

After three months, the knowledge retention of both Group A and Group B concerning important issues about schizophrenia were tested. The knowledge retention testing for research participants in Group A took place on the 26th of July 2007. The research participants were interviewed again individually and in focus group discussions, using the same interview schedule that was used to interview them on the 3rd of May 2007. The knowledge retention testing for research participants in Group B participants took place on the 28th of September 2007. The research participants were also interviewed again individually and in focus group discussions, using the same interview schedule that was used to interview them on the 5th of July 2007. Findings of both groups (A & B) were again compared, so as to also determine which *Alliance Programme* (the adapted or original version) is more effective and/or appropriate for disseminating information on schizophrenia to patients suffering from schizophrenia in South Africa.

3.4.4 Data analysis

During or after the data have been collected, a researcher needs to make sense of it. This is what is referred to as data analysis. Data analysis is, according to Struwig & Stead (2001:168), the process that enables the researcher to organise and bring meaning to large amounts of data collected. It takes place whenever theory and data are compared and data is interpreted (Singleton et al, 1993: 415). It involves drawing conclusions about data, representing it in tables, figures and pictures to summarise data, as well as explaining the conclusions in words in order to provide answers to research questions (Cresswell, 2005: 10).

In this study, after the data had been collected through focus groups, participant observation and individual semi-structured interviews, the data was analysed. This was done according to the phases of the formative research process that was undertaken in this

study. Immediately after collecting the data in each phase, the researchers separately analysed the data using pre-determined criteria.

The data analysis in this study was done using inductive qualitative content analysis, where research participants' answers were examined question by question to determine common themes. The researchers of this study coded and utilised the data by allocating numbers to the respondents. They then discussed the findings by comparing the common themes and categories that were identified. Since messages were grouped into frames, frames were also numbered. All this combines to form what is known as an audit trail (Struwig & Stead, 2001). An audit trail permits the core-researcher and other researchers, at a later date, to check the process by which the research arrived at the findings and conclusions.

3.5 ISSUES OF VALIDITY AND RELIABILITY

In qualitative research it is very important for any knowledge brought forward to be verifiable in terms of validity and reliability (Kvale, 1996). Reliability and validity are said to be the two most important variables in research (including in qualitative research), thus they will be discussed here.

Validity refers to whether the study measures what it is suppose to measure. "Validity is the truth and correctness of a statement" (Kvale, 1996). In qualitative research, validity refers to the extent to which the account seems to fairly and accurately represent the data collected (Hanock, 2002). To maintain the dignity and welfare of the research participants, before commencement, the project was first approved by the University of Pretoria (Faculty of Health Sciences) Research Ethics committee and the research participants were given consent forms which they signed in order to give their informed consent to participate in the study.

Reliability refers to the consistency of research findings (Kvale, 1996). In qualitative research, reliability relates to being able to demonstrate that the methods used are consistent (Hanock, 2002). Golafshani (2003) uses the term 'dependability' as a term more appropriate to describing 'reliability' in qualitative research. In qualitative research, reliability is relevant particularly with reference to leading questions, which may

Chapter 4

RESEARCH FINDINGS AND DATA ANALYSIS

4.1 INTRODUCTION

In this chapter, the results and findings of the research, as inferred from the data collection processes that took place in this study, will be presented. Findings were analysed by referring to the data collection methods used to collect data in this study, namely individual interviews, focus group interviews and participant observation.

The findings of this study will be presented as follows:

- Findings of the screening interviews conducted with all research participants of this study (Group A and Group B) regarding their demographic information, socio-economic status and baseline knowledge regarding their illness.
- Results of individual interviews and focus group discussions conducted with Group A regarding the comprehension, acceptability and usability of the original version of *The Alliance Programme*.
- Results of individual interviews and focus group discussions conducted with Group B regarding the comprehension, acceptability and usability of the adapted version of *The Alliance Programme*.
- Results of the participant observation during individual interviews and focus group discussions of both Group A and Group B.
- Results regarding how much knowledge the participants retained after three months of being exposed to *The Alliance Programme*.

4.2 FINDINGS

All the findings of this study will be presented in this section. The data will be presented according to the stages and/or steps of the research procedure used in this study. First, a short description of a particular stage will be provided, as well as the data obtained concerning that stage.

STAGE 1

According to the diagrammatical representation of the stages and/or steps of the formative research procedure (described in Chapter 3, paragraph 3.4.3.1) that was undertaken in this study, the expert-focused and a text-focused evaluation method was used to test the effectiveness of the communication of information about schizophrenia as facilitated by the classes based on *the Alliance Programme*. In this section the findings obtained from the expert-focused and text-focused evaluation methods are presented.

The findings from both expert-reviewers regarding the material of *The Alliance Programme* currently used to disseminate information to Tshwane speaking patients of schizophrenia at the Weskoppies Hospital is summarised and listed below.

When using the criteria of (Doak *et al* 1996:22) and taking into regard the specific target audience the expert-reviewers concluded that this material is unsuitable and inappropriate for this target audience.

The material does not conform to the most basic guidelines for ensuring the effective communication of information.

They are:

- The material is too rich in content for the specified target audience.
- Key points and objectives are not adequately emphasized.
- The material focuses on facts rather than the skills needed to deal with the illness.
- The information presented does not relate to the context of receivers' lives.
- The information is not presented into easy-to-understand and/or chunked sections that will enhance reception.
- Little opportunity for interaction exists, leaving the receiver a bystander

In the two expert-reviewers' opinion the way in which this material is presented would not lead to the effective communication of information.

STAGE 2

After the selection of research participants, screening interviews were conducted to:

- obtain the demographic information and socio-economic status of the research participants; and
- find the baseline knowledge of the research participants regarding their illness before attending any schizophrenia information discussion session based on *the Alliance Programme*.

After the screening interviews the research participants were then divided into two groups (Group A and Group B).

The data obtained in this phase will be presented according to the two above-mentioned purposes of the screening interviews. It will also be presented in tables which are further explained.

- **DEMOGRAPHIC AND SOCIO-ECONOMIC INFORMATION**

It was important to determine the demographic and socio-economic information of the research participants of this study so to identify certain habits and deviations of the research participants. Questions about gender and age, education level and employment, language profile and residence, duration of the mental illness were asked to determine the demographic and socio-economic information of the research participants.

The demographic data of the research participants collected is summarised in the tables below.

Table 1 below represents the gender and ages of research participants

Table 1: Gender and age of research participants

AGE	GROUP A		GROUP B	
	MALE	FEMALES	MALES	FEMALES
18-20 years	-	-	-	-
21-30 years	-	1	1	-
31-40 years	4	-	2	1
41-50 years	1	1	-	-
51-60 years	-	-	2	1
TOTAL	5	2	5	2

The age of the research participants ranged from 21-60 years. The distribution could be due to the fact that this illness begins mostly when people are under stress from outside the world. People in early adult life (e.g. years between 18-25 years) are most vulnerable to stress as this is when they strive to get good jobs, develop close friendships and establish their independence.

Schizophrenia occurs with equal frequency in men and women (*Schizophrenia*, 1995). In this study however, more men participated than women (as indicated in the table above). The reason for women being in the minority as research participants may be attributed to one of the following factors.

- According to the clinical files/records of the research participants at the Weskoppies hospital, there are more males than females admitted in the hospital.
- Most of the outpatients female patients are housewives and stay at home to look after their children, thus they were reluctant to take part in this research as they are needed at home by their children.

The education level of the research participants is represented in Table 2 below.

Table 2: Education level of research participants

	GROUP A	GROUP B
HIGHEST LEVEL OF EDUCATION	NUMBER OF PARTICIPANTS	NUMBER OF PARTICIPANTS
Grade 6	1	1
Grade 7	-	1
Grade 8	2	-
Grade 9	2	-
Grade 10	1	1
Grade 11	1	-
Grade 12	-	3
Tertiary level	-	1
TOTAL	7	7

The table above indicates that the research participants' education level range from Grade 6 to Tertiary level. These research participants are considered to be functionally literate and are likely to have knowledge of written vernacular language. It was also noticed that research participants

in Group A seemed to be more educationally disadvantaged than research participants in Group B.

Table 3 below represents the employment status of research participants.

Table 3: Employment status of research participants

PARTICIPANTS	EMPLOYED	UNEMPLOYED	TOTAL
Group A	2	5	7
Group B	-	7	7

The main aim of this question was to determine the employment status of the research participants. The table above shows that the majority of the research participants were unemployed during the data collection stage of this research. This high unemployment rate amongst the research participants could have been brought on by the fact that once patients suffer from schizophrenia they lose abilities and/or skills of doing things or performing duties effectively and appropriately and therefore cannot manage to keep jobs.

The table below analyses the language profile of research participants.

Table 4: Language profile of research participants

The reason why research participants were asked which languages they spoke fluently was to verify if all research participants spoke Tshwana fluently, since the selection criteria for research participants (target audience) of this study was highly functional Tshwana-speaking patients.

LANGUAGE	GROUP A NUMBER OF PARTICIPANTS	GROUP B NUMBER OF PARTICIPANTS
Tshwana	7	7
English	5	6
Afrikaans	2	2
Zulu	1	4
Other (Tsonga)	1	-

The table above indicates that the majority of the research participants indicated that they are more fluent in Tshwana than in any other language because Tshwana is their mother tongue.

This was seen when most of the research participants could not understand the questions read in English and the researchers had to translate the questions into Tshwana. It was also verified that all patients live in and around Tshwane (Pretoria).

Summary of demographics

The results indicate that the ages of the research participants in this study range from 21 to 60 and that the majority of the research participants of this study are men. Their socio-economic status is low because most of the research participants are unemployed. Their level of education is also low. They all speak Tshwana fluently and live in or around Tshwane (Pretoria).

- **BASIC KNOWLEDGE OF MENTAL ILLNESS**

During the screening interviews, the basic knowledge of all research participants regarding their mental illness was evaluated before the information on schizophrenia was communicated to them. In this section, the basic findings regarding the knowledge of research participants about their illness will be presented according to the questions in the interview schedule used to conduct the screening interviews.

1. Do you know the name of the disease you are suffering from?

- 14%¹ of the research participants stated that they do not know what their illness is;
- 21% of the research participants knew they suffered from a mental or psychiatric illness but were not sure of the specific name of the mental illness;
- 21% of the research participants had totally wrong ideas regarding what their illness was (“Scandal”-4A); and
- 44% of research participants knew the name of the illness they suffered from.

¹The percentages (%) of the screening interviews’ results were calculated out of the 14 research participants (from both Group A and Group B) who were interviewed during the screening interviews.

¹ The reason why percentages (%) were used to reflect findings of this study was for ease of comparison.

2. How did you learn about your mental illness? / Who first told you that you have a mental illness?

- 13% of research participants were told by friends and relatives;
- 27% of research participants said they were never told they had a mental illness;
- 27% of research participants learnt about the mental illness on their own (“I saw it written in my file”- 1B); and
- 33% of research participants were told by doctors.

3. Explain the things you were experiencing when the condition started?

- 11% of what the research participants referred to experiences that are not described in *The Alliance Programme* as symptoms or early warning signs of schizophrenia. The following are examples of what the research participants listed: “I stopped doing things for myself”; “My head was sore it felt like I had a ring on my head”; “I was not feeling well, I was in pain”; “I could not get my erection”; “People were avoiding me”; and
- 89% of what the research participants described concurs with what is described in *The Alliance Programme* as symptoms of schizophrenia or its early warning signs. The following is a list of what the research participants listed as the things that happened at the beginning of their illness: “I slept a lot”; “I stopped taking care of myself”; “I was not happy”; “I was problematic to people”; “I was moody and irritable”; “I was aggressive and violent”; “There were people who wanted to kill me , I could not see them but I could hear them”; “I was thinking a lot”; “I believed I was Jesus Christ, so used to go around praying for people”; “I could not sleep well”; “I was talking to myself”; “I was always down, had a lot of worries”; “I use to see strange things”; “I was told my grandmother is dead then I got disturbed psychologically”.

4. What other symptoms can a person suffering from your condition have?

- 12%² of what participants described as other symptoms that a person with their condition can have were, according to *The Alliance Programme*, not symptoms of

¹The percentages (%) of the screening interviews’ results were calculated out of the 14 research participants (from both Group A and Group B) who were interviewed during the screening interviews.

schizophrenia. These included: “Always shaking”; “They cannot look at me straight in the eye”;

- 33% of research participants also indicated that they do not know what other symptoms can people suffering from their condition have; and
- 88% of what the research participants described as other symptoms that a person with their condition can have, concurred what is described in *The Alliance Programme* as symptoms of schizophrenia. It was noted that these research participants did not know the specific scientific names of these symptoms, but from their descriptions it was clear that the research participants knew the symptoms a person suffering from their condition can have. These included symptoms like: “Become aggressive again”; “Talk a lot of nonsense”; “Talk to themselves”; “They are mad”; “They are seen talking to things like Satan or demons”; “Do not sleep well at night”; “Cannot finish duties well”; “Stay naked without clothes or wear toned clothes”; “Hear voices”; “Have weird visions”; “They are always quiet”.

5. Which symptoms tell you that you are going to become ill again (early warning signs)?

- 7% of the participants also stated that they do not know what symptom tells you that you are going to become ill again;
- 12% of what the research participants described as symptoms that tells you that you are going to become ill again is not described in *The Alliance Programme* as early warning signs of schizophrenia. These are: “My eyes get bigger”; “My body and head become numb”;
- and, 88% of what the research participants described as the symptoms that indicate to them that they are going to become ill again (early warning signs) was what was described in *The Alliance Programme* early warning signs of schizophrenia and/or symptoms of schizophrenia. The research participants again did not know the specific scientific names of the early warning signs of schizophrenia, their descriptions were not clear enough. The examples given by the research participants were: “Talk alone/ to myself”; “I become irritable”; “I become restless, unable to relax”; “When I hear people talking, I then suspect they are talking about me”; “I Get afraid, frighten by the things I hear in my ears”; “Unable to sleep well at night”; “I get aggressive”; “I become less energetic”; “I stop speaking in Tshwana, then start speaking in English

and Afrikaans only”; “My mind stops working”; “Become stressed”; “Loose appetite”; “I wonder around aimlessly”.

6. How does medication help in your illness?

- 5% of the research participants admit that medication helps them but they do not like the medication because it gives them side effects (“They make me feel better but I do not like that they make me shake if I take them for a long time”- 6A);
- 5% of the research participants stated that they do not like medication thus they do not care how it helps them in their illness;
- 5% of the research participants who did not know how medication helps them with their illness;
- and, 86% of the research participants feel that medication really helps them a lot to recover from their illness by removing the symptoms of schizophrenia (“It removes the voices”- 2A).

7. Who is supporting you in your illness?

- 7% of the research participants are supported by doctors;
- 7% indicated that no one actually supports them with their illness;
- and, 86% of the research participants stated that their relatives at home give them a lot of support with their illness.

8. What do you think about your mental illness?

- 8%³ of the research participants are still in denial about their illness (“I see people who are mentally ill, I am not mentally ill” -7B);
- 8% of the research participants do not know what to think about this illness;.
- 17% of the responses on this question showed that the research participants have now placed everything in Gods hands, whom they pray will help them to cope with the illness (“I hope God will be with me so that I do not catch it again”- 6B);

¹The percentages (%) of the screening interviews’ results were calculated out of the 14 research participants (from both Group A and Group B) who were interviewed during the screening interviews.

- 25% of the responses represents the research participants who hate this illness because it wasted their future (“My future is wasted, I wanted to go back to school, I cannot grasp anything, I think slowly”- 1B);
- And, 33% of the research participants indicated that in-order to cope with the illness they need to take care of themselves and take their medication exactly as prescribed by their doctors and nurses (“If you take advices from doctors and take your treatment you will be better” -7A).

9. What do you think causes people to suffer from this mental illness (e.g. schizophrenia)?

- 6%⁴ indicated that it was depression;
- 6% indicated the fact that it runs in the family;
- 6% had unrealistic ideas (“It was not there before, since Mandela came back, it is all over...-1B);
- 7% of the research participants stated that they do not know what makes people suffer from this mental illness;
- 11% indicated worries and thinking a lot;
- 28% indicated bewitchment or witchcraft; and
- 44% of the research participants believed that people suffer from this mental illness due to alcohol and drug abuse.

Summary of basic knowledge results

It was noticed that the responses that the research participants gave when asked to:

- explain the things they were experiencing when their condition started;
- list the symptoms and the early warning signs that people suffering from their condition have;
- lists all the causes of the illness

concluded with the information described in *The Alliance Programme* as symptoms of schizophrenia, early warning signs of schizophrenia and causes of schizophrenia. Even though the research participants explained this information in simpler terms, it was clear

that the research participants have a vague knowledge on their illness. This was also evident when most of the research participants stated that taking medication as prescribed by their doctors and nurses could help them cope with their illness.

It seems that a lack of information about schizophrenia is one of the problems faced by the patients suffering from schizophrenic patients (participants of this research). This shows that either mental health information is not disseminated effectively or is not provided at all to patients with schizophrenia in South Africa. This was evident when most of the research participants did not know the name of the illness they suffer from, the signs and causes the illness *etc.* Some of the research participants have totally wrong ideas of what their disease is. When the research participants were asked who told them they have the illness, most of them indicated they were never told by anyone that they have the illness. From the findings discussed above, it seems as if in South Africa, there is a need for an effective health communication program that could be used when providing or communicating information about schizophrenia to schizophrenic patients in South Africa.

STAGE 3

Immediately after the screening interviews the research participants of this study were divided into two groups (Group A and Group B). Three discussion classes were conducted by Linda with the research participants in Group A, where information about schizophrenia was communicated based on the original version of *The Alliance Programme*. This group of research participants were never issued *The Alliance Programme* before or during the discussion classes to read in class or at home.

Immediately after the three discussion classes with Group A were completed, this group was interviewed first individually then in a focus group using an interview schedule with questions designed to elicit opinions about the use of the original version of *The Alliance Programme*, along dimensions such as comprehension, acceptability, selection and application.

The data obtained in this phase will be presented according to the questions in the interview schedule that was used to conduct both the individual interviews and the focus group discussions. In this section the results obtained from the questions asked to determine the research participants' understanding of the information communicated in the original version of *The Alliance Programme* are discussed.

1. What is the name of the disease you are suffering from?

- 17% of the research participants knew that the illness they suffer from is a psychiatric or a mental illness but they were not sure of the specific scientific name of the illness;
- 83% of the research participants knew that the illness they suffer from is a mental illness called schizophrenia.

2. How did you learn about your mental illness? / Who first told you that you have a mental illness?

- 17% of the research participants were never told they have a mental illness;
- 83% of the research participants were first told that they have a mental illness by their (psychiatric) doctor.

3. Who can diagnose you with schizophrenia?

- 17%⁵ still believe that a relative can diagnose you with schizophrenia;
- 33% of the research participants believe any psychiatric health professional (e.g. doctors, nurses, social workers) can diagnose you with schizophrenia;
- 50% of the research participants believe only (psychiatric) doctors can diagnose you with schizophrenia.

4. Why do you think we have schizophrenia information discussions classes like the ones you had in the past three weeks?

- 17% of the research participants thought schizophrenia information discussion classes are meant for them to be taught about medication;

⁵ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants (from Group A) that were interviewed during the screening interviews.

- 17% of the research participants thought schizophrenia information discussion classes are there to help them accept their illness;
- 67% of the research participants thought the reason they have discussion classes like the ones they had for three weeks is for them to be taught about a lot of important issues about their illness.

COMPREHENSION

1. What symptoms can people who suffer from this illness experience?

- 7% of the responses indicated loss of function;
- 7% of the responses indicated that tiredness is the symptom that people who suffer from this illness can experience;
- 7% of the participants stated that they do not know any symptoms of this illness;
- 20% of the responses indicated aggression;
- 27% of the responses indicated that hallucination;
- 33% of the research participants responses indicated that delusion is the symptom that people who suffer from this illness can experience.

2. Which of these symptoms did you experience?

- 17% of the research participants stated they experienced hallucination;
- 17% of the research participants indicated they experienced delusion;
- 17% of the research participants indicated that they did not experience any of the symptoms;
- 50% of the research participants stated that they experienced all the symptoms listed in question 2 above (delusion, hallucination, aggression, loss of function and tiredness).

3. What tells you that you are going to become ill again (early warning signs)?

- 10% of the symptoms that the research participants described were not mentioned in *the Alliance Programme* as early warning signs of schizophrenia. This include: “my heart becomes painful”;
- 90% of what the research participants described as the symptoms that tells them that they are going to become ill again (early warning signs) were described in *the Alliance Programme* as early warning signs. It was also noted that some of the participants this time were able to remember the specific scientific names of the early warning signs. The following is a the list of what the research participants listed as early warning signs: “Hearing voices”; “Suspicious”; “Aggressive”; “I become very forgetful”; “Isolate myself from other people”.

4. Do all patients with schizophrenia experience the same symptoms?

- 17% of the research participants stated that they do not know;
- 33% said yes, all patients with schizophrenia experience the same symptoms;
- 50% of the research participants said no, not all patients with schizophrenia experience the same symptoms.

Participants were not able to give the reasons for their yes or no responses in this question.

5. What is a delusion?

- 17%⁶ of the research participants gave the correct answers of what delusion is (“Believing you are God” -1A);
- 33% of the research participants stated that they do not know what delusion is;
- 50%⁷ of the research participants had totally wrong ideas of what delusion is (Its about the culture of healthy living”- 4A).

⁶ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group A) who were interviewed during the screening interviews.

6. What is a hallucination?

- 17% of the research participants had totally wrong ideas of what hallucination is (“You should not go pass a dumping place to search for things”- 4A);
- 33% of the research participants knew what hallucination is (“Seeing things that other people can’t see”-7A);
- and 50% of the research participants indicated that they do not know what hallucination is.

7. What does it mean to be psychotic? / When they say you psychotic, what do they mean?

- 20% of the research participants had totally wrong ideas of what it means to be psychotic (“A liar, always ask for things from other people..”-4A);
- 80% of the research participants knew what it means to be psychotic.

8. Why can we say that schizophrenia is like a “thief”?

- All the research participants provided the correct reasons of why schizophrenia is said to be like a thief. The following is a list that the research participants listed as the things that schizophrenia steals from their lives: “a person’s future”; “a person’s life”; “a persons mind/memory”; “a person’s energy”; “a person’s writing/reading skills”;” a person’s skills and ability of doing things well like he/she was able to do them before becoming ill”;” a person control of himself”;” a person’s intentions and personality”; “it changes your body”; and “it makes people to become suspicious of everything”.

9. Can schizophrenia be inherited? Explain

- 33% said schizophrenia cannot be inherited (“no, it is bewitchment which you get by food poisoning”- 4A);
- 67% of the research participants said that schizophrenia can be inherited (“Yes because they asked me in hospital, if someone in my family has the same illness, I said yes so they said I have inherited it”-2A.

10. How many people of every 100 people in the world suffer from schizophrenia?

- 17% of the research participants stated that they do not know;
- 33% of the research participants gave totally wrong figures of the number of people suffering from schizophrenia in world. (“17”-3A);
- 50% of the research participants gave the right/correct answers to this question as they stated that one to two people in every 100 people in the world suffer from schizophrenia.

11. What can you do to cope with this illness?

- 17%⁸ of the research participants said that in order to cope with the illness one needs to do physical exercises;
- 17% of the research participants said that in order to cope with the illness one needs to do healthier things that are inexpensive;
- 67% of the research participants said that in order to cope with the illness one needs to take medication as prescribed by doctors.

12. Can anything make this illness disappear completely?

- 33% of the research participants said no, nothing can make the illness disappear completely;
- 67% of the research participants said yes there is something that can make the illness disappears completely.

If yes, what is it? How does it work?

- 50% of the research participants who said yes believed that taking medication exactly the way the doctors prescribes, can make the illness disappear since medication stops the symptoms of schizophrenia; (“Yes, ,if you treat it well, use medication and go to hospital..”- 3A);
- 50% of the research participants believed that taking good care of yourself like eating healthy food can make the illness disappear (“Eat healthy food because it kills damaging stuff e.g. dandruff”-4A).

⁸ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group A) who were interviewed during the screening interviews.

If no, why not?

- All the research participants who said no, nothing can make the illness disappear, believed what they were told by their doctors, namely that they will have the illness for life but they just have to take their medication according to their doctors' prescriptions to prevent relapses (“No, I’ll have it for the rest of my life. My doctors told me it is for the rest of my life, thus I should take medication”- 2A).

13. What type of support do you receive for your illness?

- 17% of the research participants stated that they receive emotional support from their relatives and friends;
- 33% of the research participants stated that the type of support they receive is clothes and money from their relatives;
- 50% of the research participants stated that the type of support they receive for their illness is medication.

14.1 How can the symptoms of schizophrenia be treated?

- 17% of the research participants believed that there is nothing that can treat the symptoms of schizophrenia but medication can make the symptoms better;
- 83% of the research participants believed that taking your medication according to doctors' prescription can treat the symptoms of schizophrenia.

14.2 What type of treatment do you receive for the symptoms of schizophrenia?

- All the research participants receive tablets and/or injections for treating the symptoms of schizophrenia. It was noticed with that some of the participants of this group knew the specific scientific names of their medication (“Depot injections every four weeks and orphenodinne tablets”-6A).

15. How can medication help you with your illness?

- 17% of the research participants believe medication helps them to communicate better with other people (“It makes me communicate better with my friends, family and other people”- 3A);
- 83% of the research participants believed that taking medication makes them feel better with their illness (“It makes me feel much better with my illness”- 7A).

16. How do you feel about your mental illness?

- 17% feel positive that one day they will be cured from this illness (“I am not against other people, I am positive that I will be cured”- 3A);
- 17% of the research participants believe the illness was caused by following unhealthy lifestyles e.g. not washing your hands before eating (“ In my early life, people who used to cook never washed their hands, we ate their filth and became ill” - 4A);
- 67% of the research participants feel sad about the fact that they suffer from this disease and feels that it has wasted their future, that they now cannot do the things they used to do well before. Nevertheless these research participants also state that they need to accept the fact that they have the illness and to take medication according to the doctors prescriptions (“I feel better now but before, I was aggressive did not want to accept I have the illness, but now have accepted I have the illness”- 1A).

17. Why do you think people suffer from schizophrenia?

- 13% of the research participants indicated that stress and/or having a lot of problems (...having problems at home with your family”- 7A);
- 13%⁹ of the research participants did not know what causes schizophrenia;
- 38% of what the research participants described the causes of schizophrenia as alcohol and drug abuse (“Drug abuse, like me I also drank alcohol a lot”- 1A);
- 38% of the research participants descriptions referred to unhealthy lifestyle (“People are not healthy, do not wash hands or eat proper food”- 4A).

⁹ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group A) who were interviewed during the screening interviews.

¹ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants (from Group A) that were interviewed during the screening interviews.

Inferences

More than 50% of the research participants were able to give correct answers to all the comprehension questions about their illness and related issues. More than 25% of the research participants were not able to answer all the questions. When one compares these results to the results of screening interviews' results in phase 2 of this study, it seems as if the communication of information about schizophrenia based on the original version of *The Alliance Programme* did improve the research participants' knowledge or understanding of their mental illness to a certain degree. There were however still research participants who gave incorrect answers to the questions or indicated that they do not know, meaning they did not understand the information about schizophrenia communicated to them. It can be inferred that the communication of information about schizophrenia based on the original version of *The Alliance Programme* was not effective enough to improve all the research participants' knowledge or understanding of their mental illness.

ACCEPTABILITY

The results obtained from the questions asked to determine the acceptability of the original version of *The Alliance Programme* are discussed in this section.

1. What do you think about the schizophrenia information discussions classes you attended the past three weeks?

- 17%¹⁰ of the research participants felt the discussion classes were presented very well (“They were all done first class”- 6A); and
- 83% of the research participants felt that the schizophrenia information discussion classes they attended the past three weeks were helpful to them, since they learnt a lot of important things about their illness.

¹⁰ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants (from Group A) who were interviewed during the screening interviews.

2.1 What did you like about it?

- 20% of the research participants stated that they liked the schizophrenia information discussion classes because the support they got from the presenter and the other patients provided consolation (“It consoles me, the support I got from Linda the presenter of the classes” -2A);
- 20% of the research participants stated that the reason they liked these discussion classes was because they enjoyed the classes a lot and they liked the way the classes were presented to them (“I enjoyed it, everything was nice presented well, everything was good actually”- 7A); and
- 60% of the research participants stated that the reason they liked these discussion classes was because the classes were very informative, they learnt a lot about their illness (“we never knew about the illness and my doctor never told me but, these classes explained everything I wanted to know about the illness”- 1A).

2.2 What did you not like about it?

- All research participants indicated that there was nothing that they did not like about the schizophrenia information discussion classes.

3. How do you think can the presentation of these schizophrenia information discussion classes be improved?

- 17%¹¹ of the research participants felt group activities in between the discussion classes can improve the presentation of these classes (“Makes groups to talk about the illness e.g. have group assignments” – 1A);
- 33% of the research participants felt the presentation of these discussion classes can be improved by involving more people e.g. more family members and/or caregivers and more patients;
- 50% of the research participants were satisfied with the presentation of the schizophrenia information discussion classes

¹¹ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group A) who were interviewed during the screening interviews.

4. What would be the best way for you to learn more about your illness (schizophrenia)?

- 17% of the research participants felt attending schizophrenia information discussion classes like the ones they had for three weeks are the best way for them to learn about their illness (“I must try get time and energy to attend classes like these ones” -4A);
- 17% of the research participants indicated that the best way for them to learn about their illness is when they can get booklets on their illness that are in Tshwana (“Booklets in Tshwana” – 6A);
- 33% of the research participants indicated that being issued with books that they could use in the schizophrenia information discussion classes as well as after the classes would be the best way for them to learn more about their illness (“books about the illness and discussions”- 1A);
- 33% of the research participants felt that being taught by their doctors, nurses and social workers would be the best way for them to learn more about their illness (“Being taught by doctors, nurses, social workers etc.”- 7A).

5. Which language would you prefer for the schizophrenia information discussion classes? Why?

- 33% of the research participants indicated that they prefer English (English since in South Africa most or majority of the people know the language...”- 7A);
- 67% of the research participants indicated that they prefer Tshwana because they understand Thswana better since it is their mother tongue (“Tshwana because I understand it better”-4A ; “Tshwana it is my mother tongue” -3A).

6. How do you feel about the presenter?

- All the research participants liked the presenter and they stated that she teaches well and make it easy for them to understand the information (“She teaches well, made it easy to understand”- 4A).

7. How do you feel about the interpreter?

- All the research participants liked the interpreter because she interpreted very well making them to understand better all the information delivered by the presenter (“I feel great about her because she made us to understand the whole story better”-7A).

Inferences

The responses above indicate that the research participants appreciated the information communicated in the schizophrenia information discussion classes. Most of them stated that these discussions classes were very helpful because they learnt a lot of important things about their illness. Most of the research participants liked the way these discussion classes were presented. They all liked both the presenter and the interpreter. They all stated that there was nothing that they did not like about these schizophrenia information discussion classes.

Most of the research participants also indicated that schizophrenia information discussion classes like these ones are the best way for them to learn about their illness. Most of them stated that if they could be issued with books in these classes that could be used both in class as well as at home that would make it even better for them to learn about their illness. They also said they would like the books to be in their local language, Tshwana.

USABILITY

In this section, the results from questions asked to determine how research participants feel about the usability of the original version of *The Alliance Programme* are discussed.

1.1 What did you learn from the schizophrenia information discussion classes that are suppose to help you cope better with your illness?

- 33% of the research participants felt that these schizophrenia information discussion classes helped them to know more about the symptoms of schizophrenia and knowing more about this help them to cope with their illness better (“To know the symptoms of schizophrenia”- 1A);

- 67% of the research participants said that one of the important issues that they learnt from the schizophrenia information discussion classes was the importance of medication and the fact that they need to take it exactly as the prescribed it (“The importance of medication and the fact that we need to take it for life”-7A).

1.2 What did you learn from the schizophrenia information discussion classes that made you understand your illness better?

- 17%¹² of the research participants felt that the schizophrenia information discussion classes taught them about the importance of medication and this helped them to understand their illness better (“That it would be lifelong if I do not use medication” – 6A);
- 33% of the research participants stated they do not know what they learnt from these discussion classes that helped them to understand their illness better (...they helped me to understand my illness better”- 3A);
- 50% of the research participants stated that knowing more about the symptoms of schizophrenia helped them to understand their illness better (“The discussions about the symptoms of schizophrenia as it helped me to be able to tell when I experience them”- 7A).

2. Were you able to read and understand what the presenter wrote on the board during the discussions classes?

- 17% of the research participants indicated that no, they could not read and understand what the presenter wrote on the board during the discussions because they have poor reading skills (“difficult to read, I have a weakness for written words”- 6A);
- 83% of the research participants indicated that they were able to read and understand what the presenter wrote on the board during the discussions classes (“I was able to see, read and understand”- 7A).

¹² The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group A) who were interviewed during the screening interviews.

3. Would you like such schizophrenia information discussion classes to include drawings and photographs? Why?

- 17% of the research participants said diagrams and photographs would not add to better comprehension of the information provided (“No because we can understand even without” – 2A);
- 83% of the research participants stated that drawings and photographs would help them so to understand what is taught in these discussions better (“Yes so we would be able to see what the presenter is talking about, thus understand better” – 1A).

4. Would you like to be issued with booklets to read during these schizophrenia information discussion classes and at home?

- All research participants indicated that they would like to be issued with booklets to read during the schizophrenia information discussion classes and at home (“Yes, to understand better”- 7A).

5.1 Which words did you find difficult to understand?

- 13% mentioned hallucination;
- 25% mentioned paranoia;
- 25% of the research participants’ responses indicated that there was no word that they found difficult to understand. They could understand everything even after the interpreter explained words, they were able to understand all the words even better;
- 37% of the research participants mentioned delusion.

5.2 Which words do you think other patients might find difficult to understand?

- 17% of the research participants felt that the word “symptom” would be difficult for other patients to understand;
- 17% of the research participants said that the phrase “loosing function” would be difficult for other patients to understand;
- 33%¹³ of the research participants referred to the words listed in question 5.1 (Delusion, paranoia, hallucination) other words that other patients might find difficult to understand;

¹³ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group A) who were interviewed during the screening interviews.

- 33% of the research participants stated that there is no word that other patients might find difficult to understand because everything is easy to understand.

Inferences

Most of the research participants stated that they learnt a lot from the schizophrenia information discussion classes they attended for three weeks. It helped them to understand their illness better and also cope better with the illness. This means that most research participants were able to see and understand the value of the information communicated to them. There were however some research participants who did not understand or see the value of the information communicated. They could not relate the importance of this information to their situations. Most of the research participants were able to read and understand what the presenter wrote on the boards, which implies that the presentation of the information was very good and appreciated by most of the research participants.

The research participants also gave some suggestions on how the presentation of these schizophrenia information discussion classes could be improved. They believed for instance, that drawings and photographs will make them understand the information better. They also stated that books to read during the classes and at home will help them retain the information that was communicated to them in these schizophrenia information discussion classes longer.

STAGE 4

The original version of *The Alliance Programme* was adapted using the following sets of evidence:

- Summary of how Linda adapted *The Alliance Programme*
-

- Literature (principles of adapting text-based and oral information materials)
- Results from testing the communication of schizophrenia information based on the original version of *The Alliance Programme*, using the expert-focused evaluation method
- Findings from the interviews of Group A

From these four sets of evidence, common themes were grouped together, then a summary and/or a conclusion of effective methods/principles of adapting *The Alliance Programme* was drawn. More details on the adaptation of *The Alliance Programme* are provided in chapter 3 (paragraph 3.4.3.2- Phase 3).

STAGE 5

Again, three discussion classes were conducted by Linda with research participants the in second group (Group B), where information about schizophrenia was communicated based on the adapted version of *The Alliance Programme*. This group of research participants was also issued with the adapted version of *The Alliance Programme* to read during the discussion classes or at home. Immediately after the three discussion classes with Group B were completed, this group was also interviewed first individually then in a focus group using the same interview schedule that was used to interview research participants in Group A, with questions designed to elicit opinions about the use of the adapted version of *The Alliance Programme*, along dimensions such as comprehension, acceptability, selection and application.

Just like in phase 3, the data obtained in this phase will be presented according to the questions in the interview schedule that was used to conduct both the individual interviews and the focus group discussions. The results obtained from the questions asked to determine the research participants' understanding of the information communicated in the adapted version of *The Alliance Programme* are discussed in this section.

1. What is the name of the disease you are suffering from?

- All research participants knew that the illness they suffer from is a mental illness called schizophrenia.

2. How did you learn about your mental illness? / Who first told you that you have a mental illness?

All research participants were first told they have the illness in hospital:

- 43% of the research participants cannot remember who exactly told them they have this illness but they do remember that they were first told they have this illness in hospital;
- 57% of the research participants were first told that they have the illness by their doctors.

3. Who can diagnose you with schizophrenia?

- 14%¹⁴ of these research participants stated that it is not just any doctor that can diagnose you with schizophrenia, but only psychiatric doctors;
- All research participants believe only doctors can diagnose you with schizophrenia.

4. Why do you think we have schizophrenia information discussion classes like the ones you had in the past three weeks?

- All research participants indicated the aim of the classes is for them learn more about their illness so as to understand it better (“To help us understand our mental illness”- 3B).

COMPREHENSION

1. What symptoms can people who suffer from this illness experience?

- 5% of the responses indicated isolation;
- 5% of the responses indicated sleeping too much;
- 5% of the responses indicated impatience;

¹⁴ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group B) who were interviewed during the screening interviews.

- 10% of the responses indicated loss of function is the symptom;
 - 10% of the responses indicated lack of motivation;
 - 10% of the research participants indicated delusion;
 - 15% of the responses indicated aggression is the symptom;
 - 15% of the responses indicated disturbances in thinking;
 - 25% of the responses indicated hallucination.
- 90% of the responses given by the research participants as symptoms that people who suffer from schizophrenia can experience was what was described in the Alliance Programme as symptoms of schizophrenia. It was noted that most of the research participants in this group used specific scientific names like hallucination to list the symptoms instead of describing it in simpler terms like how Group A did. It was also noticed that this group listed more symptoms that people who suffer from this illness can experience than Group A. No research participant in this group stated they do not know what symptoms people who suffer from this illness can experience.

2. Which of these symptoms did you experience?

With this group, each research participant listed multiple symptoms that he/she experienced.

- 8% of the responses listed slept a lot; 8% of the responses loss of function;
 - 15% of the research participants listed aggression;
 - 16% of the responses disturbances in thinking;
 - 23% of the responses listed lack of motivation;
 - 31% of what the research participants listed hallucination.
- All of the things that the research participants described as things that happened at the beginning of their illness was what was described in the Alliance Programme as symptoms of schizophrenia and/or early warning signs of schizophrenia.

3. What tells you that you are going to become ill again (early warning signs)?

- Only 10%¹⁵ of the early warning signs that research participants described was not according to the Alliance Programme;
- 90% of what the research participants described the early warning signs that were described in the Alliance Programme. It was also noted that most of the research participants this time were able to remember the specific scientific terms of the early warning signs.

4. Do all patients with schizophrenia experience the same symptoms?

- 33% of the research participants said yes, all patients with schizophrenia experience the same symptoms. Not all of them were able to give a reason for their answers, but those who were able to state the reason, said that since they all suffer from the same illness they therefore will experience the same symptoms;
- 67% of the research participants said no, not all patients with schizophrenia experience the same symptoms. Not all of these research participants could give reason for their answers, but those who were able to provide the reason, indicated mostly that people are all different and consequently experience the disease differently. That is why they have different symptoms from each other.

5. What is a delusion?

- 33% of the research participants reflect totally wrong ideas of what a delusion is (“...poor concentration”- 4B);
- 67% of the research participants answered this question correctly (“Believing in something that is not there”- 2B).

6. What is a hallucination?

- 17% of the research participants reflect totally wrong ideas of what hallucination is (“Being suspicious”- 3B);

¹⁵ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group B) who were interviewed during the screening interviews.

- 17% of the research participants did not answer this question or simply stated that they forgot what a hallucination is;
- 67% of the research participants answered correctly
("Hearing/seeing/touching/smelling/testing things that are not there"- 7B).

7. What does it mean to be psychotic? / When they say you are psychotic, what do they mean?

- 33% of the research participants stated they had forgotten what being psychotic means ("Forgotten the meaning"- 4B);
- 67% of the research participants knew what it means to be psychotic ("Lost contact with reality"- 7B).

8. Why can we say that schizophrenia is like a "thief"?

- 17% of the research participants did not answer this question or simply stated they do not know;
- 83% of the research participants indicated the reason why schizophrenia is said to be like a thief is because it steals certain things/functions from people. The following is a list that the research participants listed as the things that schizophrenia steals from them: "a person's life"; "a person's future"; "one's thoughts"; "a person's ambitions"; "a person's memory"; "a person's good qualities"; "a person's concentration"; "a person's reading and writing skills"; "a person's hearing and seeing abilities".

9. Can schizophrenia be inherited? Explain

- All research participants said yes schizophrenia can be inherited; some even stated that they themselves have inherited it from a family member who also has the same illness. ("Yes it runs in genes, maybe some of your forefathers or relatives had it"- 2B).

10. How many people out of every 100 people suffer from schizophrenia?

- 33% of the research participants had the answers totally wrong ("50"- 3B);
- 67% of the research participants got this question right stating that one to two people in every 100 people in the world suffer from schizophrenia.

11. What can you do to cope with this illness?

- 17%¹⁶ of the research participants indicated that in order to cope with the illness one needs not only to take medication as prescribed by doctors but also attend classes like the ones we had for three weeks (schizophrenia information discussion classes) so to learn more about the disease (“come together with other who suffer from schizophrenia to support each others and also use medication”- 4B);
- 83% of the research participants indicated that in order to cope with the illness one needs to take medication as prescribed by doctors (“Take medication exactly as doctors told you” – 2B).

12. Can anything make this illness disappear completely?

- 17%¹⁷ of the research participants said yes there is something that can make the illness disappear completely;
- 83% of the research participants said no there is nothing that can make the illness disappear completely.

If yes, what is it? How does it work?

- All the research participants who said yes believed that taking medication exactly the way the doctors prescribed it and also taking good care of yourself can make the illness disappear completely.

If no, why not?

- All the research participants who said no nothing can make their illness disappear completely said their doctors explained it clearly to them that they will have this illness for life, the only thing they can and need to do is to take their medication exactly as the doctors prescribed to them so as to minimise the symptoms of the illness.

¹⁶ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group B) who were interviewed during the screening interviews.

13. What type of support do you receive for your illness?

- 17% of the research participants stated that they receive financial support from their relatives (“My sister buys me things that I need”- 5B);
- 17% of the research participants stated that the type of support they receive is free medication and schizophrenia information discussion classes from the hospital (“Get medication at Weskoppies hospital and those classes”- 7B);
- 17% of the research participants stated that they do not receive any type of support from anyone for their illness (“none”- 1B).
- 50% of the research participants stated that the type of support they receive for their illness is emotional support from relatives and/or nurses in the hospital wards (“My uncle, he knows how I feel or I tell him how I sometimes feel”- 3B);

14.1 How can the symptoms of schizophrenia be treated?

- 17% of the research participants believed that staying away from drugs can help in treating the symptoms of schizophrenia;
- 83% of the research participants believed that taking your medication according to the doctors’ prescription can make the symptoms of schizophrenia be treated (“Taking your medication as prescribed”- 7B).

14.2 What type of treatment do you receive for the symptoms of schizophrenia?

- All research participants receive tablets and/or injections for treating the symptoms of schizophrenia. It was also noticed with this group that most of the research participants knew the specific scientific names of their medication (“Rivotric, Serenax, Aknuton, medication injection”- 7B).

15. How can medication help you with your illness?

- All research participants believed that medication makes them feel better by taking away or minimising the symptoms (“Takes away symptoms”- 7B).

16. How do you feel about your mental illness?

- 33% of the research participants there is nothing they can do besides accepting the fact that they have the disease and drink their medication according to doctors prescriptions because life goes (“I’ve come to accept it just need to take my medication to prevent relapsing”- 7B);
- 67% said it wasted their future an (“It has changed my life a lot, now I cannot read or write” – 3B);
- All research participants feel sad about having the disease:

17. Why do you think people suffer from schizophrenia?

- 17%¹⁸ of the research participants feel that nothing actually causes the illness, it is just bad luck;
- 33% of the research participants feel that stress and/or thinking a lot can cause the illness;
- 50% of the research participants feel that drug and/or alcohol abuse cause the illness (“Drinking alcohol a lot and dagga”- 5B).

Inferences

Most of the research participants (more than 75% of the research participants) were able to give correct answers to all the comprehension questions. The number of research participants who were not able to answer some of the questions (e.g. research participants who stated they do not know the answers or gave incorrect answers to the questions) was much lower in Group B when compared to Group A. When you compare these results to the basic knowledge results (phase 2 of the study) and the comprehension results of Group A, the results shows that the information about schizophrenia communicated in the discussion classes based on the adapted version of *The Alliance Programme* improved the participants’ knowledge and understanding of their mental illness better than the schizophrenia information discussion classes based on the original version of *The Alliance Programme*. More research participants were able to give correct answers. This study therefore concludes that communication of information based on the adapted

¹⁸ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group B) who were interviewed during the screening interviews.

version of *The Alliance Programme* was effective and improved most, if not all, of the research participants' knowledge and understanding of their mental illness.

ACCEPTABILITY

In this section, the results obtained from the questions asked to determine the acceptability of the original version of *The Alliance Programme* are discussed.

1. What do you think about the schizophrenia information discussion classes you attended the past three weeks?

- All research participants liked the schizophrenia information discussion classes they attended for three weeks stating that these classes were really helpful to them, since they learnt a lot of important issues about their illness (“Very helpful made me learn more about my illness and its origin...”- 1B).

2.1 What did you like about it?

- 17% of the research participants stated that the reason they liked these schizophrenia information discussion classes was because they were able to interact with other patients, share ideas, experiences and advices about this illness;
- 83% of the research participants stated that the reason they liked these schizophrenia information discussion classes was because the classes were very informative, they learnt a lot about their illness and they now have a better understanding of this illness.

2.2 What did you not like about it?

- 17% of the research participants stated that they were not clearly told why they forget information;
- 83% of the research participants said that there was nothing that they did not like about the schizophrenia information discussion classes.

3. How do you think can the presentation of these schizophrenia information discussion classes be improved?

- 17% of the research participants felt the presentation of these schizophrenia information discussion classes can be improved if the presenter uses pictures and photographs (“Getting pictures to see or television”- 5B);
- 17% of the research participants felt that the explanations could be shorter, briefer and more straight to the point, so that they would not lose concentration (“Sometimes the explanations are too long, they need to be brief and to the point. I lose concentration easily”- 4B);
- 67% of the research participants felt the presentation of these schizophrenia information discussion classes was fine and that nothing needs to be improved (“... they are ok”- 7B).

4. What would be the best way for you to learn more about your illness (schizophrenia)?

- 17% of the research participants felt like getting pictures, photographs etc. about schizophrenia information would be the best way for them to learn about their illness, as it would not be easy for them to forget that information (“To add pictures and text”- 1B);
- 17%¹⁹ of the research participants felt that being taught about their illness by their doctors, nurses and social workers would be the best way for them to learn more about their illness (If doctors could be more open”- 3B);
- 33% of the research participants felt attending schizophrenia information discussion classes like the ones they have been attending for three weeks would be the best way to learn about their illness (“Reading books about schizophrenia and attending more classes”- 7B);
- 33% of the research participants stated being taught about how to generate more income as well would be the best way for them to learn about their illness (“About how I can help myself to generate more income”- 4B).

¹⁹ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group B) who were interviewed during the screening interviews.

5. Which language would you prefer the schizophrenia information discussion classes? Why?

- 17% of the research participants stated that they would prefer the classes to be presented in either English or Tswana whichever is best for the presenter because they understand both languages;
- 33% of the research participants indicated that they prefer English because English is an international language so most of the people would understand English;
- 50% of the research participants indicated that they would prefer the schizophrenia information discussion classes to be presented in Tswana because they understand Tswana better since it is their mother tongue.

6. How do you feel about the presenter?

- All the research participants liked the presenter as they stated that she teaches well, knows how to communicate well with patients and she made it easy for them to understand better about their illness.

7. How do you feel about the interpreter?

- All the research participants liked the interpreter because she interpreted very well helping them to understand the information delivered by the presenter much better (“It was very important to get things further explained in our mother tongue”- 4B).

Inferences

The responses above indicate that the research participants really appreciated the information communicated in the information discussion classes that were presented to them based on the adapted version of *the Alliance Programme*. This was evident when all of the research participants stated that they liked these discussion classes because they were really helpful to them and they learnt a lot about their illness. Just like the research participants in Group A, most of the research participants in this group (Group B) liked the way these classes were presented; they all liked the presenter and the interpreter. When the research participants were asked if there was anything that they did not like in these classes, most of the research participants stated that there was nothing that they did not like. Most of the research participants stated that they liked the schizophrenia information discussion classes the way they are, nothing needs to be improved.

Most of the research participants even stated that schizophrenia information discussion classes like the ones they attended for three weeks are the best way for them to learn more about their illness. From this, it would seem that most of the research participants liked and appreciated the discussion classes where they are issued with booklets in which are in their local language that they could use during the classes and at home. Some thought that if the presenter could use more pictures and photographs in the classes it would really help them to learn more about their illness.

When Group B's findings are compared to Group A's findings, it was noticed that research participants from Group B appreciated the information communicated in this schizophrenia information discussion classes more than Group A. Most of the research participants in Group B even stated that the best way for them to learn more about their illness would be attending information discussion classes like the ones they attended for three weeks. I therefore conclude that the information discussion classes based on the adapted version of *the Alliance Programme* were appreciated and liked much better by the research participants than those discussion classes based on the original version of *the Alliance Programme*.

USABILITY

The results from the questions asked to determine how research participants feel about the usability of the original version of *The Alliance Programme* are discussed in this section.

1.1 What did you learn from the schizophrenia information discussions classes that are suppose to help you cope better with your illness?

- 17% of the research participants felt that the discussion classes helped them to know more about what schizophrenia really is (“That it is a thief stealing our thoughts”- 4B);
- 17% of the research participants felt that attending the schizophrenia information discussion classes helped them to know the importance of schizophrenia discussion classes in helping schizophrenia patients to know better about their illness (“Others at home when they are mentally ill, I will use the same method Linda used to explain”- 4B);
- 33% of the research participants stated that these schizophrenia information discussion classes helped them to know what causes the illness, and that will help them to try and avoid those causes so to cope better with the illness (“I learnt that I’m

really ill. I learnt not to indulge in alcohol and dagga, they are causes of the illness” - 7B);

- 33% of the research participants said that one of the important issues that they learnt from the schizophrenia information discussions classes was the importance of medication and the fact that they need to take it so as to cope better with their illness (“How to take care of myself and drink my medication to prevent relapsing”- 3B).

1.2 What did you learn from the schizophrenia information discussion classes that made you understand your illness better?

- 17% of the research participants stated that these schizophrenia information discussion classes taught them a lot about their illness and that made them to understand their illness better (“I learnt more about the illness basically”- 2B);
- 17%²⁰ of the research participants felt that the psycho-education classes taught them about the importance of medication and this helped to understand their illness even better (“I learnt that I have to drink my medication so not to get sick again and not become suspicious again”- 5B);
- 67% of the research participants stated that they learnt to understand their illness better (“I learnt what schizophrenia is”- 7B).

2. Were you able to read and understand what the presenter wrote on the board during the discussions?

- 33% of the research participants indicated that no, they could not read and understand what the presenter wrote on the board during the discussions classes they just depended on what she said (“No, I depended mostly on what she said”- 4B).
- 67% of the research participants indicated that they were able to read and understand what the presenter wrote on the board during the discussions classes;

²⁰ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants (from Group B) who were interviewed during the screening interviews.

3. Would you like such schizophrenia information discussion classes to include drawings and photographs as well? Why?

- 17% of the research participants said no they do not need diagrams and photographs in the schizophrenia information discussion classes because they can understand the information presented in the schizophrenia information discussion classes even without the diagrams and photographs (“Not necessarily”- 7B);
- 83% of the research participants stated that they would love the schizophrenia information discussion classes to include drawings and photographs so to understand what is taught in these discussions better and be able to remember the information better (“ Yes, we are very forgetful so it make us to remember easily”- 3B).

4. Would you like to be issued with booklets to read during these schizophrenia information discussion classes and at home?

- All research participants indicated that they would like to be issued with booklets to read during these schizophrenia information discussion classes and at home. All research participants could not give any reason why.

5.1 Which words did you find difficult to understand?

- 20% listed words was hallucination;
- 40% of the research participants listed understand was the word delusion;
- 40% words listed symptoms;

- 50% of the research participants specified that there was no word that they found difficult to understand; they could understand everything and were able to understand even better when the interpreter explained.

5.2 Which words do you think other patients might find difficult to understand?

- 17% listed words symptoms;
- 33% listed delusion;

- 33%²¹ of the research participants specified that there was no word that they think other patients will find difficult to understand. Everything is explained well in the presentations and it is easy to understand;
- 50% of the research participants the word hallucination.

Inferences

It was noticed that with the usability questions, results from Group A and results from Group B were similar. Just like the results from Group A, most of research participants in Group B stated that they learnt a lot (e.g. symptoms of schizophrenia, causes of schizophrenia and medication of schizophrenia) from the discussion classes they attended for three weeks. It helped them to understand their illness better and also to cope better with the illness. This means, most of the research participants in Group B were able to see and understand the value of the information communicated in these classes and how it can/will help them improve their lives.

Most of the research participants in Group B, just like research participants in Group A, were able to read and understand what the presenter wrote in the boards, which implies that the that most of the research participants of this study are literate. This could also imply that the presentation of the schizophrenia information discussion classes was very good and appreciated by most of the research participants. Research participants of this group (Group B) would also like drawings and photographs for illustrations during the classes, as well as being issued with books to read during the classes and at home.

FOCUS GROUP DISCUSSIONS

In the following section, results obtained in the focus group discussion sessions from the research participants in both Group A and Group B will be presented. The same questions that were used for the individual interviews were also used as a discussion framework to guide the focus group discussions. The framework was designed to elicit questions again about comprehension, acceptability and usability of the schizophrenia information discussion classes based on *the Alliance Programme*. The findings are categorised and tabulated according to the

²¹ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants (from Group B) who were interviewed during the screening interviews.

questions used as the discussion framework. The findings of the research participants from both Group A and Group B are presented in a table format so as to reflect the differences and/or similarities of the findings found in the two groups.

Comprehension

In this section, the focus group results obtained from the questions asked to determine the research participants' understanding of the information communicated in the adapted version of *The Alliance Programme* are discussed.

QUESTIONS	GROUP A	GROUP B
1. What is the name of the disease you are suffering from?	All research participants in both groups agreed on the fact that the name of the illness they suffer from is a mental illness called schizophrenia.	
2. How did you learn about your mental illness? / Who first told you that you have a mental illness?	Most ²² of the research participants indicated that they were first told they have a mental illness by their (psychiatric) doctors.	All the research participants were first told they have a mental illness in hospital. Most of the participants indicated that they were first told by their (psychiatric) doctors.
3. Who can diagnose you with schizophrenia?	All research participants felt that any mental health professional (e.g. doctors, nurses, social workers) can diagnose you schizophrenia.	All research participants felt that only (psychiatric) doctors can diagnose you with schizophrenia.
4. Why do you think we have schizophrenia information discussion classes like the ones you had during the past three weeks?	All research participants in both groups agreed on the fact that schizophrenia information discussion classes like the ones they had for three weeks are made to teach them a lot of important issues about their illness, so to understand their illness much better.	

QUESTIONS (Comprehension questions)	GROUP A	GROUP B
1. What symptoms can people who suffer from this illness experience?	All research participants agreed on the following symptoms as symptoms that people who suffer from their illness can experience:	All research participants agreed on the following symptoms as symptoms that people who suffer from their illness can experience: hallucination; delusion; isolate

²² Bold text in the focus group responses were used to indicate differences.

	hallucination; delusion; isolate themselves and talking nonsense.	themselves; loss of function and disturbance in thinking.
2. Which of these symptoms did you experience?	The following is a list of symptoms that the research participants in both groups listed as the symptoms they experienced: hallucination; delusion; isolate themselves; aggression; lack of motivation; loss of function; and disturbances in thinking. From this list it was also noticed that the patients did not experience the same symptoms but, different patients experienced different symptoms of schizophrenia.	
3. What tells you that you are going to become ill again (early warning signs)?	All the signs that the research participants in both groups (Group A and Group B) listed as signs that tells you that you are going to become ill again are according to <i>The Alliance Programme</i> early warning signs.	
4. Do all patients with schizophrenia experience the same symptoms?	Most of the research participants agreed on the fact that patients do not experience the same symptoms but it is possible to find a person who also experienced some or most of the symptoms that you experienced	All the research participants agreed on the fact that patients do not experience the same symptoms but it is possible to find a person who also experience some or most of the symptoms that you experienced.
5. What is a delusion?	Most of the research participants gave the correct answer of what delusion is.	All the research participants gave the correct answer of what delusion is.
6. What is a hallucination?	Most of the research participants knew what hallucination is.	All research participants knew what hallucination is.
7. What does it mean to be psychotic? / When they say you psychotic, what do they mean?	All research participants in both groups gave the correct explanation of what it means to be psychotic.	
8. Why can we say that schizophrenia is like a “thief”?	All research participants in both Group A and Group B agreed on the fact that schizophrenia is said to be like a thief because it steals a lot of things/functions from people. These include: people’s good qualities; people’s reading and writing skills; people’s future; people’s memory; people’s ambitions.	
9. Can schizophrenia be inherited? Explain	Most of the research participants believe schizophrenia can be inherited, whilst a small portion of the participants believe schizophrenia cannot be inherited.	All the research participants believed that schizophrenia can be inherited. If a family member have the same illness it is most likely that another family member can inherit it from him/her.
10. How many people of every 100 people in the world suffer from schizophrenia?	All research participants in both groups agreed that one in every 100 people in the world suffers from schizophrenia.	
11. What can you do to cope with this illness?	Most of the research participants in both Group A and Group B agreed on the fact that in order to cope with the illness one needs to take medication as prescribed by doctors	

<p>12. Can anything make this illness disappear completely? If yes, what is it? How does it work? If no, why not?</p>	<p>Most of the research participants believed that nothing can make this illness disappear completely but they just have to take their medication exactly as the doctors prescribed to them so to minimise the symptoms.</p>	<p>All research participants agreed on the fact that nothing can make the illness disappear completely. Most of them stated that they know they will have the illness for life but they just have to take their medication according to their doctors' prescriptions so to prevent relapsing.</p>
<p>13. What type of support do you receive for your illness?</p>	<p>Most of the research participants stated that their relatives and/or nurses in their hospital wards help them a lot in making sure they drink their medication according to doctors' descriptions and also take them to doctors for consultations.</p>	<p>Most of the research participants stated that their relatives and/or nurses in their hospital wards give them a lot of emotional support, if they have any problems they are always available to help them with those problems and advice them on what to do.</p>
<p>14.1 How can the symptoms of schizophrenia be treated</p>	<p>Most of the research participants indicated that taking your medication as prescribed by doctors can make the symptoms of schizophrenia be treated.</p>	<p>All research participants indicated that taking your medication as prescribed by doctors can make the symptoms of schizophrenia be treated.</p>
<p>14.2 What type of treatment do you receive for the symptoms of schizophrenia?</p>	<p>All research participants in both Group A and Group B receive tablets and/or injections for treating the symptoms of schizophrenia.</p>	
<p>15. How can medication help you with your illness?</p>	<p>Most of the research participants said that medication takes away or minimise negative symptoms.</p>	<p>All research participants said that medication takes away or minimises the symptoms</p>
<p>16. How do you feel about your mental illness?</p>	<p>Most of the research participants indicated that they feel sad about having the illness as the illness wasted their future and they cannot do things that they use to do well before.</p>	<p>All research participants indicated that they feel sad about having the illness as the illness wasted their future and they cannot do things that they use to do well before.</p>
<p>17. Why do you think people suffer from schizophrenia?</p>	<p>Most of the research participants believe that only alcohol and drug abuse causes schizophrenia.</p>	<p>Most of the research participants believe that alcohol and drug abuse and stress can cause schizophrenia.</p>

Inferences

When one compares the focus group findings of the research participants from both Group A and Group B with the individual interviews findings regarding the comprehension questions. It seems as if more correct answers were given by the research participants from both Group A and Group B in the focus group discussions compared to the individual interviews. This could maybe be explained by the fact that it was observed that most of the research participants during the focus group interviews, where they were with fellow patients, looked more at ease, comfortable, free and contributed more information concerning the comprehension questions the researchers asked them; as compared to individual interviews where the participants were in a room with only the researchers. In this situation most of them looked nervous, scared and therefore contributed less information concerning the comprehension questions the researchers asked them. This also shows that the setting in which the interviews took place also had an impact on the findings obtained from the comprehension questions asked in this study.

However, when Group A's findings of the focus group interviews are compared to Group B's findings, it was noticed that research participants from Group B had better understanding of the information communicated to them in the discussion classes they attended which were based on the adapted *Alliance Programme* as compared to the research participants in Group A. This was demonstrated by the fact that more participants in Group B gave correct answers than the Group A research participants. In most of the comprehension questions asked in the focus group discussions **all** the research participants in Group B gave the correct answers whilst **most** of the research participants in Group A gave the correct answers. This then support what was found in the individual interviews, that the communication of information based on the adapted version of *The Alliance Programme* was effective and improved most of, if not all of the research participants' knowledge and understanding of their mental illness (schizophrenia).

Acceptability

In this section, the focus group results obtained from the questions asked to determine the acceptability of the original version of *The Alliance Programme* are discussed.

QUESTIONS	GROUP A	GROUP B
1. What do you think about the schizophrenia information discussions classes you attended the past three weeks?	All research participants in both groups appreciated the schizophrenia information discussion classes they attended the past three weeks stating that these classes really helped them to know more about their illness.	
2.1 What did you like about it?	Most of the research participants in both Group A and Group B indicated that the reason they liked these schizophrenia information discussion classes was because the classes were very interesting and informative; they learnt a lot of important issues about their illness.	
2.2 What did you not like about it?	Most of the research participants indicated that there was nothing that they did not like about the schizophrenia information discussion classes they had for the past three weeks.	All research participants indicated that there was nothing that they did not like about the schizophrenia information discussion classes they had for the past three weeks.
3. How do you think can the presentation of these schizophrenia information discussions classes be improved?	Most of the research participants felt the presentation of these schizophrenia information discussion classes can be improved by getting: books to be used during the classes, illustrations and examples, group assignment between the classes and involving more patients, caregivers, doctors, nurses, family members and caregivers.	Most of the research participants felt the presentation of these schizophrenia information discussion classes were okay the way they are, nothing needs to be improved.
4. What would be the best way for you to learn more about your illness (schizophrenia)?	Most of the research participants indicated that being taught by their doctors, nurses and social workers would be the best way to learn more about their illness.	Most of the research participants indicated that schizophrenia information discussion classes like the one they attended for three weeks would be the best way for them to learn about their illness.
5. Which language would you prefer the schizophrenia information discussions classes? Why?	Most of the research participants in both Group A and Group B indicated that they would prefer the schizophrenia information discussion classes to be presented in Tshwana because they understand Tshwana better since it is their mother tongue.	

6. How do you feel about the presenter?	All the research participants in both groups liked the presenter and they indicated that she teaches well and make it easy for them to understand.
7. How do you feel about the interpreter?	All the research participants in both Group A and Group B liked the interpreter because she interpreted very well making them to understand the information delivered by the presenter much better.

Inferences

From the above focus group findings, it is indicated that research participants in Group B appreciated the information communicated in the schizophrenia information discussion classes based on the adapted version of *The Alliance Programme* better than research participants in Group A. This then supports what was also found with the individual interviews that the schizophrenia information discussion classes based on adapted version of *The Alliance Programme* was appreciated and liked much better by the participants that the schizophrenia information discussion classes based on the original version of *The Alliance Programme*.

Usability

The focus group results from the questions asked to determine how research participants feel about the usability of the original version of *The Alliance Programme* are discussed in this section.

QUESTIONS	GROUP A	GROUP B
1.1 What did you learn from the schizophrenia information discussions classes that are suppose to help you cope better with your illness?	Most of the research participants in both groups stated that from these schizophrenia information discussion classes they learnt the symptoms of schizophrenia, causes of schizophrenia and the importance of taking medication. The research participants also said that knowing more about these issues will help them to cope better with their illness.	
1.2 What did you learn from the schizophrenia information discussions classes that made you understand your illness better?	Most of the research participants in both Group A and Group B felt that the issues that they learnt from the schizophrenia information discussion classes that made them to understand their illness better were the importance of medication and the symptoms of schizophrenia.	
2. Were you able to read and understand what the presenter wrote on the	All research participants indicated that they were able to read and	Most of research participants indicated that they were able to read and

board during the discussions?	understand what the presenter wrote on the board during the discussions classes.	understand what the presenter wrote on the board during the discussions classes.
3. Would you like such schizophrenia information discussions classes to include drawings and photographs as well? Why?	All the research participants in both groups said that they would like the schizophrenia information discussion classes to include drawings, photograph and pictures so to understand what is taught in these discussions better and be able to remember the information easily.	
4. Would you like to be issued with booklets to read during these schizophrenia information discussions classes and at home?	All research participants in both Group A and Group B indicated that they would like to be issued with booklets to read during these schizophrenia information discussion classes and at home.	
5.1 Which words did you find difficult to understand?	Most of the words listed by the research participants as words they found difficult to understand were: delusion, paranoia and hallucination	Most of the research participants stated that there was no word that they found difficult to understand, they could understand everything. However, for those participants who listed the words they found difficult, most of the words they listed as words they found difficult to understand were: delusion, symptoms and hallucination.
5.2 Which words do you think other patients might find difficult to understand?	Most of the research participants indicated that the words listed words in question 5.1 (Delusion, paranoia, hallucination) are the words that they think other patients might find difficult to understand.	Most of the research participants indicated that words that they think other patients might find difficult to understand are: hallucination, delusion, and symptoms.

Inferences

From the above focus group responses, it is indicated that most of the research participants in both groups (Group A and Group B) were able to see and understand the value of the information communicated in the schizophrenia information discussion classes and how it will help them to improve their lives. This was evident when most of the research participants in both groups stated that they learnt a lot of important issues (e.g. symptoms of schizophrenia, causes of schizophrenia and the importance of medication) from the schizophrenia information discussion classes they attended for three weeks that will help them cope better with their illness and understand the illness better.

OBSERVATION

Results from the participant observation indicated that:

- Male research participants were dominant among the research participants selected for research in both Group A and Group B.
- Most of the research participants in both groups believed and valued the information communicated to them in these classes. This was also evident in the reaction of the research participants who were very angry when a psychotic research participant disrupted the classes. One research participant even confronted him and told him to keep quiet or leave because he is disturbing them; they are listening to information that is important to their lives.
- Research participants in Group B liked, valued and appreciated to be issued with the booklet to read during the discussion classes and at home. Every time before the discussion classes would begin, it was noticed that the research participants would be seen browsing through the booklets and discussing it (their “homework”) with fellow research participants. It is assumed that the research participant were probably discussing with each other about the homework that they would have been given to do at home.
- Research participants in Group A arrived late for the schizophrenia information discussion classes, whilst on the other hand it was observed that research participants in Group B arrived on time or even earlier than the presenter and the researchers.

Based on the above observations, it seems that the research participants in Group B liked, enjoyed and valued the schizophrenia information discussion classes more than research participants in Group A.

STAGE 6

In this section, results from both the individual interviews and the focus group interviews of Group A (the group that attended schizophrenia information discussion classes based on the original version of *The Alliance Programme*) will be compared to results from both the individual interviews and the focus group interviews of Group B. The main reason for comparing the results of the two groups is to find out which schizophrenia information discussion classes (those based on the original version of *The Alliance Programme* or those based on the adapted version of *The Alliance Programme*) communicated information more effectively to the research participants of this study. This section will be categorised according to the criteria used to categorise the research question of this study regarding comprehension, acceptability and usability.

• **Comprehension**

From the findings of both the individual interviews and the focus group discussions regarding comprehension, it seems as if the communication of information in the schizophrenia information discussion classes based on the adapted version of *The Alliance Programme* was more effective than the communication of information in the schizophrenia information discussion classes based on the original version of *The Alliance Programme*. From the research findings of this study, the impression is created that the communication of information based on the adapted version of *The Alliance Programme* improved most, if not all, of the research participants' knowledge and understanding of their mental illness. The group that attended schizophrenia information discussion classes based on the adapted version of *The Alliance Programme* (Group B) had a much greater understanding of the information communicated to them, as compared to the group that attended the schizophrenia information discussion classes based on the original version of *The Alliance Programme*.

- **Acceptability**

From the results of both the individual interviews and the focus group discussions regarding the acceptability questions, the impression is created that information communicated in schizophrenia information discussion classes based on the adapted version of *The Alliance Programme*, were appreciated and liked much better by the research participants as compared to the information communicated in the schizophrenia information discussion classes based on the original version of *The Alliance Programme*. All the research participants in Group B indicated that there was nothing that they did not like about the discussion classes they attended, whilst not all of the research participants Group A stated that there was nothing that they did not like about the schizophrenia information discussion classes they attended.

This then indicates that the research participants in Group B appreciated and liked the information communicated in the schizophrenia information discussion classes they attended better than how the research participants in Group A.

- **Usability**

The individual interviews and focus group interviews' results of both groups (Group A and Group B) regarding the usability questions were similar. It seems that most of the research participants in both groups were able to see and understand the value of the information communicated in these schizophrenia information discussion classes. Most research participants in both groups were able to read and understand all the information communicated and written on boards during the schizophrenia information discussion classes, indicating that the communication of information about schizophrenia in the discussion classes attended by both groups was very good and appreciated by most of the research participants in both groups.

Conclusion

Results/findings gathered from the research participants of this study indicate that the communication of information about schizophrenia based on the adapted version of *The Alliance Programme* seems to be more effective for the communication of information about schizophrenia to the research participants. From the research findings, it seems like research participants in Group B (the group that attended schizophrenia information discussion classes based on the adapted version of *The Alliance Programme*):

- understood the information communicated in the schizophrenia information discussion classes better than the research participants in Group A;
- appreciated and liked the information communicated in the schizophrenia information discussion classes they attended better than the research participants in Group A.

STAGE 7

In this section, the research findings of how much knowledge the participants retained after three months are discussed.

After three months from the data collection stage (semi-structured interviews and focus group interviews), knowledge retention of the research participants in both Group A and Group B concerning important issues about schizophrenia was tested. The research participants were interviewed again individually and in focus group discussions using the same interview schedule that was used for the usability testing in phase 3 and phase 5. The findings of the research participants in both groups (A & B) are presented in a table format so to reflect differences and/or similarities of findings found in the two groups.

The data obtained in this phase are also presented according to the questions in the interview schedule that was used to conduct both the individual interviews and the focus group discussions.

THE INDIVIDUAL INTERVIEWS: FINDINGS

In this section, the knowledge retention results obtained from the questions asked during the individual interviews, to determine the research participants' understanding of the information communicated in *The Alliance Programme* are discussed.

1. What is the name of the disease you are suffering from?

GROUP A	GROUP B
All research participants in both groups knew that the illness they suffer from is a mental illness called schizophrenia.	

2. How did you learn about your mental illness? / Who first told you that you have a mental illness?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 33%²³ of the research participants were first told they have the mental illness by a social worker in the hospital; • 67% of the research participants were first told that they have a mental illness by their doctors. 	<p>All research participants were first told that they have a mental illness by their doctors.</p>

3. Who can diagnose you with schizophrenia?

GROUP B	GROUP B
<ul style="list-style-type: none"> • 17% believe nurses can diagnose you with schizophrenia; • 33% of the participants believe any psychiatric health professional (e.g. doctors, nurses, social workers) can diagnose you with schizophrenia; • 50% of the participants believe only (psychiatric) doctors can diagnose you with schizophrenia. 	<ul style="list-style-type: none"> • All participants believe only doctors can diagnose you with schizophrenia; • 40% of the participants believe that not just any doctor but psychiatric doctors can diagnose you with schizophrenia.

4. Why do you think we have schizophrenia information discussion classes like the ones you had in the past three weeks?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 17% of the research participants thought schizophrenia information discussion classes are meant to teach them about how to take care of themselves and how to avoid the relapsing; • 17% of the research participants thought schizophrenia information discussion classes like the one they attended for three weeks are meant for the researchers to see if psycho-education classes like those would be helpful and/or satisfactory to other patients with schizophrenia; • 17% of the research participants stated they do not know why they have schizophrenia information discussion 	<p>All research participants stated that the reason they have schizophrenia information discussion classes like the ones they had for three weeks was to get informed or learn more about their illness.</p>

²³ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants in each Group (Group A or Group B) who were interviewed during the screening interviews.

<p>classes like the ones they attended for three weeks;</p> <ul style="list-style-type: none"> • 50%²⁴ of the research participants thought the reason they have schizophrenia information discussion classes like the ones they had for three weeks is for them to learn more about their illness, learn all the important issues about their illness (schizophrenia). 	
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Comprehension questions

1. What symptoms can people who suffer from this illness experience?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 8% of the research participants responses indicated that delusion is the symptom that people who suffer from this illness can experience; • 8% of the responses showed that social withdrawal is the symptom; • 8% of the responses showed that doing nonsensical things is the symptom; • 8% of the responses showed that shaking is the symptom; • 8% of the responses showed that irritable and moody is the symptom that people who suffer from this illness can experience; • 8% of the responses represented the research participants who stated that they do not know what symptoms can people who suffer from this illness experience. Some of the symptoms the research participants listed are not from <i>the Alliance Programme</i> and were never taught in the schizophrenia information discussion classes, these symptoms include: doing nonsensical things, shaking, irritable and moody; • 23% of the responses showed that aggression is the symptom; • 31% of the responses indicated that hallucination is the symptom. 	<ul style="list-style-type: none"> • 9%²⁵ of the responses showed that patients isolating themselves is the symptom that people who suffer from this illness can experience; • 18% of the responses showed that aggression is the symptom; • 27% of the research participants responses indicated that delusion is the symptom that people who suffer from this illness can experience; • 46% of the responses indicated that hallucination is the symptom.

2. Which of these symptoms did you experience?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 12.5% of the research participants stated that the symptoms they experienced was lack of motivation; • 12.5% of the research participants stated that they experienced was poor concentration; • 12.5% of the research participants stated that the symptoms they experienced was shaking; • 25% of the research participants indicated they experienced aggression; • 38%²⁶ of the research participants stated they experienced hallucination. 	<ul style="list-style-type: none"> • 12.5% of the research participants stated that the symptoms they experienced was <u>delusion</u>; • 12.5% of the research participants indicated they experienced <u>aggression</u>; • 12.5% of the research participants indicated they experienced <u>depression</u>; • 12.5% of the research participants indicated they experienced <u>loss of appetite</u>; • 12.5% of the research participants stated that the symptoms they experienced was <u>isolating themselves</u>; • 12.5% of the research participants stated that the symptoms they experienced was <u>mixed up thoughts</u>; • 25% of the research participants stated they experienced <u>hallucination</u>.

3. What tells you that you are going to become ill again (early warning signs)?

GROUP A	GROUP B
<p>Everything (100%) that the research participants described as the symptoms that tells you that you are going to become ill again (early warning signs) was what is described in <i>the Alliance Programme</i> early warning signs. Research participants this time also remembered the specific scientific names of the early warning signs. One research participant however stated that he is now fine so he does not experience any early warning signs symptoms, which mean the illness will never come back.</p>	<p>Everything (100%) that the research participants described as the symptoms that tells you that you are going to become ill again (early warning signs) was what was described in <i>the Alliance Programme</i> as early warning signs. Research participants from this group also remembered the specific scientific names of the early warning signs.</p>

²⁶ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

4. Do all patients with schizophrenia experience the same symptoms?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 29%²⁷ of the research participants said yes, all patients with schizophrenia experience the same symptoms. These participants could not give reason why they say yes. • 71% of the research participants said no, not patients with schizophrenia experience the same symptoms. Not all of these research participants were able to give a reason why they say no, but those who were able to state the reason, the reason was the fact that people are all different from each other so they definitely experience the disease differently from each other. Others stated that they do not know why exactly but they know for a fact that patients do not experience the same symptoms because they were taught by Linda in the schizophrenia information discussion classes they attended. 	<ul style="list-style-type: none"> • 20% of the research participants indicated that they do not know if all patients experience the same symptoms or not; • 40% of research participants said no, not patients with schizophrenia experience the same symptoms. Not all of these research participants were able to give a reason why they say no, but those who were able to state the reason, the reason was the fact that patients are different from each other, so they definitely experience different symptoms; • 40% of the research participants said yes, all patients with schizophrenia experience the same symptoms. These research participants could not give reason why they say yes.

5. What is a delusion?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 14% of the research participants knew what delusion is, • 43% of the research participants had totally wrong ideas of what delusion is; • 43% of the research participants stated they do not know what delusion is or they forgot. 	<ul style="list-style-type: none"> • All research participants knew what delusion is, • 20% of the research participant stated that it is when someone thinks or believes he is important, superior or famous yet he is not; • 80% of the research participants stated that it is believing in something that is not true.

²⁷ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

6. What is a hallucination?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 29%²⁸ of the research participants had totally wrong ideas of what hallucination is; • 29% of the research participants stated they do not know what hallucination is or they forgot; • 43% of the research participants knew what hallucination is. 	<ul style="list-style-type: none"> • 20% of the research participants indicated that they do not know what hallucination is or they forgot. • 80% research participants gave the correct definition of what hallucination is, as they stated that it is seeing/hearing/touching things that are not there in reality.

7. What does it mean to be psychotic? / When they say you are psychotic, what do they mean?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 29% of the research participants had totally wrong ideas of what being psychotic means; • 29% of the research participants stated they do not know what it means to be psychotic or they forgot; • 43% of the research participants knew what it means to be psychotic. 	<p>All participants knew what being psychotic means, as they all gave the correct explanations of what it means to be psychotic.</p>

8. Why do we say that schizophrenia is like a “thief”?

GROUP A	GROUP B
<ul style="list-style-type: none"> • Most of the research participants indicated the reason why schizophrenia is said to be like a thief is because it steals certain things/functions from people. The following is a list that the research participants listed as the things that schizophrenia steals from their lives: “a person’s future”; “a person’s mind/memory”; “a person’s energy”; “a person’s writing/reading skills”; “a person’s skills and ability of doing things which he/she liked doing and/or could do them well before being ill”; “a person control of himself”; “a person’s intentions and personality”; “it changes 	<p>All research participants indicated the reason why schizophrenia is said to be like a thief is because it steals certain things/functions from people. The following is a list that the research participants listed as the things that schizophrenia steals from their lives: “a person’s future”; “a person’s mind/memory”; “a person’s concentration”; “a person’s writing/reading skills”; “a person’s skills and ability of doing things which he/she liked doing and/or could do them well before being ill”; “and a person’s feelings”.</p>

²⁸ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

your body”.

- Whist 14% of the research participants indicated that they do not know or have forgotten.

9. Can schizophrenia be inherited? Explain

GROUP A	GROUP B
<ul style="list-style-type: none"> • 86%²⁹ of the research participants said yes schizophrenia can be inherited. Not all of these participants were able to give reasons why they say yes, but those who were able to state the reason, the reason was the fact that schizophrenia runs in the family, so if a family member has schizophrenia then another member of the family is likely to get have (inherit) it as well; • 17% of the research participants said no schizophrenia cannot be inherited.. 	<p>All research participants said yes schizophrenia can be inherited. Not all of these participants were able to give reasons why they say yes, but those who were able to state the reason, the reason was the fact that one can get schizophrenia from a family member who also have the same disease. One research participants even said that, “I inherited this illness from my uncle who also have the same illness”.</p>

10. How many people out of every 100 people in the world suffer from schizophrenia?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 14% of the research participants stated they do not know how many people in every 100 people in the world suffer from schizophrenia or simply did not answer this question; • 29% of the research participants got this question right stating that one to two people in every 100 people in the world suffer from schizophrenia; • 57% of the research participants had totally wrong figures of people suffering from schizophrenia in world. 	<ul style="list-style-type: none"> • 20% of the research participants had totally wrong figures of people suffering from schizophrenia in world; 80% of the research participants got this question right stating that one to two people in every 100 people in the world suffer from schizophrenia.

11. What can you do to cope with this illness?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 7% of the research participants 	All research participants indicated that in

²⁹ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

<p>indicated that in order to cope with the illness one needs to do healthier things that are inexpensive;</p> <ul style="list-style-type: none"> • 29%³⁰ of the research participants mentioned totally wrong ideas which they were never taught in the schizophrenia information discussion classes (e.g. “In order to cope with the illness one needs to stay at home and eat food from town”); • 57% of the research participants indicated that in order to cope with the illness one needs to take medication as prescribed by doctors. 	<p>order to cope with the illness one needs to take medication as prescribed by doctors.</p>
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12. Can anything make this illness disappear completely? If yes, what? How does it work? If no, why not?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 25% of these research participants believed that eating food with proteins and vitamins can make the illness disappear; • 57% of the research participants said yes there is something that can make the illness disappear completely, whilst 43% of the participants said no there is nothing that can make the illness disappear completely; • 75%³¹ of the research participants who said yes there is something that can make the illness disappear completely believed that taking medication exactly as the way the doctors prescribed it to you can make the illness disappear since medication stops the symptoms of schizophrenia; • Most of the research participants who said no, nothing can make the illness disappear completely believed that they will have the illness for life but they just have to take their medication according to their doctors’ prescriptions so to prevent relapsing and make the symptoms better. 	<ul style="list-style-type: none"> • 60% of the research participants said no there is nothing that can make the illness disappears completely; and 40% of the research participants stated they do not know. • The research participants who said no, nothing can make the illness disappear completely believed that they will have the illness for life but they just have to take their medication according to their doctors’ prescriptions so to prevent relapsing and make the symptoms better.

³⁰ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

13. What type of support do you receive for your illness?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 17% of the research participants stated that they receive emotional support from their relatives at home and nurses in hospitals; • 57% of the research participants stated that the type of support they receive is financial support from their relatives and their doctors/nurses/social workers in the hospital. 	<ul style="list-style-type: none"> • 20% of the research participants stated that they receive emotional support from nurses and social workers in hospitals; • 20% of the research participants stated that they receive a lot of support from The Mental Health Federation of South Africa, who helps them to get jobs; • 20% of the research participants stated that they do not receive any support from anyone for their illness; • 40% of the research participants stated that the type of support they receive is financial support from their relatives.

14.1 How can the symptoms of schizophrenia be treated?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 14% of the research participants believed that taking care of yourself (e.g. wash hands before you eat) can make the symptoms of schizophrenia be treated; • 14% of the research participants had totally wrong ideas of what can cure the illness (e.g. Staying at home can cure the symptoms of schizophrenia); • 71% of the research participants believed that taking your medication according to doctors' prescription can make the symptoms of schizophrenia be treated. 	<ul style="list-style-type: none"> • All research participants indicated that taking your medication according to doctors' prescription can make the symptoms of schizophrenia be treated.

14.2 What type of treatment do you receive for the symptoms of schizophrenia?

GROUP A	GROUP B
All research participants receive tablets and/or injections for treating the symptoms of schizophrenia. Most of the participants knew the specific scientific names of their medication.	<ul style="list-style-type: none"> • 20%³² of the research participants receive only tablets for treating the symptoms of schizophrenia. Most of the participants knew the specific scientific names of their medication; • 80% of the research participants receive tablets and injections for treating the symptoms of schizophrenia.

15. How can medication help you with your illness?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 17% of the research participants stated that medication helps them to become their normal selves, behave normally like all normal people; • 29% of the research participants believe medication helps them to sleep well at night; • 57% of the research participants believed that medication makes them feel better with their illness by making the symptoms to be better. 	<ul style="list-style-type: none"> • 20% of the research participants believed that medication makes them feel better with their illness by making the symptoms to be better; • 20% of the research participants stated that medication balances the chemicals in their brains thus make them to become better with their illness; • 20% of the research participant did not answer this question, which implies that they did not know the answer of this question; • 40% of the research participants believe medication helps them not to relapse again.

16. How do you feel about your mental illness?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 25% of the research participants feel ashamed of having the illness, however at the same time they feel lucky because other people have worse situations than theirs (e.g. they cannot walk); 	<ul style="list-style-type: none"> • 20% of the research participants stated that thinking about the fact that they have this mental illness worries them a lot; • 20% of the research participants feel

³² The percentages (%) of the individual interviews' results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

³³ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

<ul style="list-style-type: none"> • 75%³³ of the research participants feel sad that they have this illness; they cannot continue living a normal life since they do not feel well they think they are mentally damaged. These patients have not accepted that they have the illness. 	<p>sad that they have this illness, as they are no longer clever like they use to be;</p> <ul style="list-style-type: none"> • 60% of the research participants stated they have already accepted that they have the illness and are coping with it.
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17. Why do you think people suffer from schizophrenia?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 11% of what the research participants' description of what causes schizophrenia was inherited; • 11% of what the research participants described as causes of schizophrenia was stress and/or having a lot of problems; • 22% of the research participants s stated that witchcraft can make people suffer from schizophrenia; • 56%³⁴ of what the research participants described as causes of schizophrenia was alcohol and drug abuse. 	<ul style="list-style-type: none"> • 17% of the research participants stated that stress can make people suffer from schizophrenia; • 17% of what the research participants' description of what causes schizophrenia was inherited; • 33% of what the research participants stated that schizophrenia is just a mental illness people should not stress about but drink their medication as prescribed by their doctors; • 33% of what the research participants described as causes of schizophrenia was alcohol and drug abuse.

Inferences

More research participants in Group B were able to give correct answers as compared to the research participants in Group A. The number of research participants who were not able to answer some of the questions (e.g. research participants who stated that they do not know the answers or simply gave incorrect answers to the questions) was much lower among research participants in Group B as compared to Group A. There were certain instances where the research participants in Group A did better in terms of giving correct answers to the questions asked, but overall the research participants in Group B did better in terms of giving correct answers to the question asked. After comparing Group A's research participants results to Group B's results, it is evident that research participants who attended the schizophrenia information discussion classes based on the adapted version of the *Alliance Programme* were able to retain more knowledge than research participants schizophrenia information discussion classes based on the original version of the *Alliance Programme*.

This then also implies that the schizophrenia information discussion classes based on the adapted version of the *Alliance Programme* seems to be more effective and/or appropriate for the research participants as compared to the schizophrenia information discussion classes based on original version of the *Alliance Programme*.

Acceptability

In this section, the knowledge retention results obtained from the questions asked during the individual interviews to determine the acceptability of *The Alliance Programme* are discussed.

1. What do you think about the schizophrenia information discussion classes you attended during the past three weeks?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 17% of the research participants felt the schizophrenia information discussion classes were presented very well; • 86% of the research participants felt that the schizophrenia information discussion classes they attended the past three weeks were really helpful to them, since they learnt a lot of important things about their illness. 	<p>All research participants felt that the schizophrenia information discussion classes they attended the past three weeks were really informative; they helped them to gain more knowledge about their illness.</p>

2.1 What did you like about it?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 11%³⁵ of the research participants stated that the reason they liked these classes was because they enjoyed the classes a lot and they liked the way the classes were presented to them; • 22% of the research participants stated that the reason they liked these schizophrenia information discussion classes was because from these classes they got a lot of support and/or skills on how to take care of themselves; • 67% of the research participants stated 	<ul style="list-style-type: none"> • 20% of the research participants stated that the reason they liked schizophrenia information discussion classes was because these classes taught them more about the symptoms of schizophrenia; • 80% of the research participants stated that the reason they liked these schizophrenia information discussion classes was because they learnt a lot of important issues about their illness.

³⁵ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

<p>that the reason they liked these schizophrenia information discussion classes was because they learnt a lot of important issues about their illness.</p>	
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2.2 What did you not like about it?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 14% of the research participants stated that they did not like the fact that in these classes they were taught a lot of information/things in one time (the classes were bulky), which made it very difficult for them to understand; • 86% of the research participants indicated that there was nothing that they did not like about the schizophrenia information discussion classes they attended for the past three weeks. 	<p>All research participants stated that there was nothing that they did not like about the schizophrenia information discussion classes they attended for the past three weeks.</p>

3. How do you think can the presentation of these schizophrenia information discussion classes be improved?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 14% of the research participants felt the presentation of these schizophrenia information discussion classes was okay the way it was, everything was fine; • 14% of the research participants felt if the classes can be made simple (not bulky) where they could be taught little information at a time, that would improve the schizophrenia information discussion classes; • 29% of the research participants felt the presentation of these schizophrenia information discussion classes can be improved if videos and pictures could be used during the classes for demonstration; • 43% of the research participants felt the presentation of these schizophrenia information discussion classes can be improved if the patients could be offered books and pamphlets to read during the class and at home. 	<ul style="list-style-type: none"> • 20% of the research participants felt the presentation of these schizophrenia information discussion classes can be improved if more explanations about hallucination, delusion, symptoms etc. could be provided to the patients; • 20% of the research participants felt the presentation of these schizophrenia information discussion classes can be improved if videos and pictures could be used during the classes for demonstration; • 20% of the research participants felt if the presenter of the discussion classes can support the patients a lot in every possible way, that would improve the schizophrenia information discussion classes; • 40% of the research participants felt the presentation of these schizophrenia information discussion classes was okay the way it was, everything was fine.

4. What would be the best way for you to learn more about your illness (schizophrenia)?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 14%³⁶ of the research participants indicated that the best way for them to learn about their illness would be attending schizophrenia information discussion classes and being issued with books to read during the classes and after the classes; • 14% of the research participants did not answer this question, which implies that they did not know the answer or could not remember it; • 29% of the research participants indicated that being issued with books that they could use in the schizophrenia information discussion classes as well as after the classes would be the best way for them to learn more about their illness; • 43% of the research participants thought schizophrenia information discussion classes like the one they attended would be the best way for them to learn about their illness; 	<ul style="list-style-type: none"> • 17% of the research participants indicated that being taught by the doctors could be the best way for them to learn about their illness; • 17% of the research participants did not answer this question, which implies that they did not know the answer or could not remember it; • 33% of the research participants thought schizophrenia information discussion classes like the one they attended would be the best way for them to learn about their illness; • 33% of the research participants indicated that the best way for them to learn about their illness would be attending schizophrenia information discussion classes and being issued with books to read during the classes and after the classes.

5. In which language would you prefer the schizophrenia information discussion classes to be presented? Why?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 14% of the research participants stated they would prefer the schizophrenia information discussion classes to be presented in both English and Tswana; • 29% of the research participants indicated that they would prefer the schizophrenia information discussion classes to be presented in Tswana because they understand Tswana better 	<ul style="list-style-type: none"> • 20% of the research participants indicated that they would prefer the schizophrenia information discussion classes to be presented in Tswana because they understand Tswana better since it is their mother tongue; • 80% of the research participants indicated that they prefer English because English is an international

³⁶ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

<p>since it is their mother tongue;</p> <ul style="list-style-type: none"> • 57%³⁷ of the research participants indicated that they prefer English because majority of the people in South Africa can speak English and besides there are words that cannot be expressed or are not available in Thswana. 	<p>language, almost everyone in South Africa can speak English.</p>
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6. How do you feel about the presenter?

GROUP A	GROUP B
<p>All the research participants liked the presenter and they indicated that she is a good presenter, she teaches well, she's encouraging and they learnt a lot from her.</p>	<p>All the research participants liked the presenter and they stated that she is a good presenter, she explained the information clearly, and thus it was easy for them to understand the information she was communicating to them.</p>

7. How do you feel about the interpreter?

GROUP A	GROUP B
<p>All the research participants liked the interpreter because she interpreted very well making them to understand the information delivered by the presenter much better.</p>	<p>All the research participants liked the interpreter because she interpreted very well making them to understand the information delivered by the presenter much better.</p>

Inferences

The responses above for research participants in both Group A and Group B indicate that the research participants in both groups appreciated the information that was communicated to them during the schizophrenia information discussion classes based on the original version or adapted version of *the Alliance Programme*. This was evident when most of the research participants stated they liked the schizophrenia information discussion classes because they were really helpful to them and they learned a lot of important issues about their illness.

When the findings on how much knowledge did the research participants in Group B retain after 3 months were compared to those for the research participants in Group A, it

was noticed that the research participants in Group B appreciated the information communicated in the schizophrenia information discussion classes more than how the research participants in Group A did. All the research participants in Group B liked the schizophrenia information discussion classes whilst most of the research participants in Group A (not all of them) liked these classes. All research participants in Group B stated that there was nothing that they did not like about the schizophrenia information discussion classes they attended. Yet in Group A, only 80% of the research participants indicated there was nothing that they did not like about the schizophrenia information discussion classes.

Therefore, it seems like the schizophrenia information discussion classes based on adapted version of *the Alliance Programme* were appreciated and liked better by the participants than the schizophrenia information discussion classes' original version of *The Alliance Programme*.

Usability

The knowledge retention results from the questions asked during the individual interviews to determine how research participants feel about the usability of *The Alliance Programme* are discussed in this section.

1.1 What did you learn from the schizophrenia information discussion classes that are suppose to help you cope better with your illness?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 14% of the research participants did not answer this question; • 14% of the research participants felt that the schizophrenia information discussion classes taught them that having schizophrenia is not the end of the world, life goes on; 	<ul style="list-style-type: none"> • 20% of the research participants said that one of the important issues that they learnt from the schizophrenia information discussion classes was the importance of medication and the fact that they need to take it so to cope better with their illness;

<ul style="list-style-type: none"> • 29% of the research participants felt that these schizophrenia information discussion classes helped them to know all the important issues about schizophrenia and knowing more about this will help them to cope with their illness better; • 43%³⁸ of the research participants said that one of the important issues that they learnt from the schizophrenia information discussion classes was the importance of medication and the fact that they need to take it so to cope better with their illness. 	<ul style="list-style-type: none"> • 20% of the research participants felt that the schizophrenia information discussion classes taught them to accept they have the illness; • 20% of the research participants felt that these schizophrenia information discussion classes helped them to know more about the symptoms of schizophrenia; • 40% of the research participants stated that the psycho-education classes helped them to learn about all the important issues about schizophrenia and knowing more about this will help them to cope with their illness better.
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1.2 What did you learn from the schizophrenia information discussion classes that made you understand your illness better?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 14% of the research participants stated that the schizophrenia information discussion classes helped to be able to discuss with other people about schizophrenia and that will help them to understand their illness better; • 14% of the research participants stated that one of the important issues that they learnt from the schizophrenia information discussion classes that made them to understand their illness better was the importance of medication and the fact that they need to take it so to cope better with their illness; • 29%³⁹ of the research participants felt that the schizophrenia information discussion classes taught them that having schizophrenia is not the end of the world, life goes on; • 43% of the research participants felt that these schizophrenia information discussion classes helped them to know all the important issues about 	<ul style="list-style-type: none"> • 20% of the research participants stated that one of the important issues that they learnt from the schizophrenia information discussion classes that made them to understand their illness better was the explanation of what exactly is schizophrenia; • 40% of the research participants felt that these schizophrenia information discussion classes helped them to know more about the symptoms of schizophrenia; • 40% of the research participants stated that the schizophrenia information discussion classes helped them to learn about all the important issues about schizophrenia and knowing more about this will help them to cope with their illness better.

³⁹ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

schizophrenia and knowing more about this will help them to understand their illness better.	
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2. Were you able to read and understand what the presenter wrote on the board during the discussions?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 14% of the research participants indicated that no, they could not read and understand what the presenter wrote on the board during the discussions classes; • 86% of the research participants indicated that they were able to read and understand what the presenter wrote on the board during the discussions classes. 	<ul style="list-style-type: none"> • 40% of the research participants indicated that no, they could not read and understand what the presenter wrote on the board during the discussions classes; • 60% of the research participants indicated that they were able to read and understand what the presenter wrote on the board during the discussions classes.

3. Would you like such schizophrenia information discussion classes to include drawings and photographs? Why?

GROUP A	GROUP B
All research participants stated that they would love the schizophrenia information discussion classes to include drawings and photographs so to understand what is taught in these discussions better.	<ul style="list-style-type: none"> • 20%⁴⁰ of the participants stated they would not like the classes to include drawings and photographs because it is not necessary, its easy to understand the information even without the photographs, as long as the information is explained clearly; • 80% of the research participants stated that they would like the schizophrenia information discussion classes to include drawings and photographs so to understand what is taught in these discussions better.

⁴⁰ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

4. Would you like to be issued with booklets to read during these schizophrenia information discussion classes and at home?

GROUP A	GROUP B
All research participants indicated that they would like to be issued with booklets to read during these schizophrenia information discussion classes and at home.	All research participants indicated that they would like to be issued with booklets to read during these schizophrenia information discussion classes and at home, so that they can have something to refer when they need the information about their illness.

5.1 Which words did you find difficult to understand?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 10% of the words listed by the research participants as words they found difficult to understand was <u>delusion</u>; • 10%⁴¹ of the words listed by the participants as words they found difficult to understand was <u>psychosis</u>; • 10% of the words was <u>suspicious</u>; • 20% of the words was <u>paranoia</u>; • 20% of the research participants' responses was where the respondents specified that there was no word that they found difficult to understand, they could understand everything; • 30% of the words was <u>schizophrenia</u>. 	<ul style="list-style-type: none"> • 10% of the words was <u>paranoia</u>; • 10% of the words was <u>symptoms</u>; • 10% of the research participants' responses was where the respondents specified that there was no word that they found difficult to understand, they could understand everything; • 20% of the words listed by the participants as words they found difficult to understand was <u>hallucination</u>; • 20% of the words listed by the research participants as words they found difficult to understand was <u>delusion</u>; • 30% of the words was <u>psychosis</u>.

5.2 Which words do you think other patients might find difficult to understand?

GROUP A	GROUP B
<ul style="list-style-type: none"> • 10% of the research participants stated they do not know, because people are different so some people would find it easy to understand everything; • 10% of the participants felt that the 	<ul style="list-style-type: none"> • 10% of the research participants stated that there is no word that other patients will find difficult to understand as long as there would be explanations given for each word, everything would be easy to

⁴¹ The percentages (%) of the individual interviews' results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

<p>word “paranoia” would be difficult for other patients to understand;</p> <ul style="list-style-type: none"> • 20% of the research participants said that the word “hallucination” would be difficult for other patients to understand; • 30% of the research participants felt that the word “delusion” would be difficult for other patients to understand; • 30%⁴² of the research participants stated that there is no word that other patients will find difficult to understand as long as there would be explanations given for each word, everything would be easy to understand. 	<p>understand;</p> <ul style="list-style-type: none"> • 10% of the participants felt that the word “paranoia” would be difficult for other patients to understand; • 20% of the participants said that the word “hallucination” would be difficult for other patients to understand; • 20% of the research participants felt the “schizophrenia” is a word that other patients could find difficult to understand; • 20% of the participants thought that the word “psychosis” could be difficult for other patients to understand; • 20%⁴³ of the research participants felt that the word “delusion” would be difficult for other patients to understand.
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Inferences

Results of both Group A and Group B show that research participants in both groups had indicated that they learnt a lot of important issues (e.g. symptoms of schizophrenia, causes of schizophrenia and medication of schizophrenia) from the schizophrenia information discussion classes they attended and that would/will help them to understand and/or cope better with their illness. This means, most of the research participants in both groups were able to see and understand the value of the information communicated in these classes and how it can/will help them improve their lives. When Group A’s findings were compared to Group B findings, they were similar. Most of the research participants in Group B were able to read and understand what the presenter wrote on the boards during the presentation of the classes, this implies that the presentation of these schizophrenia information discussion classes was very good and appreciated by most of the research participants.

⁴³ The percentages (%) of the individual interviews’ results were calculated out of the 7 research participants in each group (Group A or Group B) who were interviewed during the screening interviews.

FOCUS GROUP DISCUSSIONS: FINDINGS

Comprehension

The knowledge retention results obtained from the questions asked during the focus group discussions, to determine the research participants' understanding of the information communicated in *The Alliance Programme* are discussed in this section.

QUESTIONS	GROUP A	GROUP B
1. What is the name of the disease you are suffering from?	All participants in both groups agreed on the fact that the name of the illness they suffer from is a mental illness called schizophrenia.	
2. How did you learn about your mental illness? / Who first told you that you have a mental illness?	Most of the participants indicated that they were first told they have a mental illness by their doctors/nurses/social workers in the hospital. Some participants also indicated that Linda (the schizophrenia information discussion classes' presenter) was the first person to tell them they have the illness.	All participants indicated that they were first told that they have a mental illness by their doctors.
3. Who can diagnose you with schizophrenia?	All participants believe that only (psychiatric) doctors can diagnose you schizophrenia.	All participants believe that only doctors can diagnose you schizophrenia.
4. Why do you think we have schizophrenia information discussion classes like the ones you had in the past three weeks?	All participants in both Group A and Group B agreed on the fact that schizophrenia information discussion classes like the ones they had for three week are made for them to learn more about their illness, learn all the important issues about the illness.	

QUESTIONS (Comprehension questions)	GROUP A	GROUP B
1. What symptoms can people who suffer from this illness experience?	All participants agreed on the following symptoms as symptoms that people who suffer from their illness can	All participants agreed on the following symptoms as symptoms that people who suffer from their illness can

	experience: hallucination; delusion; isolate themselves; and talking nonsense.	experience: hallucination; delusion; and aggression.
2. Which of these symptoms did you experience?	The following is a list of symptoms that the participants listed as the symptoms they experienced: hallucination; delusion; isolate themselves; aggression; and disturbances in thinking.	The following is a list of symptoms that the participants listed as the symptoms they experienced: hallucination; delusion; isolate themselves; and aggression.
3. What tells you that you are going to become ill again (early warning signs)?	All the signs that the participants in both groups (Group A and Group B) listed as signs that tells you that you are going to become ill again are described in <i>the Alliance Programme</i> early warning signs.	
4. Do all patients with schizophrenia experience the same symptoms? (Probing question)	All the participants agreed on the fact that patients do not experience the same symptoms but it is possible to find a person who also experience some or most of the symptoms that you experienced.	All the participants agreed on the fact that yes schizophrenia patients experience the same symptoms of schizophrenia, stating that they all(participants in the class) experienced the hallucination and the delusion.
5. What is a delusion?	Most of the participants did not know what delusion is.	All participants knew what delusion is, since they all agreed on the fact that it is believing on things that are not there.
6. What is a hallucination?	Most of the participants knew what hallucination is.	All participants knew what hallucination is, as they agreed on the fact that it is seeing/hearing/touching things that are not there in reality.
7. What does it mean to be psychotic? / When they say you psychotic, what do they mean?	Most of the participants in both groups gave the correct explanations of what being psychotic means.	
8. Why can we say that schizophrenia is like a “thief”?	All participants in both Group A and Group B agreed on the fact that schizophrenia is said to be like a thief because it steals a lot of things/functions from people. These include: people’s energy; people’s reading and writing skills; people’s intentions for a better future; people’s thoughts and feelings.	
9. Can schizophrenia be inherited? Explain	Most of the participants believe schizophrenia can be inherited, whilst a small portion of the participants believe schizophrenia cannot be inherited.	All participants agreed on the fact that schizophrenia can be inherited.
10. How many people of every 100 people in	Most of the participants agreed one in every 100 people in the	All participants agreed that one in every 100 people in the

the world suffer from schizophrenia?	world suffer from schizophrenia.	world suffer from schizophrenia.
11. What can you do to cope with this illness?	All participants in both Group A and Group B agreed on the fact that in order to cope with the illness one needs to take medication as prescribed by doctors.	
12. Can anything make this illness disappear completely? (<i>Probing question depending on the answer</i>) If yes, what is it? How does it work? If no, why not?	Most of the participants believed that taking medication exactly as the doctors prescribed can make the illness disappear completely.	All participants believed that nothing can make this illness disappear completely but, taking medication exactly as the doctors prescribed can make the symptoms of the illness become better.
13. What type of support do you receive for your illness?	Most of the participants in both groups stated that the type of support they receive is financial and/or emotional support from their relatives and their doctors/nurses/social workers in the hospital.	
14.1 How can the symptoms of schizophrenia be treated?	Most of the participants indicated that taking your medication/treatment as prescribed by doctors can make the symptoms of schizophrenia be treated.	All participants indicated that taking your medication/treatment as prescribed by doctors can make the symptoms of schizophrenia be treated.
14.2 What type of treatment do you receive for the symptoms of schizophrenia?	All participants in both groups receive tablets and/or injections for treating the symptoms of schizophrenia.	
15. How can medication help you with your illness?	Most of the participants said that medication takes away negative symptoms.	All participants said that medication makes the symptoms of their illness to become better.
16. How do you feel about your mental illness?	Most of the participants feel sad about having the illness as they cannot do things that they use to do well before and they cannot continue with a normal life.	Most of the participants have accepted the fact that they have this illness , however at first they felt sad they had the illness.
17. Why do you think people suffer from schizophrenia?	Most of the participants believe that alcohol and drug abuse causes schizophrenia. A small portion of the participants believe that stress and witchcraft can also cause this illness.	Most of the participants believe that schizophrenia is caused by: stress; alcohol and drug abuse.

Inferences

When one compares the findings of the focus groups of the research participants from both Group A and Group B with the individual interviews findings regarding the comprehension questions, it was observed that most of the research participants during the focus group interviews were more at ease, felt free and contributed more information as compared to the individual interviews. During the individual interviews, most of them looked nervous, scared and therefore contributed less information concerning the comprehension questions the researchers asked them.

However, when Group A's focus group findings are compared to Group B's focus group findings, it was noticed that the research participants from Group B remembered more the information better than the research participants in Group A. This was demonstrated by the fact that more research participants in Group B gave correct answers than the research participants in Group A. This then supports what was found with the individual interviews, that the communication of schizophrenia information based on the adapted version of *The Alliance Programme* is more effective than the communication of schizophrenia information based on the original version of *The Alliance Programme*.

Acceptability

The knowledge retention results obtained from the questions asked during the focus group discussions to determine the acceptability of *The Alliance Programme* are discussed in this section.

QUESTIONS	GROUP A	GROUP B
1. What do you think about the schizophrenia information discussion classes you attended the past three weeks?	All participants in both groups appreciated the schizophrenia information discussion classes they attended the past three weeks stating that these classes really helped them to learn more about our illness.	
2.1 What did you like about it?	All participants indicated that the reason they liked these schizophrenia information discussion classes was because the	All participants indicated that the reason they liked these schizophrenia information discussion classes was because the

	classes helped them to gain confidence, and it consoled them to see other people suffering from schizophrenia.	classes were nice and presented in a good way.
2.2 What did you not like about it?	All participants in both Group A and Group B indicated that there was nothing that they did not like about the schizophrenia information discussion classes they had for the past three weeks.	
3. How do you think can the presentation of these schizophrenia information discussion classes be improved?	Most of the participants felt the presentation of these schizophrenia information discussion classes can be improved by getting books that they can use during the classes and at home; also if in these classes they can be taught little by little (not a lot of information at once) that would definitely improve the classes.	Most of the participants felt the presentation of these schizophrenia information discussion classes can be improved by adding more group members in the classes and more lessons about schizophrenia should be taught to the patients. Participants also suggested that participants should be asked how they feel during these classes.
4. What would be the best way for you to learn more about your illness (schizophrenia)?	Most of the participants indicated that having classes like the ones they had and being issued with books that they could read during the classes and at home would be the best way to learn more about their illness.	All participants indicated that attending schizophrenia information discussion classes like the ones they attended for three weeks would be the best way to learn more about their illness.
5. In which language would you prefer the schizophrenia information discussion classes to be presented? Why?	Most of the participants indicated that they would prefer the schizophrenia information discussion classes to be presented in English because majority of the people in South Africa can speak English and most books are in English.	All participants indicated that they would prefer the schizophrenia information discussion classes to be presented in English because majority of the people in South Africa can speak.
6. How do you feel about the presenter?	All the participants in both groups (Group A and Group B) liked the presenter and they stated that she presented the classes very well, in a way that it was easy for them to understand the information.	
7. How do you feel about the interpreter?	All the participants in both groups liked the interpreter because she interpreted very well making them to understand the information delivered by the presenter much better.	

Inferences

From the above focus group responses, it seems like the research participants in Group B appreciated the information communicated in the schizophrenia information discussion classes based on the adapted version of that *the Alliance Programme* better than the research participants in Group A. This was evident when all the research participants in Group B stated that attending schizophrenia information discussion classes like the ones they have attended for three weeks is the best way for them to learn about their illness. Whilst most of the research participants in Group A (not all of them) stated that attending schizophrenia information discussion classes like the ones they attended for three weeks is the best way to learn about their illness.

This then supports what was found with the individual interviews that still the schizophrenia information discussion classes based on the adapted version of *The Alliance Programme* was appreciated and liked much better by the research participants as compared to the schizophrenia information discussion classes based on the original version of *The Alliance Programme*.

Usability

The knowledge retention results from the questions asked during the focus group discussion to determine how research participants feel about the usability of *The Alliance Programme* are discussed in this section.

QUESTIONS	GROUP A	GROUP B
1.1 What did you learn from the schizophrenia information discussion classes that are suppose to help you cope better with your illness?	Most of the participants stated that from these schizophrenia information discussion classes they learned all the important issues about schizophrenia and the importance of taking medication. The participants also said that knowing more about these issues will help them to cope better with their illness.	Most of the participants stated that from these schizophrenia information discussion classes helped them to learn about the causes of schizophrenia, thus it will be easier for them to avoid this causes in the future.

<p>1.2 What did you learn from the schizophrenia information discussion classes that made you understand your illness better?</p>	<p>Most of the participants felt that the issues that they learnt from the schizophrenia information discussion classes that made them to understand their illness better was all the important issues about schizophrenia and the fact that having schizophrenia is not the end of the world, life goes on.</p>	<p>Most of the participants felt that the issues that they learnt from the schizophrenia information discussion classes that made them to understand their illness better was all the important issues about schizophrenia and the causes of schizophrenia.</p>
<p>2. Were you able to read and understand what the presenter wrote on the board during the discussions?</p>	<p>All participants in both groups indicated that they were able to read and understand what the presenter wrote on the board during the discussions</p>	
<p>3. Would you like such schizophrenia information discussion classes to include drawings and photographs as well? Why?</p>	<p>All the participants said that they would like the schizophrenia information discussion classes to include drawings, photograph and pictures so to understand what is taught in these discussions better.</p>	<p>Some of the participants said that they would like the schizophrenia information discussion classes to include drawings, photograph and pictures so to understand what is taught in these discussions better. Whilst some stated no they would not like the classes to include drawings, photographs and pictures.</p>
<p>4. Would you like to be issued with booklets to read during these schizophrenia information discussion classes and at home?</p>	<p>All participants in both groups (Group A and Group B) indicated that they would like to be issued with booklets to read during these psycho-education classes and at home.</p>	
<p>5.1 Which words did you find difficult to understand?</p>	<p>Most of the words listed by the participants as words they found difficult to understand were: delusion, paranoia, schizophrenia, suspicious and schizophrenia.</p>	<p>Most of the words listed by the participants as words they found difficult to understand were: delusion, hallucination; and symptoms.</p>
<p>5.2 Which words do you think other patients might find difficult to understand?</p>	<p>Most of the participants in both groups indicated that the words: delusion, paranoia and hallucination are the words that they think other patients might find difficult to understand.</p>	

Inferences

From the above focus group responses, it is indicated that most of the research participants in both groups (Group A and Group B) were able to see and understand the value of the information communicated in the schizophrenia information discussion classes, and how it will help them improve their lives. This was evident when most of the research participants in both groups stated that they learnt a lot of important issues (e.g. symptoms of schizophrenia, causes of schizophrenia and the importance of medication) that will help them cope better with their illness and/or understand their illness better.

• **The knowledge retention results of both Group A and Group B**

In this section, the knowledge retention results of both groups (Group A and Group B) are compared. When comparing the knowledge retention results from both the individual interviews and the focus group interviews of both Group A and Group B, it seems as if research participants in Group B (the group that attended schizophrenia information discussion classes based on the adapted version of *The Alliance Programme*) retained the knowledge that they acquired better when compared to Group A. This impression was created by the fact that most of the research participants in Group B were able to give correct answers during the knowledge retention interviews, as compared to the research participants in Group A. There were certain instances where the research participants in Group A did better in terms of giving correct answers to the questions asked, but overall the research participants in Group B did better in terms of giving correct answers to the question asked. From the research findings, it seems like the research participants in Group B retained most of the information communicated to them for three months better than research participants in Group A. These findings also indicate that the communication of information about schizophrenia based on the adapted version of *The Alliance Programme* was more effective for the communication of information about schizophrenia to the research participants.

4.3 SUMMARY

In this chapter, the analysis of data on demographic and socio-economic factors and the evaluation of both the original and the adapted version of *The Alliance Programme* were discussed. The findings about comprehension, acceptability and the usability of the information communicated to the research participants were also presented.

The conclusions will be made and recommendations are discussed in the next chapter.

influence the research participant's response, more especially when such questions are not part of the interview technique (Kvale, 1996). In this study, the researcher(s) were very careful not to use leading questions, and to keep the questions as open as possible in order to allow the research participants to give their understanding on the subject matter. The main ways in which qualitative researchers can ensure the reliability of their analysis is by maintaining meticulous records of interviews and observations, and by documenting the process of analysis in detail (Mays & Pope, 1995).

There are many forms of reliability. The fact that in this study, two experts from two different disciplines (Psychiatry and Information Science) evaluated *The Alliance Programme* using a checklist, demonstrates an *inter-rater* form of reliability, which is defined by Leedy (1997:26) as "the extent to which two or more individuals evaluating the same product or performance give identical judgement".

The *equivalent* form of reliability is "the extent to which two different versions of the same instrument (e.g. 'Form A' and 'Form B' of a scholastic aptitude test) yields the same results/similar results" (Leedy, 1997:26). In this study, this is demonstrated by the fact that the two different forms of interviews (focus groups and individual, semi-structured interviews) were used with the same research participants in order to yield similar results. The literature indicates that no single method can adequately treat all problems of research, but a combination of various methods in the same study may bring reliability to the researcher's findings (Mouton, 1993: 206).

In collecting data for this study, the researchers did therefore not resort to a single method of data collection. The data for this study came from different data collection instruments:

- the expert-focused evaluation method and text-focused evaluation method, and
- the receiver-focused evaluation method (focus group discussions, semi-structured individual interviews and participants' observations).

These different data collection methods were used to complement each other, in order to ensure that as rich as possible data was collected. Mouton's (1993: 206) suggestion that a researcher must investigate as many angles as possible was considered when collecting data in this study.

This strategy is called triangulation, and it has the advantage of illuminating some of the hidden facts of a research project. Triangulation refers to the use of more than one data collection method in order to test and supplement the data (Mouton, 1993: 206). It is the extent to which independent measures confirm or contradict the findings (Struwig & Stead, 2001: 145). Triangulation was also used to compare the findings after data analysis. The findings from the different sources of data support one another. This adds to the reliability of the research findings, and also strengthens the validity of the research findings.

3.6 SUMMARY

The research methodology, research design and research process undertaken in this study were discussed in this chapter. The data collection methods were also outlined according to the order of the research procedure that was followed in this study. The geographic area of the research was identified, and also the dates of the fieldwork.

The analysis of the data and findings of the research are discussed in the next chapter.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter reports on all the results of the research study and provides conclusions, summaries and recommendations based on the findings. The objectives and/or sub-questions of the study are revisited, and conclusions are provided in which the findings of the study are weighed and/or considered in relation to the aim of the study. Lastly, recommendations derived from the findings of this study are also made.

5.2 RESEARCH QUESTIONS REVISITED

This study set out to evaluate the effectiveness and/or appropriateness of the information about schizophrenia based on *The Alliance Programme*, communicated orally to patients suffering from schizophrenia at the Weskoppies Hospital in Pretoria (South Africa). The aim of the study was to find out if the information about schizophrenia contained in *The Alliance Programme* met the information needs and profile of the target audience.

The main aim/objective of this study is answered through the sub-questions and/or sub-aims, which will be discussed in the following sections.

5.2.1 How effective and/or appropriate is *The Alliance Programme* in the South African context?

In order to determine the effectiveness and/or appropriateness of *The Alliance Programme*, three factors: comprehension, acceptability and usability, were considered in this study. Summaries of the research findings concerning these three factors are discussed in this subsection. Results of the original and adapted versions of *The Alliance Programme* in terms of these issues are compared. Then, a conclusion regarding which version of *The Alliance Programme* was more effective and/or appropriate for the South African context is made.

- Comprehension

The results on the ability of the target audience (research participants) to understand the information about schizophrenia contained or communicated via *The Alliance Programme* are discussed in this section. Findings from the research participants in Group B showed a higher level of comprehension in comparison with the research participants in Group A. The number of research participants who were not able to answer some of the questions (e.g. research participants who stated that they did not know the answers or gave incorrect answers) was much lower with research participants in Group B than those in Group A. This shows that the communication of information about schizophrenia based on the adapted *Alliance Programme* improved the research participants' knowledge and understanding of their mental illness much more than the communication of information about schizophrenia based on the original version of *The Alliance Programme*. The research findings obtained from the research participants three months after the communication of information about schizophrenia also indicated that research participants in Group B tended to retain more information that was communicated to them based on the adapted *Alliance Programme* compared to research participants in Group A.

This study then concludes that using a multi-media communication approach, that is, using different forms of media to communicate/disseminate information (for instance, in this study, for the communication of information about schizophrenia based on the adapted version of *The Alliance Programme*, a combination of two communication media were used, namely oral and print-based communication media) leads to a more effective communication of information. As indicated in paragraph 2.5.3.3, each communication medium has its own characteristics, advantages and disadvantages that are appropriate to certain circumstances and/or receivers, but not necessarily best for all circumstances and/or receivers. "There is no single medium that is likely to have properties that make it best for all situations" (Nyirenda, 1998: 26). There are certain messages that can be better understood when a certain communication medium is used, compared to when other communication media are used.

Using a combination of oral and print-based communication media to communicate or provide information to low-literate communities leads to an effective and successful communication campaign (Leach, 1999). The oral communication medium has an interactive nature when used for information provision, while the print-based information communication medium does not allow for a two-way [interactive] process. The print medium is something that the receivers can go away with and then refer back to any time they need to remind themselves of the information/message that was communicated to them orally. Thus, it could be used to support and reinforce what took place orally. This is the reason why, in most cases (most information provision campaigns), the oral communication medium is used as the main or only means of providing information, and the print-based communication medium is used as a medium to support oral communication. These two communication media complement each other, and therefore when they are used together for any information communication campaign, the most effective and/or successful information provision/communication will be achieved.

This study also concludes that including illustrations (such as diagrams, photos, pictures etc.) in any information material enhances the understanding of information communicated to the target audience. Illustrations complement and reinforce messages, enhancing the understanding of information being communicated (Price & Everest, 1995). In this study, illustrations in the form of cartoons and pictures were incorporated into the adapted version of *The Alliance Programme* booklet, in order to complement the information communicated to research participants. Consequently, the receivers of information about schizophrenia based on the adapted version of *The Alliance Programme* had a much better understanding of the information in comparison to the receivers of information about schizophrenia based on the original version of *The Alliance Programme*, in which no illustrations were used.

- Acceptability

The results and conclusions regarding how research participants felt about the schizophrenia information discussion classes they attended for three weeks, where information about schizophrenia was communicated to them via *The Alliance*

Programme, are discussed in this sub-section. The aim was also to determine the research participants' attitudes (e.g. appreciation) towards the schizophrenia information discussion classes that they attended.

The acceptance level displayed by research participants in terms of these schizophrenia information discussion classes was greatly influenced by the level of understanding of the information communicated to them via *The Alliance Programme* in these classes. As indicated in the previous section, research participants in Group B understood the information from *The Alliance Programme* better than research participants in Group A. The same applies to the acceptability factor, as research participants in Group B liked and appreciated the schizophrenia information discussion classes better than research participants in Group A. Most of the research participants in Group B indicated that they liked the way in which these schizophrenia information discussion classes were presented. This implies that the better the research participants understand the information communicated to them, the more easily they will accept the information.

Information providers/communicators should design information communication processes in a way that will make it as easy as possible for the target audience to understand the communicated information, so that the information will be better liked, appreciated and accepted.

- Usability

In this section, summaries and conclusions of results on how research participants value the information/message communicated by *The Alliance Programme* are provided - how they think this information will help them to better cope with and/or understand their illness. Literature shows that appropriate and/or effective information is valued by any target audience, since it helps them to fulfil their information needs and to be in a position to make informed decisions (McGarry, 1975; Mchombu, 1995; Stonier, 1996; Leach, 1999; Hargie & Dickson, 2004).

This is supported by the findings of this study. All the research participants in this study, both in Group A and Group B, valued the information about schizophrenia that was communicated to them via *The Alliance Programme*. They indicated that they learnt a lot about schizophrenia that would help them to better understand and/or cope with their illness, thus improving the quality of their lives. It is however possible that this positive attitude towards the schizophrenia information discussion classes was also due to the character of the person who presented the discussion classes (Linda).

This study concludes that when appropriate information is effectively communicated to a target audience, such information is most likely to be valued by that target audience.

5.2.2 Did the information about schizophrenia communicated via *The Alliance Programme* meet the information needs, demographic information and socio-economic status of the target audience?

In order for effective communication and/or understanding of information to occur, information material/message designers need to take certain factors of the target audience (e.g. demographic information, socio-economic status, information needs, level of education etc0.) into consideration when developing messages (Mody, 1991; Doak, Doak & Root, 1996; Servaes, 1999; Morris, 2001; Snyman & Penzhorn, 2004). This is also emphasised by Megwa (1996: 61) who says that “Communication should be visualised as an interactive enterprise in which both the sender and the receiver of information actively take part in the creation, transmission and reception”.

The results from Group B, who received the adapted version of *The Alliance Programme* which was designed to incorporate the information needs and characteristics of the target audience, agreed that this version of *The Alliance Programme* was better understood and accepted. This was in contrast to the research participants in Group A, who had difficulties in understanding the information communicated to them via the original version of *The Alliance Programme*. It can be accepted that the adapted version of *The Alliance Programme* was better able to solve the information needs of the target audience than the original version of *The Alliance Programme*. This means that the receivers of the information based on the adapted version of

The Alliance Programme (Group B) will be in a better position to use or apply this information in order to solve their information needs/problems, and thus to live a healthy lifestyle, compared to the research participants in Group A. The message from the adapted version of *The Alliance Programme*, which was produced in terms of an audience participatory communication design, did improve the participants' reception of information communicated to them.

This can be attributed to the fact that the original version of *The Alliance Programme* was created or designed without taking the research participants of this study's specific features e.g. demographic information, socio-economic status, information needs, preferences, level of education etc into consideration prior to the creation of the programme. Therefore, this study suggests that information materials should be designed with inputs from the target audience, in order to ensure that effective communication and/or understanding occurs. The findings of this study indicates that it is necessary that messages should be adapted or created to suit the needs of a specific audience. These findings are not conclusive - the relapse rates for instance are not know. There are, however, enough indications that such a work method would provide of better outcome.

5.3 RECOMMENDATIONS

This study has once again supported the premise that in any information communication process, the information material that is used should be designed using a participatory communication approach, rather than a top-down communication approach. Literature repeatedly indicates this premise with regard to the development of promotional health materials, because it results in more effective information transfer which is also cost-effective (Ratzan, 1994; Piotrow et al, 1997; National Centre for Health Statistics, 2003; Snyman & Penzhorn, 2004). Designers of information materials should consider the demographic and socio-economic features of the target audience in order to produce messages that are relevant to the target audience.

Based on the results discussed in the evaluation of *The Alliance Programme*, the following recommendations can be made:

- The results on how the target audience understood the content of the information material (*The Alliance Programme*) indicated that research participants had some difficulty in understanding the information/message based on the information material of the original version of *The Alliance Programme*, because of the low level of literacy among the target audience and the fact that a single communication medium (oral) was used to disseminate the information. It is more effective to use a multiple media communication approach when communicating information to low-literates such as the target audience of this study.
- The adapted version of *The Alliance Programme* was better liked by research participants. This indicates that, in order for an information material to be usable and effective, the producers of the material need to involve the target audience when designing it.
- Based on the results of how research participants value the information messages communicated by *The Alliance Programme* (information material) obtained in this study, it is recommended that, in order for the target audience to value the information/messages communicated to them (apply and/or use it effectively to solve problems in their lives), the information designers/communicators should design and present the information in such a way that it is easy for the target audience to understand it.
- To overcome the demographic barriers indicated in this study's research findings, certain features of the target audience, such as illiteracy, should be taken into consideration when designing messages for a disadvantaged target audience such as the research participants in this study. Effective and/or appropriate communication methods for communicating information to low literates should be established and used.

In summary, in order to ensure that information about schizophrenia is communicated effectively and/or appropriately to any group of patients suffering from this illness, this study recommends that a participatory communication design may yield optimal results but it is not mandatory, a larger study will have to be done to provide more conclusive data. This is because

this design could ensure that patients suffering from schizophrenia develop their knowledge about schizophrenia and information materials.

5.4 SUMMARY

In this study, conclusions were presented and recommendations were made regarding how to improve the communication of information about schizophrenia using schizophrenia information material (eg *The Alliance Programme*) in South Africa.

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APPENDIX A

Screening Interview schedule

(The following questions were in Tshwana)

INTERVIEW SCHEDULE

Name:

Registration number:

Gender:

Date of birth:

Age:

Language:

Residence:

Contact details:

Highest level of education:

Employment:

Duration of mental illness:

Consent: Yes/No

1. Do you know the name of the disease you are suffering from?

.....
.....

2. How did you learn about your mental illness? / Who first told you that you have a mental illness?

.....
.....

3. Describe the things you were experiencing when the condition started

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

4. What other symptoms can a person suffering from your condition have?

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

5. Which symptoms tell you that you are going to become ill again (early warning signs)?

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

6. How does medication help in your illness?

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

7. Who is supporting you during your illness?

.....
.....

8. What do you think about your mental illness?

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

9. What do you think makes people suffer from mental illness (schizophrenia)?

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

APPENDIX B

Interview schedule for individual interviews and focus group discussions

(The following questions were asked in Tshwana)

INTERVIEW SCHEDULE

Name:

Gender:

Date of birth:

Age:

Language:

Residence:

Contact details:

Highest level of education:

Employment:

Duration of mental illness:

Opening questions

1. What is the name of the disease you are suffering from?

.....
.....

2. How did you learn about your mental illness? / Who first told you that you have a mental illness?

.....
.....

3. Who diagnosed you with schizophrenia?

.....
.....

.....4. Why do you think we have schizophrenia information/discussion classes like the ones you have had in the past three weeks?

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

Comprehension

1. What symptoms can people who suffer from this illness experience?

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

2. Which of these symptoms did you experience?

.....
.....



.....3. What tells you that you are going to become ill again (early warning signs)?

.....

4. Do all patients with schizophrenia experience the same symptoms?
(Probing question)

.....

5. What is a delusion?

.....

6. What is a hallucination?

.....

7. What does it mean to be psychotic? / When someone tells you that you are psychotic, what does he/she mean?

.....

8. Why do we say that schizophrenia is like a “thief”?

.....

9. Can schizophrenia be inherited? Explain

.....

10. How many people out of every 100 people in the world suffer from schizophrenia?

.....

11. What can you do to cope with this illness?

.....
.....

12. Can anything make this illness completely disappear?

.....
.....

If yes, what?

.....
.....

How does it work?

.....
.....

If no, why not?

.....
.....

13. What type of support do you receive for your illness?

.....
.....

14.1 How can the symptoms of schizophrenia be treated?

.....
.....

.....14.2 What type of treatment do you receive for the symptoms of schizophrenia?

.....
.....

.....15. How can medication help you with your illness?

.....
.....

.....16. How do you feel about your mental illness?

.....
.....

17. Why do you think people suffer from schizophrenia?

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

Acceptability

1. What do you think about the schizophrenia information/discussion classes you have attended in the past three weeks?

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

.....2.1 What did you like about them?

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

.....2.2 What did you not like about them?

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

3. How do you think the presentation of these classes can be improved?

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

4. What would be the best way for you to learn more about your illness (schizophrenia)?

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

.....5. In which language would you prefer the schizophrenia information/ discussion classes to be presented? Why?

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

.....6. How do you feel about the presenter?

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

.....7. How do you feel about the interpreter?

APPENDIX C

INFORMED CONSENT

Title of study: Testing the effectiveness of existing psycho-educational material (The Alliance Programme) for patients suffering from schizophrenia in the South African context

I hereby confirm that I have been given information about the nature of the research that I am about to participate in. I have also received, read and understood the abovementioned information.

I am aware that the results of the study, including personal details regarding my sex, age, date of birth, name and diagnosis will be anonymously incorporated into the study's report. I understand that the data collected will be kept in a safe place, and that confidentiality will be maintained at all times.

I may, at any stage and without prejudice, withdraw my consent to and participation in the study. I have had sufficient opportunity to ask questions, and of my own free will declare myself to be prepared to participate in the study.

Name of Participant:.....

Signature:.....

Date:.....

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

Usability

1.1 What did you learn from the schizophrenia information/discussion classes that is supposed to help you cope better with your illness?

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

.....1.2 What did you learn from the classes that helped you to understand your illness better?

.....
.....

2. Were you able to read and understand what the presenter wrote on the board during the discussions?

.....
.....

.....3. Would you like such schizophrenia information/discussion classes to include drawings and photographs as well? Why?

.....
.....

.....4. Would you like to be issued with booklets to read during these classes and at home?

.....
.....

.....5.1 Which words did you find difficult to understand?

.....
.....

.....5.2 Which words do you think other patients might find difficult to understand?

.....
.....



APPENDIX D

The original version of *The Alliance Programme*

Chapter one of *The Alliance Programme*

(The part of the text used for evaluation in this study)

1. SIGNS, SYMPTOMS (INCLUDING EARLY WARNING SIGNS), FREQUENCY, COURSE AND PROGNOSIS OF SCHIZOPHRENIA





1. SIGNS, SYMPTOMS (INCLUDING EARLY WARNING SIGNS), COURSE, FREQUENCY AND PROGNOSIS OF SCHIZOPHRENIA

The objectives of this section are to help patients learn about:

- What the typical symptoms of schizophrenia are
- What the frequency and course of schizophrenia are
- The fact that in the majority of patients many symptoms can improve through treatment
- What psychosis is
- What the early warning signs are
- The fact that a psychotic relapse is often preceded by specific symptoms
- How schizophrenia is diagnosed.

1. Signs and symptoms of schizophrenia

The symptoms of schizophrenia can be quite varied. Many patients and relatives doubt whether the illness really is schizophrenia, since they do not realise that very different individual symptoms can arise in patients with schizophrenia. This is sometimes very difficult for the layperson to understand and can lead to confusion and uncertainty, especially since not all of these symptoms need be present at the same time.

Three major groups of symptoms are especially characteristic of schizophrenia:

- Symptoms of reality distortion
 - *Hallucinations*
 - *Delusions*
- Symptoms of disorganization
 - *Disturbances in thinking*
 - *Inappropriate affect*
- Symptoms of psychomotor poverty
 - *Poverty of speech*
 - *Flat affect*
 - *Decreased movement*

Sometimes schizophrenia symptoms are divided into so called 'positive' and 'negative' symptoms. Symptoms such as hearing voices or feeling persecuted are called **positive** symptoms, because they refer to experiences that go beyond the experiences of normal life. Negative symptoms are, for example, flat affect, blunted feelings, poverty of speech and movement. They are called **negative** symptoms because they refer to a loss of normal activity or function.

Symptoms of reality distortion

Hallucinations (e.g. hearing voices):

Seeing, hearing or feeling something that other people cannot sense is called a hallucination. For example, patients with schizophrenia sometimes complain that they hear a voice that comes from the television set, or from a radio. This experience is often very frightening and disturbing. Most frequently encountered hallucinations are: hearing voices talking about the patient, or commanding the patient to do something, or hearing messages from a TV or radio specially meant for him/her.



Delusions (e.g. feelings of persecution):

Delusions are firmly held beliefs that are untrue as well as contrary to a patient's educational and cultural background. They seem very real to a patient with schizophrenia, and are difficult to change. Common delusions are: being followed or persecuted by someone; that the telephone is bugged, and conversations taped; or that the patient is controlled by others. They are a common feature of schizophrenia, but why they occur is not clear. There are many different types of delusions, but the most common ones are the belief that one's thoughts, feelings and actions are known or controlled by others, that someone is trying to harm them; or that one has special powers. Other people may find such ideas frightening, however, it is important to discuss them with the care team.

Symptoms of disorganization

Disturbances in thinking (cognitive dysfunction):

The term 'cognitive functions' is used to describe various aspects of thinking, such as attention, concentration, comprehension, memory, orientation, abstraction and judgment. Cognitive functions are important in allowing us to think, learn, memorise and understand things, as well as to communicate. They also allow us to perform a range of tasks in everyday life, from simple ones such as counting change, to complex tasks requiring concentration and coordination such as playing chess, driving a car or writing poetry.

Today there is scientific evidence available to show that cognitive impairment is commonly associated with schizophrenia. The relationship between cognitive disturbances and other symptoms of schizophrenia is not clearly understood at present. It has been observed that some people experience cognitive problems much sooner than they develop positive symptoms, while others acquire cognitive impairment after the first episode and with subsequent relapses. However, the extent of cognitive involvement varies between affected individuals, with the majority of patients experiencing subtle difficulties.



The person experiencing cognitive difficulties usually complains of having muddled or mixed-up thoughts, poor concentration or having memory problems such as being forgetful. Such a person may consequently have difficulties with reading, writing or watching TV. People with a greater degree of cognitive problems will have difficulties in carrying out everyday activities such as shopping or cooking, and looking after themselves. This may result in poor hygiene, malnutrition, and self-neglect. In rare cases cognitive impairment results in potentially dangerous behaviours such as walking into traffic, leaving the stove on, or mixing up medications. Cognitive problems may cause patients to forget to take medications, and keep appointments with their care team. The new generation antipsychotic medications seem to have a favourable effect on cognitive dysfunction associated with schizophrenia (see Section 4). Other simple steps that help in performing everyday tasks include the use of various memory aids (e.g., using a dosing box to take medications regularly, and a calendar to note down appointments), generally maintaining an active, structured routine (see Section 6), and adapting one's lifestyle to the actual level of functioning. It should be also remembered that use of alcohol or street drugs may worsen cognitive functioning (see Section 7).

If symptoms such as hearing voices or feeling persecuted occur, the illness is generally rapidly recognised. These symptoms usually disappear within a few months in most patients if they are treated with antipsychotic drugs.

Symptoms of psychomotor poverty

Symptoms such as flat affect, reduced speech and content of speech, and reduced motor activity may come to the fore anytime during the course of the illness. Patients with schizophrenia often feel tired all the time or can not be bothered to do things they used to enjoy. They may find it hard to do normal daily activities such as getting washed and dressed every morning. Some patients say they feel 'empty' and lack feelings for people, others feel hopeless and sad. Family and friends frequently find these symptoms difficult to cope with, and sometimes think it is only laziness.



In some patients, symptoms such as blunted feelings and lack of energy are more prominent. The patient is exhausted and it is often a long time before they feel well again. Treatment of these symptoms can be difficult and time consuming, and patients need patience with themselves and from their families and friends on whom they depend at this time. By means of various treatments however, most patients may also succeed in overcoming these symptoms and find new energy.

Symptoms of anxiety and depression

Patients with schizophrenia are at risk of becoming depressed, and clear signs and symptoms of depression could be present frequently. This is usually related to the very nature of the illness that impacts on all their hopes and expectations for the future, and also frequently leads to a change in life circumstances (for example, job loss, interrupted education, impaired relationships or social isolation).

The symptoms of depression are:

- *Feeling miserable and unhappy*
- *Not wanting to take part in everyday activities*
- *Changes in sleep patterns (usually difficulties in falling asleep and waking too early)*
- *Changes in eating patterns (usually lack of appetite)*
- *Low self-esteem*
- *Self-neglect and poor hygiene*
- *Thoughts of death*
- *Increased drinking.*

If any of the above symptoms are noticed, it is important to discuss them with a doctor or other health professional so that an adequate treatment is started.



Anxiety symptoms are also frequent in schizophrenia. Fearfulness, nervousness, muscle tension, apprehension, dizziness and stomach discomfort could be experienced when patients are exposed to stressful situations or when a sudden change in routine or lifestyle, such as going on holiday or moving house, occurs. As with all other symptoms, it is important to discuss them with a treating physician or other health care worker.

Aggression

There is a concern that patients with schizophrenia are violent and dangerous. Although they present with violent behaviour more frequently than the people without a mental illness, this type of behaviour is less frequent than in people with alcohol abuse or dependence. Patients with schizophrenia are more prone to react violently when under stress or the influence of alcohol or illicit drugs, or if they have a history of violent behaviour before becoming ill. In some cases, hallucinations or delusions may lead to violent behaviour that tends to be targeted at family members and friends, and most often takes place in the home. There are still many myths and misconceptions surrounding the violent behaviour of patients with schizophrenia, but in reality most patients with schizophrenia are not violent; rather they tend to be withdrawn and prefer to be left alone.

Suicidality

Unfortunately, suicide is common in patients with schizophrenia. It is not possible to predict who will actually commit suicide, but the risk appears to be highest in young unemployed males, recently discharged from a hospital, with symptoms of depression.



Psychosis or psychotic disorder

Symptoms such as hallucinations or delusions that cause a patient to lose touch with reality are also called **psychotic** symptoms or symptoms of **psychosis**. Other medical or mental illnesses (for example, serious infectious diseases with high fever such as typhoid; or mania) can present with psychotic symptoms, or they can be caused by excessive alcohol and drug abuse. Most patients with schizophrenia find that their symptoms vary over time: they may go through periods when experiences and interpretation of the outside world become disturbed, which may make them lose touch with reality, see or hear things that are not there or act in unusual ways, and it is then said that a person is suffering from a psychosis.

Frequency of schizophrenia

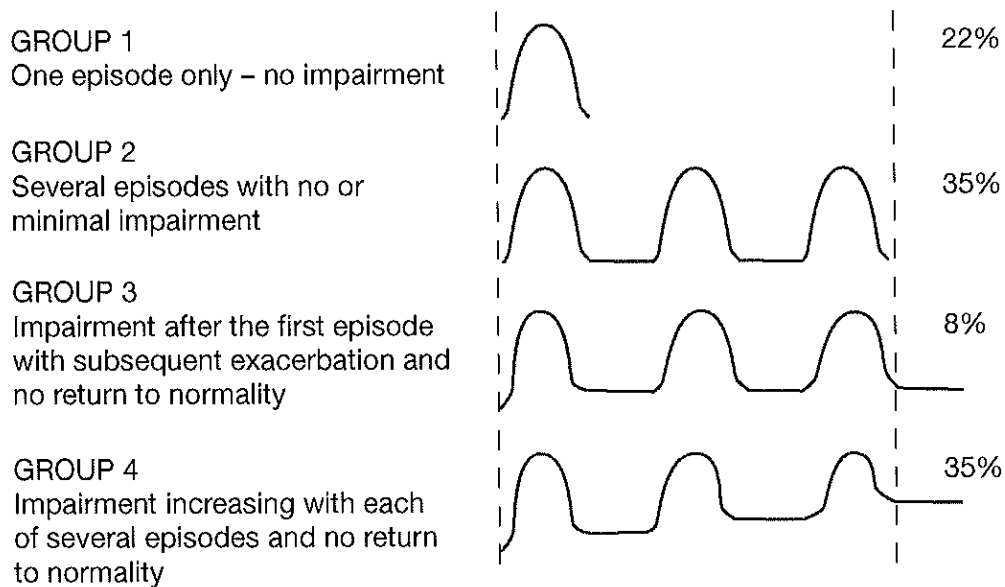
Schizophrenia is far more common than many people realise. It affects people from all cultures and walks of life. Over the course of a lifetime, the chance of falling ill with schizophrenia is 1 in 100. In other words, about 1% of the population is affected by this illness.

2. The course and prognosis of schizophrenia

Schizophrenia is an illness with a high risk of relapse, or return of symptoms, particularly if treatment is interrupted. Without treatment, as many as 8 out of 10 patients will have a relapse after a first episode of the illness within 2 years. This falls to 2 in 10 when patients are taking medication. Fortunately, the symptoms can be treated with a combination of medication and psychosocial therapies, although they do not always disappear completely. With continued treatment, many patients recover well from an episode of the illness and learn to cope with their symptoms. However, if someone stops treatment and becomes ill, recovery may become more difficult with each episode of illness.

The figure below illustrates possible courses schizophrenia may have.

COURSE OF SCHIZPHRENIA



(Accessed at http://www.openthedoors.com/english/03_09.html)

Patients with schizophrenia are more likely to experience a good outcome today than they were 100 years ago, as antipsychotic medication and other treatments have altered the natural course of the disease. Unlike 100 years ago, the majority of patients do not spend their entire life in psychiatric hospitals any more.

If someone becomes ill with symptoms of schizophrenia they may need to be treated in hospital or a special centre for patients with mental disorders. This is the best place for the sort of intensive support and care needed when the illness is at its peak. Some patients may become very sensitive and may benefit from some time in a secluded environment within the hospital. However, modern day treatments mean that many patients with schizophrenia may now receive the help and support they need without having to stay in hospital for a long period of time.



Early warning signs

Schizophrenia can thus have very different appearances. However, a new episode may begin with discrete, non-specific symptoms such as nervousness, depression or sleep disturbances (called 'early warning signs'). At this stage, schizophrenia is often difficult to recognise, because even healthy people can have such symptoms from time to time.

The most common signs that the illness may be coming back are presented in the table below.

Early warning signs

- *Nervousness*
- *Changes in sleep pattern*
- *Unusual thoughts or experiences*
- *Reappearance or increase of*
- *Hallucinations*
- *Delusions*
- *Disturbances in thinking*
- *Concentration problems*
- *'Strange' or 'odd' behaviour*
- *Social withdrawal*

Patients who have already experienced several episodes of schizophrenia often report that they notice the approach of a new episode days, weeks, or sometimes months ahead on the basis of symptoms – so-called 'early warning signs'. These can include changes in mood, changes in thinking or perception, changes in behaviour and changes in general physical condition. It is important to recognise that symptoms may be coming back, and discuss that with the care team. By acting at the time when early warning signs appear, a psychotic relapse may quite often be prevented.

3. How is schizophrenia diagnosed?

Many patients and their caregivers find a diagnosis of schizophrenia difficult to accept. An additional problem is that there are no routine tests, for example laboratory tests or scans, for diagnosing schizophrenia. Consequently, the diagnosis is made by a health care professional using a mental health assessment, a combination of an interview and observations to evaluate:

- Appearance and behaviour
- Mood
- Thinking (including attention, concentration, level of consciousness, comprehension, memory and ability to understand abstract ideas)
- Thought processes and content:
 - *Awareness of one's surroundings (so-called orientation)*
 - *Understanding of time, place (where you are), and person (who you are)*
 - *Checking whether one has any suicidal thoughts, thoughts of hurting others, strange and unreal thoughts or experiences (like hearing voices others do not hear or seeing things others do not see)*
- Ability to express oneself by assessing one's body posture, eye contact, and verbal communication
- Physical functioning by evaluating areas such as sleep, appetite, or physical symptoms
- Insight and judgment
- One's ability to relate to others and the status of present relationships.



Because the diagnosis is based on observation, the scientists have come to an agreement that schizophrenia is accurately diagnosed when:

- A person has at least two of the following symptoms in the active phase of the disorder, each having lasted for at least 1 month:
 - *Hallucinations*
 - *Delusions*
 - *Disorganised speech*
 - *Grossly disorganised behaviour*
 - *No emotion, inability to experience pleasure, and problems concentrating (so called negative symptoms)*
- A person has problems functioning on the job or with other people
- Continuous signs of schizophrenia have been present for at least 6 months, with active phase symptoms being present for at least 1 month
- Substance abuse or other mental health problems have been ruled out.

As with most serious illnesses, it is important to get diagnosis and treatment as quickly as possible.

Summary:

- **In schizophrenia, a variety of symptoms can arise**
- **Other patients with experience of schizophrenia have similar symptoms**
- **Schizophrenia is a relatively common illness all over the world**
- **It is an illness with a high risk of relapse, or return of symptoms, particularly if treatment is interrupted**
- **Specific symptoms (so-called 'early warning signs') can precede a psychotic relapse or a first outbreak of the disease**
- **The diagnosis of schizophrenia is made by a health care professional using a mental health assessment, a combination of an interview and observation of behavior, communications and functioning.**



2. CAUSES OF SCHIZOPHRENIA



2. CAUSES OF SCHIZOPHRENIA

The objectives of this section are to help patients learn that:

- **Schizophrenia can have different causes**
- **The stress has a role in triggering symptoms of schizophrenia in some patients**
- **Chemicals in the brain called neurotransmitters play a role in the development of symptoms and are also important in the treatment of schizophrenia**
- **Heredity is not the only cause of schizophrenia**
- **Stress alone cannot cause schizophrenia.**

1. Causes of schizophrenia

After learning about the symptoms of schizophrenia, it would be interesting to know how these symptoms arise. Although this question cannot be answered in full scientific detail yet, it is well accepted that schizophrenia is a brain disease. It is also known that it is caused by a variety of factors – including changes in the chemistry of the brain, changes in the structure of the brain, genetic factors and stressors from the environment. This brain disorder interferes with the ability to think clearly, knowing what is real, managing emotions, making the right decisions and relating to others.

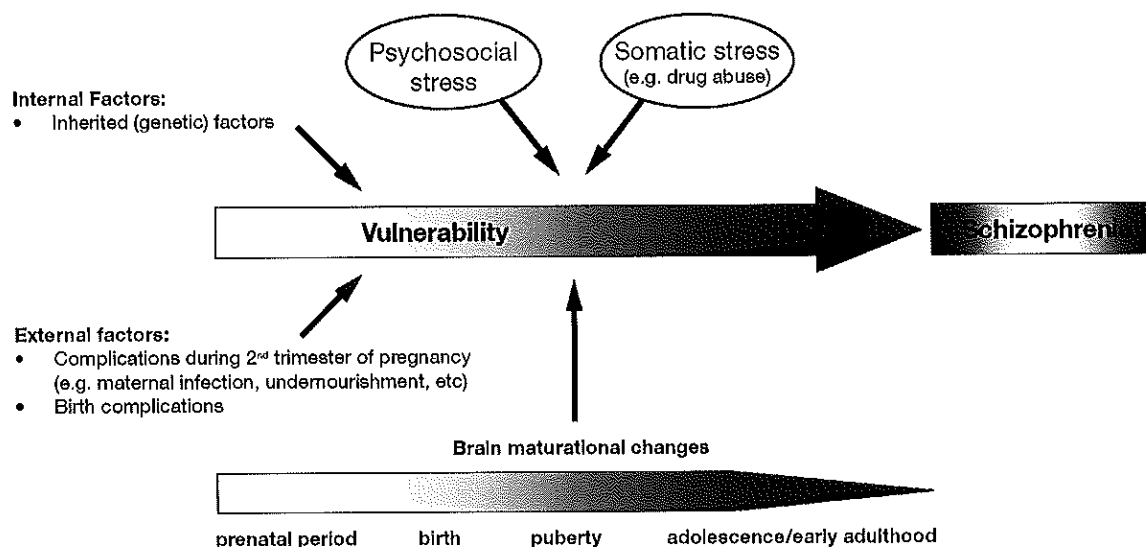
Patients diagnosed with the illness and their caregivers are very often interested in knowing what causes the symptoms of schizophrenia. They often ask themselves if it is their fault in any way or if they have done something wrong. When they learn what is responsible for the symptoms of schizophrenia, they may accept the illness better, may feel less guilt and may better understand how a psychiatric illness like schizophrenia develops.

2. The role of stress in schizophrenia

In some patients who have an inherited vulnerability or predisposition to schizophrenia, stress (life events, daily hassles) may trigger the symptoms of schizophrenia, or cause a relapse of the illness. If a healthy person is put under stress, they are likely to become irritable, but as a rule they do not become psychotic. But if a person with a genetic predisposition for schizophrenia is subjected to a lot of stress, this may trigger illness because the person is more vulnerable to stress. Patients with such vulnerability do have an increased risk of developing schizophrenia, but they are otherwise not necessarily less capable or even permanently handicapped. The research data show that two developmental periods (the 2nd trimesters of pregnancy and puberty), when intensive brain maturation occurs, appear to be particularly relevant for the development of vulnerability. It is thought that some sort of brain damage occurring during those periods may contribute to the development of subtle brain abnormalities that predispose to illness development.

In many cases, reducing stress may help to avoid a relapse. This is important to know, as stress reduction techniques are a valuable tool in the overall management of the illness (See Section 5).

STRESS – VULNERABILITY MODEL

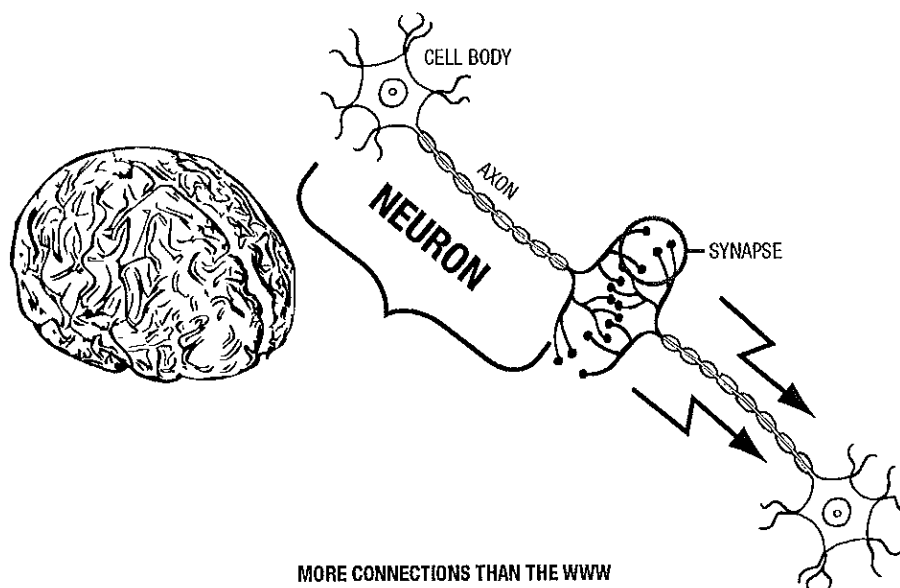


3. Disturbed neurotransmission in schizophrenia

To better understand how neurotransmission works, imagine how sound is transmitted. When talking to someone, sound waves go out from the mouth, arrive at the ear and are translated into electric nerve impulses. This is because the brain cannot understand the sound waves directly – they must first be translated into electric impulses. These impulses are then transmitted over various nerves into the brain where the words that were spoken are heard and understood in the hearing centre. This is how to imagine it in a simplified manner.

The transmission of the electric impulses takes place over a number of nerve cells connected together by so-called 'synapses'. So that the electric impulses or signals can jump across these connections, the body produces special chemical substances called neurotransmitters, which carry the signal from one nerve cell to the next one. The human brain has billions of cells and trillions of connections: in fact it has more connections than the whole World Wide Web (Internet). The most important neurotransmitters for the development of schizophrenia appear to be dopamine and serotonin.

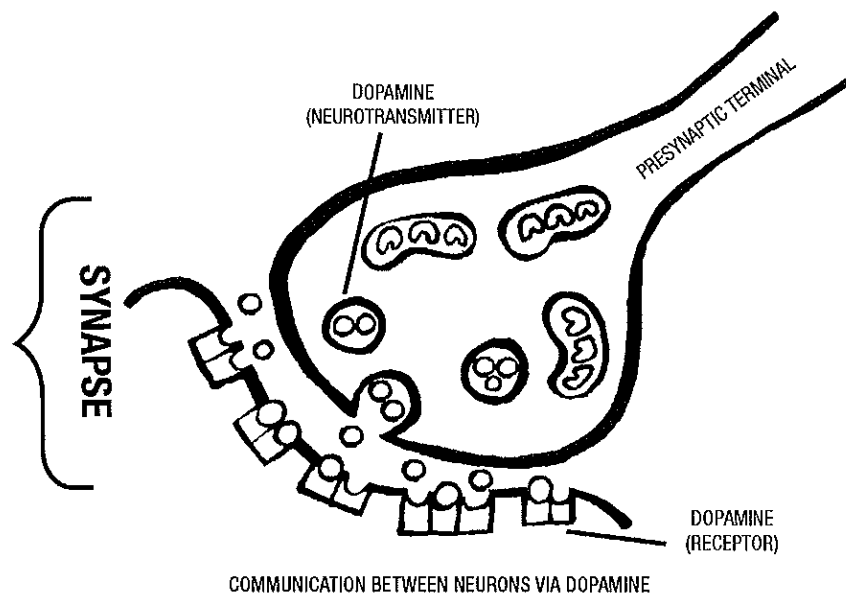
BRAIN = 100 BILLION NEURONS



MORE CONNECTIONS THAN THE WWW

In schizophrenia the transmission of the electric impulse is disturbed in the region of the connections between nerve cells. There are numerous scientific data indicating that during a schizophrenic episode there is too much dopamine in some brain areas, and too little in others and, as a result, the wrong amount of many of the signals is transmitted. The same holds for the neurotransmitter serotonin but, for the sake of simplicity, the explanation will be limited to dopamine.

Stress – Vulnerability Model



Dopamine has several important roles in the human body: it coordinates motor and mental functions, and controls the filtering and prioritisation of information that the brain receives from the outside world. In schizophrenia, due to the wrong amount of signals, the brain gets many more messages than normal at the same time. As a result, the brain cannot monitor and control all the messages, and it starts to mix up reality with unreal feelings and impressions, leading to symptoms of schizophrenia (such as hallucinations, delusions, thought disorder, etc.). This is what scientists believe happens, although all the questions have by no means been clarified. The antipsychotic drugs used to treat symptoms of schizophrenia work on this neurotransmitter system (see Section 4).

4. Can schizophrenia be inherited?

It has long been known that schizophrenia tends to run in families. The close relatives of patients with schizophrenia are more likely to develop schizophrenia than those who have no relatives with the illness. For example, having a parent who has schizophrenia means that their offspring have a 6% chance of developing schizophrenia. Even in identical twins, only 50% may become ill. By comparison, the lifetime risk of schizophrenia in the general population is about 1%. Turn this around however, and you can say that the offspring have a 90% chance of not developing the illness. This makes it clear that heredity cannot be the only cause otherwise all siblings would fall ill. Other factors (e.g. environmental ones) should also be present for schizophrenia to develop. Most scientists agree that what may be inherited is a vulnerability or predisposition to the disorder – an inherited potential that requires an additional illness risk to lead to schizophrenia. In some patients therefore, a genetic factor may play a role in the development of the disorder; in others, it may not.

Summary:

- **Science has not succeeded in identifying a single cause of schizophrenia**
- **It is known however, that schizophrenia is a brain disease caused by a variety of factors including changes in the chemistry of the brain, genetic factors and stressors from the environment**
- **The stress-vulnerability model currently provides the best explanation for the development of schizophrenia.**



APPENDIX E

The adapted *Alliance Programme*

(Available in Tshwana)

The adapted *Alliance Programme* that was issued to research participants in Group B.

Workbook

for patients with schizophrenia

An adapted version for the South African context

Based on Pfizer's *Alliance Programme*: a resource for patients with schizophrenia, their caregivers and mental health care professionals

Schizophrenia ke eng?

Schizophrenia ke eng?



A Schizophrenia ke ge motho a gafa?



Nyaa,ke bolwetse jwa tlhogo



Motho yo a tshwereng ke bolwetse ba tlhogo o itshwara ka mokgwa o o sa tlwaelegang.

Go kaya eng go runyegelwa ke bolwetse?



Go kaa gore motho o a lwala mo a sa tthaloganyeng maemo a gagwe mabapi le bonnete. Ga a tthaloganye ebile o kopane tlhogo.

Tiro yak o gae

Tthalosa gore go diragetse eng fa o ne o lwala. Kgotsa dira setshwantsho.

Schizophrenia se dira eng mo mothong?



Schizophrenia se tshwana le legodu. Se utswa boleng ba rona.



Se utswa

- menagano ya rona (bokgoni ba rona ba go gopoa dilo)
- go tsea dilo tsia (go kgona ga rona go tsepama le nagana sentle)
- maikemisetso a rona a a siameng a botshelo
- maatla a rona
- kitso ya rona ya go ngwala le go buisa

Ke go reng batho ba tshwere ke bolwetsi jwa Schizophrenia?



Batho bangwe ba bo bona mo batswading kgotsa lesika. Ba a bo neelwa.

Tiriso e e sa siamang ya nnotagi kgotsa diritibatsi d etsa gore go nne bonolo go tshwara ke bolwetsi jwa Schizophrenia.

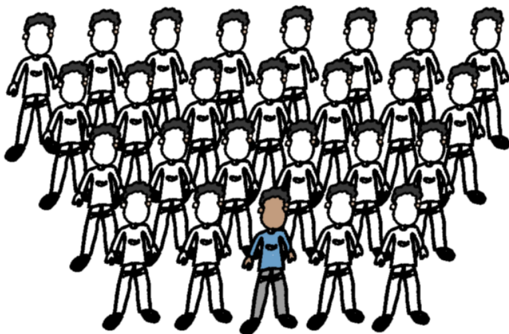
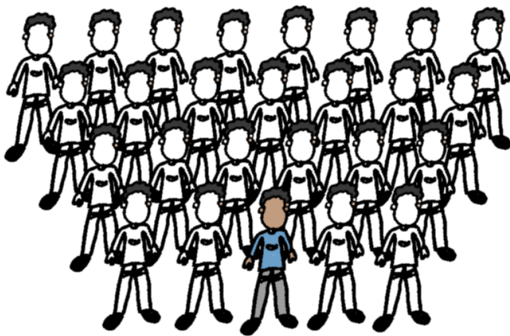


Ka makgetlo a le mantsi ga go se o ka se dirang o tsena ke bolwetsi jo. Go

Ke batho ba ba kae ba ba tshwerng ke bolwetsi jwa Schizophrenia?



Ga o esi.Motho a le mongwe mo go bo lekgolo lefaseng lotlhe o tshwere ke bolwetsi jwa Schizophrenia.



Tiro ya ko gae

1 Go kaya eng ka Schizophrenia?

2.Ke go reng Schizophrenia se tshwana le legodu?

3.Go kaya eng fa go twe o a tsenwa?

4.Ke batho ba ba kae go ba ba lekgolo mo lefaseng ba ba tshwereng ke bolwetsi jwa Schizophrenia?

5.Schizophrenia se tiholwa ke eng?

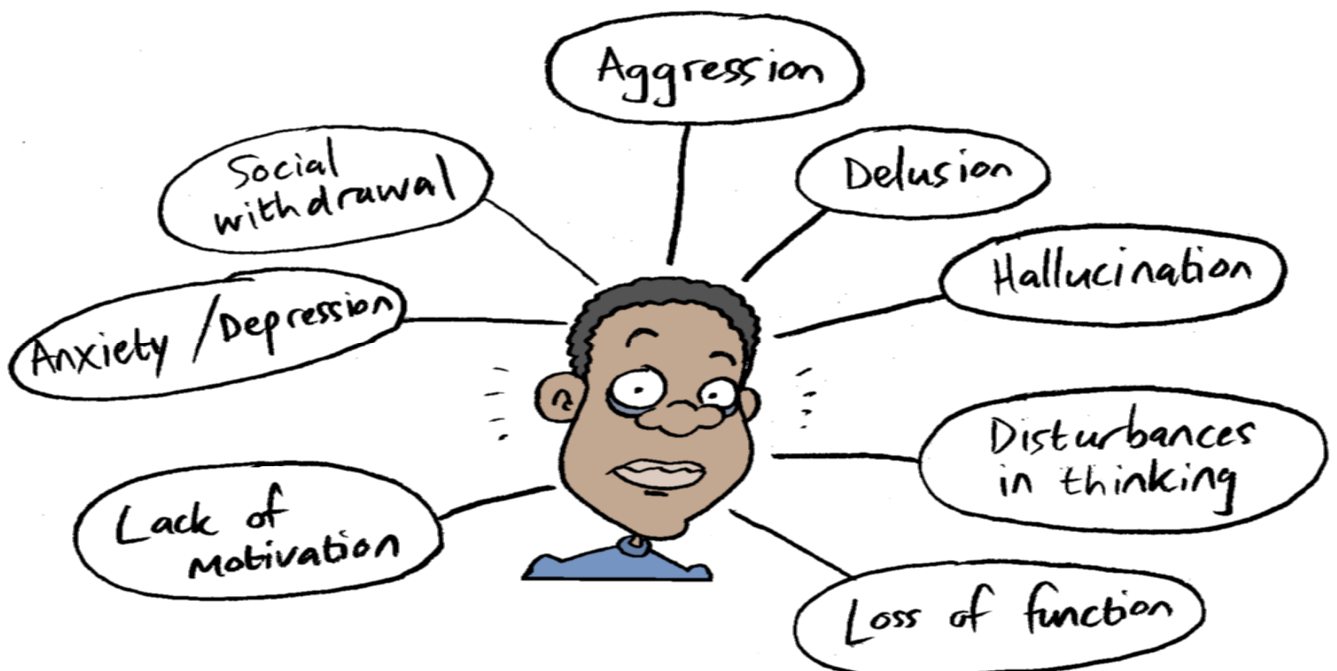
Matshwao le dikao tsa bolwetsi jwa Schizophrenia?

Matshwao ke eng?



ingaka di bitsa
shwao dikao. Matshwao ke dilo tse
re di ut lwana qa re sa e kutlwe

Go latela matshwao le dikao tsa bolwetse jwa Schizophrenia:



Go fagamoga



Ke eng go fagamoga?

Ke fa motho a itemogelwa dilo
tse bangwe bas a di lemogeng
jaaka go utlwa, bona
,latswa,nkgelela kgotsa
tsikinyega



Go tshwana le go utlwa mongwe a
bua le wena, le mororo go se ope
tota.



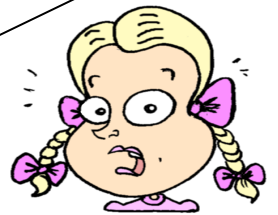
Tlhalosa ka go ngwala kgotsa ka setshwantsho maitemogelo a gago fa o ne o fagamoga.

Go ithamaka



Ke eng go ithamaka?

Ke nagana gore ke fa motho a tshepa dilo tse e seng nnete go nna bonnete. Balwetsi ba Schizophrenia ba itseea e le batho ba ba itsegeng kgotsa botlhokwa thata le fa go se jaalo.



Ka dinako tse dingwe ba belaela gore bangwe ba bua ka bone le fa go se jaalo. Ba belaela gore bangwe ba rata go ba dira kotsi.

Tlhalosa kgotsa dira setshwantsho ka ga maitemogelo a gago fa o ne o ithamaka.

Go latlhegelwa ke go dira



Go kaya eng go latlhegelwa ke go dira?



Go kaya go latlhegelwa ke maatla le matlhagatlhaga a go dira dilo.



Ga ke kgone go buisa sentle ka metlha,ka dinako tse dingwe

**Tlhalosa kgotsa dira setshwantsho ka maitemogelo a gago
a go latlhegelwa k eke go dira**

Go tlhoka tshusumetso.



Go kaya eng go tlhoka
tshusumetso?

Kef a o ikutlwa o lapile ka dinako
tlhe,mm eke sa rate go tshwenya ke



Ga ke rate go simolola sepe
se se ntsha.

Ke ikutlwa ke lapile thata.



Re tthalosetse ka maikutlo a gago kgotsa o dire setshwantsho go kaya maitemogelo a gago ga o tlhoka tshusumetso.

Go ikgatholosa bangwe

Go ikgatholosa bangwe go kaya eng?

Ke fa motho yo a tshwereng ke bolwet
jwa Schizophrenia a ikgatholosa mc
bathing ba bangwe



Ka dinako tse dingwe
ga ke rate go nna mo
gare gab a bangwe.Ke
rata go nna ke le esi.



**Re tthalosetse ka dinako tse o ikutlwang o rata go nna o
le esi**

Go tlhakatlhakana mo tthaloganyong..



Ke fa dikakanyo tsa motho di
tlhakatlhakane.

Dikai e ka nna go tlhoka go
tlhwaya tsebe, go lebala le go
sa itlhaloganye.



Ke atisa go lebala tota. Ka
dinako tse dingwe ga ke itse
gore ke mo kae.

**Ngwala kgotsa o tthalose ka setshwantsho go bontsha
fa tthaloganyo ya gago e tthakatlhakane**

Boganka

Bangwe ba batho ba na le go nna bogale le go nna kotsi ka dinako tse dingwe.



Ke atisa go fela pelo ga ke na le matswenyego kgotsa ke dirisa bojalwa kgotsa diritibatsi.



fagamoga kgotsa go ithamaka ka dira motho a nne bogale.



Ke atisa go nna bogale le go ikutlwa ke rata go lwa.

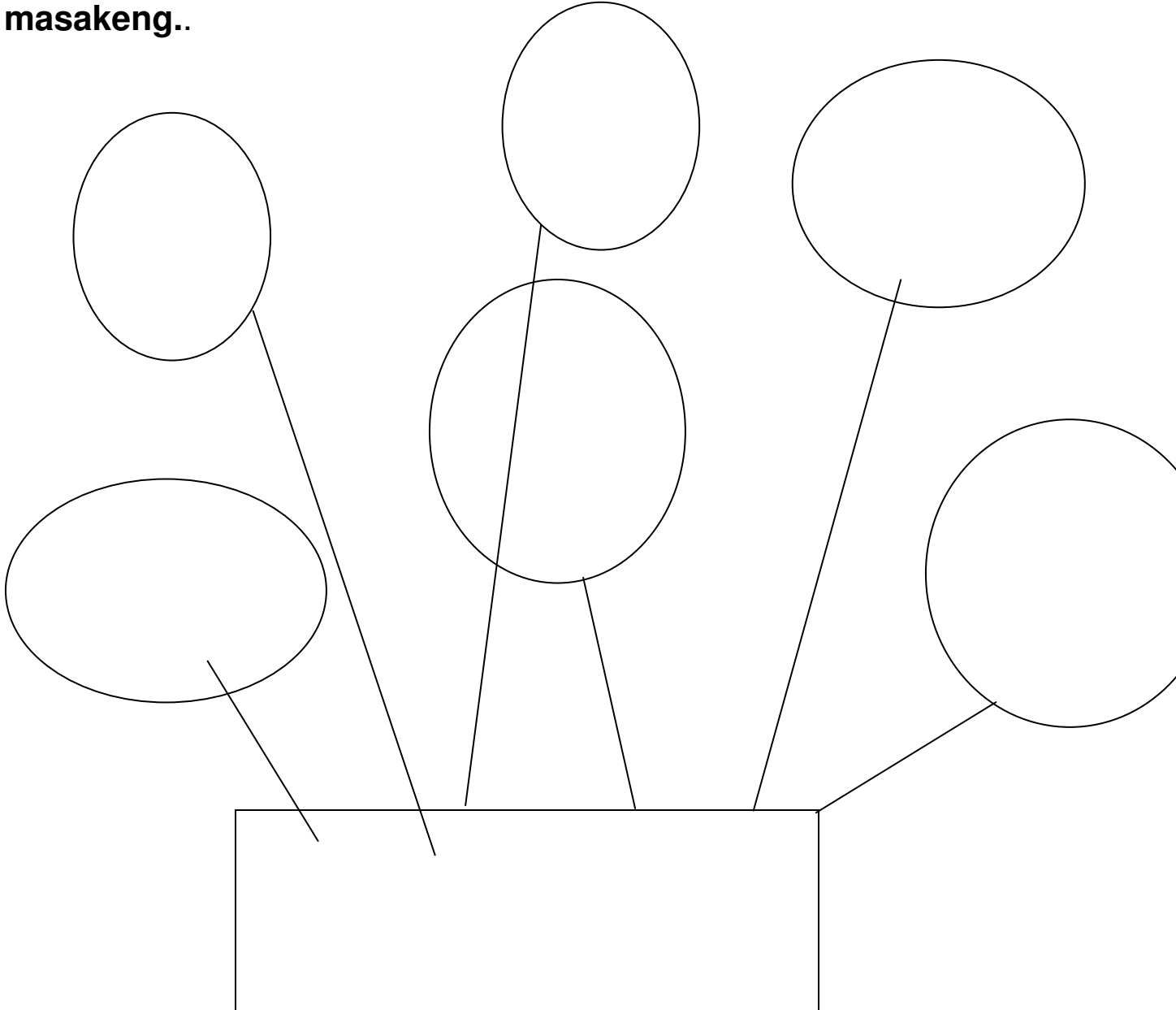


Tlhalosa gore o ikutlwa jaang ga o fela pelo me o rata go lwa.O ka dira sekai ka setshwantsho.

Tiro yak o gae

Dira setshwantsho sa sefatlhego sa gago ka mo khutlonneng e e fa tlase.

Tlatsa matshwao otlhe a o kileng wa itemogela one mo masakeng..





A go na le kalafi
ya bolwetse jwa
Schizophrenia?



Fa o dirisa melemo ya gago
bolwetsi jwa Schizophrenia bo
ka okobala. Lemoga gore a ka
se timelele sa leruri.

GOPOLA

O tshwanetse go dirisa melemo ya gago
jaaka o laetswe ke dingaka kgotsa
baaki.



Tlhalosa/Ngwala gore melemo e go thusitse jaang.

Matshwao a re tsibosang ka bolwetsi



Matshwao a re tsibosang ka ga bolwetse ge bo boa.



Go latela dikao le matshwao a re tsibosang fa bolwetse bo boa:

- Go se iketle
- Go fetoga ga mekgwa ya go robala
- Menagano le maitemogelo a a sa tlwaelegang
- Go boa kgotsa go oketsega ga go fagamoga
- Go boa kgotsa go oketsega ga go ithamaka
- Go tlhakatlhakana mo monaganong
- Go retelelwa ke go tsea dilo tsia
- Boitshwaro jo bo sa tlwaelegang

Go ikgatholosa bangwe(go rata go nna o le esi)

APPENDIX F

The adapted *Alliance Programme*

(English version)

Workbook

for patients with schizophrenia

An adapted version for the South African context

Based on Pfizer's *Alliance Programme*: a resource for patients with schizophrenia, their caregivers and mental health professionals

What is Schizophrenia?

What is Schizophrenia?



It is
when someone is mad



No, schizophrenia is a
mental illness



Someone who has
schizophrenia sometimes acts
strangely and abnormally.
This is called being **psychotic**

What does it mean to be psychotic?



It means that a patient is ill and has lost contact with reality.

Homework

Write down what happens to you when are psychotic. Or draw a picture of yourself.

What does schizophrenia do to a person?



Schizophrenia is like a thief. It steals who we are from us



It steals

- our memory
- our concentration
- our good plans for our life
- our strength and energy
- our writing and reading skills

Why do people suffer from schizophrenia?



Some people get it from their parents or relatives. They inherit it

The use of illegal drugs and alcohol can make some people ill



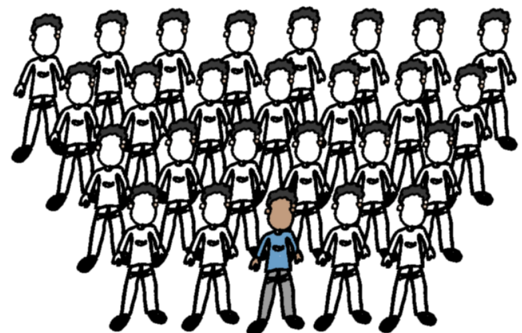
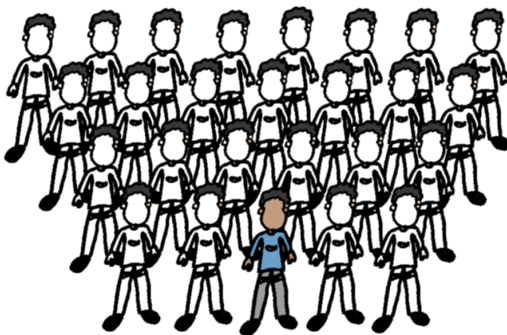
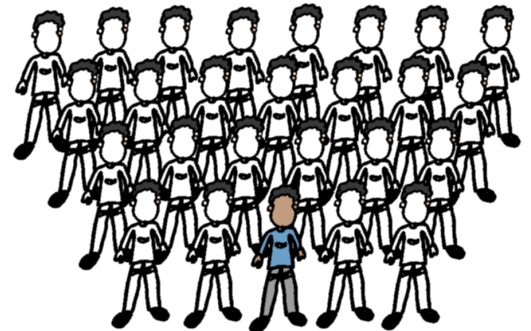
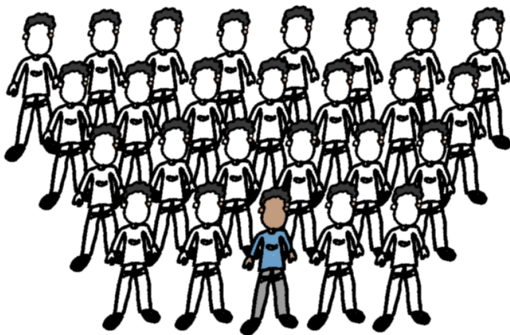
It can also be triggered by stress or trauma

How many people suffer from schizophrenia?



You are not alone

One in every 100 people suffers from schizophrenia all over the world. That is 1 percent of all the people in the world



Homework

1 What does schizophrenia mean?

2 Why is schizophrenia like a thief?

3 What does it mean to be psychotic?

4 How many people out of every 100 people in the world suffer from schizophrenia?

5 What causes schizophrenia?

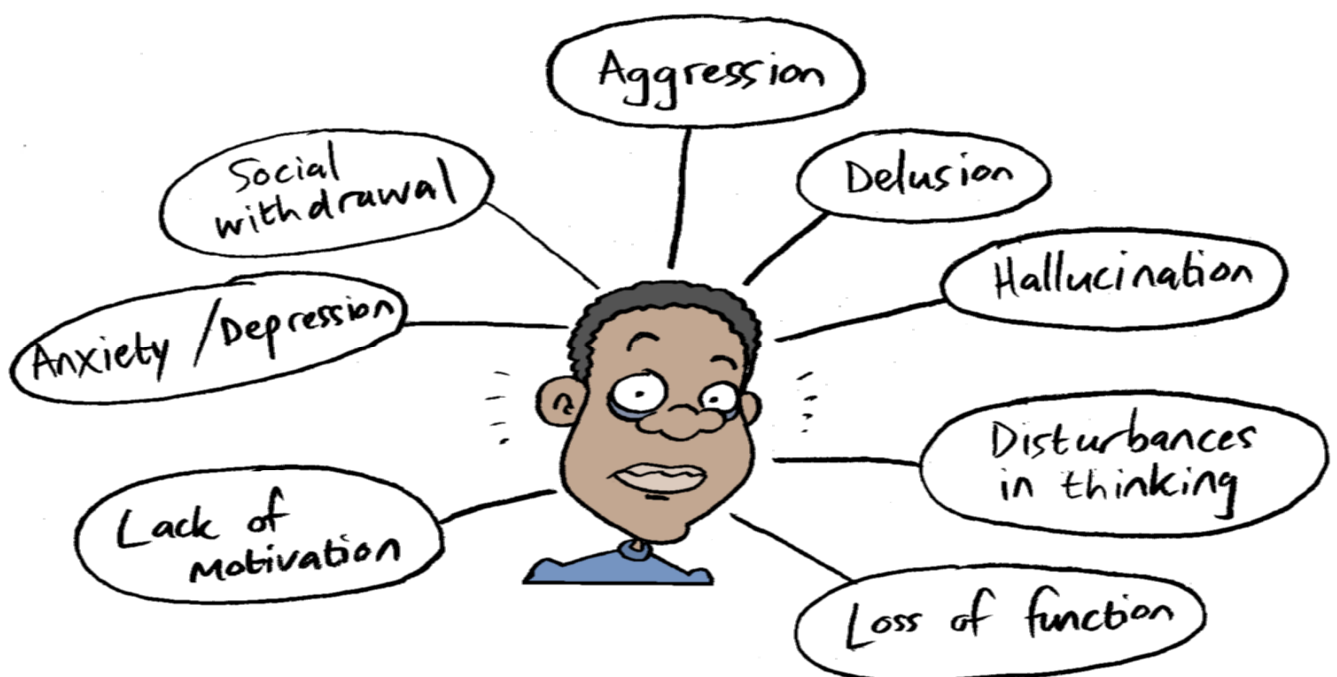
Symptoms of schizophrenia

What is a symptom?



Symptoms are things we feel when we are not well

The following are signs and symptoms of schizophrenia:



Hallucination



What is a hallucination?

It is when a person experiences things that other people can't hear, see, smell, taste or feel



It is like hearing someone talking to you, when in fact nobody is really speaking

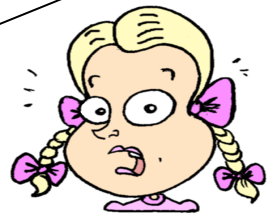
Write down or draw an example of a hallucination that you have experience before

Delusion



What is a delusion?

I think it is when a person believes in things as if they are true when they are not. Sometimes people who suffer from schizophrenia believe they are famous or powerful



People who suffer from schizophrenic sometimes think people want to harm them or kill them, or are talking about them

Write down or draw an example of a delusion that you have had

Loss of function



What does loss of function mean?

It means losing energy and the drive to do things



Sometimes I cannot read as well as I usually do

Tell us about a time when you experienced a loss of function. You can also draw it below

Lack of motivation



What
is a lack of motivation all about?

It is when I am feeling tired all the
time. I do not want to be bothered with
anything



I do not want to start
anything new

I feel very tired



Tell us how you feel when you experience a lack of motivation. You can also draw a picture of yourself when this happens

Social Withdrawal



What does social withdrawal mean?

It is when people who suffer from schizophrenia exclude themselves from other people



I sometimes hate being around other people. I really love to be alone



Tell us about the times that you felt like being alone all the time

Disturbances in thinking



It is when someone's thoughts are mixed up


Examples of this could be poor concentration, forgetfulness and confusion




I often forget a lot.
I sometimes don't know where I am

Tell us about any disturbances in thinking that you have experienced. You can also draw it


Aggression



Some people who suffer from schizophrenia are violent and dangerous



I am more likely to feel irritable when I am under stress or the influence of alcohol or drugs



Hallucinations or delusions can lead to violent behaviour



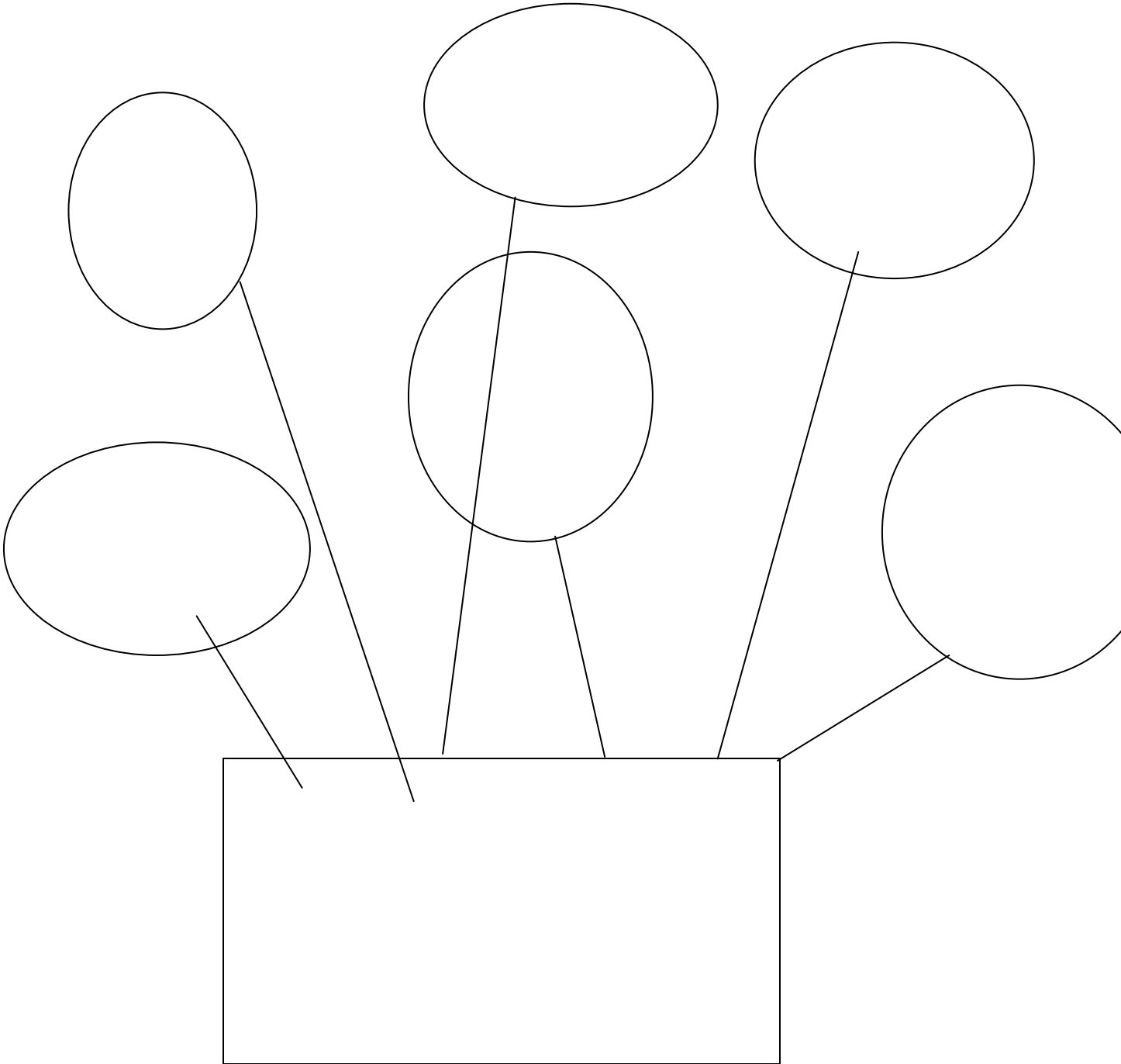
I am sometimes violent and feel like beating people

**Explain how you feel when you are irritable or violent.
You can also try to draw your feelings**

Homework

Draw a picture of your face in the box below.

Then fill in all the symptoms of schizophrenia you experience when you are not feeling well in the circles



Treatment of schizophrenia



What is the
cure for
schizophrenia?

Taking your medicine can help
to make schizophrenia better.
But **remember**, the symptoms
do not go away forever



Remember:

You must take your medicine **exactly** as the doctors or nurses tell you to



Write down how the medicine helps you

Early warning signs



Early warning signs are signs that the illness is coming back



The following are the signs that can tell you that the illness is coming back:

- Nervousness
- Change in sleeping pattern
- Strange thoughts and experiences
- Return or increase in hallucinations
- Return or increase in delusions or false beliefs
- Disturbances in thinking
- Concentration problems
- Strange behaviour
- Social withdrawal or wanting to be alone

Homework

1. How can the symptoms of schizophrenia be treated?
2. . What medicine must you take?
3. How often must you take it?
4. Why is it important to take your medicine?
5. Can schizophrenia be cured when you take your medicine?
6. What signs tell you that you are going to become ill again (early warning signs)?

Remember this

Schizophrenia is a **mental illness**

Symptoms differ from person to person

People experience schizophrenia in different ways.

It is important to take your **medicine** in exactly the same way that your doctor or nurse has told you to.

Medicine can treat the symptoms of schizophrenia, even though it cannot make them go away forever.



There are signs, called early warning signs, which tell you that you are going to become ill again.

Go and see your doctor or nurse when you experience these signs

Tiro ya ko gae

Schizophrenia se ka alafiwa jaang?

2.Ke melemo e feng e o e dirisang?.

3.O dirisa melemo ya gago ga kae?

4.Ke go reng go lr bothokwa go dirisa melemo ya gago?

5.A bolwetse jwa Schizophrenia bo ka fola fa o dirisa melemo ya gago?

6.Ke matshwao a a feng a a re tsibosang ga bolwetsi bo boa?

Tlhokomela se;

Schizophrenia ke bolwetse jwa monagano

Matshwao a farologane go ya ka go farologana ga batho. Batho ba itemogela matshwao ka go farologana.

Go botlhokwa go dirisa melemo ya gago go ya ka mo o laetsweng ke ngaka kgotsa mook

Melemo e ka kgona go alafa matshwao a bolwetse jwa Schizophrenia, le fa tota e sa kgone go fedisa bolwetse gotlhelele.

Go na le matshwao le dikao tse di re tsibosang fa boletsi bo boa.

Etela ngaka kgotsa mooki ga o simolola go ikutlwa jaalo.