

Testing the effectiveness of existing psycho-educational material (The Alliance Programme) for patients suffering from schizophrenia in the South African context

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Abstract

Objective: The objective of this study was to test the effectiveness of the existing psycho-educational material (The Alliance Programme) for patients suffering from schizophrenia in the South African context. **Method:** A qualitative research approach was used. Fifteen Setswana speaking participants, with a diagnosis of schizophrenia were exposed to the programme. Semi-structured and screening interviews were used to collect demographic and clinical data. The participants were divided into two groups and were exposed to either the Alliance Programme or on adapted version of the programme. Participatory communication instruments including focus groups, were used to assess comprehension and knowledge retention of the material over time. **Results:** Participants who were exposed to the original Alliance Programme experienced the contents of the programme to be technical, difficult to read or recall. They were unable to relate their previous symptoms to the psycho-education given. Participants who were exposed to the adapted version fared much better, gained more insight and were able to relate better to their illnesses. Participants preferred booklets with examples and illustrations, video clips and films over formal lectures. **Conclusion:** Psycho-education material given to people suffering from schizophrenia and their caregivers has to be adapted to their context to be effective.

Key Words: Schizophrenia; Psycho-education; Participatory communication: comprehension.

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Introduction

Schizophrenia is a chronic illness that is often characterized by periodic relapses and incomplete remissions. It affects 1% of the population worldwide, and is rated as the 8th leading cause of disability-adjusted life years (DALYS) worldwide in the age group 15-44 years.¹ It is first diagnosed in late

adolescence and early adulthood.² It often follows a chronic course in which the person may experience reduced social and occupational functioning, loss of independent living skills, impaired quality of life, and increased risk of suicidal and violent behaviour.² Co-morbid conditions and substance abuse are common in schizophrenia and approximately 10% of patients are likely to commit suicide, 44-59% are likely to have stopped their medication by the end of the first year after diagnosis, worsening their prognosis.³⁻⁶ For these reasons it is important for people with schizophrenia to gain insight into the disorder, to understand what precipitates it and its course.⁴⁻⁸ However, studies have shown that about 50-80% of patients diagnosed with schizophrenia partially or

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totally lack insight into their mental illness.⁴ This could be due to the lack of understanding of their mental illness. Therapeutic interventions like psycho-education offered in the early stages of the disorder have been shown to benefit the sufferers and caregivers.⁷⁻⁸ Other studies have also highlighted the adverse impact that gaining insight can have on sufferers, however. In these studies, improved insight is associated with depression and increased suicidal tendencies in high functioning, recently diagnosed vulnerable individuals.⁴ Psycho-education, therefore, has to be introduced in a systematized and controlled manner to minimize such risks. Psycho-education involves teaching patients about their illness, how to treat it and how to recognize signs of a relapse, so that they get treatment before the psychosis worsens or reoccurs.⁶⁻⁸ The main purpose of psycho-education is to increase the knowledge and understanding of schizophrenia so as to improve their quality of life.

As desirable as psycho-education may be, limited resources in countries like South Africa make this intervention difficult to apply. Low and middle income countries [LAMIC] tend to allocate less than 1% of the national budget to mental health resources, which makes mental health a non-priority, invariably.⁹⁻¹² The situation in South Africa may not be that different, as there are limited mental health facilities and personnel to provide these services.¹⁰⁻¹³ There is often little help from the communities in which the families and their afflicted participants stay, due to unavailability of resources. Added to this, communities with diverse cultural and belief systems, such as seen in South Africa, tend to seek mental health care from other sources like traditional healers (including sangomas, spiritualists, faith healers and inyangas), rather.¹⁰ (Sangomas rely on dreams and premonitions to arrive at a diagnosis and use herbs to heal their client's problems, whereas inyangas throw the bones to diagnose a client's problems and use herbs to heal them. Spiritualists and faith healers both use the holy Bible to make a diagnosis, and prayer and water to offer some form of healing.) To ensure a meaningful quality of life for an affected member and his caregivers, it is important for them to receive psycho-education immediately after the point of first contact with a mental health care provider and to integrate such education with their belief systems. Mental health care providers need to be sensitive to the cultural background and beliefs of the patients and their families and accommodate their faith and value systems, especially towards traditional healers.

In this ongoing collaborative study between the departments of psychiatry and information sciences of the University of Pretoria, Phase I explored the profile of the target audience and their expectations of what psycho-educational material should include using participatory communication methods.¹⁴ Phase II (the current study) aimed to test the effectiveness of existing psycho-educational material and to adapt such to suit the audience profile.

The effectiveness of psycho-educational material has been shown to be dependent on the communication approach chosen. The ineffectiveness and/or inappropriateness of psycho-educational material, is in

most cases due to the material not being adapted to adequately address the needs of a specific target audience.¹⁵ This problem is caused by the exclusion of the target audience from the design and production of the psycho-educational material, which leads to a top-down communication approach. According to literature, the most effective approach is participatory communication, which argues that the point of departure must be the community or the target audience.¹⁶ In order to communicate information about schizophrenia to patients suffering from the disorder effectively, research and/or knowledge of the target audience is necessary. There is a wealth of evidence in the scientific literature (including neurobiological and imaging studies) that demonstrates that there are identifiable neuronal changes consistent with the diagnosis of schizophrenia.¹⁷⁻²¹ It is therefore imperative that the adaptation of psycho-educational material accommodates for the neurobiological and cognitive deficits of patients with schizophrenia.

"The Alliance Programme" is a Pfizer funded project developed in Austria, Europe. The contents thereof were reviewed in Spain, Argentina, and Hungary by experts on schizophrenia.²² The company intended to make it available in several countries, including South Africa. The purpose of the programme was to impart information about schizophrenia, offer practical advice on treatment, provides support and tools on how to cope with the condition. It was intended for patients, their caregivers and mental health care providers. Its effectiveness had not been tested in South Africa prior to this study.

The aim of this study was to evaluate existing psycho-educational material for effectiveness and appropriateness, and to add to the knowledge base in order to develop guidelines for the design of psycho-educational material in the South African context. Very little research about the effectiveness of material used in the psycho-education of patients has been conducted in this setting.¹⁴ Moreover, the limited available material does not appear to cater for the needs of certain population groups of patients with schizophrenia. Some of the trials used in South Africa's mental health services have not been adapted to the local context. It is in this light that this study aimed to test the effectiveness and appropriateness of the Alliance Programme using Setswana speaking patients with schizophrenia. The study further attempted to adapt and develop guidelines and make recommendations on psycho-educational material to suit the needs of target audiences in South Africa. It is hoped that the information derived from this study will be used to support mental health care providers in offering scientifically validated and appropriate psycho-education. This prevent or minimize the number of relapses and readmissions that continue to drain the country's limited mental health care resources.

Method

Subjects

A total of twenty one patients were recruited from Weskoppies Hospital. Only eighteen participants turned up for the initial evaluation meeting. Nine of the participants were in-patients and the other nine were

following up at the out-patients department. Only fifteen of the participants managed to complete the study. One out-patient and two inpatients were lost at follow-up. Informed written consent was obtained from the participants. Medical records of the patients were retrieved to confirm their demographic data, diagnosis, duration of mental illness and the medication that they were receiving. All the patients met the diagnostic and statistical manual IV- TR (DSM IV-TR) criteria for schizophrenia.²³ The diagnosis had to have been made at least 6 months before the commencement of the study (Table I). Upon recruitment, firstly, a semi-structured interview was used to gather information about the diagnosis. Secondly, the participants were all interviewed using a questionnaire in which the following information was elicited:

- baseline assessment of their awareness of mental illness,
- where and when they were diagnosed,
- by whom they were diagnosed, and
- whether they had been exposed to any psycho-educational program previously.

Table I :Criteria of the participants

INCLUSION	EXCLUSION
Age :18-60 Setswana speaking Able to give consent	Current active psychosis Active substance abuse Recent history of violence or mutilation

Two focus groups (group A and B) were planned. Group A would be exposed to the original version of the Alliance Programme. Group B would be exposed to the adapted version of the Alliance Programme.

Instruments

The Global assessment of functioning scale (GAF) was used to assess the patient's level of functioning.

A mini-mental state examination (MMSE) was done to assess the level of cognitive functioning of each participant, first during the initial meeting and then 3 months later, after exposure to either the Alliance Programme or the adapted programme.

Data collection instruments:

- Semi-structured interviews were, also referred to as "moderately scheduled interviews" were used to elicit responses in the screening interviews and focus groups. These are informal interviews that are based on a set of basic questions that are used for informal analysis.¹⁶ The set of questions prepared are open, allowing the people being interviewed to express opinions through discussions. Semi-structured interviews are conducted with a fairly open framework which allows for focused, conversational, two-way communication.¹⁶
- Focus groups were used and a free and interactive communication style was preferred. Focus group interviews are participatory communication instruments used to combine the advantages of both the individual interview and the participant observation. A focus group can be described as a carefully planned discussion group designed to elicit perceptions on a defined area of interest

in a permissive, non-threatening environment. The goal of a focus group is to produce data on perceptions, feelings and the manner of thinking about an issue, and not to reach consensus or to make decisions about possible courses of action.^{15,16}

- Participant observation was undertaken by one of the researchers, whilst another was capturing the process in writing.
- In addition, a tape recorder was used to capture the dialogue in the focus group discussions, so as to aid in the transcription of data at a later stage.
- Formal or structured interviews instead of informal or semi-structured interviews were used to answer the prepared questions. In a structured interview the questions are provided in a systemic order, with minimal or no deviation from the prepared script.

Procedure

The study was conducted with the approval of the Health Science Research Committee, of the University of Pretoria. Informed consent procedures as approved by this committee were strictly adhered to throughout.

The participants were randomly allocated into two groups, namely group A and B, each comprising of seven and eight participants respectively.

Provision was initially made to support the participants financially for their transport needs.

Group A participants were introduced to the original version of The Alliance Programme, dealing specifically with signs, symptoms (including early warning signs) frequency, course and prognosis of schizophrenia (pages 15-34). One of the long-term objectives of the study was to ensure that the participants would recall what they would learn during the psycho-education so as to use that knowledge in future assessments. Two qualified mental health care professionals were tasked with the work of providing the material; one offered psycho-education, whilst the other translated for the participants. The participants spoke different Setswana dialects and an agreement about a common language was necessary at times. In some instances it became necessary to use English to explain medical terminology not available in Setswana. Mental health care providers, fluent in Setswana, were chosen to communicate with the participants to limit any distortions and misinterpretations of the researcher's intentions. Three one hour sessions were conducted over a period of three weeks. In the fourth week the participants were given a questionnaire to test their retention of recently imparted information concerning the programme. The same was repeated at week seven.

Group B participants were presented with an adapted version of The Alliance Programme. This simplified and illustrated version was developed specifically for this particular group of participants (as described elsewhere). A reader- focused approach was used to develop the adapted version of the Alliance program. The content of the material was structured in easy to understand language. Cartoon illustrations and simplified explanations were used to enhance interest and understanding. An attempt was made to keep the information simple yet accurate and appropriate for the target group. The booklet

was written in Setswana, using the language, phrases and examples that were coined and used by the participants of Group A. A copy was issued for each member of group B to take home. After each session participants were handed a list of questions or tasks that were to be completed as homework. Examples of these are:

- Describe the circumstances surrounding the initial and subsequent episodes of your illness?
- What were your interpretations of the hallucinations, delusions and psychosis?
- What do you think contributed to your mental illness?

At the end of 3 weeks the participants of Group B were interviewed individually and also in a focus group to assess how much understanding and retention of the psycho-education had occurred.

At the end of data collection sessions for each group, the material was analysed respectively using inductive qualitative content analysis. Responses from participants were reviewed to identify common themes. The findings described below were compiled by identifying emerging common themes and categories and by comparing the two groups' responses.

Results

Group participants had different perceptions of mental illness depending on the type of psycho-education they had received. Also, within each group, the perceptions evolved over time. The following themes were identified from both group A and B:

- **Denial**
Initially most participants said that they were told that they were suffering from schizophrenia without concrete proof of the illness. Comments like "How do the doctors know that I have schizophrenia? There were no tests done. They just talked to me and thereafter told me that I suffer from schizophrenia." Most participants (more than half) identified with this line of thought. However, later, later during the information retention assessment group, 83% of Group A and 100% of Group B participants believed that they were correctly diagnosed.
- **Rejection**
Participants of both groups complained about feelings of loneliness and lack of support from family, friends and the community. "I told my neighbour that I have mental illness, now she avoids me. It feels painful." As a result they preferred rather to withdraw from social interaction than risk people "laughing at you as you leave, it is as if they know that you have mental illness." After the modified version of the Alliance Programme was issued to the participants of Group B they felt more accepted as their families took an interest in the booklet. This is illustrated by a relative of one of the group B participants who called one of the facilitators to express her appreciation for the booklet on behalf her family. She reported that the family found the booklet informative, easily accessible and helped them understand the participant better. Group A participants were not provided with any booklet and there was no contact with their families.

- **Traditional belief system**
In the beginning almost all the participants overtly or covertly believed that witchcraft played a role in the fact that they had mental illness. Some even expressed disappointment in the way in which their family and care-givers handled that first episode of mental illness. They would have preferred to have been taken to traditional or spiritual healers first. Statements like "I was very intelligent, good in English and Mathematics. After eating food at a party that had poison in it I started to have mental illness." "I had a dream in which my ancestors told me that I would become a very famous sangoma if I went for initiation."

The rest of the participants supported them and wondered loudly what could have happened to them had they consulted with traditional healers from the onset.

At the end of the study period, participants still had strongly held views but were less likely to act based on their beliefs.

- **Feelings of hopelessness/worthlessness**
The pervasive theme in all the group session was that participants perceived their lives as having no purpose. "When I learnt that my paternal grandmother had mental illness, I ended up hating her and myself. Why me? Sometimes you think of committing suicide." One member said that if she gets angry at home over anything, the family calls the police to bring her back to the hospital. Others agreed and claimed that other people do not take their opinions seriously. By the end of the program, the participants admitted that they now find themselves interacting more with their families and friends. "Parents now treat me accordingly", one member said.

Understanding mental illness

a) Causes

More than 50% of the participants cited hereditary factors and use of illicit drugs as contributory factors that led to them having mental illness. The others also blamed bewitchment, stress and childhood trauma. One member stated that he was first admitted after continuous use of cannabis. He also said he was admitted several times but "always went out to smoke cannabis just to prove that cannabis and mental illness were not related. A lot of people smoke it and they are not suffering from mental illness". He went on to say that since he stopped using cannabis ten years ago, he remained symptom free and had had no readmissions. Most agreed that their symptoms were better controlled after they stopped smoking cannabis.

One participant said "I grew up in an abusive home. I used to be alone all the time." She claimed that people confused her behaviour as mental illness, whereas she was just thinking a lot. At the end of the session most of the participants tried to convince her that there must have been reason to believe that she had mental illness. The participant remained convinced that she had no mental illness.

b) *Symptomatology*

Only half of the participants of Group A could explain their symptoms and signs in the event of a relapse. They used terms like "I feel confused" directly translated from Setswana "Ke tlhakatlhakane". They indicated that in Setswana language, a specific name for a mental disorder does not matter as all mental disorders are collectively called "bolwetse ba tlhogo". At the end of the programme, they still believed that lay people would struggle to remember the medical terms that were used. They rather preferred to explain the signs and symptoms in their own words. There was one participant who claimed that he had never experienced any of the signs and symptoms mentioned or any behavioural changes, and yet he was diagnosed with schizophrenia.

c) *The role of medication*

More than 90% of the participants responded that they believed that medication helps by providing relief from the hallucinations and suicidal thoughts, improving the quality of sleep and their eating habits. Less than 10% of Group A participants believed that the medication made no difference, or offered very little change, "made you lazy or overeat". At the end of the sessions all the participants in both groups believed that medication was helpful. About half of the participants claimed to have tampered with their medication by increasing, decreasing or stopping the medication altogether. Some claimed that they did so to test whether they are cured whilst others actually believed that they did not need medication. At the end of the program, all the participants agreed that medication will make the symptoms better and recognised that they need to use medication for a long time.

d) *Previous exposure to psycho-education*

About 80% of the participants in Group B knew the name of the illness that they were suffering from and nothing else about the illness. This was in comparison to a third of participants in Group A. They claimed to have been told by mental health care workers (doctors, nurses, and social workers) about their mental illness. Sixteen percent claimed that they were never given information about their illness. They rest said they had learnt about their diagnoses from family and friends. One participant stated that she had read about her disorder from her medical records. Those who were told about their illness said that they were never given an opportunity to ask questions around their illnesses. At the end of the program, all the participants knew more about schizophrenia, the causes thereof, the course, management and risk factors.

Group dynamics

- *Group A sessions*

Group A participants seemed bored and uncomfortable; there was very little interaction between the participants. The facilitator did most of the talking, a top-down form of interaction. The participants interacted directly with the facilitator and

much less with each other. The facilitator used a chalkboard to write down what she was teaching to the participants. The participants were so passive that when a fellow participant interrupted the others, they didn't intervene and the responsibility of managing him was left to the facilitator. However in subsequent groups they seemed to be more relaxed and spontaneous. The interaction was with the facilitator and amongst themselves. When asked questions on what was previously taught, they found it difficult to explain in simple language the signs and symptoms that they had previously experienced, or been taught about. They used their own words to describe the signs and symptoms that were discussed in the previous section.

- *Group B sessions*

This group of participants was more engaging than the Group A. The interaction was spontaneous amongst group participants and with the facilitator. 80% of the group participants already knew what type of mental illness they were suffering from. Only 20% of the participants denied mental illness. The facilitator had a modified version of the Alliance Programme workbook. The participants given an overall picture of what the booklet entailed and what the expectations were from the group. The participants in this group had divided attention as they were busy paging through the booklets whilst the facilitator was talking.

During the second session the participants were even more engaging and were eager to share their experiences. Interactions occurred freely amongst them. The participants were able to identify with the signs and symptoms of schizophrenia and cite from the booklet. They were also able to come up with other symptoms of mental illness that they had observed in other patients in Weskoppies Hospital. The atmosphere in this group was that of acceptance, companionship and relief as the participants gained insight into their mental illness.

- *Differences in group responses to the The Alliance Programme and the Adapted version*

During the screening interview session, group A participants displayed little knowledge about the name of the mental illness from which they were suffered. They also struggled to describe their symptoms. They lacked the vocabulary to express themselves well. The interaction in the first group was mostly bi-directional, from facilitator to member, and vice versa. They used their own words to explain their understanding of schizophrenia.

Group B participants fared better from the point of first contact. Most of the participants formed meaningful relationship with other participants by sharing their experiences and identifying with each other. They needed little input from the interpreter. They had higher levels of education, were of more advanced age, with a longer duration of mental illness. This group was issued with booklets to read by themselves and to take home for self-study and to do

tasks. Their retention of knowledge exceeded that of the other group who were using only the chalkboard for their psycho-education.

Both groups had each participant's mini-mental status examination (MMSE) done before and after the psycho-educational sessions. Participants of group A had scores ranging from 24/30 to 30/30. Participants of Group B had scores ranging from 28/30 to 30/30. The participants of Group B's higher MMSE scores tied in with their higher educational status, their older age and their superior level of interaction, perhaps.

The original version of the Alliance Programme is written for health professionals, caregivers and patients and uses medical terminology that is highly technical. There are no illustrations or examples to highlight and explain a concept better. The adapted version is written in simplified language, replacing the medical terms with what lay people would use to describe mental illness. Illustrations and cartoon pictures were used to explain difficult concepts.

Group A's feedback on the original version was that it was difficult; the language used was too technical. They believed that lay people and not just patients with schizophrenia would struggle to understand the programme.

Group B participants found the adapted version easy to read and understand. They particularly liked the fact that even their relatives could understand it. They claimed to understand their mental illness better due to the examples given in the booklet.

Discussion

The participants that were exposed to the original Alliance Programme (group A) experienced it as being difficult and of a highly technical format. Those who were exposed to the specifically tailored adapted version of the Alliance Programme (group B), found it to be readable, easy to understand and acceptable.

When tested on comprehension and information retention at the end of the session, Group B participants fared much better than Group A. It has to be noted though, that Group B participants had higher scores on MMSE compared to Group A initially. Group A did improve by the end of the study however. Schizophrenia is associated with progressive cognitive decline and we would have expected this to affect all the participants.²⁴⁻²⁶ The participants from Group B proved the contrary. Although the prognostic features of schizophrenia were not specifically investigated during the screening sessions, it became apparent during the interviews that Group B participants shared a higher educational level and had a history of skilled employments, suggesting that they most probably also had a good pre-morbid history. Table II represents the demographic data. The advanced ages of the participants in Group B may also reflect the cumulative years the participants were suffering from mental illness and their adaptation to their diagnosis. The assumption could be that Group B participants were more likely to have been exposed to psycho-education in the past. This finding will need to be replicated in future studies however.

Table II: Characteristics of the participants

VARIABLES	GROUP A	GROUP B
Sex	Males: 5 Females: 2	Males: 6 Females: 2
Age	18 – 28: 0 29 – 38: 5 39 – 48: 2 49 – 58: 0	18 – 28: 2 29 – 38: 3 39 – 48: 0 49 – 58: 3
Education	Primary: 2 Secondary/Tertiary: 1	Primary: 2 Secondary/Tertiary: 5
Previous Occupation	Skilled: 1 Unskilled: 2	Skilled: 3 Unskilled: 2
Employment	Unemployed: 4	Unemployed: 3
MMSE	Pre: 24/30 – 30/30 Post: 27/30 – 30/30	Pre: 28/30 – 30/30 Post: 29/30 – 30/30
In vs Outpatient	Inpatient: 4 Outpatient: 3	Inpatient: 4 Outpatient: 4

The top-down method of communication used in Group A was less effective than the participatory interactive method used in Group B. Group A participants fared poorly on tests for comprehension and retention of information. Free flowing communication was limited due to the top down approach in the group. The type of communication used for their sessions is used in some settings by health care professional to educate the patients about schizophrenia and yields limited results. During the screening sessions of this study, it was found that only about 50% of the participants had been told what mental illness they are suffering from previously. This was despite the fact that the diagnosis had been made at least six months before the commencement of the study.

Limitations

Although the sample size was small and may not have been representative of the larger community of participants with schizophrenia, the results are significant from a qualitative research perspective. Learning about the real world of the participants was more important than concerns over quantitative values. Moreover, information gained from this, can be adjusted to other language groups. Further limitations included:

- Due to the different dialects of Setswana spoken around Tshwane, the situation necessitated an interpreter to allow for a uniform language. This however proved to be an expensive exercise as a lot of time was wasted. This will be difficult to replicate in natural settings.
- The participants completed their homework at home and it remains speculative whether they completed the questionnaires themselves always or they were assisted by their family.
- The group sample consisted of both in- and out-patients in different stages of the illness, and this could have an influence on the discrepancy observed from the results.

- Group B participants had an advantage over Group A participants in that their MMSE was higher at baseline, had advanced educational status and a good pre-morbid history
- No assessments were done to test if Group B had been exposed to psycho-educational programmes before.

Conclusion

It is recommended, that a multi-professional team approach be used in patient psycho-education as this seems beneficial and effective. The collaboration between researchers and professionals from the Information Science department and those from the Psychiatry department (including psychiatrists and social workers) enhanced the process of formulating a booklet for schizophrenia sufferers. The combined efforts of the two departments - from the conception of the project to the production of appropriate, effective psycho-educational material - was essential. Feedback from the participants suggest that:

- Simple and easy to read booklets with examples and illustrations are useful as a source of supportive information
- Use of simple English is still useful if there is no other option (the assumption is that Setswana would have been preferred)
- Video clips and films are preferred over formal lecturers
- Families of schizophrenia sufferers also need to be educated about the diagnosis

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