

# In touch with reality

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## Abstract

**Objective:** A descriptive study in which the audience profile of patients suffering from schizophrenia, their families and caregivers was determined to establish whether information on schizophrenia is disseminated effectively. This is an ongoing project aimed at designing appropriate psycho-educational material on schizophrenia using the audience-based media production approach. **Method:** A Qualitative research method using screening interviews, focus groups discussions and participant observation. Undertaken at Weskoppies Hospital, Pretoria, Tshwane, South Africa. Using Sotho-speaking patients and their families from the greater Tshwane region. Three researchers from the Departments of Psychiatry and Information Science at the University of Pretoria facilitated four focus groups comprising of 18 participants. A schedule was used to guide the discussions and after each focus group, emergent themes were identified and analysed. Tape recordings and written notes were used to capture information. These were later transcribed and used for data analysis. The participants were asked to indicate how they understand schizophrenia and how living with this disorder influences their lives. **Results:** It seems that information about schizophrenia is not effectively disseminated to this group. Myths about the disorder prevail. The majority of the participants did not understand what schizophrenia is. The participants' perceptions regarding schizophrenia reflected the influence of their culture, religion and their experiences of stigmatization by the society in which they live. **Conclusion:** In the endeavor to effectively disseminate information about schizophrenia to patients and care givers, the prevalent top-down approach should be replaced by a more participatory approach where the target audience is consulted and involved in the process of psycho-education. **Declaration of interest:** None

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Schizophrenia is a chronic and debilitating neuropsychiatric illness for which there may be multiple unknown aetiologies.<sup>1</sup> It is a disease that is not well understood. Most of what people think they know about schizophrenia is incorrect.<sup>2</sup> The stigma of schizophrenia is a barrier in the rehabilitation process of patients and also affects the families of those who suffer from this disorder. Misconceptions about this illness are still rife.

The disease burden of schizophrenia in the community is severe. Studies from the United States show that patients with schizophrenia occupy up to 50% of all mental-hospital beds and account for about 16% of all psychiatric patients who receive any treatment.<sup>3</sup> In the South African context, poor understanding of the disease process makes the burden greater.

Denial of illness that may be based on attitudes common to the patient's social and cultural groups, may worsen the burden.<sup>4</sup> The denial may be part of the pathological process, but it is almost always influenced by the social context.

Despite the well-documented efficacy of psycho-educational and behavioural approaches in family interventions for persons with serious mental illness, clinicians have rarely included these methods in their professional repertoires.<sup>5</sup>

Thus far very little research into the psycho-education of patients and their families has been conducted in the South African setting. The result of this is that South Africa's mental health services have not adapted to the South African context. Information about diseases is often communicated without taking the specific environment and target audiences into account.

Historically, communication theories and practices excluded the target audience from the design and production of the message.<sup>1</sup> This led to a one-way mode of communication.<sup>7</sup> Participatory communication theory on the other hand argues that the point of departure should be the community or the target audience. Such an audience participation based approach creates a circular dialogue where the audience is the sender as well as the receiver of information.<sup>8</sup>

## Method

### • The Rationale for Qualitative Studies

Qualitative methods are useful for areas of research that are poorly understood, ill-defined and for which controls cannot easily be devised. In this study it was attempted to understand the participants' subjective experiences. Phenomenology acknowledges that a person's "life world" is a social, cultural and historical product, as well as a pole of individual subjectivity.<sup>9</sup>

### • Data collection instruments

Data collection instruments used, included screening interviews, focus group discussions and participant observation.

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Screening interviews were used to determine the mental status of the patients and collect their demographic data.

A focus group discussion is a useful instrument to explore sensitive issues, because it allows individuals from marginalized groups to engage freely in a non-threatening environment. Focus group discussions were originally used for marketing research but have now become a popular method of conducting qualitative research.<sup>10</sup> Focus groups discussions involve a small number of respondents (usually 6-10). Under the guidance of a facilitator the subject of investigation is explored extensively<sup>11</sup> in an informal group discussion that should engender an atmosphere in which participants feel comfortable to express their ideas freely and discuss their attitudes and behaviours.<sup>12</sup> This is especially important in health research where sensitive issues are often explored.

Data collected during focus group sessions can be enriched by participant observation during the focus group discussions. This involves taking notes of nonverbal cues and dynamics at play during the group discussions.

- **Procedure for recruitment of participants**

A research protocol was written and submitted to the Ethics committee of the Faculty of Health Sciences at the University of Pretoria. Permission was granted to proceed with the study. Initially the researchers planned to randomly sample patients from files at the outpatients department at Weskoppies Hospital. This plan was discarded because contact details were not always accessible. Ultimately, the researchers approached individuals at the outpatients department. Eighteen patients in total were recruited. Two of these participants were chronic inpatients at the hospital.

- **Group facilitators**

Three researchers and two supervisors were involved in the study. The researchers - two with a medical background and one with a background in development communication - facilitated the focus groups. During the sessions the facilitators were divided into a main interviewer; a scribe; and an observer and audio-recorder monitor. Two of the facilitators could speak Sotho fluently and one was a non-fluent Sotho speaker. All the facilitators lived or worked in the Tshwane area. They were familiar with local cultures and social trends. The role of the facilitator(s) was to pose questions from the interview schedule, to reflect and summarize responses and to encourage and allow free-flow of ideas from the participants.

### **The research process**

First, recruits were invited, introduced to the study and were then given written consent forms in which the study was explained in detail. Those who agreed to take part in the study were asked to sign the consent forms and were informed that they could withdraw from the study at any given time.

Subsequently a screening interview was performed to ascertain demographic details, exclusion and inclusion criteria, mini-mental status examination (MMSE) and the global assessment of functioning score (GAF). Arrangements were then made for the future focus group meeting.

In total four focus groups, each with an average of five participants, were conducted. All the group sessions were held at Weskoppies Hospital. Audio-recordings and note taking were used to record verbatim and non-verbatim information.

The focus groups were generally made up of a combination of

patients and their caregivers. One group had patients only and another a predominance of caregivers. The other two groups had a more proportional distribution. Although not initially foreseen, the average number of five participants per group worked well as far as group interaction was concerned. Interaction between those who had diminished levels of functioning and those who were at a relatively higher level was enhanced by the space created by lower numbers of patients.

The focus groups were homogenous in that all the participants were Sotho-speaking (Pedi, Tswana and SeSotho) and lived in the Greater Tshwane region (Pretoria). They were also all previous or current users of Weskoppies hospital in and outpatient services. Five of the participants were caregivers and thirteen were patients. The groups were further also heterogeneous as far as age, gender and in some cases diagnosis, were concerned. Eleven of the participants were male and seven were female. Of the thirteen patients ten had been diagnosed with schizophrenia and three with schizoaffective disorder. In Table I, the age distribution of the participants is presented.

**Table I: Age distribution of participants**

Age group	Number
18-29 years	3
30-39 years	8
40-49 years	5
50-65 years	2
<b>Total</b>	<b>18</b>

Three of the participants were professionals in the medical field – one specifically in mental health.

Except for patients who came with their caregivers, the participants were strangers to each other. This had positive and negative implications. Initial discomfort and anxiety of being amongst strangers was observed. In most cases the discomfort soon made way for reassured security and confidentiality. Intimate information could be shared with strangers. This facilitated meaningful sharing in a non-threatening environment.

The focus groups were generally open and interactive. Rapport was facilitated by the fact that all the participants knew at least one of the medical facilitators. Group session rules of sharing and confidentiality issues were discussed openly. Hesitance in divulging information was noted in some and was ascribed not only to personality differences (introversion vs. extraversion) but also to the type of mental disorder the patient was suffering from. It is known that different subtypes of schizophrenia present with various thought disorders and different levels of social skills. Although the selection criteria had ruled out patients who were at a relatively low functional level (GAF scale), thought disorder and/or poor social skills were present in some of the individuals who met the inclusion criteria.

It was noted in almost all of the groups that there was a domineering person. In all cases but one, the domineering person happened to be a patient. The domineering individual would also be noted to have had a recent psychosocial stressor or to have residual symptoms of mental illness. In some instances this tended to derail the discussion as the rest of the participants were marginalized. In such cases the facilitators were detonators of explosive situations. Personal problems were then taken up after the focus groups.

Most people were multi-lingual and moved from one language to

another without any external prompting. Languages used interchangeably were Sotho, Tswana, Pedi, Zulu, Xhosa and English in most of the groups. Communication with the facilitator who was a non-fluent Sotho-speaker did not lead to any loss of communicated information as might have been anticipated.

Finally data collected through the use of screening interviews, focus groups discussions and participant observation was analysed using inductive, qualitative content analysis.

## Results

The results of the data analysis revealed the following themes:

- **Perceptions of illness**

### *Causes of illness*

The responses ranged from known medical causes to perceived social causes. Developmental causes, mental retardation, head-injury, "a nasal operation" and substance abuse were listed at the one extreme. Bewitchment, dirty blood and bad luck were listed at the other extreme. "I believe that the illness was because of dirty blood in my head." Social stressors such as isolation, marital discord, unemployment and a lack of family support were seen as contributing factors. One respondent mentioned that having a child with schizophrenia was seen as "retribution for having a child out of wedlock".

### *Symptomatology*

The perceptions of the participants regarding the symptomatology of the illness included: aggression, destruction of property, paranoia, irritability, hearing voices and impaired social judgement. "I prefer being on my own because any kind of noise makes the noise inside my head worse." Yet another participant remarked: "I can believe that people are talking about me whereas they are not. When I get better I realise that this is not true."

### *Defining schizophrenia*

In keeping with our hypothesis, the majority of our participants did not know what schizophrenia was. Even those participants who had been exposed to the term schizophrenia were unable to define it. Later they offered their own ideas on what it could mean. Schizophrenia was given many names; "bohafi"(madness) and "boloi"(bewitchment). "It's not madness. It's mental illness – a disturbance of the brain or maybe something in the head." The absence of an equivalent name in Sesotho was discussed. The use of acronyms by mental health care workers and the confusion and conflict that it created in patient management came to light.

- **Knowledge and belief systems**

### *Traditional healers*

In our sample, more than half (60%) of the patients had first consulted a traditional healer before presenting themselves to psychiatric services. Those patients whose course of treatment with the traditional healer was unsuccessful were more sceptical about whether the illness had anything to do with bewitchment as indicated in the following response: "If I have a problem it's because of another person ... it's not because I'm bewitched but because the next person is troubling me." Others did not abandon their beliefs that they had somehow been given potions, herbs, or had evil befall them as a result of bewitchment.

The traditional healer not only provided the framework for understanding their illness, but he/she provided support and advice e.g. that the smoking of cannabis was detrimental to the

patient's condition.

In spite of these strongly held beliefs, the patients continued to take their medication. The level of education did not appear to alter the prevalence of these beliefs. One of the participants, a trained nursing professional, depicted the dichotomy of operating in the traditional healing and medical models. He was in the process of being trained as a traditional healer. He also believed in the healing power of prayer.

### *Religion*

A few of the participants sought help from the church before and whilst on the medication. They had faith in the healing power of prayer - "miracles do happen ..." "I do not like medication because God is there, we must pray He helps us and we will be healed." Often it appeared that the roles of the church, traditional healers, rituals and medication were inextricably linked. "We must combine prayer with faith and action."

### *Medication*

There was a general feeling in all the groups that taking medication helped but there were some exceptions. The general feeling about medication can be summarized in the words of one of the respondents: "Taking medication continuously is not right but because we are ill we have no choice." Fear of going into a relapse and stigmatization was another reason for compliance: "I have to take my medication otherwise the illness will get worse and friends and family will laugh at me."

- **Denial**

At least one patient in each of the second, third, and fourth focus groups was diagnosed with a condition other than schizophrenia at some stage of their illness. The diagnoses made initially were of mood disorders; major depressive disorder and bipolar disorder. It was noted that these patients had difficulty in accepting their diagnoses, i.e. they were in denial. One participant believed that he was not ill because "I can tell the difference between right and wrong". Another blamed side effects of medication for her illness. "The way I see it my main problem comes from the treatment side effects. I do not think I am ill. Maybe I become bipolar because I become angry". Some of the participants expressed very strong views on the stigmatisation of their illness, which may have in part contributed to their denial.

- **Stigmatisation**

Many obstacles need to be overcome for patients to achieve successful integration into their communities. According to one of the participants who was a mental health worker "it is difficult for them to hide their illness for long". Several patients described how they devised strategies for coping with their illness. Finding a job and staying away from gossipmongers prevented one of the patients from relapsing.

The patients felt their woes were exacerbated by their being misunderstood, rejected and persecuted at times because of the failure on the part of the community to understand their illness. "You can tell when people think nothing of you. They treat you with no respect but because I know my work there is nothing they can do... I tend to keep to myself a lot."

Most of the participants thought the community psycho-education would alleviate some of the problems they confront. "They need to be educated about the cause of my illness so they can be more supportive."

A few patients expressed a yearning for empathy, respect from and a chance to prove their worth, especially to their families. "When I get angry they say it's true he's really mad. When I keep quiet they say I'm stupid, it's a case of damned if you do, damned if you don't."

#### • **Communication**

The overwhelming majority of the participants never had their diagnosis explained to them. Those who had been informed did not understand the meaning of the term schizophrenia. The informant was either a doctor or a nurse at a local clinic. The information was communicated verbally. Only one participant was given reading material. "The student doctor at Weskoppies (hospital) told me and gave me a pamphlet." The same participant heard of the illness in a radio talk show.

Finally, it was established that most participants preferred to be informed about their diagnosis by a doctor. See recommendations below for participants' suggestion on effective communication material.

### **Discussion**

#### **Limitations of this study**

This was a descriptive and investigative study. The sample used was small and focused only one language group of the South African population. The results can therefore not be applied to all communities in South Africa. Other cultures and/or language groups in other centres may perceive and experience the disorder differently. Some generic recommendations with regard to information dissemination amongst psychiatric patients can however be made.

#### **Recommendations**

From the descriptive analysis above the authors make the following recommendations. These recommendations are applicable to both psychiatry and communication studies.

- Before the dissemination of any information where the audience is unknown, a profile of the target audience must be constructed.
- The content should be honest, reliable and believable. It should have resonance with the prevailing local beliefs as this is centrally related to the acceptance of the message content.
- Although the traditional approach is often viewed with disdain by the medical profession, it has become clear in that in our context the medical and traditional medicine disciplines have to collaborate to make sense of the mental health user's world.
- The notion that the more educated one is, the further away one is from the traditional way of thinking has been challenged in our study. Further research into this will be necessary. The aim of such research might be to review the effect of so-called western culturalisation in the South African context.
- The following issues were extracted from the study and should be included in any future psychoeducational material:
  - a definition of schizophrenia that uses language that is accessible and familiar to the target audience;
  - the causes of schizophrenia;
  - the symptoms of schizophrenia and the management thereof;
  - the relationship between substance use and schizophrenia;
  - side effects of medication and the impact they have on compliance;
  - concomitant use of traditional remedies and prescribed medical drugs;

- respect of patients' rights to confidentiality;
- social support vs. stigmatization;
- The target audience should determine the media used to disseminate information. In this study the participants preferred television and radio to written media e.g. pamphlets or leaflets that cover only schizophrenia as a topic.
- In this study the participants emphasized that for effective communication all eleven of the official languages in South Africa ought to be used to address the audience.
- All mental health care workers should use accepted medical terms to minimize miscommunication of information.
- Mental health care-workers need to be aware that message repetition is essential for optimal understanding.

### **Conclusion**

This study supports the hypothesis that the dissemination of information about schizophrenia is ineffective in certain population groups in South Africa. In the course of the research process it became apparent that psycho-education is about much more than simply conveying a message to an audience. It became clear that the patient's culture, religion and education inform his/her understanding of the illness. Any message designed to address issues surrounding the clinical features and treatment of schizophrenia must therefore be sensitive to the target audience's worldview in order to be effective.

Although psycho-education seeks to redress the ills of stigmatisation, knowledge about schizophrenia does not guarantee that discrimination will cease. Certain information in the wrong hands may in fact provide fuel for further acts of discrimination.

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