Subjective wellbeing in a sample of South African, Xhosa people with schizophrenia

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Declaration

I, **Judith Boshe,** declare that the work on which this dissertation is based is my original work (except where acknowledgments indicate otherwise) and that neither the whole work nor any part of it, has been, is being or will be submitted for another degree at this or any other university.

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CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

Severe mental illness (SMI) is responsible for 7.4% of the global disease burden (1) and is estimated to account for 6% of the disease burden in South Africa (2). Schizophrenia is a disorder with positive symptoms (disturbance in perception, belief or thinking and disorganized behavior), negative symptoms (weak social interaction, poverty of speech and or anhedonia), mood symptoms and cognitive deficits (3). Evidence shows schizophrenia to have the highest disability burden compared to other diseases in this category of SMI (4). Almost half of those diagnosed with schizophrenia meets the criteria for a specific substance use disorder (SUD) (5). The term dual diagnosis is clinically used to categorize individuals diagnosed with mental illness and a co-occurring substance use disorder. The occurrence or presence of a dual diagnosis compounds the existing disability burden, affects the overall outcome, predicts poor prognosis, and has treatment implications (6-9). The cost of failing to address mental health is higher than the cost of treating mental illness by a range of two to six times more (6). Low and middle-income country (LMIC) such as South Africa, cannot sustainably afford the estimated financial cost attached to poor treatment outcomes and existing treatment gap (2).

Global mental health efforts in reducing the burden associated with schizophrenia call for clinical practices that improve quality of life by prioritizing functional recovery (10). The mainstay management of schizophrenia is antipsychotic treatment with adjunct individualized psychosocial interventions (11, 12). Despite available effective treatments options, more than 75% of those living with SMI in LMICs do not receive the care they need. Hence a greater than half of those receiving treatment, fail to comply with their prescribed treatment and relapse (13, 14). Poor adherence to prescribed antipsychotic treatment remains a key obstacle in achieving the targeted functional recovery among individuals with schizophrenia (10). Desired outcomes could be attained by incorporating early treatment and interventions that target poor treatment adherence(15, 16).

Poor treatment adherence can be predicted by an individual's subjective wellbeing while on neuroleptic treatment (SWBN) (17).SWBN is also a good predictor early response and prognosis in patients with schizophrenia (17-19). The term “subjective well-being” has been defined as an individual’s perceived mental, physical and emotional assessment of themselves(20) and among the constructs used to asses a patient’s quality of life (21). Factors that influence subjective well-being and consequently, the quality of life include those related to the i) patient, ii) treatment or iii) the illness (22). Interventions that target these factors at an individual and community level provide for an opportunity to address challenges in the management of SMI, improve outcomes, and subsequently reduce direct and indirect costs of SMI. Predictors of subjective well-being are extensively researched, but the availability of data limited to studies conducted in high-income countries (HICs). Little is known about factors that are specific to patients living in LMICs and particularly in an African setting (23-26). This chapter reviews evidence for specific scale to quantify SWBN, summarises available literature on the predictors of SWBN, and concludes with proposed research questions aimed at addressing identified knowledge gaps.

METHODOLOGY OF THE LITERATURE REVIEW

The literature search was performed using PsychInfo via EBSCOhost. The search was restricted to research and reviews published in scientific journals between January 2006 and March 2016 with an adult (greater than 18 years of age) population sample. The search terms used were "Schizophrenia "and" "subjective well-being." A total of 25 publications were identified. A narrative review was conducted. A paucity of data and literature from LMICs has been observed. A comprehensive meta-analysis looking at the quality of the papers was not performed due to the heterogeneity of the available published data.

1. The Measure

SWBN is quantitatively measured using a validated questionnaire, calibrated into a scale known as the SWBN scale. The SWBN scale is an internationally established measure used to evaluate the overall subjective experiences of patients with psychotic disorders who are on treatment, irrespective of their psychopathology (19). The scale was initially developed in Germany to assess perceived reduction in patient quality of life, focusing on emotion, cognition, and spontaneity (27). It was initially a 54-item scale, later reduced to a 38-item scale, and has now been modified to a 20-item scale to facilitate easy administration in clinical and research settings. The 20-item Subjective Well-Being Under Neuroleptic Treatment Scale (SWN-K 20) captures subjective experiences cross five dimensions of mental functioning: i) self-control, ii) emotional regulation, iii) physical functioning, iv) mental functioning and v) social integration, which is demonstrated through its 5-factor psychometric structure. Each dimension consists of 4 questionnaire items. The scale is a self-report inventory with a Likert-scale comprising six response categories ranging from 1 (not at all) to 6 (very much). This shorter version, with the same dimensions, has demonstrated similar psychometric properties to the original 38 item scale (28), with high internal consistency for the total scale (Cronbach's alpha=0.97) and subscales (Cronbach's alpha between 0.73 and 0.88). The SWN-K 20 has demonstrated good construct validity with other patient-rated scales used to assess the quality of life such as the Profile of Mood Scale (POMS), Self-rating Depression Scale (SDS) and Befindlichkeits Scale (BFS).

The SWN-K 20 has since been translated into more than 40 languages (29) including Italian (23), Korean (25), Greek (26) and Estonian (24), with acceptable psychometric properties. (20, 23-26). Evidence suggests that this scale has not been adapted for use in an African setting. Authors of European and Asian translations have concluded that intercultural variations in the conceptualization of one's perception of well-being are likely to occur among people with schizophrenia across different contexts (25). The phrasing of particular SWN-K 20 items has also been shown to influence response bias. For example, in the Turkish language adaptation of the scale(30), the total score of the scale was seen to be more reliable than sub scores when method effects were controlled for. Based on these findings, the first step was to translate the SWN-K 20 into isiXhosa and to examine the evidence of its psychometric properties. It was also essential to determine and describe the dimensions of the Xhosa translated version of the scale to inform its application.

2. Predictors of SWBN

As highlighted above, the patient's demographics, the treatment, and the disease (schizophrenia) itself are three categories of factors that have been shown to influence subjective well-being (22). A review of studies exploring the association between SWBN and these factors suggests the following:

a) Patient demographics

Available studies undertaken in high-income countries have demonstrated a consistent relationship between patient demographics such as sex, age, education, income, and employment status and subjective well-being in schizophrenia (24, 26, 31). It is yet to be established whether the same trends would be observed in an LMIC context.

b) Treatment factors

Overall, SWBN is reported to improve with ongoing treatment (31). Schizophrenia patients accessing outpatients' services would then be expected to report better SWBN than those who are receiving care as inpatients. The type of neuroleptic, the dosage, duration of treatment, and extrapyramidal side effects induced by the medication have been highlighted in the literature as factors that may influence SWBN. A review of recent research suggests that optimal dosage of a specific neuroleptic rather than the actual class it belonged to, positively correlates with SWBN in HICs population (32). Conversely, extrapyramidal side effects and changes to the medication have demonstrated significant negative correlations with SWBN in the same population (31). While all neuroleptics have a potential of causing extrapyramidal side effects, first-generation neuroleptics are known to have more propensity of doing so compared to second generation neuroleptics. The two classes of neuroleptics are documented to have equal efficacy towards psychotic (positive) symptoms of schizophrenia while second generation neuroleptics have superior efficacy on negative symptoms(33-38). These are observations made on studies involving Caucasian populations in North America and European settings; hence, it is unknown if the same treatment-related factors are of relevance in the South African setting. In this setting, there are limited neuroleptic options when compared in HICs. The options are further reduced in state facilities, where all involuntary admissions are attended to in addition to the bulk of the voluntary mental health services. Furthermore, patients in state facilities who need or opt for neuroleptics in a depot formulation are treated with first-generation neuroleptics due to availability and accessibility(39). State facilities in South Africa have access to only one-second-generation depot, Risperidone Consta; this is prescribed to relatively few individuals who need to be on a depot formulation due to poor adherence and cannot tolerate first-generation neuroleptics.

c) Illness factors

HICs cohorts of individuals with schizophrenia have consistently demonstrated that psychotic symptoms, as well as depression and anxiety symptoms, influence SWBN(24, 31, 40). This was expected as active symptoms at a specific point in time are known to influence an individual's perceived well-being. What was unexpected were the findings that the chronicity of the illness did not

influence perceived well-being. Those who had a single episode reported significant improvements in their SWBN compared to those who have had multiple episodes (31). It is clear that specific illness factors such types of symptoms, the severity of symptoms, co-occurring conditions have a role in the SWBN among schizophrenia patients(31). These results are yet to be replicated in an LMIC context. Adjunct treatment or psychosocial interventions could modify illness factors, and it is, therefore, essential to investigate their roles in these settings.

Globally, little is known about the specific role of SUD on the SWBN in an individual with schizophrenia. SUD is an illness related factor that warrants exploration in light of the high prevalence of use in individuals with schizophrenia and its established complex multifactorial interaction in modifying the course of this illness. Furthermore, SUD is a confirmed independent predictor of one's quality of life. This has translated into treatment guidelines that call for specific integrated care approaches for those with schizophrenia and a co-occurring SUD(6). Hence it is crucial to explore the role of co-occurring substance use in SWBN among individuals with schizophrenia.

This study aimed to explore the associations between SWBN and i) demographic characteristics, ii) treatment and iii) illness-related factors that have already been established in European and North America populations with schizophrenia, in a sample of South African Xhosa people with schizophrenia. Understanding these associations in more detail has the potential to provide targets for psychosocial interventions aimed at improving adherence and overall treatment outcomes.

HYPOTHESES

The following hypotheses guided the study:

1. While patient demographics have not proven to be significant predictors of SWBN in European and North American patients with schizophrenia, South Africa still contends with social, economic, environmental, and historical legacies. The hypothesis is that as a result, patient demographics may show more significant associations with SWBN in this sample.

2. The associations between subjective well-being and schizophrenia treatment and illness factors that have been established in North American and European cohorts can be replicated in the sample of South African Xhosa people with schizophrenia.

RESEARCH AIM

This study aimed to:

A. Translate the 20 items Subjective Well Being under Neuroleptic Treatment scale (SWN-K 20) into Xhosa and evaluate its psychometric properties.
B. To investigate and identify demographic and clinical predictors of subjective well-being in a sample of Xhosa people with schizophrenia on neuroleptic treatment.

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2. Chapter 2: Publication-ready Manuscript

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ABSTRACT

Background:
Subjective well-being when on neuroleptic treatment (SWBN), has been established as a good predictor of adherence, early response, and prognosis in patients with schizophrenia(1, 2). The 20-item subjective well-being under neuroleptic treatment scale (SWN-K 20) is a self-rating scale that has been validated to measure SWBN(3). However, the SWN-K20 has not been previously used in a Low- and Middle-income country (LMIC).

Aims and Objectives:
This study explored the psychometric properties of SWN-K20 in a sample of Xhosa speaking African patients with schizophrenia and investigated factors associated with SWBN in this population.

Methods:
As a part of a large genetic study, 244 study participants with a confirmed diagnosis of schizophrenia completed the translated SWN-K 20 scale. Internal consistency analysis was performed, and convergent analysis and exploratory analysis were conducted using Principal Component Analysis (PCA). . Linear regression methods were used to determine predictors of SWBN in the sample population.

Results:
The PCA extracted four components, which cumulatively explained 52.21% of the total variance. The internal consistency of the SWN-K 20 was 0.86, and those of the sub-scales ranged between 0.47 and 0.59. The total scores of the SWN-K 20 demonstrated moderate correlation r= 0.44 with GAF scores. The sub-scale scores had lower correlations ranging between r=.41 and r=.30 with the GAF scores. The total scores on SWN-K20 scale were used to explore factors influencing SWBN. There was a significant correlation between overall subjective well-being score with a higher education level, increased illness severity, and GAF scores.

Discussion and Conclusion:
The isiXhosa version of the SWN-20 scale can be used for clinical and research purposes in LMICs, but predictors of SWBN in this population differed from those previously established in (high-income countries) HICs. The individual sub-scales of the SWN-K20 were less reliable when translated

into isiXhosa, and hence the sub-scales were not a meaningful measure of specific domains of well-being. These findings merit evaluation to determine whether cultural and linguistic specific sub-scales might provide further insight and recommendations for use in the South African context.
t.
Keywords: Schizophrenia, subjective well-being, subjective well-being under neuroleptic, SWBN

Predictors of SWBN in this LMICs population were not comparable to those in HICs setting(5, 6). Older patients with a lower baseline level of education, poor global functioning, and less severe symptoms were noted to have lower SWBN and hence at risk of poor compliance. This information could guide clinicians, researchers, and interventions that aim at improving compliance and the treatment experiences of this patient group.

CHAPTER 2: BACKGROUND

Severe mental illness (SMI) is responsible for 7.4% of the global disease burden(1) and is estimated to account for 6% of the disease burden in South Africa(2). Schizophrenia exerts the highest disability burden compared to other diseases within this category of SMI (4) Schizophrenia is a disorder with positive symptoms (disturbance in perception, belief or thinking and disorganized behaviour), negative symptomsweakor social interaction, poverty of speech and or anhedonia), mood symptoms and cognitive deficits (3). About half of those diagnosed with schizophrenia will also meet criteria for a substance use disorder (SUD) (5).Dual diagnosis is a term that is useto categorize individuals with mental illness and a co-occurring SUD clinicallyUD. This co-occurrence or presence of a dual diagnosis compounds the existing disability burden and has treatment implications(6, 7). Efforts towards reducing this burden have identified overall improvement in patient's quality of life and functional well-being among the key goals in the treatment of schizophrenia(10). Poor adherence to prescribed treatment is one of the hindering factors in attaining functional recovery for people with schizophrenia(10). The society incurs an additional burden ithe n form othe f increased burdetoon clinical resources in cases of poor treatment outcomes often as a consequence of poor treatment adherence(5).

Identification of factors that influence adherence to treatment among individuals with SMI such as schizophrenia is an area of global concern(41-43). Several studies have identified, individual's subjective well-being while on neuroleptic treatment (SBWN), as a good predictor of adherence, early response, and prognosis in patients with schizophrenia (17-19). The term "subjective well-bei,"", has been defined as an assessment of one's own perception the mental, physical and emotional state of wellness(20), it is also a construct used to asses an individual's quality of life (21). Factors that influence subjective well-being and consequent,ly the quality of life include those related to the i) patient, ii) treatmenoror iii) the disease itself (22). While there is available literature on the SWBN among individuals with schizophrenia, less is known about the role of co-occurring SUD on SWBN despite thsignificantlynt high prevalence of dual diagnosis. Treatment guidelines for those with schizophrenia and a co-occurring SUD call for specific integrated care approaches and have cost implications(5-.
Furthermorere, SUD is a confirmed independent predictor oan f individual's quality of life. This raises the question about the role of SUD in SWBgivenof its complex interaction in SMI and general wellbeing(44). There is, therefore, a need to include SUD when exploring predictors of SWBN in individuals with schizophrenia.

The absence of data on factors influencing SWBN within LMIs, translates into an absence of customized evidence-based interventions targeting poor adherence. This gap needs to be addressed in order to decrease the overall disease burden by improving functional recovery with better treatment adherence. Moreover, all disease-related factors could potentially be targeted by revising treatment approaches, inclusive of psychosocial intervention. It , s thereforeessentialnt to establish evidence to inform population-specific interventio.ns

Factors that may influence SWBN

As highlighted abovethe , patient's demographics, the treatme, t and the illness itself are three categories of factors that have been shown to influence SWBN (22). Below is a review of studies considering the association between SWBN and these factors:

Patient demographics

Studies have demonstrated no consistent relationship between patient demographics such as sex, age, education, income, and employment status and SWBN within the Caucasian population with a diagnosis of schizophrenia (24, 26, 31). It had not been established whether the same trends would be observed in an African population from LMICs.

Treatment factors

Overall subjective well-being is noted to improve with ongoing treatment (31). Treatment-related factors that may influence SWBto N include 1)The class of neuroleptic, 2) the dosage, 3) duration of treatme, t and 4) side effects experienced by patients on treatmen t.A review of recent research suggests that optimal dosage of a specific neuroleptic rather than the class it belonged to, positively correlates with SWBN, while treatment side effects and change in medication negatively correlates with SWBN (31). All neuroleptics have the potential of causing extrapyramidal side effects, but first-generation neuroleptics are known to have more propensity of doing so compared tthe o second generation. The two classes of neuroleptics are documented to have equal efficacy towards positive sympto, s while the secongeneration neurolepticscs are noted to be superior in addressing negative symptoms of schizophrenia(35, 45). The available research, however, has been limited to Caucasian populations in North America and European settin;gs hen,ce it was unknown if the same treatment-related factors are relevant ithe n South African setting. A setting with limited treatment options for individuals accessing state facilities and need to be on depot formulation. Available depot neuroleptics are from the first generation clasexcept forof Risperidone Consta, which is limited to a few individuals wituniqueal motivation(39). Such motivation typically occurs in a specific tertiary or specialized facilities by a specialist practitioner.

Illness factors

Depression, anxie, y and psychotic symptoms have been shown to consistently influence SWBN in people with schizophrenia(24, 46, 47). This was expected as active symptominfluencees an individual's perceived well-being. What was unexpected were the findings that the chronicity of the illnesdid not influenceon one's SWBN while those who had a single episode reported significant improvements in their SWBN compared to those who have had multiple episodes (31). It is clear that specific illness factors such as symptomatology, illness severity, number of episodes and co-occurring disorders have been shown to play a role in the SWBN among European and North America schizophrenia population(31). It was not clear if the same illness-related factors are of relevance ithe n African setting. Co-occurring SUD waincluded inin disease-related factors due to

its unique contributiotoin functional well-being and its high prevalence among schizophrenia patients accessing care in South Africa(48, 49).

The Measure

The SWBN scale is an internationally established measure used to evaluate the overall subjective experience among patients with psychotic disorders who are on neuroleptic treatment, irrespective of their psychopathology (19). The scale wainitiallyly developed in Germany to assess perceived reduction in patient quality of life, focusing on emotion, cognition, and spontaneity (27). It wainitiallyly a 54-item scale, later reduced to a 38-item scale, and has now been modified to a 20 item scale to facilitate easy administration in both clinical and research settings. The 20-item Subjective Well-Being Under Neuroleptic Treatment Scale (SWN-K 20) captures subjective changes acrosfive 5 dimensions of functioning: self-control, emotional regulation, physical functioning, mental functioning, and social integration, which are demonstrated through its 5-factor psychometric structure. Each dimension consists of 4 items. The scale is a self-report inventory using a Likert rating scale of 6 response categories ranging from 1 (not at all) to 6 (very much). This shorter version has been found to have psychometric properties similar to the original 38 item scale(28). In its original English form, the scale has demonstrated high internal consistency for the total scale (Cronbach's alpha = 0.97) and subscales (Cronbach's alpha between 0.73 and 0.88). The scale has demonstrated good construct validity with other patient-rated scales to asses' quality of life such as the Profile of Mood Scale (POMS), Self-rating Depression Scale (SDS) and Befindlichkeits Scale (BFS) (50).

The SWN-K 20 has since been translated into more than 40 languages (29) including Italian (23), Korean (25), Greek (2,) and Estonian (24). Studies have demonstrated comparable psychometric properties of the translated language versions of the SWN-K 20 similar to the original version (20, 23-26). Howeverthe , authors concluded that intercultural variations in the conceptualization of one's perception of well-being are likely to occur among people with schizophrenia across different contexts (25). The phrasing of particular SWN-K 20 items has also been shown to influence response bias. For example, in the Turkish language adaptation of the scale(30), the total score of the scale was seen to be reliable than sub scores when method effects were controlled for. Available translations have also not been able to replicate the same factor structure as the original long or short versions of the scales. Therefore, it iessentialnt to determine and describe the dimensions of the Xhosa translated version of the scaltoto inform its application in LMICs settings.

From literature and research, this scale had not been used to measure SWBN ian a LMICs African setting. It was not known if this scale could be used to asses SWBN in this population. Specific factors that play a role in the subjective well-being among individuals with schizophrenia in this context were yet to be determined. Adapting this scale for use in South African Xhosa people with schizophrenia to determine factors influencing SWBN was a step towards bridging identified gaps. The scale was first translated into Xho, a and its psychometric properties were assessed. The translated scale was then used to determine demographic and clinical predictors of SWBN in a sample of Xhosa people with schizophrenia on neuroleptic treatment. Contrary to other studies, the hypothesis wathat thoseat patient demographics have significant associations with SWBN in this sample

due to social, economic, environment, l and historical legacies. Patterns of association between treatment and illness-related factors and SWBN were expected to be comparable to other similar studies.

METHODS

a) Sample

The study population was extracted from a larger cohort of Xhosa people recruited from the Genomics of schizophrenia in South African Xhosa People (SAX) study. The SAX's participants were recruited from the Western and Eastern Cape Provinces of South Africa. These are areas with the highest density of Xhosa speakers in the country. The minimum sample size requirement for thtwo 2 specific aims of the study was guided by their respective analytical principles(51). The first aim required a minimum of 200 participants while the second aim of the study required a minimum of 160 participant s.(51-53) The study ended up recruiting all participants who completed the Xhosa version of the SWN-K 20 questionnaire in the specified period and met the inclusion criteria. A total of 244 participants were recruited in this sub-study. The sample size satisfied both analytical principles.

b) Data Collection

Only the identified variables of interest for each participant were extracted, link, d ananalyzeded. Participants' scores for the different scales were linked to the main database to facilitate this. A total of 9 sociodemographic and clinical variables were extracted and linked to specific study identification code assigned to each participant. The SWN-K 20 score, GAF score, age, sex, the highest level of education, medication details, illness severity, treatment setting, and substance use status were extracted for each participant. Below are the variables, how they were collected and defined in this study.

Socio-Demographic characteristics

Socio-Demographic variables of interest were age, s, x and the highest level of education. These variables were grouped as categorical variables for the analysis. Age was categorized into younger (20-39 years) and older (40-59years), sex was categorized into male and fema, e and education level was categorized into those with primary school education and with high school and above. High school education was defined as having passed grade eight and above while those who had less than a grade 8 education were classified as having a primary school education.

SWN-K 20

The SWN-K 20 was used to measure the subjective well-being of the study participants. The SWN-K 20 was translated into Xhosfollowingth translation guidelines prescribed by the World Health Organisation(54). The steps included:

i) Forward translation of SWN-K items from English into Xhosa by a team of first language Xhosa speaking psychiatric nurses;

ii) The team then discussed the resultant translated Xhosa version, m and necessary edits or amendments were made as per agreement

iii) Back-translation of the scale into English was performed by an independent first language Xhosa speaking psychiatric nurse to deliberate ovethe r conceptual equivalent.

The translation team included five-first language Xhosa speaking psychiatric nurses, and a psychiatric registrar. All clinicians were aged between 24-50 years, bilingual in English, with extensive training and experience in conducting clinical interviews and assessments with Xhosa people with schizophrenia.

The SWN-K 20 produces a score that ranges between 20 (lowest) and 120 (highest). This scale was used as a continuous variable. The SWN-K 20 also providefive subscalele scores across thfive 5 specific domains of subjective well-being. However as noted in the literature, it has beechallenginglt to replicate the psychometric structure of the tool across different language versions, detracting from the validity of thessubscalele scores in translated language versions of the tool ( ). .

Global functioning

The global functioning of SAX participants was assessed using the Global Assessment of Functioning (GAF) scale. This is a standardized method of assessing the severity of psychiatric illness against the overall level of functioning(55). Participant functioning is rated on a scale from 0-100 (56). These GAF scores were used as a measure of convergent validity with scores obtained from the Xhosa version of SWN-K 20 used ithir s study.

Diagnosis, Illness severity and co-occurring SUD

The Structured Clinical Interview DSM-IV Axis I Disorders (SCID-I) (57), was used during the clinical interview with SAX participants to determine whether participants met the DSM-IV diagnostic criteria for schizophrenia. Data on illness severity and co-occurring conditions such as SUD were also collected as per the DSM-IV classification using the SCID-I. The following four illness and treatment-related variables (see table below), extracted from this clinical assessment, were grouped and used as categorical variables in our analysis.

Illness antreatment-relateded variables with their assigned categories

Variable	Categories
Severity	1. Full remission to mild symptoms 2. Moderate to severe symptoms
Treatment setting	1. Outpatient 2. Inpatient
SUD status	1. Y, s i.,e. those who met the DSM-IV diagnostic criteria for a SUD. 2. No, i.,e. those who did not meet the DSM-IV criteria for a SUD.

Variable	Categories
Medication	1. Second generation neuroleptics 2. First generation neuroleptics

b) Statistical analysis

Statistical analysis was carried in 2 consecutive steps;

First step: Principal component analysis (PCA) was used to investigate the psychometric structure of the translated SWN-K 20 questionnaire, while internal consistency was established across the total scale and subscales using Cronbach alpha. Cronbach alpha above 0.7 was considered as acceptable. Convergent validity was established using correlations with participant GAF scores using Pearson's correlation coefficients.

Second step: Linear regression was used to identify significant predictors of SWBN. The group difference was determined using a 95% confidence interval where p-values less than 0.05 were regarded as statistically significant. Frequencies (in percentages) and means were used to describe numerical data in both step 1 and 2 of the analysis.

RESULTS

Descriptions of the data

Participants Demographics

The total sample of 244 Xhosa people with Schizophrenia was recruited between August 2015 and January 2017. The sample included 222 males and 22 females. Participants were recruited from in/out-patient facilities and required a diagnosis of schizophrenia. The participant age ranged from 20 to 59 years of a, e with a mean age of 36.45 years. Only one participant reportehavingve no formal education. This participant was merged with those with less than primary education during the analysis. A majority (66%, n=161) of the participants had obtained some form of secondary school education. These demographics are summarised in **Table 1**.

Treatment factors

Almost equal numbers of participants were recruited from inpatient (n=129, 52.9%) and outpatient facilities (n=115, 47.1%). Second generation neuroleptics were used by 20.9% (n=51) of participants.

Illness factors

The majority of the participants (82.8%, n=202) exhibited moderate to severe symptoms, and about half of the entire sample study (49.2%, n=120) met the diagnostic criteria for a co-occurring SUD.

Table 1: Sociodemographic characteristics and clinical profile of the study population

SOCIODEMOGRAPHIC CHARACTERISTICS (N=244)	
SEX	
Male	222 (90.0%)
Female	22 (9.0%)
AGE	
Younger: 20-39	153 (62.7%)
Older: 40-59	91 (37.3%)
EDUCATION	
Primary school education	83 (34.0%)
High school and above	161 (66.0%)
CLINICAL PROFILE (N=248)	
SEVERITY	
Full Remission to mild symptoms	42 (17.2%)
Moderate to Severe symptoms	202 (82.8%)
TREATMENT SETTING	
Outpatient	115 (47.1%)
Inpatient	129 (52.9%)
MEDICATION	
Second generation	51 (20.9%)
First generation	193 (79.1%)
SUBSTANCE USE	
Yes	120 (49.2%)
No	124 (50.8%)

Psychometric Properties of the SWN-K 20 questionnaire

Exploratory Factor analysis

An exploratory factor analysis (EFA) was performed using Principal Component Analysis (PCA) and Varimax rotation. The varimax rotation method was select, d as no assumption was made regarding any correlation between the factors(58). Emerging patterns were explored, and the findings were compared to those of other translations and the original version of the SWBN scale. The Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy was 0.879 and a significant Bartlett's Test of Sphericity ($x^2 = 1437.595$, $p<0.001$) suggestenn a adequate sample size for the analysis. Unlike the original version that hafive 5 components, analysis of the Xhosa version extractefour 4 components with an Eigenvalue of greater than 1 **(see Figure 1 below).** The first component explained 28.6% of the total varian, e while thfour 4 components together explained 52.2% of the total variance. **Table 3** summarises the loadings of the questionnaire items across thfour 4 components. Coefficients of less than 0.3 were suppressed.

Table 2: Figure 1: Scree plot illustrating the extracted components with their Eigenvalues

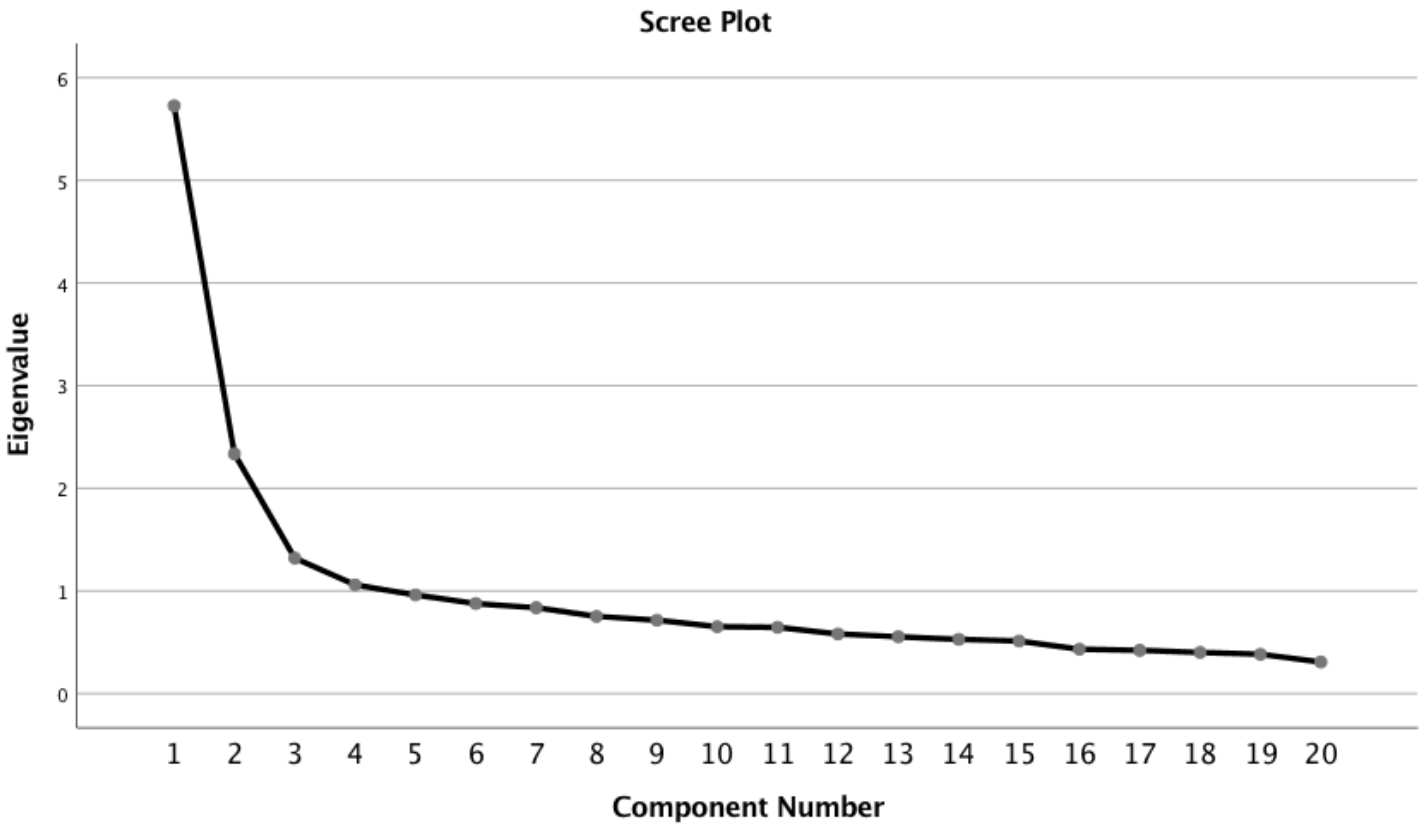

Table 3: Thfour 4 extracted components and their specific item loading on of the SWN-K 20 Xhosa version

Item No	Item	Domain	Component				
			1	2	3	4	*
20	I am full of confidence, everything will be alright.	Emotional Regualtion	0.64				
18	I am interested in what is happening around me, and it is important to me.	Emotional Regualtion	0.66				
13	I find it easy to keep in touch with people around me.	Social Intergation	0.59				
6	I am very shy about getting to know people.*	Social Intergation	0.42				
19	My feelings and behaviour are appropriate in the particular situation*	Self Control	0.64				
15	I find it easy to draw a line (separate) between myself and others.	Self Control	0.72				
7	I am imaginative and full of ideas (I have thoughts and opinions/ideas).	Mental functioning	0.62				
17	My thoughts are flighty and undirected. I find it difficult to think clearly.	Mental functioning		0.63			
11	My thinking is difficult and slow.	Mental functioning		0.59			
4	I have no hope for the future	Emotional Regualtion		0.59			
14	I perceive my environment as being changed, strange and threatening.	Social Intergation		0.60			
12	My feelings and behaviour are inappropriate to situations. I get upset over small things, important ones hardly affect me.	Self Control		0.69			
16	I perceive my environment as being changed, strange and threatening.	Physical Functioning		0.58			
2	I feel very comfortable with my body.	Physical Functioning			0.73		
5	My body feels familiar (normal).*	Physical Functioning			0.53		
3	I find it easy to think.*	Mental functioning			0.64		
8	My environment seems friendly and familiar to me.*	Social Intergation			0.60		
10	My emotions and sensations are dull. Nothing matters to me (There is nothing I care about).*	Emotional Regualtion			0.45		
9	I feel weak and exhausted.*	Physical Functioning				0.57	
1	I feel powerless and not in control of myself.	Self Control				0.73	

∗Items which loaded on more than one component. Only the highest loading is shown in the table and grouped accordingly.

SWN-K 20 questionnaire items clustered together in different ways in the analysis, compared with the original English language version of the tool. Some (7) items, had loadings of greater than 0.3 in more than one component. These items were placed in the component where they had the highest loadi, g i.,e. Item 6 loaded in Component 1,, 2 and 4 with 0.422, 0.3, 7 and 0.3, 1 respectively. The remaining 13 items that had only one loading with greater than 0.3. These 13 items were explored for possible themes within their respective components.

The first component in the analysis contained 7 SWN-K 20 items. Items that only loaded once, in this specific component (those without an Asterix onhe t table) appear to tap into a positive sense of control over one's emotional, social and cognitive wellbeing. The items highlighted autonomy, agen, y and creativity as one navigates between being an individual entity with several functional facets and being part of a larger functional unit such as a family or community. The second component was the converse of this. It grouped items that expressea d loss of control and connection within the individual and with the external environment. The theme was that of loss of control, autonomy, agen, y and connection with both internal and external environment. The third and fourth components had the least number of items, focusing on physical functioning and loss of self-contr, l respectively. Further analysis of these components and their emerging themes was beyond the scope and aims of this thesis.

Reliability

The scale (SWN-K 20) as a whole demonstrated high internal reliability with a Cronbach alpha of 0.863, suggesting that itl items correlated well and tapped into one dominant construct. The individuasubscaleses showed lower internal reliability, with emotional regulation having the lowest value (α=0.468) and physical functioning the highest (α=0.588). This range was at best "poor" ant worst "not acceptable" (59), however, Cronbach's alpha is known to be subjected to inflation or deflation by too many or too few items (60).

Validity

All subscales had a strong correlation with the overall scale (SWN-K 20), suggesting good scale validity. When correlated with the GAF score, the overall scale demonstrated the highest convergence validity (r=0.44) while the subscales yielded values ranged from 0.30 to 0.41. These results indicate that the SWN-K 20 overall scale score and the GAF score are positively associated, consistent with the expectation that people who experience higher subjective well-being also tend to have better overall functioning in their lives. However, correlations between the SWN-K 20 subscale scores and GAF scores were less than 0.4 and closer to 0, 3 suggesting a weak correlation (61, 62).

These findings when combined with the results of the psychometric structure and internal reliability presented above, indicate that the overall score on Xhosa version of the SWN-K 20 to be relativelyly reliable and valid indicator of subjective well-being. However, thsubscalele scores are less mean-

ingful and should be cautiously interpreted. Based on this observation, the second step of the analysis (determining predictors of SWBN) used the total score on the SWN-K 20 for each participant. The subscales scores and the emerging components were not used in any further analysis. The mean SWBN score for the sample was 91.85 (SD=14.89).

Table 4: Psychometric properties of the SWN-K 20

Scale and Sub-scales	Cronbach's alpha	Correlation with SWN-K 20	Convergent validity with GAF scores
SWN-K 20	0.86	1.0	0.44
Mental functioning	0.56	0.82	0.33
Emotional regulation	0.47	0.82	0.39
Physical functioning	0.59	0.77	0.34
Self-Control	0.50	0.78	0.41
Social Integration	0.54	0.85	0.30

Demographic and clinical predictors of SWBN

Linear regression method was applied to determine the influence of demographic and clinical factors on the SWBN scores. A total of 8 predictors (**see table 5)** were selected as guided by the literature review. A significant regression equation was found (F (8, 235) =10.259 p <.000), with an R^2 of 0.259. The model had a significant p-value (p<.000) and accounted for 23.4% of the total variance in SWBN scores. The change in SWBN scores that could be attributed to theight 8 variables was less thafavorablele (less than 30%). This suggests that theight 8 variables in the model do not influence one's subjective well-being to a significant extent.

A higher level of education and higher GAF score were significantly associated with increased SWBN. Increased symptom severity was also significantly associated with higher reports of SWBN in the sample, while participant sex, treatment setting, class of neurolept, c and co-occurring SUD did not demonstrate a significant association. Results are summarised in Table 5 below.

Table 5: Multiple linear regression table for Predictors of SWBN

Model	Unstandardized co-efficient Beta	Std. Error	P – value	CI:95%
Constant	56.61	10.68	<0.01	35.56-77.66
GAF Score	**0.39**	**0.06**	**<0.01**	**0.27-0.52**
Age	-3.54	1.81	0.05	-7.10-0.03
Sex	-0.25	3.26	0.94	-6.67-6.18
Education	**3.95**	**1.85**	**0.03**	**0.31-7.60**
Severity	**7.55**	**2.28**	**0.01**	**3.07-12.05**
Treatment setting	-0.43	1.97	0.83	-4.30-3.44
Medication	0.31	2.20	0.89	-4.02-4.63
Substance use	-1.05	1.84	0.57	-4.67-2.57

DISCUSSION

The main findings are those focused othe n psychometrics of the Xhosa version of the SWN-K 20 and those focused on predictors of SWBN among individuals with schizophrenia ian a LMIC. The findings were compared with the available literature and or similar studies addressing SWBN. This section will conclude with a reflection of what the findings mean to a patient, clinical practice, research activiti, s and identifiea d knowledge gap within the limits of the study design.

SWN-K 20 Xhosa language version

Data on the psychometric properties of the SWN-K 20 Xhosa language version indicates that this tool provides a meaningful overall indication of self-reported experiences of SWBN in the sample of Xhosa people with schizophrenia. However, the subscale scores of this measure proved more problematic. This finding is consistent with other South African studies exploring linguistic and cultural limitations when attempts are made to translate psychiatric scales or clinicainterviews intoto African languages, particularly Xhosa (63-65). Campbelet al.al in a study translating Clinical Outcomes in RoutinEvaluation-Outcomeme Measure (CORE-OM), highlighted challenges in attaining equivalent Xhosa translation for items capturing psychological distress. The CORE-OM is a measure of general distress and dysfunction developed in the UK. Phrases like "I have felt panic or terr,"", led to inconclusive debates on the appropriate Xhosa word to depict panic ("Bendinophaphazela," or “Bendinongxungupholo), while differentiating it from terror ("noloyiko"). Sections of the CORE-OM which explored physical and tangible symptomi.e. ,.e “I have felt unhappy” (“Ndizive ndingonwabanga”), proved easier to translate. The overaloutput wasas a partial measurement scale that

omitted items that had no conceptual equivalence in Xhosa language and recommendations for adaptation of specific Xhosa terms to capture psychological distress instead of engaging on translation from western constructs (64).

One reason for the difficulty in replicating psychometric structures and validatinsubscaleses across different language versions of tools could be the loss of linguistic nuances during the translation process(66). Often, translators struggle to find linguistically equivalent terminology in Xhosa for English words, particularly emotional construcs, and instead have to use descriptions that convey a broader conceptual meaning. Cultural differences in expressing physical, mental, emotion, l and or psychological well-being may also play a role in challenges faced during translation of psychometric tools from western language to African languages (67, 68).

Explanatory models for mental illness in Sub Saharan Africa (SSA) are highly varied within societies and even more diverse when compared with Western societies (69). The Xhosa community has been identified as one of the SSA communities whose classification of psychiatric symptoms overlaps more closely with Western explanatory models, and yet there remains a marked reliance on traditional cultural explanations of illness(70). In additionbehavioralal and emotional changes in a person are often used to identify mental illness in an individual. Cognitive symptoms are often missed (and translated according to societal values when recognized), while psychotic features such as hallucinations are often given a cultural interpretation (65, 69). Particular explanatory models are associated with specific illness percepti, n along with help-seekinbehaviorur and treatment satisfaction. A common cultural belief among individuals with schizophrenia in this community is the belief that one is experiencing mental illness as a result of being bewitched by a jealouneighborur or associate (65, 71, 72).This is associated witreducedor engagement with healthcare services and prognosis. More importantly, these explanatory models shape how peoplrecognizese and talk about their symptoms, and these understandings shape experiences of subjective well-being.

Therefore, while a tool like the Xhosa version of the SWN-K 20 provides some overlap in general experiences of SWBN in this sample, it is likely that more culturally and language-specific experiences of well-being are not accounted for in this measure. Similarly, the subscales may be tapping into more culturally specific experiences of subjective well-being relevant to Western contexts. While the SWN-K 20 Xhosa language version may not fully reflect or share the same measurement equivalence as the English language version, the tool does provide some insight into the self-reported experiences of subjective well-being of Xhosa people with schizophrenia on neuroleptic treatment in a broad or general sense.

Predictors of SWBN in the Xhosa population

The analysis identified some predictors of SWBN in Xhosa people with schizophrenia. However, it is acknowledged that the identified variables do not occur independently but collectively contribute to an individual patient profile.

Demographic factors

Education status was found to be a significant predictor of SWBN in this sample. Age and sex of the participants did not demonstrate significant influence on the subjective well-being scores, similar to studies conducted in HICs (19, 21, 24).

i) Education:

International studies suggest higher education to be positively correlated with SWBN(73). The same association was observed in this study population. Qualifying for high school or higher tertiary education is often an interaction of higher socioeconomic status, better functional, and goal directness. The interpretation of the observed association between education and SWBN is limited by the fact that it did not include a variable for socioeconomic status (74).

Clinical predictors

Global functioning and symptom severity are clinical predictors that demonstratea d significant association with SWBN scores of the study participants. The direction of associations varied to those observed in HICs. Observed associations between SWBN and co-occurring SUD in the sample was similar to earlier studies within HICs.

a) Global functioning

GAF scores were the most significant predictor of SWBN in the present model. This was expected as both SWN-K 20 and GAF scores are instruments used to measure constructs of quality of life. Furthermore, a moderate correlation was established between GAF scores and SWN-K 20 scores in this specific population in the first part of the study. The findings were similar to other studi,es where a correlation between the two scores was moderately correlat, d and global functioning was among the clinical factors thawereas independently associated with SWBN(24, 25).

b) Symptom severity

Moderate to severe illness was associated with higher scores of SWBN. This is contrary tgeneralal expectations with worsening of one's psychiatric symptoms. Similar studies in HICs have reported mixed findings on the association between symptom severity and SWBN(24, 31). The majority of the studies have noted SWBN to be negatively influenced by symptom severity and affective symptoms(73).

c) Co-occurring SUD

The study did not find any association between co-occurring SUD and SWBN. The influence of SUD on SWBN remains poorly understood. The review by Vothknecht et al. identified individuals studies that found no association between coffee or smoking use disorder and SWBN whila e reduction in cannabis cravings was associated with positive SWBN(73). It is evident that the role of SUD on SWBN is complex despite the paucity of data. Factors such as specifying the actual substance of abuse, the number of substances abused, the severity of the use disord, r and characteristics of the specific population could bsignificantnt when exploring this relationship. Sucan h in-depth

exploration of the multi-faceted roles of substance use or SUD on one's general wellbeing was beyond the scope of this study.

STRENGTHS AND LIMITATIONS

First, the cross-sectional study design and characteristics othe f sample populatiolimitts the inference to the broader patient population. The cross-sectional design of the study does not allow tconcludeng the influence of neuroleptics on the SWBN across time. The duration of illness does not directly translate to the period that the individual has been consistently on neuroleptic treatment. The study recruitenine 9 times more male participants than female. This is possibly a result of the recruitment strategy. It is likely that in these faciliti,es men were more often diagnosed with schizophrenia and women, presenting with more of a mood component, were diagnosed with bipolar disorder, excluding them from the study.

Second, data on three clinical factors that may hava e specific influence on one's SWBN was not collected. The dose of the neuroleptic, the presence or absence of adjunct medicati, n and dominant symptoms exhibited by the participant were not documented. The percentage of D2 receptor occupancy that is associated with the dose and individual pharmacokinetic profile is linked with the resolution of symptoms or exhibition of side effects. There is a fine line between attaining the desired effect versus unwanted side effects. This is a critical point and may tip the scale between good to poor SWBN. Neuroleptics have been observed to target positive symptoms with less impact affectiveve and cognitive symptoms. Adjuvant medications have been identified and are clinically used to target affective symptoms and improve overall cognition. Negative symptoms are known to be associated with lower SW, N while positive symptoms appear to have no to low significant influence on SWBN(75)irrespective of symptom severity. Thpotentiallyal negative effect on cognition as a result of neuroleptics and adjunct medication was not looked at anneededds to be taken into consideration. These areas were beyond the scope of this study but are potential areas for further resear.ch

Third, two psychological fallacies, affective falla, y and the reality distortion fallacy may have skewed findings. The potential of skewed findings due to psychological fallacies should be considered despite the measures taken to ensure that research participants understood the questionnaire, had the capacity for self-expression and evidence that patients with SMcanto respond to SWN-K 20. Affective fallacy is an error produced whethe emotion elicited by the content influences one's judgment, t i.,e. a depressed individual reporting to have more inferiorer quality of living while reality distortion fallacy is an error produced when the interpretation of context is influenced by individual mental sta, e i.,e. perceptual disturbances may distort one's discernment of their wellbeing. These fallacies are known to distort subjective reports of an individual's patient's quality of life and well-being and should be taken into consideration(76).

CLINICAL AND RESEARCH IMPLICATIONS

i) The SWN-K 20 Xhosa language version holds potential clinical and research utility as an overall measure of SWBN in Xhosa people with schizophrenia. However, the subscales did not demonstrate adequate validity or reliability in the current Xhosa language version.

ii) The analysis suggests that those with lower education, poorer global functioning (low GAF scores) and less severe symptoms are more likely to have lower SWBN and may be at risk of poor compliance. This informatiohelps provideng guidance for clinicians and researchers regarding interventions to improve compliance, outcom, s and the treatment experiences in a population that is characteristically similar to this patient group.

iii) The study focused on a translated measure athe a first step in cultural adaptation. Further research might be considereto tailor the items to the specific context and culture culturallyre. The newly generated components merit further evaluation to determine whether cultural and linguistic specific subscales might provide further insight and recommendations for use ithe n South African context.

CONCLUSION

Patients' perception of well-being while on neuroleptic treatment is an essential area of focus when aiming at improvinpatient-centereded treatment, complian, e and overall treatment outcome. Treating individuals with SMI ichallenginglt and madmore complicatedex whea n patient's treatment experience and expectations are not elicited. Having a self-reported measurement like the SWN-K 20 available in a validated Xhosa language version provides helpful, possibly broad insights into the subjective well-being experiences of this patient group. Future studies should explore specific symptoms domains that are associated with a change in subjective wellbeing instead of general illness severity.

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APPENDIX A: Participant information sheet and consent form

A1: ENGLISH

A2: XHOSA

The Genomics of Schizophrenia in the Xhosa People of South Africa

Primary Investigators: Profs D. Stein, O. Alonso Betancourt, R. Ramesar. E. Susser, R. Gur, R. Gur, M.C. King
University of Cape Town Human Research Ethics Committee number: 049/2013
Walter Sisulu University Research Ethics and Bio-safety Committee Number: 003/2013
Columbia University Internal Review Board number: UCT IRB of record
University of Washington IRB number: 29501

Participant Information Sheet

Dear Participant,

You have been invited to take part in our study on how DNA affects schizophrenia.

Here is some information which can help you to choose if you would like to be part of this study:

Background

Our body is made up of many tiny parts called cells. There are lots of different kinds of cells; for example, skin cells and cells in your blood. Each kind of cell has a special job. All the cells work together to make your body. Inside each cell there is something called DNA. DNA is the instructions that tell the cells how they are supposed to function. We get our DNA from both of our parents. Every cell in your body has the same DNA, but nobody else in the world has the same DNA as you, unless you are a twin. The difference between your DNA and the DNA of other people is very small. These small differences can, however, have an influence on people's characteristics, for example, differences in DNA can influence whether people are tall or short. Also, some, but not all, sicknesses can be caused by problems with DNA. In these sicknesses some cells don't work the way they should, and this is why these sicknesses can happen.

What is the study about?

This study looks at schizophrenia. Schizophrenia is a common and serious illness. It affects 1 out of every 100 people. Each case of schizophrenia is unique. It can cause delusions (strange beliefs), hallucinations (like heaving voices and seeing things). It can also cause people to behave strangely and to speak in a way that might be difficult to understand. It causes significant suffering, and disability for those affected by it, their families and the community. Sometimes people who are very ill with schizophrenia can be dangerous to themselves or others. Sometimes it may be difficult to treat, but often treatment can improve the lives of those affected by this difficult disease. We will try to find any DNA that may be related to these problems and why some people get sick while others don't.

For us to find the DNA that may be related to schizophrenia, we will need to test people who have schizophrenia, and people that do not. Therefore, you may have been approached to take part in this study because you suffer from one of the illnesses in which we are interested, or because you do not suffer from one of these illnesses. We compare the DNA of the two groups so that we can see if there is any problem with the DNA causing the sicknesses.

The reason that we want to look at how DNA may be related to schizophrenia is so that we can better understand the cause of schizophrenia. If we understand how the DNA can cause schizophrenia then we hope to be able to make better treatments to help people suffering from schizophrenia.

More information about participating in this study

If you choose to take part in this study, a nurse will want to ask you some questions about your life and your problems. This will take from 2 hours to 5 hours. The reason that this can take a long time is that some people will have more to tell us about illnesses that they have had, but people who have never had these kinds of problems will not have too much to say about them. You will be able to take breaks as you need during this interview, but not during the computer test. Please let the interviewer know if you would like to take a break. We will only see you once during this study.

You will also be asked to do a computer assessment. You don't have to worry about the computer assessment. The nurse will show you how to use the computer. This will help us to understand how you think. It will take between 30 and 60 minutes. The nurse will then take 2-3 tubes of blood, some of which will be sent to universities in the United States. We would also like to do an HIV test. Everyone who is taking part in this study has an HIV test. If the HIV test is positive you will be referred for further management if needed. We

will give you the results of the HIV test during the interview, but we will keep the result secret from everyone outside the research team.

HIV testing is being done so that we can learn if the relationship between DNA and schizophrenia is different in people who suffering from HIV. You will receive counselling and might be referred for further tests or treatments. We will make sure that your HIV status is not linked to your name, ID number or address (identifying information).

During the study, we may ask you if we may contact your mother and father so that we can ask them to also take part in the study. If they choose to join the study this would involve a full interview, the computer test, HIV testing and DNA testing. The reason we want to do this is that some illnesses are passed down in families because our DNA comes from our parents. Sometimes people will have signs of an illness, but not become ill. We want to see if schizophrenia can cause any changes in the way affected people think. If you allow us to contact your family, we will also want to do a test to be sure that your father is the person who fathered you and that some of your DNA comes from him. These results will be kept confidential and will not be available to you or your family. Your family will not be told any of your results and we will not tell you any of your family's results. If you do not wish us to contact your family we will not. This is your choice and it will not change how you are treated at any hospitals or clinics.

All information that we gather from you will be confidential and will only be used for research purposes. Nobody outside the study will be able to know which results belong to you. There is no way for anybody taking part in the study to know who else is being tested, or any of their results. All your results will have the identifying information removed.

It is your choice to take part in this study. We have tried to make sure that you can take part in this study by speaking to the doctor who is treating you. This study does not have anything to do with the care you receive at this hospital. If you do not choose to take part in this study, it will not affect the care you receive from your hospitals and clinics. If you do not want to answer some questions or if you do not want some tests to be done you do not have to do them. If you would like to stop at any time, you are free to do so. If you change your mind later, you can tell us, and we will destroy your information and specimens (such as your blood samples).

If you do not choose to take part in this study or if you change your mind during the interview, or if you do not want to have blood taken, then we will not use any information you have given us in the study. Not taking part in the study will not affect the care you receive at hospitals and clinics.

Once we have measured the DNA in your blood cells, the results will be kept on a computer, so that the researchers who are working on this study can learn from the results. The results are kept on the computer known as a "central data base". A central database is like a big list of the information that we get from all the different people who choose to be in this study. It is important to know that **identifying information** like your name, your ID number, your birthdates, and your address will not be included in this central database . Scientists who look at the database will not be able to identify you. Information which could be used to identify you will be kept in a separate computer that can be used only by local study investigators and staff who have been given special permission to use it.

Potential risks and benefits

Taking part in this study is very safe. Our nurses who will take your blood have been trained to this. Having blood taken can be uncomfortable. There is only a very small chance of infection or injury at the injection site. If you choose to take part in the study, some of the questions may make you remember or feel things which may be uncomfortable. If you get upset, you can speak with one of the staff in the ward. If a question makes you feel uncomfortable you can choose to skip answering it.

We are doing this study to look at schizophrenia and its association with differences in DNA in the Xhosa People. Many similar studies have been undertaken on people living in other parts of the world. The reason that we are researching the Xhosa people is that there may be important differences in the DNA of Xhosa people compared with other populations which are commonly studied. Most research on the genetics of

schizophrenia is taking place outside of Africa. The knowledge from these studies may not be as relevant to the Xhosa people, that is why it is so important to conduct this study. This research involving the Xhosa people may also advance knowledge to the benefit of the Xhosa people and other peoples. There is a concern that if we tell people about studies of the DNA associated with schizophrenia in the Xhosa that this will result in some people forming bad opinions of the Xhosa people. We do not have any evidence that this will happen. The Xhosa people are not known to be affected by Schizophrenia more than any other group of people. We have formed a Community Advisory Board (CAB). It is made up of people with knowledge of the Xhosa language and culture from the communities, and others. We will meet with them regularly during the study. We hope that this board will help to prevent stigma from being created. It will advise us on other stigma related matters. We hope that people do not think this study means that the Xhosa people are particularly affected by schizophrenia.

There are no direct benefits for you taking part in this study. Your participation could hopefully help us to better understand schizophrenia, and hopefully, in the future, make better treatments.

We have discussed the risks to you of participating in this research. We have also noted the possible benefits if we learn more about schizophrenia. Our view is that the possible benefits of this research outweigh the possible risks, but the choice of whether to participate is yours.

Compensation

You will be compensated for taking part in this study. The nurse running the interview will ask you a few questions, for which you will be paid R25 for your time and for the inconvenience. If you can be a part of the study and if you choose to join the study you will be paid an additional R125 for the time and inconvenience of being asked a lot more questions and having blood taken.

What will happen with the information you provide?

Everything you tell us will be kept secret, except some of your general information like age, sex, area in which you live, unless you have agreed otherwise. All identifying information like name, ID number, date of birth and address will be kept separately from the data we are sharing and will not be available to others. Even though we will be using the things you say, and the results of the tests, there will be no way to link it to you. We do our best to make sure that your identity is kept secret. We will keep all of your identifying information, like your name and address in a very safe, secure computer so that we can trace you if we need to. This information will never be shared (it will remain confidential). It very rarely occurs that this confidentiality can sometimes be broken. This can happen if there is a serious accident, if government asks for information or if there is something dangerous happening like suicide or child abuse.

It is your choice to take part in this study. We have explained what we are doing and why. You can make your choice freely and you are welcome to change your mind later. Choosing not to take part in this study will not have any effect on the care you receive at any hospitals or clinics. If you choose to withdraw from the study, it will not affect the care you receive.

If you have any questions please ask the nurse who is helping you, or you can contact Dr AZ Baldinger on: 021 650 3045/ adam.baldinger@uct.ac.za If you wish to withdraw your consent at a later date you may also contact Dr Baldinger.

If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact Professor Marc Blockman at the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee which is an independent Committee established to help protect the rights of research participants on telephone number 021 4066492

The Genomics of Schizophrenia in the Xhosa People of South Africa

Primary Investigators: Profs D. Stein, O. Alonso Betancourt, M. Nagdee R. Ramesar. E. Susser, R. Gur, R. Gur, M.C. King
University of Cape Town Human Research Ethics Committee number: 049/2013
Walter Sisulu University Research Ethics and Bio-safety Committee Number: 003/2013
Rhodes University Ethical Standards Committee Number: 2013Q4-7 "Genomics of Schizophrenia"
Columbia University Internal Review Board number: UCT IRB of record
University of Washington IRB number: 29501

Iphepha lolwazi lomthathi-nxaxheba

Mthathi-nxaxheba obekekileyo,

Uyamenywa ukuba uthathe inxaxheba kuphando lokuba i-*DNA* izichaphazela njani i-*schizophrenia*.

Nalu ulwazi oluzakunceda ukuba uyafuna ukuthatha inxaxheba koluphando:

Imvelaphi yoluphando

Imizimba yethu yenziwe ngamalungu amancinci ngezicuntsu eziwabiza ukuba yimisebe(*cells*). Kukho intlobo ezininzi zemisebe; umzekelo, imisebe yesikhumba nemisebe yegazi, nezinye-nezinye. Umsebe ngamnye unomsebenzi wawo obalulekileyo. Yonke lemisebe iyasebenzisana ukwakha umzimba. Ngaphakathi kumsebe ngamnye kukho into okuthiwa yi-*DNA*. i-*DNA* ingumyalelo ochazela imisebe ukuba kufuneke isebenze njani nokuba yenze eminye imisebe eyongezelekileyo. i-*DNA* yethu siyifumana kubazali bethu bobabini. Umsebe ngamnye emzimbeni wakho une-*DNA* efanayo, kodwa akekho omnye umntu emhlabeni one i*DNA* efana neyakho, ngaphandle kokuba uliwele. Umahluko phakathi kwe-*DNA* yakho neyabanye abantu mncinane. Lomahluko omncinane kodwa ungenza ifuthe kwinkangeleko nobunjani bomntu, umzekelo, ebudeni nasebufutshaneni bomntu. Ezinye, hayi zonke izifo zingabangwa yingxaki ekwi-*DNA*. Kwezizifo eminye yemisebe ayisebenzi ngendlela efanelekileyo, yilonto ebangela ezizifo.

Ingaba oluphando lumayelana nantoni?

Oluphando lujonge iingxaki ezenziwa lufuthe lwemeko kunye neengxaki zeengcinga (oku kubizwa ziinzululwazi ukuba yi schizophrenia kunye nezinye izigulo ezinxulumene nayo). i-*Schizophrenia* sisigulo esikhona nesiqhelekiyo. Esisigulo sichaphazela umntu omnye kubantu abalikhulu. i-*Schizophrenia* sivela ngendlela ezahlukeneyo ebantwini. Singabangela umntu akholelwe kwizinto ezingekhoyo okanye ezibubuxoki (delusions), ave amazwi okanye abone izinto abanye abantu abangaziboniyo(hallucinations). Senzabantu baziphathe ngendlela engamkelekanga, bathethe izinto ezingaphathekiyo okanye ezingenasihlahla ekuthi kubenzima ukuziqonda. Esisigulo singabangela kubenzima ukuba umntu azikhathalele kwabo bachaphazelekiyo, kusapho nasekuhlaleni. Ngamanye amaxesha abantu abagula kakhulu sesisigulo babanobungozi kubo nakwabanye abantu ekuhlaleni. Ngamanye amaxa kubanzima ukusinyanga esisigulo, kodwa ngokufuma unyango ngokufanelekileyo kwenza impilo ibengcono kwabo bachaphazelekileyo sesisigulo sinzima. Kuzakuba nenzame yokufumana i-*DNA* enokuba nonxulumanano nezingxaki nokuba kutheni abanye abantu bevuselelwa zezingxaki zithile.

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Participant consent form

1. I, _____, agree to take part in this study, which will use my DNA to try to learn about the causes of schizophrenia.
2. I give permission for my blood to be taken for DNA analysis.
3. I give permission to be interviewed and to have my answers written down. I agree to take the computer test which assesses different kinds of thinking.
4. I understand that:
    a. If I am eligible to take part in this study, I will be compensated R150 for my time and inconvenience. If I can't be part of this study because I do not fit into the right group of people, I will be compensated R25.
    b. My information gathered during this study will be linked to a unique study number, and not with my name. My identity will be kept confidential. The information gained during the interview will only be available to the people doing the study, unless otherwise specified.
5. I have read, or have been read, the accompanying information sheet in my own language. I understand this consent form and the information sheets. Any questions I had have been answered. I understand that the information sheet is a part of this consent form.
6. I understand that I may be contacted in the future to request additional information related to this project, or to see whether I am interested in participating in a new project.
7. I understand that participating in this study is my choice and that it will not affect the care I receive at any hospitals or clinics. Withdrawing my consent at any time will also not affect my medical care.

Signed in _____ (place) on _____ (day) of _____ (month) 20__ (year)

Signiture_____
_____

Witness 1 Name_____ Signature
_____

Witness 2 Name_____ Signature
_____

yofuzo, ngokuba i-*DNA* yethu iphuma kubazali. Ngamanye amaxesha abantu bangaba neempawu zesifo kodwa bangaguli. Sifuna ukubona ukuba iingxaki ezenziwa si-*schizophrenia* kwindlela abacinga ngayo abantu abachaphazelekayo. Ukuba ungasivumela ukuba siqhagamshelane nosapho lwakho siyakunyanzeleka ukuba senze uvavanyo ukuze siqinisekise ukuba uTata wakho nguyise okuzalayo nokuba ingxenye ye-*DNA* yakho uyifumene kuye. Iziphumo zoluvavanyo zizakugcinwa ziyimfihlo yaye azizukubhengezwa kuwe okanye kusapho lwakho. Usapho lwakho aluzukuxelelwa ngeziphumo zakho yaye nawe awuzukuxelelwa ngeziphumo zosapho lwakho. Ukuba awuthandi ukuba siqhagamshelane nosapho lwakho, asizukukwenza oko. Ungazikhethela oku futhi akuzukuchaphazela anyango olufumana kwisibhedlele okanye ikliniki.

Lonke ulwazi esilufumene kuwe luzakugcinwa luyimfihlo luyakusetyenziswa kwinjongo zophando kuphela. Akukho mntu ongaphandle koluphando ozokuba nolwazi ukuba zeziphi iziphumo zakho. Ayikho indlela kubantu abathatha inxaxheba koluphando, abayakhuthi bazi abanye abantu abavavanyiweyo kunye neziphumo zabo. Iziphumo zovavanyo lwakho azisayikuba nanto edibene negama lakho.

Uthatha inxaxheba koluphando ngokuthanda kwakho. Siqinisekise kugqirha wakho ukuba ungathatha inxaxheba koluphando ngokuthethisana nogqirha wakho. Oluphando aluluchaphazeli unyango olufumana kwesisibhedlele. Xa ngaba ungakhetha ukungathathi nxaxheba koluphando, unyango olufumana esibhedlele kunye nase kliniki aluzuchaphazeleka. Awunyanzelekanga ukuba uphendule yonke imibuzo okanye wenze lonke uhlobo lovavanyo. Ukhululekile okuba ungaluyeka nanini na olupahndo. Ukuba utshintsha ingqondo yakho kwixesha elizayo, ungasixelela ukuze silulahle lonke ulwazi nencukacha esinazo malunga nawe.

Ukuba ukhetha ukungathathi inxaxheba koluphando okanye utshintshe ingqondo yakho phakathi kudliwano-ndlebe okanye ungafuni ukutsalwa igazi, asisoze sisebenzise ulwazi lwakho esilufumene kuphando oluphangeleleyo. Ukungathathi nxaxheba kuphando akuzukuchaphazela unyango olufumana kwizibhedlele kunye nakwi kliniki.

Emva kokulinganisa i-*DNA* ekwimisebe yegazi lakho, iziphumo zizakugcinwa kwikhompyutha ukuze iinzululwazi ezisebenza koluphando zifunde ngezi ziphumo. Iziphumo zigcinwa "kuluhlu olusembindini"*(central database)* kwi khomputha. Uluhlu olusembindini *(central database)* luqulethe incukacha ezidwelisiweyo esizifumana kubantu abahlukileyo abakhethe ukuthatha inxaxheba koluphando. Kubalulekile ukuba uqonde ukuba ulwazi lomazisi wakho njengegama lakho, inombolo yeSazisi sakho, imini yokuzalwa kwakho kunye nedilesi yakho aluzukufakwa koluluhlu olusembindini *(central database)*. Iinzululwazi ezisebenza ngoluluhlu azizukufumana isazisi sakho. Ulwazi olunokusetyenziswa ukufumana isazisi sakho luzakugcinwa kwi khompyutha esecaleni okanye eyodwa enokusetyenziswa ngabaphandi bophando lwasekuhlaleni nabasebenzi abanikwe imvume eyodwa, kuphela.

Ubungozi nenzuzo enokubakho

Ukuthatha inxaxheba koluphando kukhuselekile. Abongikazi bethu abazakutsala igazi lakho baqeqeshelwe oko. Apho sizakutsala khona igazi kuzakuba nobuhlungu obuncinane kodwa wona amathuba okusuleleka kwakho ambalwa kakhulu.

Ukuba uthatha inxaxheba koluphando, eminye imibuzo ingakwenza ukhumbule izinto ezikwenza ungazivi kamnandi. Ukuba uyacapuka, ungathetha nomnye wabasebenzi kwigumbi lokongela. Ukuba umbuzo ukwenza ungaziva kamnandi ungangawuphenduli.

Senza oluphando sijonge i-*schizophrenia*, kwakunye nobudlelwane nomehluko kwi-*DNA* kumaXhosa. Olunye uphando olufanayo selwenziwe kubanye abantu kumazwe ahlukeneyo ehlabathini. Isizathu sokuba siphande ngamaXhosa kukuthi kungakho umahluko obalulekileyo kwi-*DNA* yamaXhosa xa ithelekiswa nezinye izizwe eziqhelwe ukuphandwa. Uphando olungamandla kwi*DNA* nge-*schizophrenia* lwenzeka ngaphandle kwe-Afrika. Ulwazi olufumaneka koluphando lwenzeka ngapandle kwe-Africa kungenzeka lungawachaphazeli amaXhosa. Oluphando kumaXhosa lungabaluncedo kumaXhosa nakwezinye iintlanga kwixa elizayo, kungako kubalulekile ukwenza oluphando. Kukho inxalabo yokuba ukuba singaxelela abantu ngoluphando lwe-*DNA* olumayelana ne-*schizophrenia* kumaXhosa, lonto ingenza ukuba abanye abantu babeneengcinga ezimbi ngamaXhosa. Asikho isiqinisekiso sokuba amaXhosa achapazela kakhulu si-*schizophrenia* okwedlula ezinye intlanga. Senze iqumrhu locucebisa abahlali*(community advisory board)* elenziwe ngabantu abanolwazi ngamasiko nezithethe zamaXhosa, nabanye abantu. Sizaku ndibana rhoqo ngelixesha lophando. Siyathemba ukuba eliqumrhu lizakuqinisekisa ukuba abantu abazuku calucalulwa ngokwesigulo sabo nango buni babo. Kwaye baya kusicebisa nangolunye ucalucalo oluyakuthi luvele. Siyathemba ukuba abantu abayikucinga ukuba oluphando luthetha ukuthi amaXhosa agula si-*schizophrenia* kakhulu ukodlula ezinye intlanga.

Akukhonto ozakuyizuza ngokuthatha kwakho inxaxheba koluphando. Sinethemba lokuba igalelo lakho lungasinceda kwimizamo yethu yokuqonda i-*schizophrenia*, ngcono, lento inokusinceda ukuba sikwazi ukwenza unyango olungcono kwixesha elizayo.

Sithethile nawe ngobungozi obunokubakho ngokuthatha inxaxheba koluphando. Siyiqwalasele nenzuzo enokubakho kwabanye abantu xa singafunda-nzulu ischizophrenia. Umbono wethu kukuthi inzuzo enokubakho ingaphezulu kobungozi obunokubakho, kodwa nguwe onokuzikhethela ukuba ungathanda na ukuthatha inxaxheba.

Okumayelena nentlawulo

Uzakuvuzwa ngokuthatha inxaxheba koluphando. Umongikazi ophethe oludliwano-ndlebe uzakukubuza imibuzo embalwa, apho uyakubhatalwa iR25 ngokuzikhathaza kwakho kunye nexesha lakho. Ukuba ungaba yingxenye yoluphando yaye ukhethe ukuthatha inxaxheba, uzokongezelelwa nge R125 ngokuzikhathaza kwakho kunye nexesha lakho olithathileyo ukuphendula eminye imibuzo engaphezulu, nokutsalwa igazi.

Kuzokwenzeka ntoni ngolwazi osinikezele ngalo?

Yonke into osixelela yona izakugcinwa iyimfihlo, ngaphandle kolwazi olunye olwakho oluphangeleleyo, njengeminyaka yakho, isini kunye nengingqi ohlala kuyo, ngaphandle kokuba usivumele ukuba silubhengeze olulwazi. Lonke ulwazi lwesazizi sakho njengegama, inombolo yesazisi, imini yokuzalwa kunye nedilesi yakho luzakugcinwa ecaleni aluzudibana nolwazi esabelana ngalo yaye aluzukubhengezwa kwabanye abantu. Nokuba sizokusebenzisa izinto ozithethayo kunye neziphumo zovavanyo, oku akuzokudityaniswa nenkcukacha zakho. Sizakwenza konke okusemandleni ethu ukuqinisekisa ukuba isazisi sakho siyimfihlo. Sizakugcina lonke ulwazi olukwisazisi sakho, njengegama nedilesi yakho kwikhompyutha ekhuselekileyo ukuze sikwazi ukukufumana xa kukhona isidingo. Olulwazi aluzukwabelwana ngalo nabanye abantu, luzakugcinwa luyimfihlo. Esisivumelwano sethu salemfihlo singophulwa kuphela xa kunokuvela ingozi emasikizi okanye urhulumente acele ulwazi oluthile okanye kwenzeke into enobungozi njengokuzibulala komntu okanye ukuhlukumezwa kwabantwana.

Uthatha inxaxheba koluphando ngokuthanda kwakho. Sikucacisile esikwenzayo sanikezela nangezizathu. Ungazikhethela ngokukhululekileyo yaye uvumelekile ukuba uyafuna ukurhoxa nanini na koluphando.. Ukuba ukhetha ukungathathi inxaxheba koluphando unyango olufumana esibhedlele okanye ekliniki aluzukuchaphazeleka. Ukuba ukhetha ukurhoxa koluphando, unyango olufumanayo esibhedlele okanye ekliniki aluzukuchaphazeleka.

Ukuba unemibuzo, nceda uthethe nomongikazi wakho okanye uqhakamshelane no Dr. AZ Baldinger kwinkcukacha ezilandelayo: 021 650 3045/ adam.baldinger@uct.ac.za. Ukuba ufuna ukurhoxisa imvume yakho kwixesha elizayo unganakho ukuqhagamshelana naye u Dr Baldinger.

Ukuba ufuna ukufumana ulwazi mayelana namalungelo wakho njengomthathi-nxaxheba kuphando-nzulu okanye unenxalabo mayelana noluphando-nzulu, ungaqhagamshelana no-*Professor* Marc Blockman kwi Yunivesithi yaseKapa, weKomiti ejongene ngendlela yokusebenza esesikweni kwicandelo lwezempilo nophando loluntu. Leyikomiti ezimeleyo injongo yayo kukukhusela amalungelo wabathathi-nxaxheba kuphando-nzulu. Ungaqhagamshelana nabo kwezinombolo: 021 4066492

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i-F*omu* yeMvume yo Mthathi-nxaxheba

1. Mna, _____, ndiyavuma ukuthatha inxaxheba koluphando, oluzakusebenzisa i-*DNA* yam ukuzama ukufunda ngonobangela we-schizophrenia.

2. Ndinikezela ngemvume yotsalo-gazi ukuze kwenziwe uvavanyo lwe-*DNA*.

3. Ndinikezela ngemvume yokuba ndingabuzwa imibuzo yaye iimpendulo zalemibuzo zibhalwe phantsi. Ndiyavuma ukwenza uvavanyo lwekhompyutha oluhlola indlela ezahlukeneyo zokucinga.
4. Ndiyavuma ukuba:

    a. Ndiye ndakethwa ukuthatha inxaxheba koluphando, ndizakunikezwa umvuzo ongange R150. Ukuba andikhethwanga ukuthatha inxaxheba koluphando, ngokuba ndingeyo ngxenye yabobantu abafunekayo, ndizakunikezwa imali engange R25 ngexesha lam endilichithileyo.

    b. Ulwazi olufumaneke kum ngoluphando luzakunxulumaniswa nenombolo ehamba yodwa yoluphando, endaweni yokusetyenziswa kwegama lam. iSazisi sam sizakugcinwa siyimfihlakalo limpendulo endizinikeze kwimibuzo yam zizakubhengezwa kubantu abenza oluphando qha. Kuxhomekeke kum ukuba ndithathe inxaxheba kwenye ingxenye ehamba noluphando.

5. Ndilifundile okanye ndilifundelwe, iphepha lolwazi oluhambisana noluphando, ngolwimi lwam. Ndiyayivisisisa le form yemvume nephepha lolwazi. Imibuzo ebendinayo iphendulwe. Ndiyalivisisa ndiqonda ukuba iphepha lolwazi liyingxenye yale-*form* yemvume.

6. Ndiyaqonda ukuba abantu abenza oluphando bangaqhakamshelana nam kwixesha elizayo ukuze bacele ulwazi olongezelekileyo mayelana nalomba, okanye kubuzwe ukuba ndingabanawo na umdla wokuthatha inxaxheba kumba omtsha.

7. . Niyavuma ukuba ulwazi olufumaneke koludliwano-ndlebe kungenzeka ukuba kobelwane ngalo kunye ne TEAM endinyangayo, kwaye/ okanye lungabhalwa kwi FOLDER yam. Lonto iquka iziphumo zovavanyo lwe- HIV, Isigulo, inxalabo yomvavanyi, kunye nenxalabo yam.

8. Ndiyayiqonda into yokuba ndithatha inxaxheba koluphando ngokuzikhethela nangokuthi unakekelo endilufumana kwi klinik nasesibedlelea aluyikuchaphazeleka. Ndingayirhoxisa imvume yam nangaliphi na ixesha, lonto ayisayi kuluchaphazela unyango lwam.

Ityikitywe e _____ (indawo) ngomhlaka_____ (usuku) kwinyanga ka-_____ (inyanga) kunyaka ka 20__ (unyaka)

Tyikitya_____

Ingqina 1 Igama_____ Tyikitya_____

Ingqina 2 Igama_____ Tykitya _____

Name: _____
Surname:

October 2014

APPENDIX B: Questionnaire

B1: ENGLISH AND iSiXHOSA

ID#	Date:

Participant could read the questionnaire themselves □ | Participant could complete the questionnaire by themselves □ | Participant understood the form when it was completed □

Subjective Well-being under Neuroleptics - Short Form

Instruction:

All statements refer to the past seven days. Please mark in the appropriate response. Please do not discuss questions with others before answering. Please answer honestly and do not leave out any questions. There are no 'right' or 'wrong' answers, please mark in accordance with your own opinion.

Medication: _____

Imiyalelo:

Zonke ezinkcukaca zijoliswe kwezi ntsuku zisixhenxe zidlulileyo. Nceda ukhethe impendulo efanelekileyo. Nceda ungathethi ngale mibuzo nabanye abantu phambi kokuba uphendule. Nceda uphendule ngokunyanisekileyo ungashiyi nayiphi na imibuzo. Akukho kulunga okanye ukungalungi kwimpendulo zakho, nceda ukhethe ngokubona kwakho.

	Not at all Hayi	A little Kancinci	Somewhat Nje ngamaxesha athile	Noticeable Ndithe ndiyiqaphele	Much Kakhulua	Very much Kakhulu ngamandla
1. I feel powerless and not in control of myself. Ndiziva ndingena mandla kwaye ndingenalo ulawulo lwesiqu sam	1	2	3	4	5	6
2. I feel very comfortable with my body. Ndiziva ndonwabile ngesiqu sam.	1	2	3	4	5	6
3. I find it easy to think. Ndifumana kulula ukucinga	.1	2	3	4	5	6
4. I have no hope for the future. Andinalo ithemba ngekamva lam	.1	2	3	4	5	6
5. My body feels familiar (normal). Uzimba wam uvakala njengesiqhelo	1	2	3	4	5	6
6. I am very shy about getting to know people. Ndibanetloni kakhulu ukwazi abantu	1	2	3	4	5	6
7. I am imaginative and full of ideas (I have thoughts and opinions/ideas). Ndinazo iingcinga nemibono	1	2	3	4	5	6
8. My environment seems friendly and familiar to me. Oku ndingqongileyo kukhangeleka kulungile kwaye kuqhelekile kum	1	2	3	4	5	6
9. I feel weak and exhausted. Ndiziva ndityhafile kwaye ndidiniwe	1	2	3	4	5	6
10. My emotions and sensations are dull. Nothing matters to me (There is nothing I care about). Ndiziva ndingena luvakalelo kwaye ndinxunguphele. Akhonto ndiyikhathaleleyo.	1	2	3	4	5	6

ID#	Date:

Participant could read the questionnaire themselves □ Participant could complete the questionnaire by themselves □ Participant understood the form when it was completed □

APPENDIX C: ETHICAL APPROVAL

11. My thinking is difficult and slow. Ukucinga kwam kunzima kwaye kuyacothoza	1	2	3	4	5	6
12. My feelings and behaviour are inappropriate to situations. I get upset over small things, important ones hardly affect me. Uhlobo endenza ngalo izinto, nendiziva ngalo alulunganga kwezinye indawo. Izinto ezingenamsebenzi zezona zindicaphukisayo, kodwa ezi zibalulekileyo andizihoyi.	1	2	3	4	5	6
13. I find it easy to keep in touch with people around me. Ndifumanisa kulula ukunxibelelana nabantu abandingqongileyo.	1	2	3	4	5	6
14. I perceive my environment as being changed, strange and threatening. Ndiva ngathi okundingqongileyo kutshintshile, akuqhelekanga kwaye kuyoyikisa.	1	2	3	4	5	6
15. I find it easy to draw a line (separate) between myself and others. Ndifumanisa kulula ukuzikhwebula kwabanye abantu.	1	2	3	4	5	6
16. My body is a burden to me. Umzimba wam uluxandava kum	1	2	3	4	5	6
17. My thoughts are flighty and undirected. I find it difficult to think clearly. Iingcinga zam zipha napha kwaye azithanga ngqo. Ndifumanisa kunzima ukucinga ngendlela ecacilelyo.	1	2	3	4	5	6
18. I am interested in what is happening around me, and it is important to me. Ndinomdla wokwazi ukuba kwenzekani kokundingqongileyo, kwaye lonto ibalulekile kum.	1	2	3	4	5	6
19. My feelings and behaviour are appropriate in the particular situation. Indlela endiziva ngayo nendenza ngayo izinto yamkelekile kwindawo endikuyo	1	2	3	4	5	6
20. I am full of confidence, everything will be alright. Ndiziva ndilizithembe kakhulu, yonke into izakulunga.	1	2	3	4	5	6

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences

Human Research Ethics Committee

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02 December 2016

HREC REF: 662/2016

Prof D Stein
Psychiatry & Mental Health
GSH

Dear Prof Stein

PROJECT TITLE: SUBJECTIVE WELLBEING IN A SAMPLE OF XHOSA PEOPLE WITH SCHIZOPHRENIA IN SOUTH AFRICA (MMed- Dr J Boshe) sub-study linked to 049-2013

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It ls a pleasure to inform you that the HREC has formally approved the above-mentioned study.

Approval is granted for one year until the 30" December 2017.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student Judith Boshe will be involved in this study.

Please note that for all studies approved by the HREC, the principal! investigator must obtain appropriate Institutional approval before the research may occur.

Please quote the HREC REFi n all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal Investigator.

Yours sincerely

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Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRBO0001938