

INTERNALISED STIGMA AMONG PSYCHIATRIC OUTPATIENTS

Rodhie D. Sapinoso

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Witwatersrand in partial fulfilment of the requirements for the degree of the Masters
of Science in Medicine in Psychiatry

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Declaration

I, Rudhie D. Sapinoso, declare that this research report is my own work. It is being submitted for the degree of Masters of Medicine in the branch of Psychiatry in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Signed :

Date: 27 May 2019

Dedication

This work is dedicated to my loving parents, Rodolfo and Dinah, for their unwavering support and guidance.

Abstract

Internalised Stigma Among Psychiatric Outpatients

Introduction:

Self-stigmatisation is when an individual cognitively and emotionally internalises negative stereotypes, prejudice and discrimination. Previous studies have shown the severe impact of internalised stigma on multiple aspects of a patient's well-being, from aggravating underlying psychiatric symptoms to severely decreasing quality of life. The aim of this study was to assess the presence and nature of self-stigma among outpatients attending psychiatric community clinics, comparing those with high levels of stigma to those with low levels in terms of demographics and clinical correlates.

Methods: The study surveyed a sample of patients who attended the Sedibeng district psychiatric clinics between October and November 2016. Demographic and clinical details were obtained from consenting participants' clinical records. The Internalised Stigma of Mental Illness (ISMI-29) questionnaire was administered by the principal investigator. An additional question was added to elucidate possible cultural or religious elements of self-stigma. Six generalised linear models were conducted to assess the influence of predictive factors on each dependent variable (i.e. alienation, stereotype endorsement, discrimination experience, social withdrawal, stigma resistance and total ISMI-29 score).

Results: Of the 123 participants, 63.4% (n=78) demonstrated high levels of internalised stigma on total ISMI-29 score. The most reliable predictor of high stigma scores was number of psychiatric admissions (0.12 ± 0.04 , 2.62, 0.010). Having schizophrenia or bipolar disorder (0.12 ± 0.04 , 2.62, 0.010), belonging to a black ethnocultural group (-0.13 ± 0.06 , 2.13, 0.036), having comorbid substance use disorders or HIV (-0.05 ± 0.02 , 2.02, 0.045) and being single (0.15 ± 0.06 , 2.27, 0.026) were shown to elevate different subsets of the ISMI-29. Although 21,2% of the sample had cultural/religious attributions of mental illness, these were not shown to correlate with higher levels of self-stigma.

Conclusions: Almost two-thirds of this sample of patients at the Sedibeng district psychiatry clinics experienced a high degree of internalised stigma, considerably higher than that reported in other settings (20-40%). A high level of internalised stigma was most reliably predicted by the number of psychiatric admissions.

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List of abbreviations

AMC – Another Medical Condition

BD – Bipolar Disorder

CHC – Community Health Centre

GLM – Generalised Linear Models

HIV – Human Immunodeficiency Virus

ISMI-29 – Internalised Stigma of Mental Illness (Full Version)

MDD – Major Depressive Disorder

RSA – Republic of South Africa

SZ - Schizophrenia

USA – United States of America

Chapter 1: Introduction

1.1 Overview and research rationale

Corrigan and Watson (2002) described stigma as consisting of two elements: public stigma and internalised stigma. Whereas public stigma deals with the attitudes and perceptions of the general population group and health care professionals, internalised stigma relates to the subjective negative self-concepts experienced by people with mental illness.

There are three components to self-stigma: stereotypes, prejudice and discrimination. Stereotypes refer to an individual's negative perceptions and beliefs about the self. Prejudice relates to agreement with these beliefs and discrimination refers to behavioural responses and actions in response to the negative self-concepts. (Corrigan and Watson, 2002)

The nature of experienced stigma has not been adequately explored in the African context. Although a study of internalised stigma (Botha et al, 2006) has been done in the South African context, the study focused on schizophrenia, rather than on other psychiatric illnesses. This study aspired to contribute to the significant paucity of information, particularly on the African continent, around the nature of internalised stigma suffered by psychiatric patients in the community. By this study, we wished to possibly highlight groups who are at risk for developing self-stigma, for efficient allocation of focused interventions. Due to poor access to tertiary care, complicated by limited available psychological and psychopharmacological interventions, it is imperative that we begin to elucidate the functional areas and patients where we need to address the most interventions, in the form of community education, personal interventions and the establishment of support groups.

1.2 Aims and objectives

The broad aim of this study was to assess the presence and the nature of self-stigma, as reported by outpatients attending psychiatric community clinics.

- 1) To describe the nature of internalised stigma experienced by a sample of psychiatric outpatients
- 2) To compare those with high levels of stigma to those with low levels in terms of demographics, clinical correlates and religious/cultural explanations for mental illness
- 3) To compare the results with the available literature

1.3 Hypothesis

I hypothesised the following:

1. Psychiatric outpatients suffer from high levels of internalised stigma.
2. People living with mental illness of black ethnicity, higher educational levels, are unemployed and on disability grants will experience higher levels of self-stigma.
3. People living with schizophrenia or bipolar disorder, individuals who have an earlier index presentation and more frequent psychiatric admissions will have higher levels of self-stigma.
4. People who do not feel supported by their religion or culture with regards to their mental illness will have higher levels of self-stigma.

Chapter two: Literature review

2.1. Internalised Stigma

Internalised stigma, otherwise known as self-stigmatisation, occurs when a person cognitively or emotionally absorbs stigmatising assumptions and stereotypes about mental illness and comes to believe and apply them to himself/herself (Drapalski et al, 2013).

2.2. Categories of Internalised Stigma

Boyd et al (2003) divided internalised stigma into five main categories:

1. Alienation relates to the subjective experience of being marginalised, being less than a full member of society, or having a “spoiled identity”.
2. Stereotype endorsement refers to an individual’s agreement with common stereotypes around mental illness.
3. Discrimination experience relates to an individual’s experience of how he/she experiences interactions, because of perceived knowledge of his/her condition.
4. Social withdrawal refers to behavioural changes due to negative self-concepts. Examples of social withdrawal are avoidance of social relationships due to the unwillingness to disclose mental illness and avoidance of relationships due to fear of rejection.
5. Stigma resistance relates to the individual’s experience of resisting or being unaffected by stigma. Corrigan and Watson (2002) described that while some individuals experience negative impacts on self-esteem and functioning due to self-stigma, others “are energised and experience righteous anger”.

2.3. Predictors of higher levels of self-stigma

Belonging to a black ethnocultural group has been shown to be associated with increased levels of self-stigma (Harrison, 1989). Being single or living alone also marks an individual for increased levels of internalised stigma (Assefa et al, 2012). Sarisoy et al (2013) found that 1 in 3 people living with schizophrenia and 1 in 5

people living with bipolar disorder are afflicted with higher levels of internalised stigma.

2.4. Studies in the African context

Studies in the African context demonstrate significant and pervasive self-stigma among psychiatric patients, mainly impacting on intimate relationships outside the family unit, the young and those with higher educational levels (Oshodi et al, 2012; Kapungwe et al 2010). Adherence is also affected by internalised stigma, precipitating both non-adherence to medication and follow-up (Assefa et al, 2012).

South African studies identified Xhosa-speaking individuals, men, patients with long psychiatric histories and multiple admissions to be particularly vulnerable to experience self-stigma (Botha et al, 2006), rooted in perceived stigma from family members, friends, the community and health care workers (Egbe et al, 2014).

2.5. The interplay of religious and cultural understandings of mental illness, on mental illness and self-stigma in RSA and the Africa

Though the effect of culture and religion has been acknowledged worldwide, very little has been written regarding the interaction of cultural and religious attributions on mental illness and subsequent stigma in the South African context. Fabrega (1991) quotes Ngumbane (1977) describing how Zulu culture handles stigma:

“Zulu handle mentally disturbed people in such a way that they do not feel responsible for their condition; they are not made to feel that anything is wrong with their minds, but merely that they are victims of external forces-the intruding alien spirits-which must be removed. The patient gets the support, sympathy and attention that depressed people often long for. Because Ufufunyane (evil spirit possession causing psychiatric illness) patients after recovery are believed to be still susceptible to. . . attacks, if provoked or annoyed, those around them must take special care to avoid situations that might make ufufunyane recur.”

On the African continent, several culture-bound syndromes are recognised, demonstrating the strong link between culture and expression of psychiatric disorders.

Supernatural forces are often deemed to be the root of psychiatric illness, either in the form of a religious calling, possession, bewitchment or indication that one has displeased the spirits (Adebowale & Ogunlesi, 1999; Ayorinde et al, 2004; Hugo et al, 2003; Mayeya et al, 2004). Studies in the South African context reveal that traditional healers are a frequently utilised pathway to care and understanding for people living with mental illness (Mkize & Uys, 2004; Mbanga et al, 2002), in Xhosa and Zulu populations.

2.6. Impact of internalised stigma on mental illness

Self-stigma significantly complicates the severe burden of mental illness (Corrigan et al, 2002) and most people with mental illness are affected in at least one area of life (Farrelly et al, 2014; Brohan et al 2011). Stigma hinders access to healthcare (Thornicroft et al, 2008), thus denying opportunities for health care professionals to intervene to address these. Higher levels of internalised stigma are associated with lower levels of self-esteem as well as a decreased recovery orientation (more likely to remain in the sick role) (Drapalski et al, 2012). Self-stigma has a reciprocal relationship with frequency of admissions (Rusch et al, 2009), in conjunction with higher symptom severity (Chan et al, 2014).

2.7. Impact of internalised stigma on social and occupational function

Internalised stigma has been linked to low self-esteem, social anxiety, negative perceptions around the ability to gain and sustain employment (Farrelly et al, 2014; Drapalski et al, 2013, Aydemir et al, 2011) and beliefs around an individual's decreased ability to manage the illness on their own (Michalak et al, 2011).

Impairments in social functioning are more directed at relationships outside the family or primary social support structure (Sarisoy et al, 2013; Moriarty et al, 2012; Ngo et al 2012), with men feeling more detachments from social relationships (Latalova et al, 2014). Internalised stigma also promotes social isolation and active avoidance of interactions outside of family members (Perlick et al, 2001). Self-stigma also hinders accessing health care and other services, impacting on the patient's experience of their

self, illness, quality of life and ability to work (El-Badri et al, 2007; Lundberg et al, 2009; Vazquez et al, 2011; Corrigan et al, 2012). In individuals with bipolar disorder, repeated admissions cause functional decline, which in turn increases self-stigma, thus causing a vicious cycle of the individual's connected to society (Rosa et al, 2009). A subjective poorer quality of life is linked to higher levels of internalised stigma (Chan et al, 2014).

2.8. Protective factors about around self-stigma

Psychotherapeutic adjuncts, especially family-oriented therapies have been shown to decrease levels of self-stigma, which in turn decrease both relapse and hospitalisation rates (Miklowitz et al, 2003, Rea et al, 2003). An individual's involvement in the social world (e.g. employment) contributes significantly to lessening the burden of self-stigma while improving function (Cerit et al, 2012).

Clinician factors related to lower levels of internalised stigma are clinicians who foster respectful relationships not only with patients, but with their families. The utilisation of a strengths-based, rather than a deficit-based model allows for an individual to take a more active role and shared decision making. Recovery orientation includes

a focus on empowerment of the individual to assume as much responsibility as possible for their recovery and an emphasis on cultivating hope, optimism, and a satisfying and meaningful life contributing to society (Anthony et al, 1993).]

2.9. Successful campaigns utilised to combat stigma

Involvement of mental health clinicians to practice evidence-based methods to address stigma are essential to decreasing the burden (Abbey et al, 2011). However, it is essential to recognise the uniqueness of our multicultural identities and to tailor a culturally-sensitive intervention (Angermeyer et al, 2004). Multiple programmes have utilized a close collaboration between mental health professionals and social media to promote positive messages. Examples of these programmes can be found in New Zealand "Like Minds, Like Mine" (Vaughan, G. & Hansen, C., 2004), UK's

“Time to Change” (Henderson et al, 2009) and Scotland’s “See Me” (Dunion et al, 2005). Besides this, the literature suggests that providing mental health care users a more active role in their treatment empowers them and combats self-stigma.

Examples of these areas of contribution included leading mental health care user service satisfaction assessments, support groups, health promotion, developing peer-support worker roles and the enabling people living with mental disorders to take part in their treatment, as well as evaluation and research (Chamberlin, 2005).

Chapter three: Methods

3.1 Introduction

The aim of the study was to examine the levels of internalised stigma among psychiatric outpatients, to identify possible risk factors, and to explore possible religious or cultural attributions of mental illness, which may predict higher levels of self-stigma.

3.2. Study procedure

This was a cross-sectional prospective study which explored the relationship between the ISMI-29 and the demographic and clinical profile of participants. This study was performed on a convenience sample of psychiatric outpatients attending community outpatient clinics, serviced by the Gauteng Department of Health. The structured interviews were conducted in English.

3.3. Setting

Study participants were recruited from the Zone12, Levai Mbatha, Johan Heyns and Meyerton psychiatric clinics in the Sedibeng district of Gauteng province. Potential study participants were invited to participate on the days in which they receive repeat medication in order to minimise the impact on service delivery on medical review days.

3.4. Participants

Participants were recruited from Zone 12, Levai Mbatha, Johan Heyns and Meyerton clinics in the Sedibeng District of Gauteng. A General invitation to participate in the study was offered to mental health care users who attended the clinic. Patients who lacked the capacity to give consent due to current mood, psychotic or cognitive symptoms (as judged by the administering clinician), as well as patients unable to communicate in English were excluded from the study.

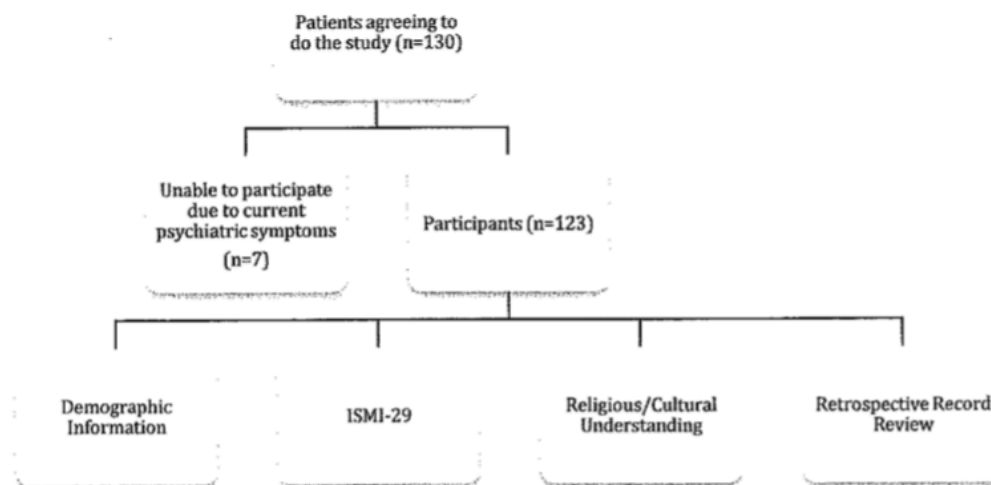


Figure 1: Flow diagram of participant progress through phases of the study.

3.5. Data collection

A demographic questionnaire was used to obtain the age, sex, population group, relationship status, employment status (and whether they are receiving a disability grant) and level of education of each participant.

Clinical data was obtained from the participants' clinical records and included the current psychiatric and medical diagnoses and psychopharmacology. The age at first psychiatric presentation and most recent admission were also collected. The principal researcher collected all data.

3.6. Rating Scales

The ISMI-29 has an internal consistency reliability coefficient of $\alpha = .90$. Test-retest reliability was $r = 0.92$ ($p < 0.05$, $N = 16$) (Boyd et al, 2003). The psychometric properties of the ISMI-29 have been validated internationally (Steverink et al. 2012, Boyd et al 2003) and has been used in South Africa (Botha et al, 2006). One qualitative question was added to explore internalised stigma in relation to the participant's cultural or religious context. This question was: "Do you feel supported by your religion and/or culture with respect to your mental illness?" Answers to this question were recorded as a yes or no.

3.7. Data analysis

The database was created with Microsoft Excel, and was assessed for any omitted or missing information, as well as for possible erroneous entries. Any identifying information was removed from the dataset and a separate key linking study number to patient identification was kept by the investigator. The variables were coded appropriately, and the relevant dataset was entered and processed for further statistical analysis.

All statistical analyses were conducted using R software (R studio version 0.99.903; <https://www.rstudio.com/>). All tests were two-tailed probability values, and statistical significance was accepted when $\alpha \leq 0.05$. The data set was first assessed for departures from normality using the Shapiro-Wilk test and visualised using Q-Q plots. All dependent variables displayed non-normal distributions (i.e. heteroscedasticity). Therefore, the data sets were analysed using generalized linear models (GLM; lme4 package), which are appropriate for analysing non-normal data. GLMs were run using gaussian error structure and an identity link function.

Six GLMs were conducted to assess the influence of predictive factors on each dependent variable (i.e. alienation, stereotype, discrimination, social, resistance and total ISMI score). The following 15 factors (either continuous or fixed) were analysed: sex; age; marital status; ethnicity; home language; highest level of education; employment status; disability grant; primary diagnosis; comorbid diagnosis; psychiatric treatment; age at index; recent admission; admission frequency; and religion/culture. Prior to analysis, the factors were tested for multi-collinearity using the variance inflation factor (VIF; car package) and visualized using principal components analysis (FactoMineR package). VIF values were low (≤ 2.1) so all factors were included in the final analyses.

Statistical data for the factors were reported as β -estimate $\pm$ SE. The relationship between statistically significant factors (continuous and fixed) and each dependent (as

applicable) were assessed graphically, using scatterplots generated by Microsoft Excel, and trend lines were added to figures to show the overall relationships between variables.

3.8. Ethics

Letters of permission were obtained from the Clinical Manager of the Sedibeng District, as well as the nursing staff of the relevant clinics. Ethics approval was obtained prior to commencement of study (Ethics M150371). Informed consent was obtained prior to interviewing the patient. Due to the delicate and possibly emotionally charged content of the study, a distress protocol was set in place to provide comfort and care for participants who may be overwhelmed in the course of the interviews. Should a participant had been unable to continue the interview, prior arrangements had been made with the Sedibeng nursing staff to provide immediate comfort and containment and to arrange follow up mental health care as necessary. The researcher would give the participant a courtesy phone call, to ensure the participant's distress had settled.

Chapter Four: Results

Table 1: Demographic characteristics of the study participants (n = 123)

Gender	Male	60 (48,8%)
	Female	63 (51,2%)
Relationship Status	Single	82 (66,7%)
	Married	27 (22%)
	Widowed	5 (4,1%)
	Divorced	9 (7,3%)
Age	18-30	26 (21,1%)
	31-40	38 (30,9%)
	41-50	29 (23,6%)
	>50	30 (24,4%)
Ethnicity	Black	110 (89,4%)
	White	12 (9,8%)
	Coloured	1 (0,008)
Home Language	English	6 (4,9%)
	Afrikaans	10 (8,1%)
	Sotho	40 (32,5%)
	Zulu	36 (29,3%)
	Xhosa	9 (7,3%)
	Tswana	22 (17,9%)
Employment	Unemployed	90 (73,2%)
	Employed	40.7 (24%)
Highest Level of Education	None	2 (1,6%)
	Primary School	12 (9,8%)
	Secondary School	53 (43,1%)
	Matric	38 (30,9%)
	Tertiary	18 (14,6%)

4.1. Participant demographics

The sample was almost evenly split by gender. 66,7% (n=82) of the participants were single and most identified themselves ethnically as black (n=110, 88,4%). Most of the respondents were in the 31-40 age group (n=38, 30,9%). The majority of the sample did not use English as a home language (total n=117, 95,1%). Unemployment was rife (n=90, 73,2%), and most of who were employed only had part-time jobs, earning less than R2000/month. Only 45,6% of the sample managed to complete their schooling (n=56).

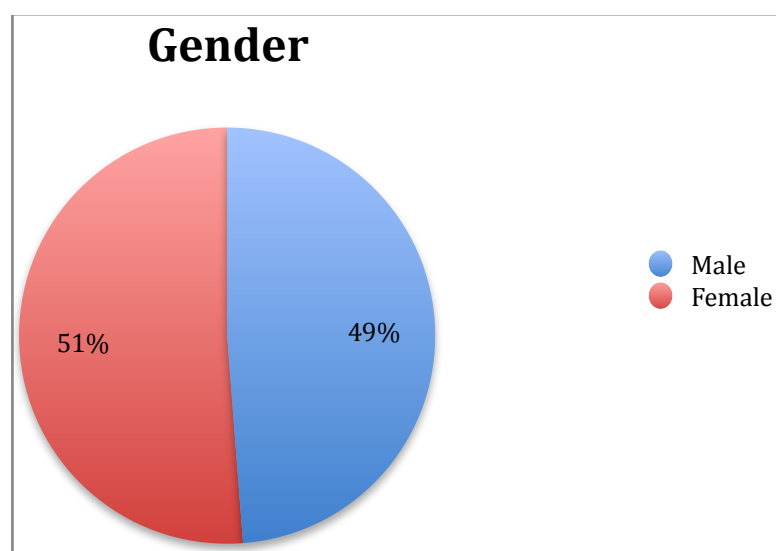


Figure 2: Participants by gender

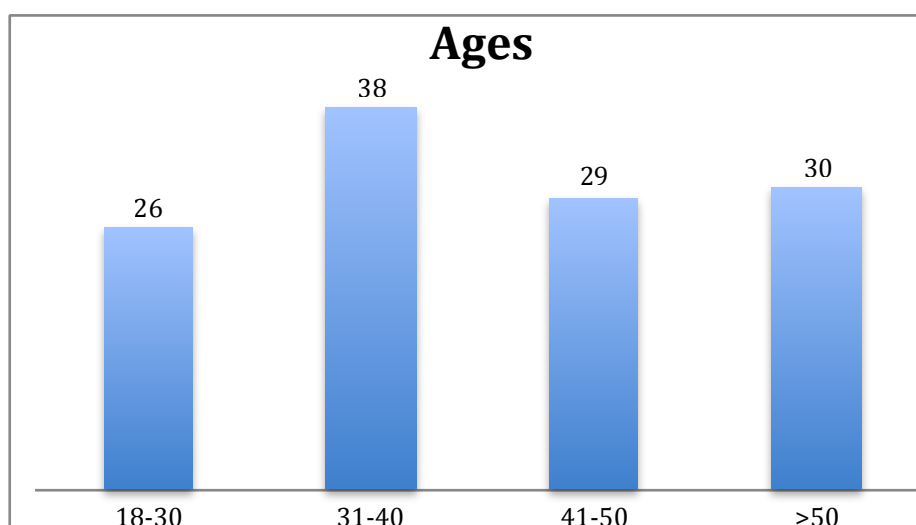


Figure 3: Participants by age category

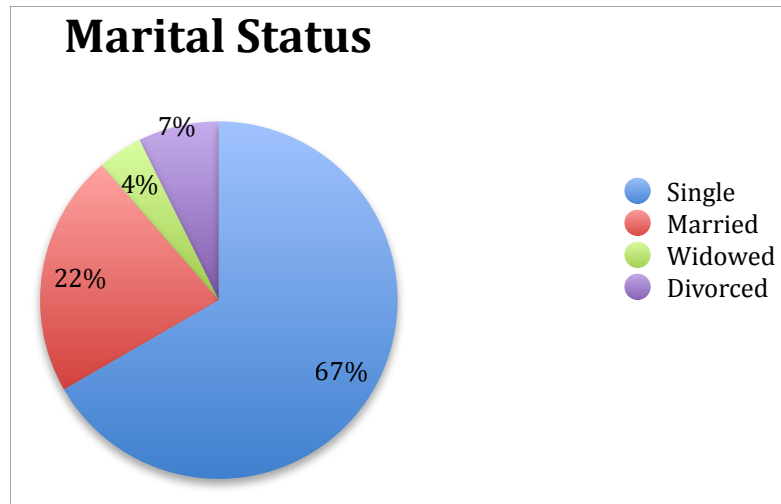


Figure 4: Participants by marital status

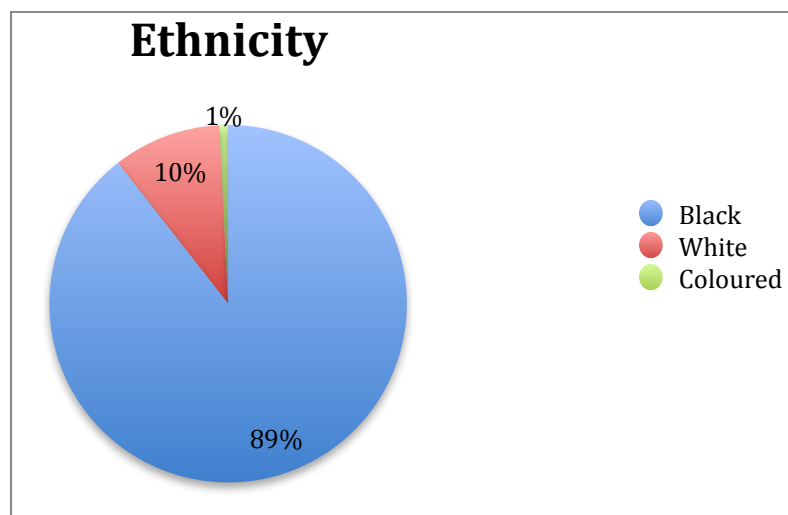


Figure 5: Participants by ethnicity

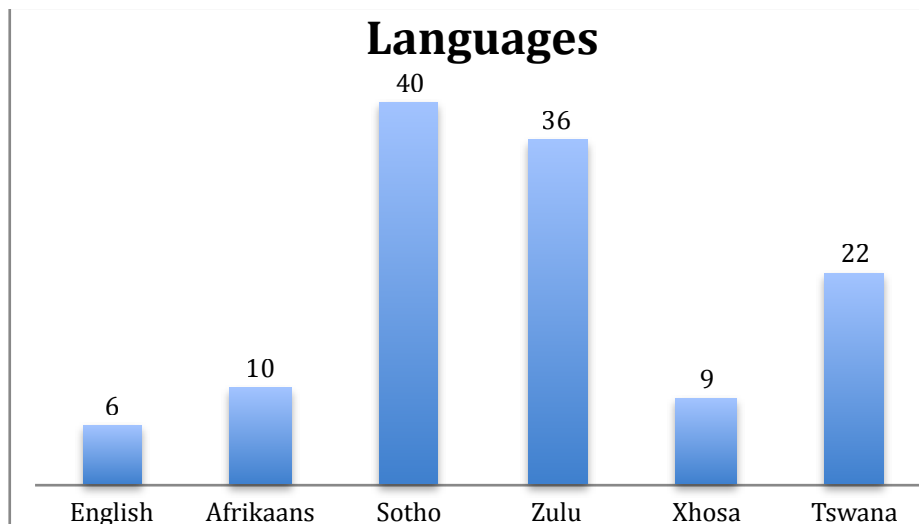


Figure 6: Participants by home language

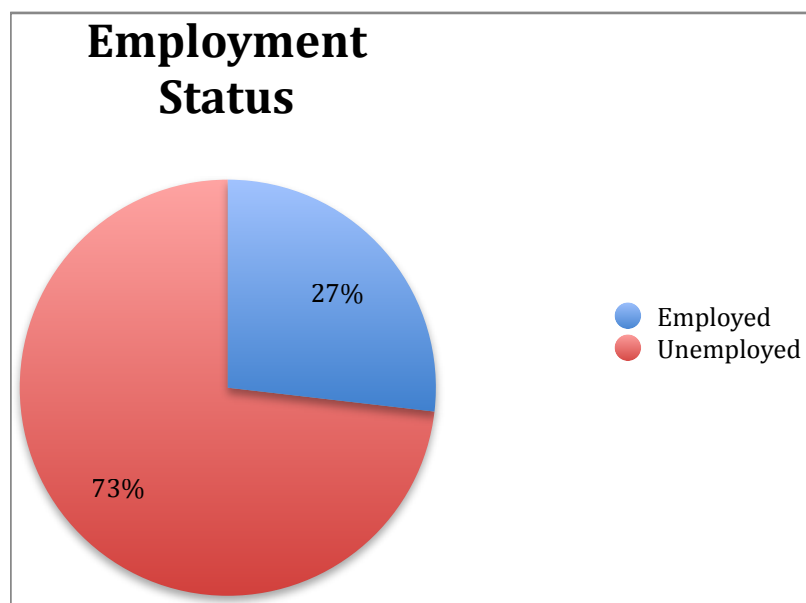


Figure 7: Participants by employment status

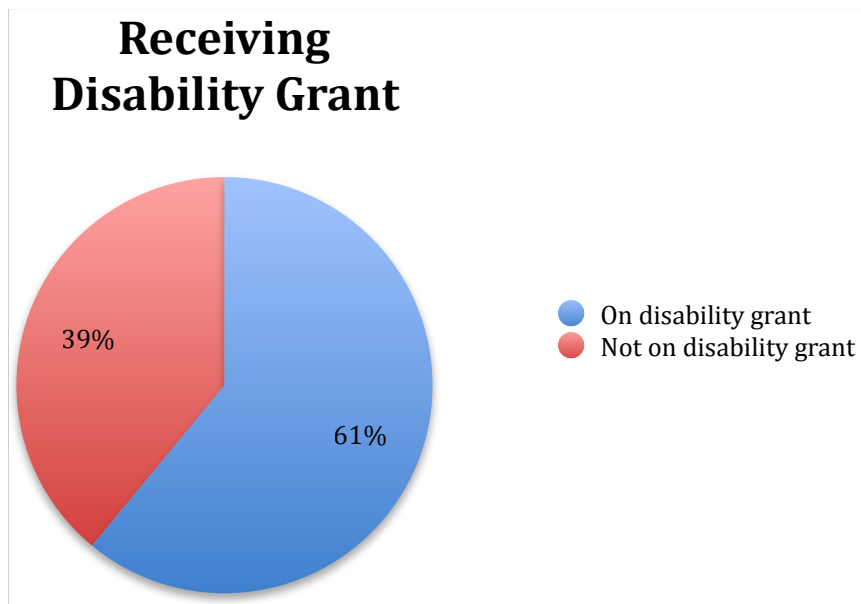


Figure 8: Participants based on whether a disability grant is received

Table 2: Clinical factors of the study participants (n=123)

Primary Diagnosis	Schizophrenia	45 (36,6%%)
	Bipolar Disorder	33 (26,8%)
	Major Depressive Disorder	24 (19,5%)
	Substance-Induced Disorder	8 (6,5%)
	Disorder due to AMC	13 (10,6%)
	Substance Use Disorders	17 (13,8%)
Comorbid Diagnosis	Substances	17 (13,8%)
	HIV	25 (20,3%)
	Other Psychiatric Conditions	6 (4,9%)
	Intellectual Disability	3 (2,4%)
	Personality Disorder	1 (0,8%)
	None	71 (57,7%)
Age at Index Presentation	<18	14 (11,4%)
	18-30	62 (50,4%)
	31-40	23 (18,7%)
	41-50	18 (14,6%)
	>50	6 (4,9%)
Number of Psychiatric Medications	1	31 (25,2%)
	2	56 (45,5%)
	3	21 (17,1%)
	4	11 (8,9%)
	5	5 (2,4%)
	>5	1 (0,8%)
Most Recent Admission	Never	21 (17,1%)
	<1 year ago	18 (14,6%)
	1-2 years ago	25 (20,3%)
	3-4 years ago	58 (47,2%)
	>5 years ago	1 (0,8%)
Total Number of Admissions	Never	21 (17,1%)
	1	48 (39%)
	2	25 (20,3%)
	3	23 (18,7%)
	>3	6 (4,9%)
Disability Grant	Receiving	75 (61%)
	Not receiving	48 (39%)
Support from Religion and Culture	Supportive	97 (78,9%)
	Not Supported	26 (21,1%)

4.3 Clinical Characteristics

Schizophrenia (n=45, 36,6%), Bipolar Disorder (N=33, 26,8%) and MDD (n=24, 19,5%) were the most common primary diagnoses in the sample. The vast majority did not have any other medical or psychiatric comorbidity (n=71, 57,7%). Substance use and HIV were the two main co-morbidities that affected this sample. 50,4% (n=62) initially presented to mental health services between the ages of 18-30. Only 31 respondents (21,2%) were stable on monotherapy (mostly long-active injectables, or single SSRI). 52% of participants had had a psychiatric admission within the preceding 3 years. 61% (n=75) were on the government disability grant.

Although a significant majority (N=97, 78,9%) of individuals reported supportive influences from their religion and culture and view their illness from a biological perspective, 21,2% feel they that they are unsupported.

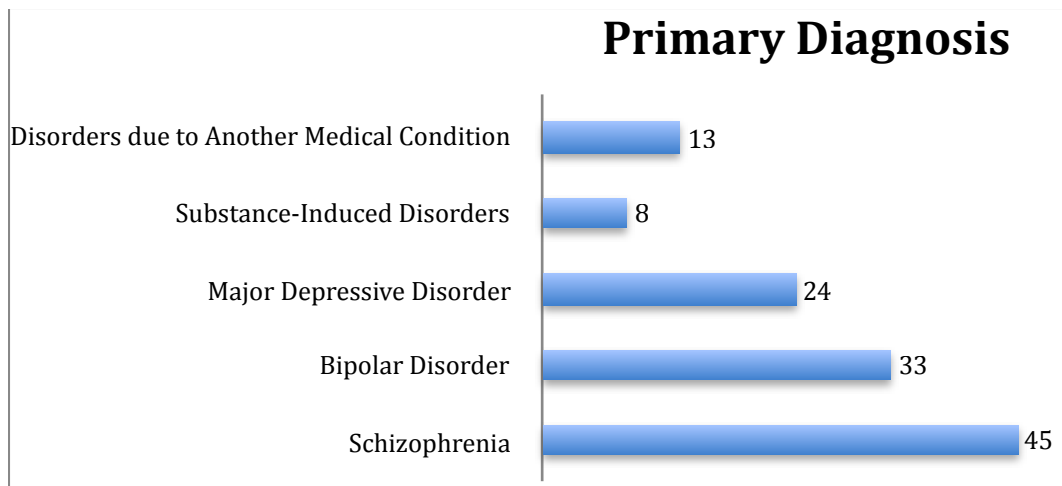


Figure 9: Participants by primary diagnosis

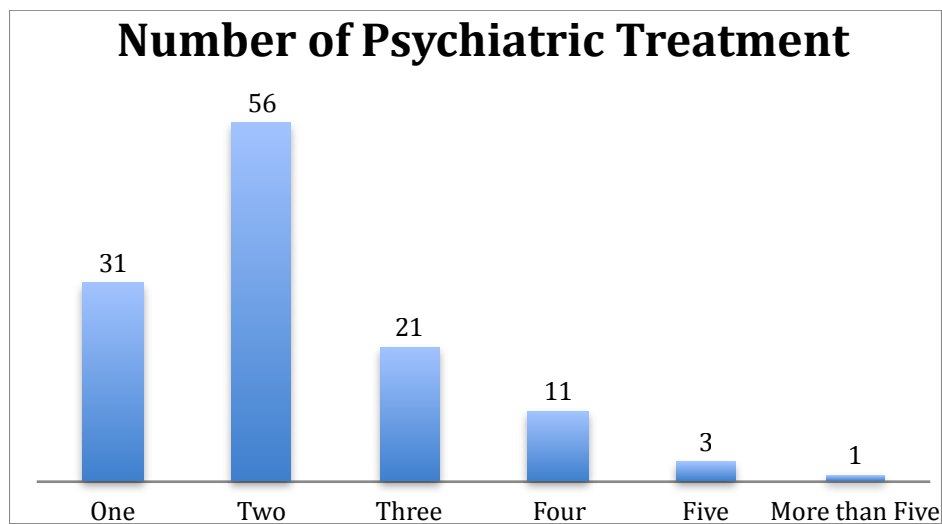


Figure 10: Participants by number of psychiatric treatment taken

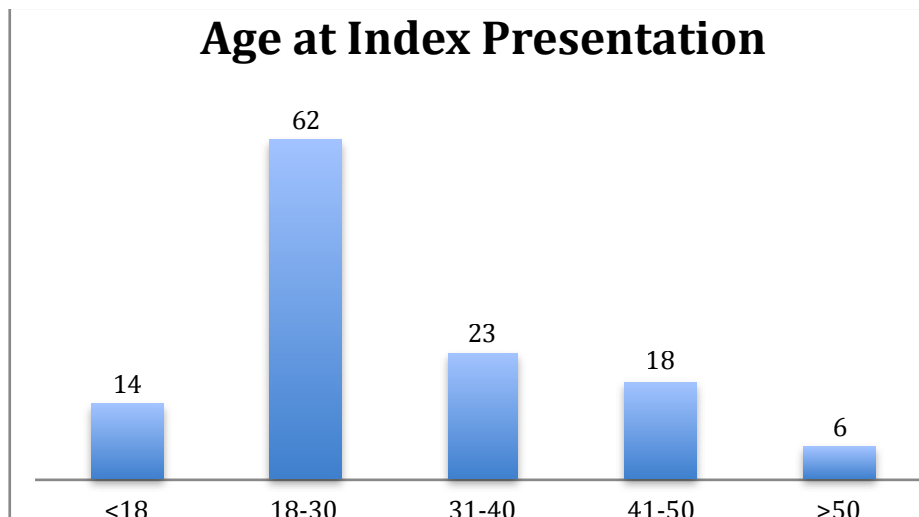


Figure 11: Participants by age at index presentation

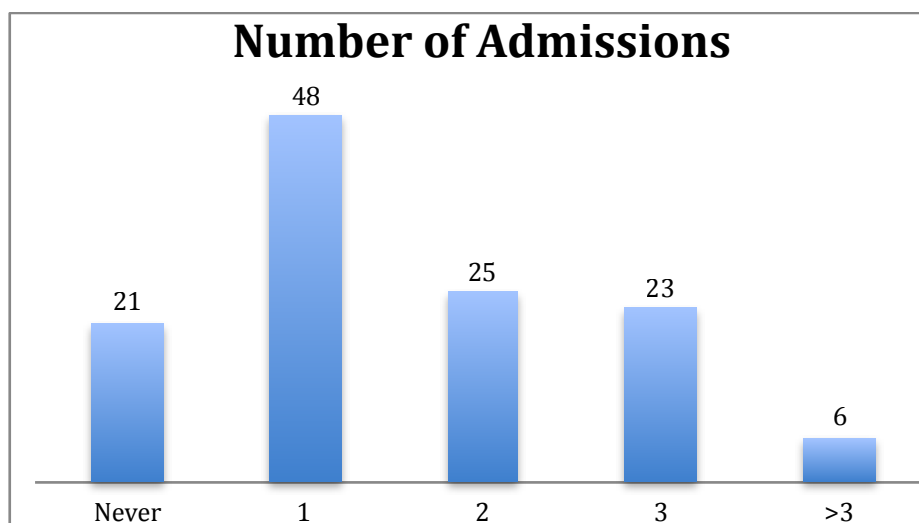


Figure 12: Participants by number of psychiatric admissions

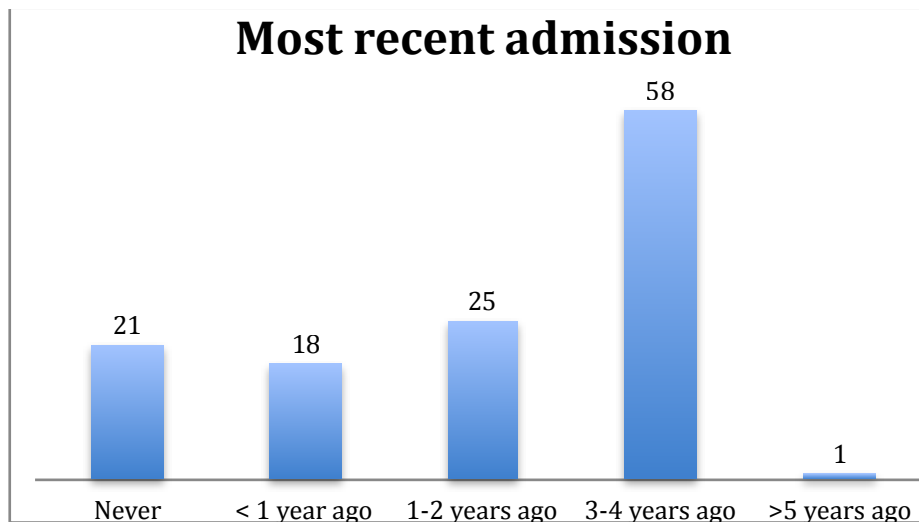


Figure 13: Participants by most recent admission

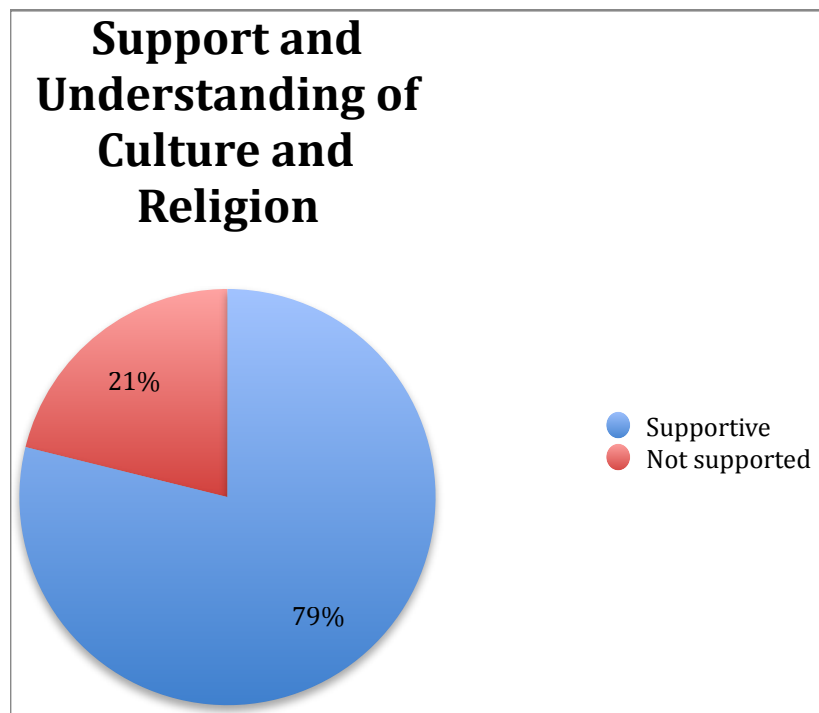


Figure 14: Participants by perceived support and understanding by their religion and culture

4.4 Internalised Stigma

Values reported as β -estimate $\pm$ SE, t and p values (considered significant if less than 0,05). Significant values are indicated in bold in Table 3. Levels of high stigma were defined as greater than 2,50 (Boyd et al, 2007). Total ISMI scores were calculated without using reverse-coded stigma resistance, which has been considered separately.

Table 3. The output of Generalized Linear Models (GLM) for the influence of 14 continuous and fixed factors on 6 dependent variables.

Factors	Alienation	Stereotype	Discrimination	Social	Resistance	ISMI-29
Sex	-0.09 $\pm$ 0.10, -0.94, 0.344	0.09 $\pm$ 0.1, 0.91, 0.364	-0.12 $\pm$ 0.09, -1.28, 0.202	-0.05 $\pm$ 0.09, -0.59, 0.552	0.04 $\pm$ 0.08, 0.51, 0.608	-0.04 $\pm$ 0.08, -0.53, 0.594
Age	0.01 $\pm$ 0.06, 0.25, 0.796	0.01 $\pm$ 0.06, 0.24, 0.807	0.01 $\pm$ 0.06, 0.23, 0.813	0.02 $\pm$ 0.06, 0.36, 0.716	-0.03 $\pm$ 0.05, -0.60, 0.549	0.01 $\pm$ 0.05, 0.32, 0.749
Marital Status	0.15$\pm$0.06, 2.27, 0.026	-0.06 $\pm$ 0.06, -0.97, 0.333	0.18$\pm$0.06, 2.88, 0.004	0.13$\pm$0.06, 2.13, 0.036	0.08 $\pm$ 0.06, 1.40, 0.162	0.10 $\pm$ 0.05, 1.78, 0.077
Ethnicity	-0.21 $\pm$ 0.17, -1.23, 0.220	-0.04 $\pm$ 0.17, -0.25, 0.797	-0.35$\pm$0.16, -2.21, 0.028	-0.27 $\pm$ 0.16, -1.63, 0.106	0.06 $\pm$ 0.15, 0.42, 0.671	-0.22 $\pm$ 0.14, -1.52, 0.130
Home Language	-0.05 $\pm$ 0.04, -1.37, 0.170	0.04 $\pm$ 0.04, 1, 0.317	-0.06 $\pm$ 0.03, -1.52, 0.129	-0.06 $\pm$ 0.04, -1.56, 0.121	0.01 $\pm$ 0.03, 0.25, 0.799	-0.03 $\pm$ 0.03, -0.98, 0.326
Highest Level of Education	-0.08 $\pm$ 0.05, -1.45, 0.141	-0.05 $\pm$ 0.05, -0.96, 0.334	0.03 $\pm$ 0.05, 0.75, 0.454	-0.10 $\pm$ 0.05, -1.94, 0.054	0.11$\pm$0.04, 2.23, 0.023	-0.05 $\pm$ 0.04, -1.08, 0.281
Employment History	-0.08 $\pm$ 0.13, -0.58, 0.562	-0.03 $\pm$ 0.14, -0.21, 0.827	0.00 $\pm$ 0.12, 0.01, 0.994	-0.04 $\pm$ 0.13, -0.33, 0.736	0.07 $\pm$ 0.12, 0.59, 0.551	-0.04 $\pm$ 0.11, -0.35, 0.725
Disability Status	-0.15 $\pm$ 0.13, -1.09, 0.277	0.02 $\pm$ 0.13, 0.16, 0.871	-0.23 $\pm$ 0.12, -1.83, 0.068	-0.11 $\pm$ 0.12, -0.88, 0.376	-0.10 $\pm$ 0.11, -0.85, 0.397	-0.11 $\pm$ 0.11, -1.04, 0.296
Primary Diagnosis	-0.09$\pm$0.04, -2.01, 0.048	-0.06 $\pm$ 0.04, -1.35, 0.179	-0.04 $\pm$ 0.04, -0.92, 0.358	-0.04 $\pm$ 0.04, -0.96, 0.048	0.04 $\pm$ 0.04, 1.13, 0.258	-0.06 $\pm$ 0.03, -1.53, 0.127
Comorbid Diagnosis	-0.02 $\pm$ 0.02, -1.05, 0.292	-0.01 $\pm$ 0.02, -0.58, 0.559	-0.05$\pm$0.02, -2.02, 0.045	0.01 $\pm$ 0.02, -0.36, 0.715	0.02 $\pm$ 0.02, 0.10, 0.915	-0.02 $\pm$ 0.02, -1.15, 0.251
Psychiatric Treatment	-0.03 $\pm$ 0.04, -0.62, 0.532	0.02 $\pm$ 0.04, 0.41, 0.677	-0.02 $\pm$ 0.04, -0.46, 0.645	-0.05 $\pm$ 0.04, -1.18, 0.239	0.05 $\pm$ 0.04, 1.26, 0.210	-0.02 $\pm$ 0.04, -0.52, 0.640
Age at Index	-0.05 $\pm$ 0.07, -0.76, 0.448	0.01 $\pm$ 0.07, 0.11, 0.909	-0.03 $\pm$ 0.07, -0.51, 0.609	-0.05 $\pm$ 0.07, -0.73, 0.465	-0.02 $\pm$ 0.06, -0.34, 0.732	-0.03 $\pm$ 0.06, -0.54, 0.586
Recent Admission	0.01 $\pm$ 0.05, 0.19, 0.850	0.08 $\pm$ 0.05, 1.66, 0.099	0.00 $\pm$ 0.04, -0.18, 0.854	0.02 $\pm$ 0.05, 0.41, 0.678	-0.02 $\pm$ 0.04, -0.52, 0.603	0.02 $\pm$ 0.04, 0.62, 0.535
Admission Frequency	-0.11$\pm$0.05, 2.08, 0.039	0.08 $\pm$ 0.05, 1.55, 0.122	0.14$\pm$0.05, 2.90, 0.004	0.13$\pm$0.05, 2.54, 0.013	-0.02 $\pm$ 0.04, -0.61, 0.540	0.12$\pm$0.04, 2.62, 0.010
Religion/Culture	0.02 $\pm$ 0.03, 0.66, 0.506	0.01 $\pm$ 0.03, 0.27, 0.787	0.02 $\pm$ 0.03, 0.59, 0.553	0.01 $\pm$ 0.03, -0.07, 0.943	0.01 $\pm$ 0.03, 0.49, 0.619	0.01 $\pm$ 0.03, 0.42, 0.671

Total ISMI-29 score

63.4% (n=78) of study participants demonstrated high levels of internalised stigma on total ISMI-29 score. For ISMI-29 total scores, admission frequency was the single significant predictor (0.12 ± 0.04 , 2.62, $p=0.010$; Table 3). The scatterplot showed an almost linear relationship, as psychiatric admissions become more numerous, the total score on the ISMI-29 increased (Figure 17) (0.12 ± 0.04 , 2.62, 0.010).

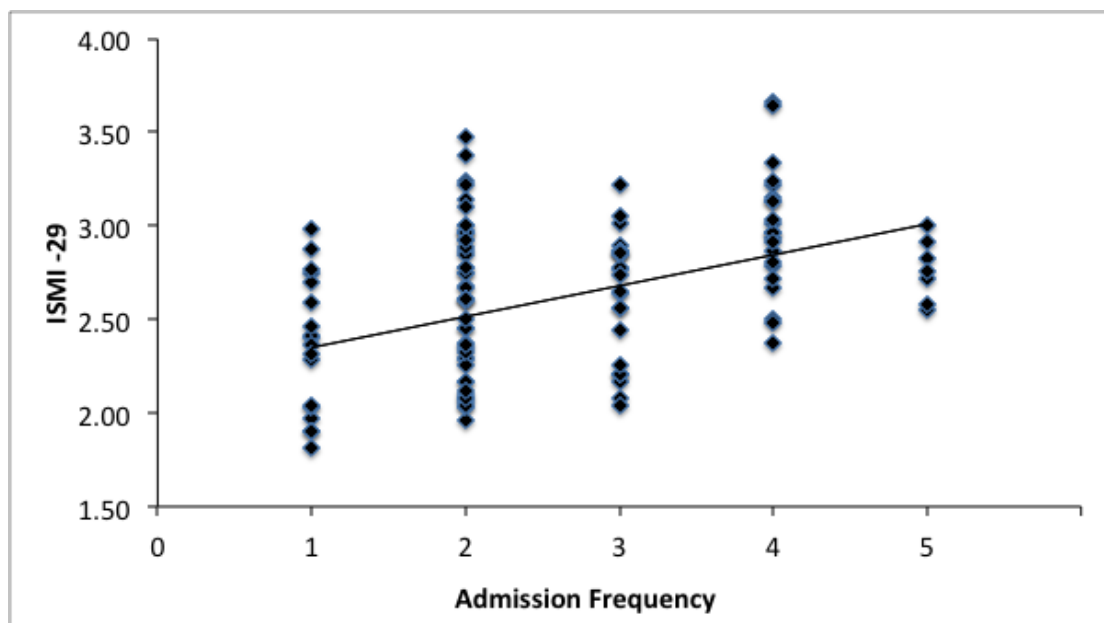


Figure 15: The relationship between ISMI-29 score and admission frequency.

The trend line shows the overall relationship between the variable generated using local polynomial models to estimate marginal effects. The admission frequency categories were 1=never, 2=1, 3=2, 4=3, 5=>3.

Alienation

78,4% of participants had strong alienation scores (n=78). For alienation, marital status (0.15 ± 0.06 , 2.27, $p=0.026$), level of education (-0.08 ± 0.05 , -1.45, $p=0.141$) and primary diagnosis (-0.09 ± 0.04 , -2.01, $p=0.048$) and admission frequency were significant predictors of alienation (Table 3). Scatterplots of alienation against the other predictor variables showed that being single, having lower educational levels,

and having schizophrenia or bipolar disorder as a primary diagnosis, and fewer admissions are strongly correlated to with feelings of alienation (Figures 15-17).

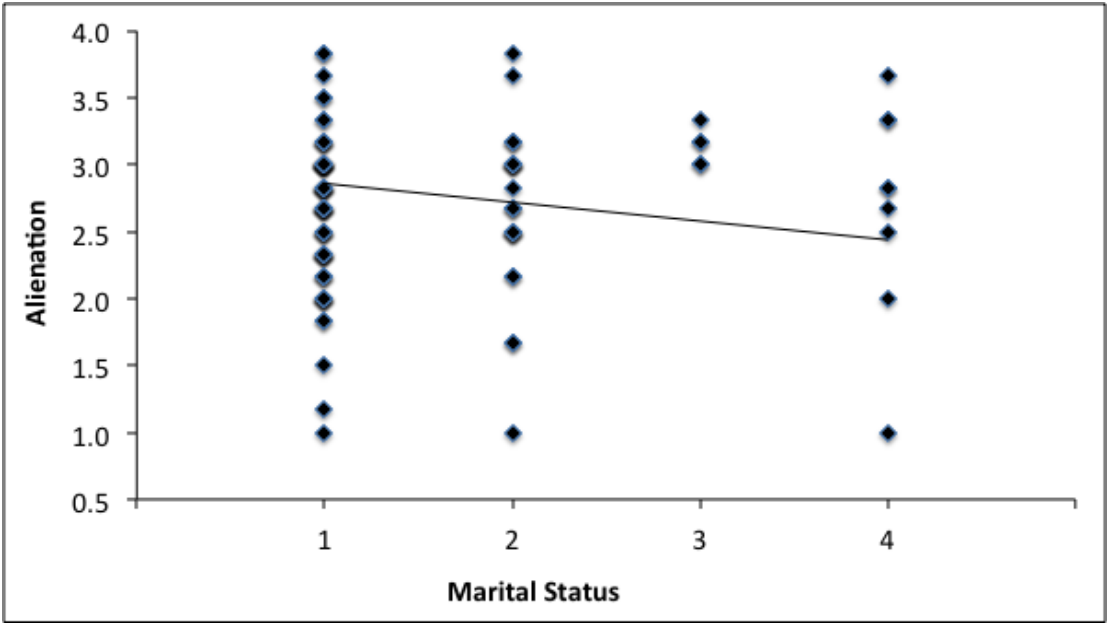


Figure 16: The relationship between alienation and marital status.

The trend line shows the overall relationship between the variables. The marital status categories were 1=single, 2=married, 3=widowed, 4=divorced.

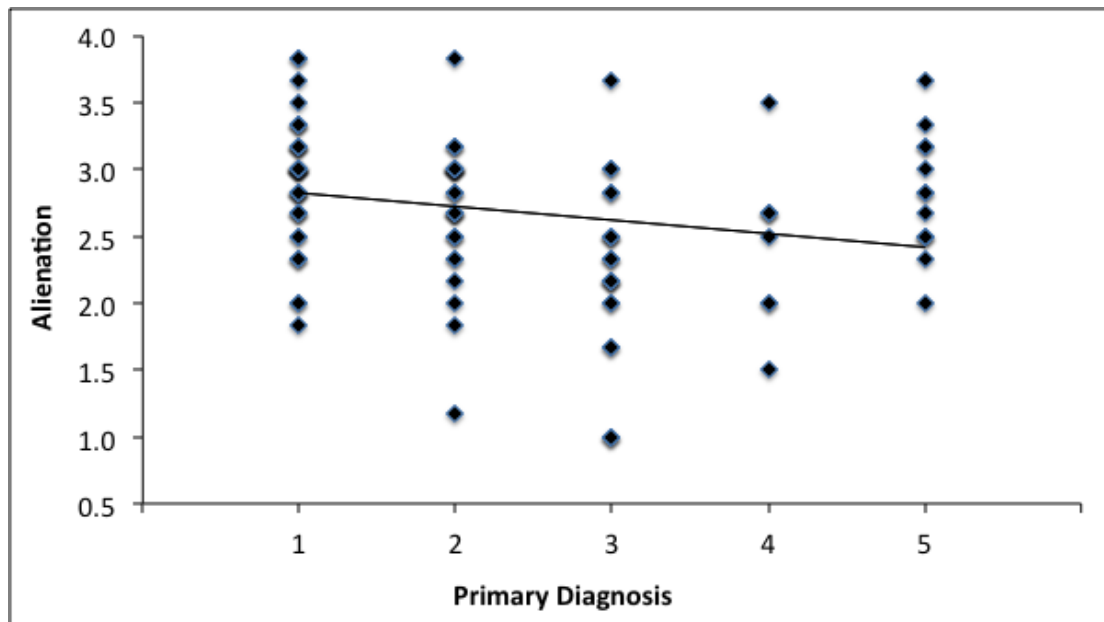


Figure 17: The relationship between alienation and primary diagnosis.

The trend line shows the overall relationship between the variables. The primary diagnosis categories were 1=schizophrenia, 2=bipolar disorder, 3=major depressive disorder, 4=substance-induced disorder 5=Disorder due to AMC

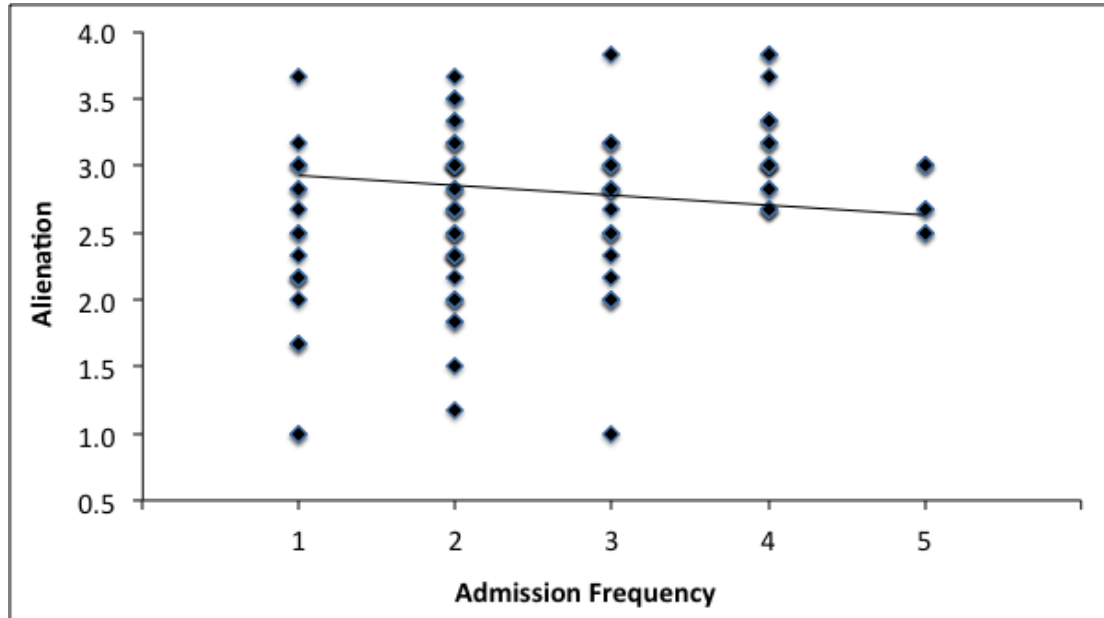


Figure 18: The relationship between alienation and admission frequency.

A trend line has been fitted to indicate the overall relationship between the variables. The admission frequency categories were 1=never, 2=1, 3=2, 4=3, 5=>3.

Social Withdrawal

Seventy-four participants (60,1%) reported high levels of social withdrawal. For social withdrawal, marital status (0.13 ± 0.06 , 2.13, $p=0.036$) and admission frequency (0.13 ± 0.05 , 2.54, $p=0.013$) were significant predictors of social withdrawal (Table 3). Scatterplots showed that being single and having multiple admissions increased the risk of self-stigma around with behavioural consequences by less social contact (Figures 18, 19).

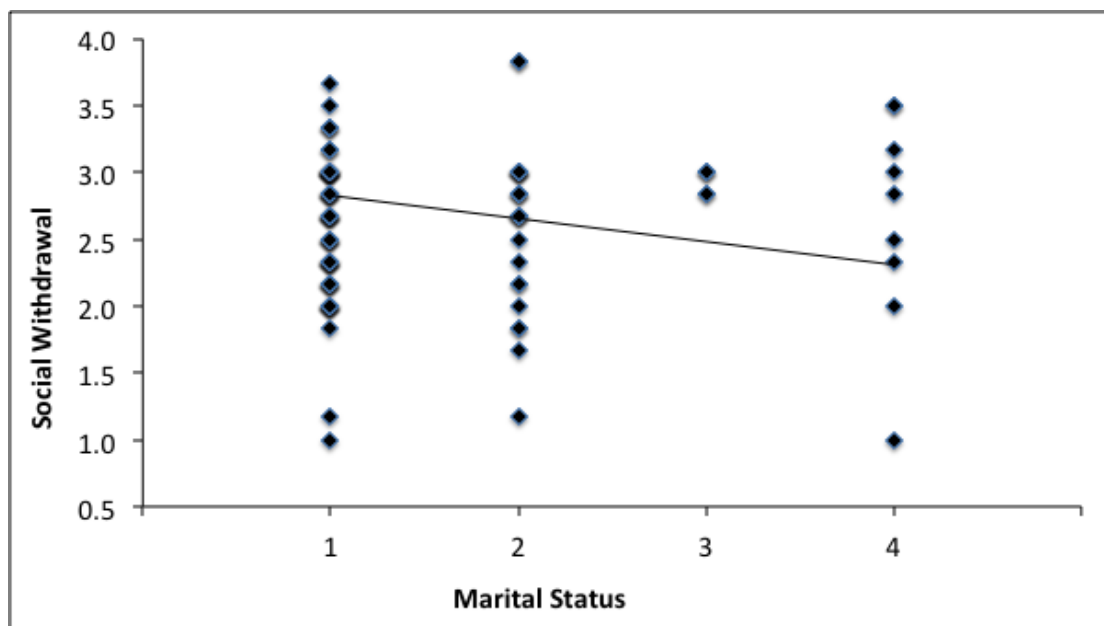


Figure 19: The relationship between social withdrawal and marital status

Generated using local polynomial models to estimate marginal effects. The trend line shows the overall relationship between the variables. The marital status categories were 1=single, 2=married, 3=widowed, 4=divorced.

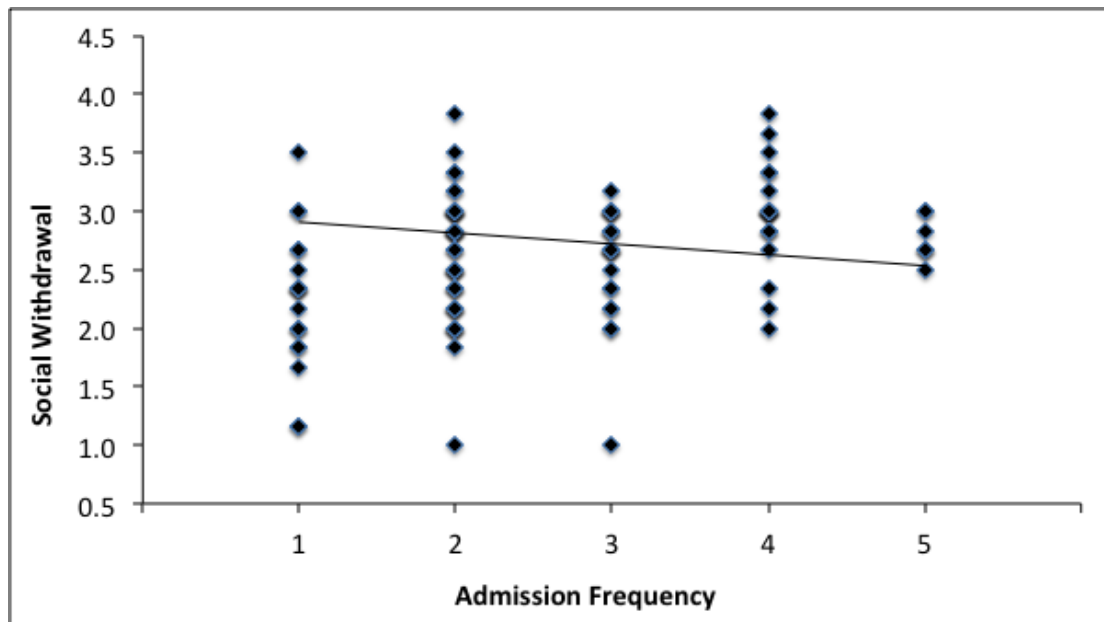


Figure 20: The relationship between social withdrawal and admission frequency
Generated using local polynomial models to estimate marginal effects. The trend line shows the overall relationship between the variables. The admission frequency categories were 1=never, 2=1, 3=2, 4=3, 5=>3.

Discrimination Experience

High levels of internalised stigma in the discrimination experience subset were reported by 63,4% (n=78) of study participants. Marital status (0.18 ± 0.06 , 2.88, $p=0.004$), ethnicity (-0.35 ± 0.16 , -2.21, $p=0.028$), comorbid diagnosis (-0.05 ± 0.02 , -2.02, $p=0.045$) and admission frequency (0.14 ± 0.05 , 2.90, $p=0.004$) were significantly associated with discrimination experience scores (Table 3). Scatterplots showed that being single, belonging to a black culture group, having a comorbid diagnosis (particularly substance use disorders and HIV) and more admissions contributed significantly to feeling discriminated (Figures 20-23).

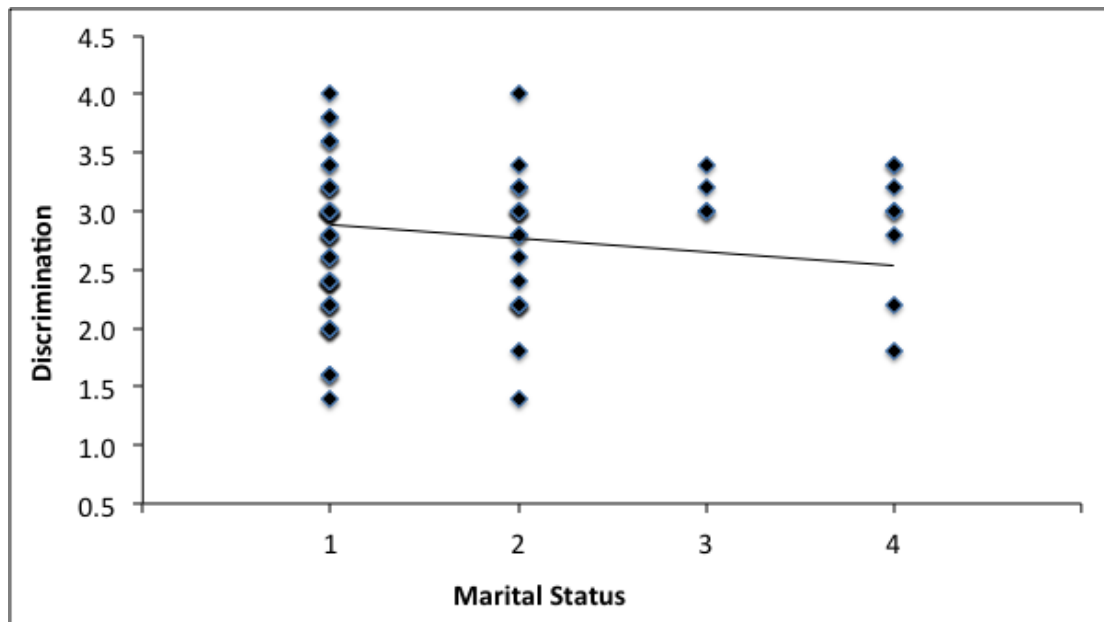


Figure 21: The relationship between discrimination and marital status

The trend line shows the overall relationship between the variables. The marital status categories were 1=single, 2=married, 3=widowed, 4=divorced.

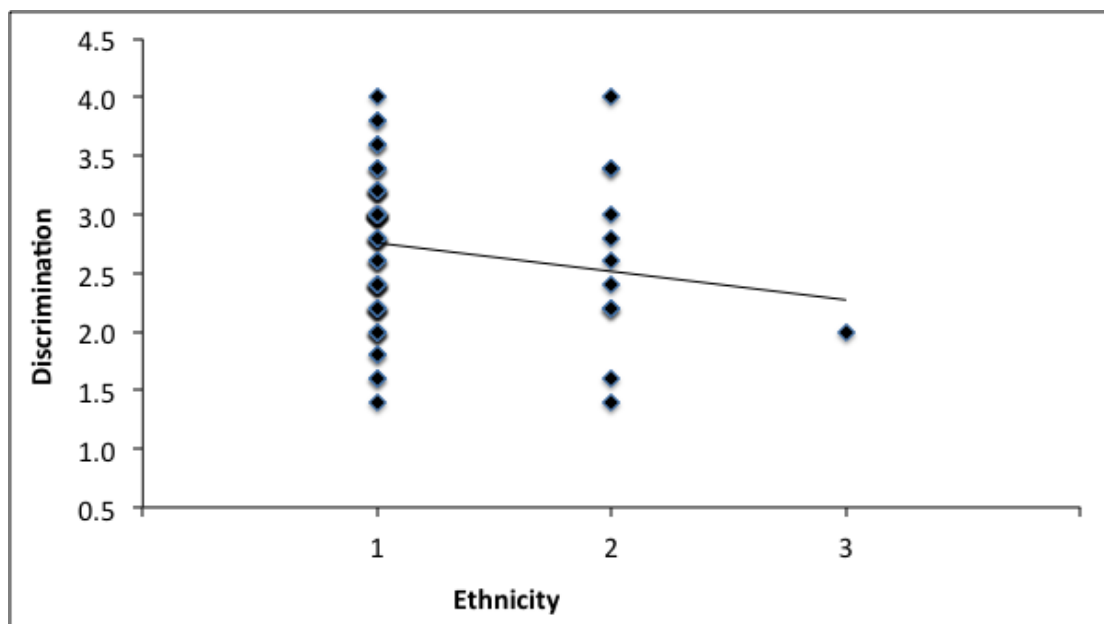


Figure 22: The relationship between discrimination experience and ethnicity

The trend line shows the overall relationship between the variables. The ethnicity categories were 1=black, 2=white, 3=coloured.

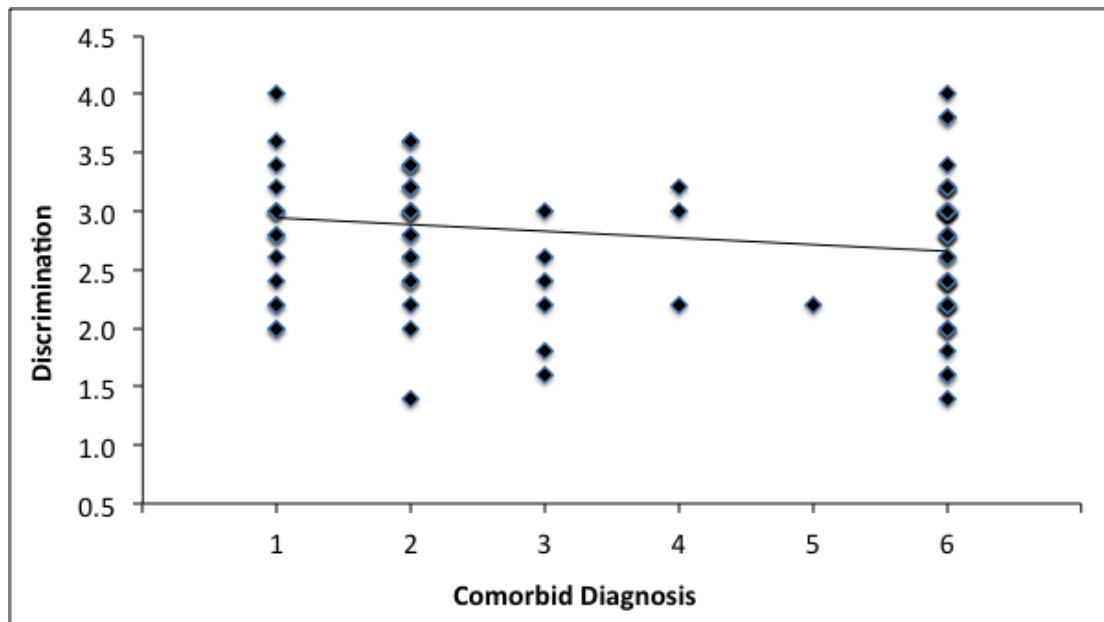


Figure 23: The relationship between discrimination experience and comorbid diagnosis.

The trend line shows the overall relationship between the variables. The comorbid diagnosis categories were 1=substance use disorders, 2=HIV, 3=other psychiatric conditions, 4=intellectual impairment, 5=personality disorder, 6=no comorbid diagnosis.

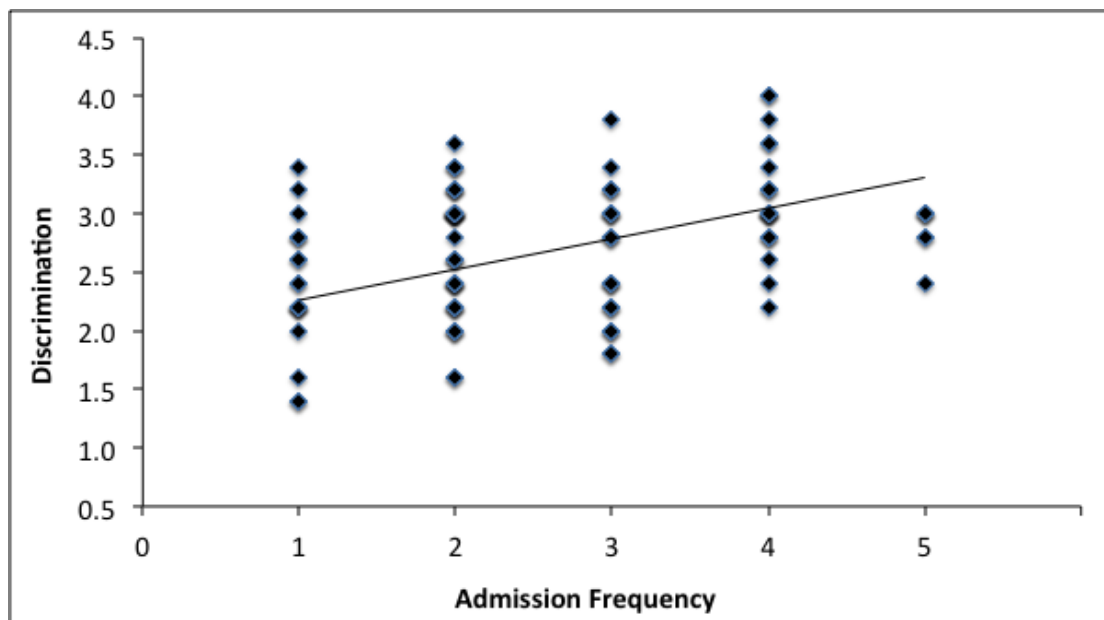


Figure 24: The relationship between discrimination and admission frequency

A trend line has been fitted to indicate the overall relationship between the variables. The admission frequency categories were 1=never, 2=1, 3=2, 4=3, 5=>3.

Stereotype Endorsement

There were no significant predictors of stereotype endorsement.

Stigma Resistance

Despite high levels of stigma, there seems to also be internal mechanisms of resilience to deal with these negative experiences. 88,6% of participants showed significant levels of stigma resistance. Level of education was the only consistent predictor of stigma resistance (Table 3). Figure 18 showed that higher education levels generally predicted better coping mechanisms and more resistance to stigma.

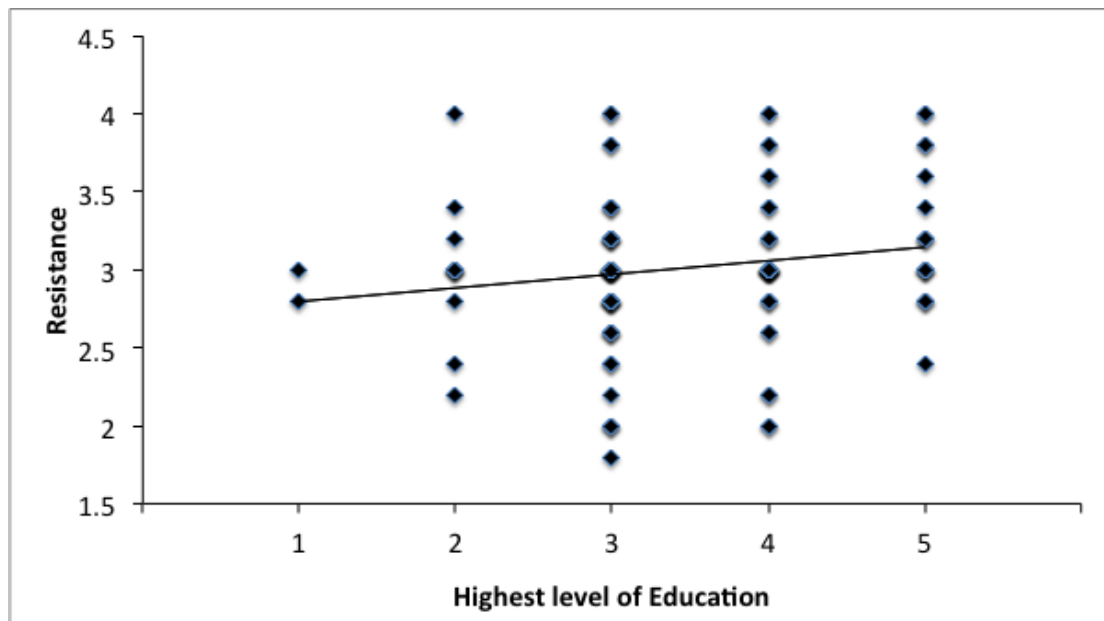


Figure 25. The relationship between stigma resistance and highest level of education

Generated using local polynomial models to estimate marginal effects. The trend line shows the overall relationship between the variables. Highest level of education categories were 1=none, 2=primary school, 3=secondary school, 4=matric, 5=tertiary.

Chapter five: Discussion and Conclusion

5.1. Summary and interpretation of main results

In general, a higher proportion of this sample population (63.4%) reported a high level of internalized stigma than other population samples both internationally (Brohan et al, 2011; Cerit et al 2012) and locally (Botha et al, 2003). The most reliable predictor of high stigma scores was number of psychiatric admissions influencing both the total ISMI-29 score, as well as alienation, discrimination experience and social withdrawal scores.

Clinical factors linked to higher levels of self-stigma included having a diagnosis of schizophrenia or bipolar disorder (as compared to other psychiatric diagnosis). However, primary diagnoses of either schizophrenia or bipolar disorder have been shown to elevate levels of stigma. This is in keeping with the research done by Sarisoy (2013). This is of significant concern as higher levels of internalised-stigma prevents timely healthcare interventions, increasing the likelihood of relapse or the development of other comorbid psychiatric illness. Thus, self-stigma perpetuates a vicious cycle negatively affecting the patient's self-perception. It is noteworthy that having a comorbid diagnosis (particularly HIV and substance use disorders) increases feelings of discrimination amongst people with mental illness. This suggests patients living with dual diagnosis and HIV feel a double burden of stigmatisation. The added weight of feeling discriminated, superimposed on already high levels of self-stigma, decreases self-esteem, their connectedness to the community and ability to adhere to treatment.

Rusch (2009) wrote about the link between admission frequency and increased self-stigma, a correlation the study supports as the most robust factor influencing self-stigmatisation, both increasing different aspects of internalised stigma, as well as the overall ISMI-29 score. This is of concern as the literature speaks about it also being associated with higher symptom severity (Chan et al, 2014). In individuals with bipolar disorder, repeated admissions cause functional decline, which in turn increases

self-stigma, thus causing a vicious cycle of the individual's connected to society (Rosa et al, 2009).

Demographic factors identified in the study as increasing self-stigma include belonging to a black ethnocultural group and being single. This seems to be in line with the literature (Harrison, 1989; Assefa et al, 2012; Botha et al, 2006).

Considering South Africa's previous institutionalised discrimination of black and other ethnic groups, the study confirms previous research. The literature (Loury, 2006) describes both "discrimination in contract" (unequal treatment and prejudice in formal transactions, business, access to health care) and "discrimination in contact" (unequal treatment and prejudice in personal and informal settings).

However, due to limited numbers, we are unable to truly qualify if higher levels of self-stigmatisation affect other cultural groups (e.g. South Africans of Asian descent/foreigners/illegal immigrants).

Low self-esteem and poor social and occupational function, particularly in seeking relationships outside the nuclear family (Farrelly et al, 2014; Drapalski et al, 2013, Aydemir et al, 2011; Sarisoy et al, 2013; Moriarty et al, 2012; Ngo et al 2012; Latalova et al, 2014; Perlick et al, 2001) possibly contribute to individuals living with mental illness to remain single feeling alienated and experiencing discrimination. This, in turn, propagates social isolation and impacts on the individual's ability to integrate into the community, and in turn their ability to engage in personal relationship and work (El-Badri et al, 2007; Lundberg et al, 2009; Vazquez et al, 2011; Corrigan et al, 2012; Hannson et al, 2013), leading to a perceived poorer quality of life (Chan et al, 2014). The reasons why fewer admissions would possibly result in increased feelings of alienation are unclear.

Unlike what has been shown in other African studies (Oshodi et al, 2012; Kapungwe et al, 2010), the study demonstrates that higher education levels are linked to better stigma resistance. Stigma resistance associated with higher education levels can perhaps be attributed to more access to information improved insight and understanding.

The study demonstrates that 21,2% of study participants did not feel supported by their religion or culture. The majority of respondents found their culture and religion as a source of support for them. The experience and perception of not being understood or supported by one's culture and religion was not associated with higher levels of stigma.

5.2. Limitations

The limited time in which this study is conducted was a contributing factor. Psychiatric resources are scarce, and possible participants may not present in the time allocated for the study. The use of English as the only language for the structured interviews limit the potential to gather information on the stigma (particularly religious and cultural understandings of mental illness) experienced by psychiatric outpatients who speak other South African languages. Patient insight into their conditions may cause data distortion, particularly in reference to diagnosis and medication.

The number of people who declined to participate, and the reasons why they declined were not recorded. Thus, the study may not be fully representative of all outpatients at these clinics.

The value of the study is also limited by the lack of quantitative or qualitative measurements revolving around quality of life. An important clinical factor that was not assessed in the study is adherence to treatment. It would have been interesting to explore if higher levels of internalised stigma predicted non-adherence to treatment and follow-up, as discovered by Assefa (2012). Another thing that could have added value to the study is a qualitative exploration of their experiences of their treating mental health care practitioners, and whether they report experiencing prejudice and discrimination in various sectors of their community.

Although patients were clinically stable, standardised rating scales assessing presence and severity of symptoms (e.g. Brief Psychiatric Rating Scale, Hamilton Rating Scale for Depression, etc.) may be helpful to elucidate possible correlations between symptom severity and self-stigmatisation.

5.3. Conclusion

Almost two-thirds of participants at the Southern Gauteng community psychiatry clinics experienced a high level of internalised stigma. A direct relationship between internalised stigma and frequency of admissions was evident. A higher level of education was found to be protective.

5.4. Recommendations

Further exploration as to why such a high proportion of patients experience internalised stigma in this setting is warranted, as well as its relationship to frequent admissions. Qualitative research would contribute to greater understanding and targeted interventions.

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R14/49 Dr Rudhie Sapinoso

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150371

NAME: Dr Rudhie Sapinoso
(Principal Investigator)
DEPARTMENT: Psychiatry
Community Psychiatry Clinics in the Johannesburg
Metropolitan District

PROJECT TITLE: Internalised Stigma Among Psychiatric Outpatients

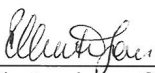
DATE CONSIDERED: 27/03/2015

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Dr Lesley Robertson

APPROVED BY:



Professor P Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 07/10/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Administrators in Room 301, 302,304, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in March and will therefore be due in the month March each year.

Principal Investigator Signature _____

Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Internalized Stigma of Mental Illness Inventory (ISMI)

We are going to use the term "mental illness" in the rest of this questionnaire, but please think of it as whatever you feel is the best term for it.

For each question, please mark whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4).

	Strongly disagree	Disagree	Agree	Strongly agree
1. I feel out of place in the world because I have a mental illness.	1	2	3	4
2. Mentally ill people tend to be violent.	1	2	3	4
3. People discriminate against me because I have a mental illness.	1	2	3	4
4. I avoid getting close to people who don't have a mental illness to avoid rejection.	1	2	3	4
5. I am embarrassed or ashamed that I have a mental illness.	1	2	3	4
6. Mentally ill people shouldn't get married.	1	2	3	4
7. People with mental illness make important contributions to society.	1	2	3	4
8. I feel inferior to others who don't have a mental illness.	1	2	3	4
9. I don't socialize as much as I used to because my mental illness might make me look or behave "weird."	1	2	3	4
10. People with mental illness cannot live a good, rewarding life.	1	2	3	4
11. I don't talk about myself much because I don't want to burden others with my mental illness.	1	2	3	4
12. Negative stereotypes about mental illness keep me isolated from the "normal" world.	1	2	3	4
13. Being around people who don't have a mental illness makes me feel out of place or inadequate.	1	2	3	4
14. I feel comfortable being seen in public with an obviously mentally ill person.	1	2	3	4
15. People often patronize me, or treat me like a child, just because I have a mental illness.	1	2	3	4
16. I am disappointed in myself for having a mental illness.	1	2	3	4
17. Having a mental illness has spoiled my life.	1	2	3	4
18. People can tell that I have a mental illness by the way I look.	1	2	3	4
19. Because I have a mental illness, I need others to make most decisions for me.	1	2	3	4
20. I stay away from social situations in order to protect my family or friends from embarrassment.	1	2	3	4
21. People without mental illness could not possibly understand me.	1	2	3	4
22. People ignore me or take me less seriously just because I have a mental illness.	1	2	3	4
23. I can't contribute anything to society because I have a mental illness.	1	2	3	4
24. Living with mental illness has made me a tough survivor.	1	2	3	4
25. Nobody would be interested in getting close to me because I have a mental illness.	1	2	3	4
26. In general, I am able to live my life the way I want to.	1	2	3	4
27. I can have a good, fulfilling life, despite my mental illness.	1	2	3	4
28. Others think that I can't achieve much in life because I	1	2	3	4