Semi-structured Interview Measure of Stigma (SIMS) in psychosis: Assessment of psychometric properties

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Abstract

Stigma is a significant difficulty for people who experience psychosis. To date, there have been no outcome measures developed to examine stigma exclusively in people with psychosis. The aim of this study was develop and validate a semi-structured interview measure of stigma in psychosis. An eleven item semi-structured interview measure of stigma (SIMS) was developed in consultation with service users who experience psychosis. 79 participants with experience of psychosis were recruited for the purposes of this study. They were administered the SIMS alongside a battery of other relevant outcome measures to examine reliability and validity. A one-factor solution was identified for the SIMS which encompassed all ten rateable items. The measure met all reliability and validity criteria and illustrated good internal consistency, inter-rater reliability, test retest reliability, criterion validity, construct validity, sensitivity to change and had no floor or ceiling effects. The SIMS is a reliable and valid measure of stigma in psychosis. It may be more engaging and acceptable than other stigma measures due to its interview format.

Key words: stigma, psychosis, schizophrenia, semi-structured interview, psychometrics

Introduction

Many outcome measures have been developed to assess the impacts of stigma on service users diagnosed with a serious mental illness (SMI). However, a recent systematic review of individual outcome measures of stigma identified that all of the available measures are self-report measures and not specific to psychosis (Brohan et al., 2010). Brohan et al (2010) identified that the three most widely-used self-report measures of stigma were; the Perceived Devaluation and Discrimination Scale (PDD: Link, 1987), the Internalised Stigma of Mental Illness Scale (ISMI) (Ritsher et al., 2003), and the Self-Stigma of Mental Illness Scale (Corrigan et al., 2006). Brohan et al (2010) identified that these outlined measure each lacked some form of reliability and validity, for example, all did not meet requirements for floor and ceiling effects. Furthermore, as stated, these measures were developed for use with individuals experiencing SMI. Arguably SMI's are not comparable in terms of their experiences of stigma which will also hinder reliability and validity. Those with a schizophrenia spectrum disorder are viewed most negatively by the public (Crisp et al., 2005; Wood et al., 2014), are most discriminated against (Dinos et al., 2004; Thornicroft et al., 2009), have the most intense internalised stigma beliefs, worst social exclusion and significantly lower levels of functioning, compared to those with a diagnosis of bipolar disorder and depression (Karidi et al., 2015; Oliveria et al., 2015).

The aim of this study was to develop a reliable and valid semi-structured interview measure of stigma in psychosis, in consultation with service users, which can be used to assess and monitor change in the impacts of stigma in psychosis. A semi-structured interview measure also provides diversity in a saturated pool of self-report measures. Furthermore, the semi-structured format of the interview measure offers the flexibility in questioning to identify culturally specific aspects of stigma which has been a criticism of the existing self-report measures (Semrau et al., 2015). Outcomes on the semi-structured interview measure of stigma (referred to henceforth as the SIMS) were compared to the ISMI (Ritsher et al., 2003) and stigma scale (King et al., 2007) to examine its ability to measure stigma. Furthermore, it was also compared to outcomes measures of self-esteem, depression, hopelessness, shame and recovery, since research indicates that these psychological variables are also related to stigma and thus assist with validation (Birchwood et al., 2007; Corrigan et al., 2006; Link et al., 2001; Livingston & Boyd, 2010; Michail & Birchwood, 2013; Rüsch et al., 2014). The psychometric properties of the SIMS were examined and it was hypothesised that there will be good validity in comparison to other relevant measures. Specifically, it was hypothesised

that the SIMS will be positively correlated with existing measures of stigma, and with measures of depression, hopelessness and shame, and negatively correlated with measures of self-esteem and recovery.

Methods

Development of the SIMS

Literature review and initial development

Item generation for the SIMS was derived from a systematic review of qualitative literature examining service user perspectives of stigma in psychosis, as described in Wood et al. (2015). Eight studies were included in this review and were analysed using thematic synthesis (Thomas & Harden, 2008). A total of 96 initial codes were identified in the data (coding for the SIMS was conducted separately from analysis published in the systematic review due to differing aims). Codes were reviewed by the research team and grouped into nine subordinate themes as follows; experienced stigma, perceived stigma, internalised stigma (comprising self-esteem, emotions, safety behaviours/avoidance, relationships, impacts on experiences of psychosis, treatments, and recovery). All items related to the stigma caused by experiencing psychosis.

Scoring criteria for the SIMS was developed through examination of a sample of current semi-structured measures utilised in psychosis. The Positive and Negative Syndrome Scale (Kay & Opler, 1987), the Psychotic Symptoms Rating Scale (Haddock et al., 1999), and the Calgary Depression Scale (Addington et al., 1994) were consulted as they offer an array of scoring criteria for consideration. Questions and prompts were developed for each theme to assist interviewers in collecting relevant stigma-related information pertaining to each theme, in a consistent manner across interviewees.

Service user consultation and piloting

A draft version of the SIMS was reviewed by a Service-User Reference Group (SURG) to enhance content validity. The SURG comprised eight service users with lived experience of psychosis. The SURG suggested that the SIMS should include two additional areas of questioning; one concerning service users' understanding of stigma and one regarding the positive impacts of stigma. In addition, the SURG offered the following suggestions: to

provide standard definitions of stigma; to make language more understandable and acceptable to service users; and to offer service users an interview agenda in advance to allay any fears about questioning. The SURG also made suggestions regarding the scoring of the SIMS preferring a likert scale rating which could be applied to each individual item. The SIMS was piloted with two service user researchers in order to further refine questions and prompts, to estimate duration of interview and to get feedback regarding the experiences of being interviewed using the SIMS.

Final measure and scoring

The final SIMS comprised eleven sections, one of which is not scored: understanding of stigma (not scored), perceived stigma, experienced stigma, internalised stigma (self-esteem, safety behaviours/avoidance, relationships, impacts on experiences of psychosis, treatments, positive impacts of stigma, and recovery). All items enquired about the impacts of stigma related to experiences of psychosis. The interview is designed to collect quantitative data based on the subjective accounts reported by the interviewee. Each section is rated on a five-point likert scale (0-4) by the interviewer where 0 indicates no impact/experience of stigma and 4 indicates a severe impact/experience of stigma. When rating, the interviewer must take into consideration the frequency, duration, amount of distress, intensity of distress, and impacts on day to day functioning. All items are rated on the interviewees experiences in the past month. Comprehensive guidance to support interrater reliability is incorporated into the measure.

Participants

Participants were recruited from two sources. Participants were either recruited from (a) the Reducing Self-stigma in Psychosis through Engagement in Cognitive Therapy (RESPECT) trial, Morrison et al. (2016) or (b) an inner London acute psychiatric inpatient unit. In both (a) and (b) participants were either identified by their care coordinator or via the nursing staff on the participating wards. Participants were included if they were (i) aged between 18-65, and (ii) met ICD-10 criteria for schizophrenia, schizoaffective disorder or delusional disorder or met criteria for an Early Intervention in Psychosis Service. Exclusion criteria were moderate to severe learning disability, organic impairment, participants not having the capacity to consent to research participation, non-English speaking participants, severe

thought disorder**,** and a primary diagnosis of drug and alcohol dependency. Severe thought disorder was determined by the referring clinician.

Additional outcome measures

Internalised Stigma of Mental Illness Revised (ISMI-R) scale (Ritsher et al., 2003). The ISMI-R is a 29-item questionnaire assessing internalised stigma. This measure was revised by the research team in partnership with SURG such that the term 'mental illness' in its original form was replaced with 'mental health problems'. Higher scores indicate increased internalised stigma.

The Stigma Scale (SS) short version (King et al., 2007). The SS is a 16-item measure of stigma. This shortened version included the subscales of 'disclosure' and 'positive aspects', but not the 'discrimination' subscale which is less likely to capture change over time. Higher scores demonstrate higher levels of stigma.

The Process of Recovery Questionnaire – Short form (QPR (Law et al., 2014)) was used to measure user-defined recovery. This is a 15-item questionnaire which was developed collaboratively with service users and which measures subjective recovery.   Increased scores illustrate higher levels of perceived recovery.

The Beck Depression Inventory for Primary Care (BDI-7; (Winter et al., 1999)) is a 7-item measure of depression. Higher scores indicate increased levels of depression.

The Beck Hopelessness Scale (BHS; (Beck et al., 1974)) s a 20-item measure of hopelessness. Higher scores show increased hopelessness.

Self-esteem was measured using the Self-Esteem Rating Scale – Short form (SERS-S; (Lecomte et al., 2006)), a 20-item questionnaire with higher scores indicating higher self-esteem.

Finally, internalised shame was measured using the Internalised Shame Scale (ISS; (Cook, 1987)), a 30-item questionnaire with higher scores indicating higher levels of shame.

A measure of psychotic symptoms was not included on the basis of feedback from the SURG, who felt that a focus on such symptoms would provide an inconsistent message regarding stigma.

Procedure

This study was carried out in three stages of assessment. Stage one baseline assessments involved participants (n=79) completing the SIMS alongside all other measures. Data from stage 1 was used to carry out the factor analysis, internal consistency, inter-rater reliability, and concurrent validity of the SIMS. The second stage follow-up involved a proportion of participants (n=25) completing the SIMS again at a 4 month time point to examine for test-retest reliability. These participants had all been included in the RESPECT study (Morrison et al., 2016). Stage 3 followed up stage 2 participants (n=28,including 3 additional participants who were unavailable at stage 2), completing the SIMS and all other measures at a 7 month time point in order to examine for sensitivity to change.

Statistical Analysis

All data analysis was conducted using IBM SPSS version 20 (IBM Corp, 2011). Where whole outcome measures were missing, data would be excluded pairwise for the respective analysis. Where less than 20% of individual items were missing from outcome measures, these would be replaced with the measure mean. Data was initially checked for normality through examination of skewness and kurtosis (Kim, 2013).

Initially, individual SIMS items were compared using the Pearson's correlation coefficient to ensure that no items were either extremely highly or poorly correlated. All SIMS items were entered into an exploratory Principal Components Analysis (PCA) with Direct Oblimin rotation, and internal consistency was examined for the identified factor's items. Test retest reliability was tested for by examining the Pearson correlation coefficients between the SIMS total scores at stage 1 and 2. The SIMS was compared to the ISMI-R to examine for criterion validity using Pearson's correlation analysis. The ISMI-R was chosen as it is currently the most reliable measure of stigma (Brohan et al., 2010). Construct validity was examined through comparisons of the SIMS to all other measures using Pearson's correlation analysis. Sensitivity to change was calculated by comparing the change score (stage 1 mean score minus the stage 3 mean score) of the SIMS to change score of all other measures. Where relevant, correlation coefficients were compared for significance using the Fishers z calculation. Floor and ceiling effects were determined as present if more than 15% of the sample scored the minimum (0) or maximum (40) score on the SIMS (Terwee et al., 2007).

Results

Participant demographics

A total of 79 participants took part in the study. Demographics can be seen in table 1.

[INSERT TABLE 1 HERE]

Initial data scrutiny

Individual items from the SIMS were initially screened for their relationship with one another (table 2). If items were either high or low item correlations ($<.200$ or$>.900$) they would be removed, but none met this criteria. Items 9 (0.142 to 0.417) and 10 (-0.175 to -0.296) had the lowest item correlations. Items 9 and 10 also had the lowest endorsements (table 2) but all ten items were included in the factor analysis.

[INSERT TABLE 2 HERE]

Examination of reliability

Principal Components Analysis

The examination of the scree plot (figure 1) and eigenvalues led to only one factor being identified. This factor explained 51.97% of the variance. Factor loadings are shown in table 2. As a consequence of the one factor solution, no sub-categories were identified within the interview measure. The full ten items will therefore be used for subsequent reliability and validity analysis.

Internal Consistency

Internal consistency was examined through the use of the Cronbach's Alpha statistic. The SIMS items showed excellent internal consistency with a Cronbach's Alpha score of $\alpha=0.87$ (Nunnally & Bernstein, 1994). Intraclass Correlations (ICCs), using a two way mixed model, were also examined to test for reliability. The measure had a fair ICC of 0.391 (CI: .307 - .489, $p<0.001$).

Inter-rater Reliability

The SIMS was also shown to have good inter-rater reliability across three raters. Authors LW and GE rated three interviews and had an ICC of 0.874, LW and EB also rated three interviews and had an ICC of 0.959, both illustrating almost perfect agreement (Landis & Koch, 1977).

Test-retest Reliability

Participants (n=25) scored a mean total of 23.76 (SD: 6.66) at stage 1 and a mean of 20.03 (SD: 8.02) at stage 2. The SIMS showed good test retest reliability with a significant ICC of 0.563 (CI: 0.214 - 0.784, $p<0.01$).

Examination of Validity

Means and standard deviations for all measures used to examine validity are shown in table 3. The Pearson correlation coefficients for each measure are also shown in table 4.

[INSERT TABLE 3 HERE]

Criterion validity

The SIMS illustrated a significant strong positive correlation with the ISMI-R (table 2). The coefficient was above 0.7 illustrating that it meets the gold standard of criterion validity (Terwee et al., 2007).

Construct validity

The SIMS illustrated significant correlations with all other outcomes (table 4). The SIMS and SS were highly correlated illustrating that the SIMS is valid in measuring the broad construct of stigma. The SIMS was also highly correlated with the BDI and BHS highlighting the relationship between stigma, depression and hopelessness as highlighted in the literature (Link et al., 2001; Lysaker et al., 2007). The SIMS was also highly correlated with the SERS and ISS showing a strong relationship between stigma, shame and low self-esteem (Link et al., 2001). The SIMS illustrated a significant positive correlation with the QPR.

[INSERT TABLE 4 HERE]

Sensitivity to Change

[INSERT TABLE 5 HERE]

Pearson correlation coefficients and follow-up descriptive statistics for all measures can be found in table 3. The SIMS was found to have significant correlations with all measures. The strongest relationship of change related particularly to the ISS and SERS indicating that changes in stigma relate most strongly to shame and self-esteem. It also has a strong relationship with the BDI, BHS and QPR. The correlations highlight that the SIMS had larger sensitivity to change correlation coefficients against all outcomes compared to the ISMI-R, with the SERS, ISS and QPR being statistically significant (BDI: Fishers z=0.88 , p=0.190; BHS: Fishers z=1.34 , p=0.090 ; SERS: Fishers z= -2.5, p<.01 ; ISS: Fishers z= 1.73, p<.05 ; QPR: Fishers z=-.659 , p<.05). The SIMS also had larger sensitivity to change correlation coefficients with the SERS, ISS, and QPR compared to the SS but the difference was not statistically significant (SERS: Fishers z= -1.41, p=0.0793; ISS: Fishers z= 0.18, p=0.428 ; QPR: Fishers z= 0.352, p=0.703).

Floor and Ceiling effects

The SIMS did not illustrate any floor of ceiling effects. No participants scored the minimum score of 0 and no participants scored the maximum score of 40. As shown in table 2, the minimum score on the SIMS was 2 and the maximum was 36.

Discussion

The aim of this study was to develop and examine the psychometric properties of the SIMS. Analysis demonstrated that it is a reliable and valid tool to assess change in stigma in psychosis. The SIMS was relatively quick to administer compared to other semi-structured tools and appeared to have high content validity. The SIMS is developed to be the first stigma measure specifically for people who experience psychosis. Having a specific target population increases the validity of the measure (Terwee et al., 2007). This may explain why the SIMS was shown to have better sensitivity to change and concurrent validity than the other comparable stigma measures. Targeting this population enabled specific questions to be included examining the impacts of stigma on auditory hallucinations and unusual beliefs. Results illustrated that this was an important subscale which contributed to the reliability and validity statistics. This accords with other research in the field as internalised stigma has also been found to be associated with both positive symptoms (Caveleti et al., 2014) and negative symptoms (Hill & Startup, 2013) of psychosis. Conversely, the SIMS examined impacts of stigma which could potentially be important to people with other mental health experiences however this would need to be examined for reliability and validity in future research.

One of the benefits of the SIMS is that it utilises a semi-structured interview format where most previous measure are self-report in nature (Brohan et al., 2010). An interview measure has a number of advantages over standard self-report measures. It improves the reliability since interviewers are on-hand to clarify questions and concepts for interviewees, and improve participant engagement (Phellas et al., 2011), which is likely to be of particular importance when discussing issues of a sensitive nature, such as personal accounts of stigma. The SIMS can be used by clinicians as a meaningful clinical tool to assess stigma and offers various prompts to engage service users in a meaningful discussion about stigma. Talking about stigma has been shown to reduce stigma (Corrigan et al., 2013), therefore administration of the measure alone may be of therapeutic benefit and reduce the internalised stigma of interviewees.

The SIMS is also the first outcome measure to delineate and examine the specific psychological impacts of stigma. The SIMS can extract rich information regarding the psychological functioning of service users. This is valuable information since it can enable clinicians to offer appropriate psychological support. For example, the SIMS scrutinises safety behaviours, emotional responses and impacts on relationships which are fundamental

to psychological models. An increasing number of clinical trials have been conducted examining the efficacy of stigma based interventions, mainly drawing upon cognitive behavioural therapy (CBT) theory, and with varying results (Knight et al., 2006; Lucksted et al., 2011; Morrison et al., 2016). One criticism of these studies is the lack of specificity in the outcome measures they use in regard to psychological mechanisms (Wood et al., 2016). The SIMS may fill this gap by examining specific psychological mechanisms relevant to stigma.

There were a number of limitations in this study. One of the limitations was the time points in which the test retest and sensitivity to change follow-ups were conducted. Usually for test retest reliability it is recommended that the measure is repeated one to two weeks after it was initially administered (Nunnally & Bernstein, 1994). However, for convenience the test retest was conducted four months after the initial administration as part of the RESPECT trial follow-up assessment. This measure examines stigma over the last month so a longer test retest period is expected, however four months may have been too long. As the SIMS is time intensive, the researchers were conscious of not overburdening the participant by completing an additional semi-structured interview. Similarly, for the sensitivity of change analysis a seven month time period was utilised as part of the RESPECT study. Although there is not as much explicit guidance on duration for sensitivity to change analysis, seven months is a long duration. A further limitation was the moderate sample size used for psychometric testing. Test-retest reliability and sensitivity to change analysis used only 25 and 28 participants respectively. Furthermore, the factor analysis was carried out with n=79 participants when it is often recommended that 10 times per number of variables is advantageous.

In conclusion, the SIMS is a reliable and valid outcome measure of stigma in psychosis. As it is a semi-structured interview measure, it offers an important alternative to all of the other self-report outcome measures.

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Table 1- Participant Demographics

Demographic	Mean (Standard Deviation)	Range
Age	36.489 (11.69)	18-62
	Category	**N**
Patient status	Inpatient	47
	Outpatient	32
Gender	Male	59
	Female	20
Ethnicity	Black heritage	12
	White heritage	52
	Asian heritage	10
	Other	5
Diagnosis	Schizophrenia	25
	Paranoid Schizophrenia	18
	Psychotic episode	19
	First Episode Psychosis	10
	Schizoaffective Disorder	2
	Recurrent Psychosis	2
	Persistent Delusional Disorder	2
	Drug Induced Psychosis	1

Table 2 – Pearson correlation coefficients, descriptive statistics and factor loadings for SIMS items

	1	2	3	4	5	6	7	8	9	M	SD	Min	Max	S	K	Factor Loading
1Percived										2.44	1.059	0	4	-.245	-.212	.762
2Experienced	.527**									1.57	1.195	0	4	.201	-.943	.683
3Self-esteem	.612**	.472**								2.05	1.290	0	4	-.243	-.999	.844
4Emotions	.531**	.511**	.685**							2.41	1.296	0	4	-.547	-.747	.790
5Behaviours	.542**	.398**	.750**	.604**						2.10	1.307	0	4	-.263	-.954	.816
6Relationships	.544**	.603**	.578**	.599**	.533**					1.96	1.275	0	4	-.118	-1.156	.794
7 Symptoms	.580**	.345**	.599**	.449**	.651**	.513**				1.22	1.346	0	4	.598	-1.103	.743
8Treatment	.142	.417**	.255*	.270*	.274*	.336**	.229*			.90	1.069	0	4	.916	-.207	.429
9Positive Impacts	-.257*	-.175	-.240*	-.212	-.213	-.257*	-.296**	-.019		.95	.904	0	3	.421	-.970	-.354
10Recovery	.550*	.446**	.623**	.603**	.656**	.608**	.543**	.388**	-.243*	1.84	1.381	0	4	-.056	-1.296	.810

*p<0.05, ** p<0.01

Table 3 – Descriptive of outcome measures at baseline and follow-up

	Baseline						Follow-up (7-months)					
	M	SD	Min	Max	S	K	M	SD	Min	Max	S	K
1SIMS	19.53	8.73	2	36	-.082	-1.011	17.26	7.91	3	29	-.497	-.836
2ISMI	69.85	16.74	32	104	-.458	-.157	65.47	19.02	0	98	-1.429	4.349
3SS	31.03	10.93	9	58	-.024	-.420	35.80	8.92	13	51	-.591	.381
4BDI	7.29	5.66	0	21	.475	-.686	6.88	4.82	0	14	-.109	-1.343
5BHS	8.41	6.42	0	20	.459	-1.168	9.85	6.83	0	19	.010	-1.502
6SERS	85.74	27.58	36	134	-.064	-1.045	78.16	27.34	33	131	.565	-.681
7ISS	60.60	29.87	1	120	-.136	-.949	63.80	26.52	6	102	-.822	-.210
8QPR	36.31	14.20	0	60	-.658	.098	35.28	12.94	7	60	-.319	.214

S=Skewness, K=Kurtosis

Table 4– Pearson Correlation Coefficients and descriptive statistics of outcome measures at baseline

|	N	1	2	3	4	5	6	7
1SIMS	79							
2ISMI	78	.752**						
3SS	76	.666**	.681**					
4BDI	77	.689**	.646**	.533**				
5BHS	76	.603**	.566**	.515**	.800**			
6SERS	77	-.775**	-.800**	-.653**	-.788**	-.754**		
7ISS	63	.741**	-.830**	.678**	.808**	.719**	-.908**	
8QPR	75	-.531**	-.433**	-.517	-.668**	-.777**	.657**	-.688**

*p<0.05, ** p<0.01

Table 5 – Pearson correlation coefficients and follow-up descriptive statistics for sensitivity to change analysis

	N	1	2	3	4	5	6	7
SIMS change	23							
ISMI change	28	.479*						
SS change	25	.571**	.420*					
BDI change	25	.482*	.255	.595**				
BHS change	25	.453*	.083	.550**	.713**			
SERS change	25	-.819**	-.380	-.622**	-.544**	-.689**		
ISS change	25	.759**	.439*	.735**	.592**	.716**	-.867**	
QPR change	25	-.659**	-.140	-.590**	-.654**	-.681**	.747**	-.731**

*p<0.05, ** p<0.01

Figure 1 – Scree plot of eigenvalues for Principal Components Analysis
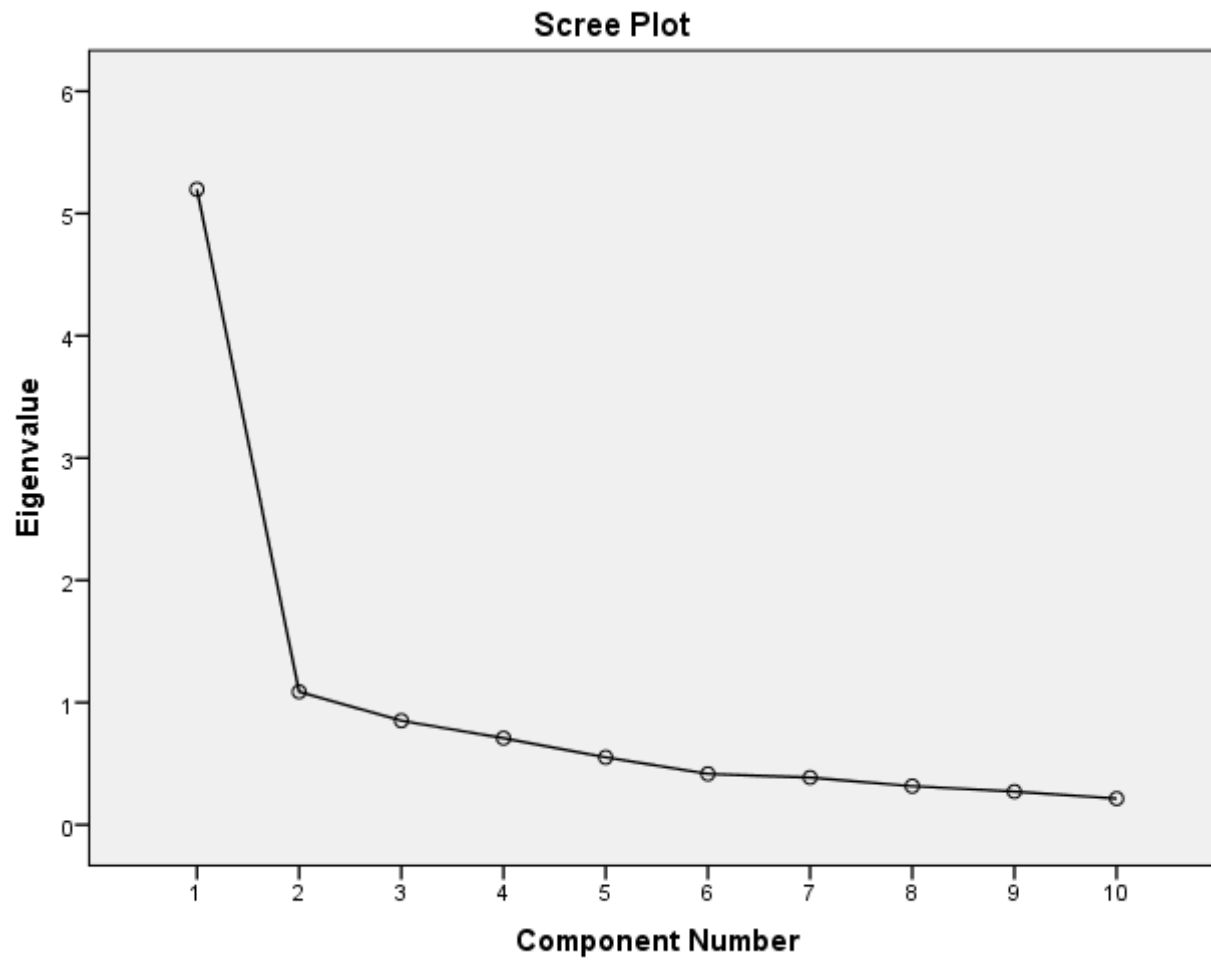
Appendix 1: SERVICE-USER INTERVIEW MEASURE of STIGMA (SIMS) – Simplified Interview Schedule

1. **Understanding of stigma:** I was wondering if you would be able to tell me about your understanding of stigma? What does it mean to you?

2. **Perceived stigma:** How do you think a person with _____/ experiences of psychosis is viewed by society? Are they viewed differently from someone who does not have _____/ experiences of psychosis? In what way?

3. **Experienced Stigma from Psychosis:** Have you had any direct experiences of stigma because of _____/ you have experiences of psychosis?

4. **Self-esteem:** How do the public's views about people who _____-/ experience psychosis make you feel about yourself? How do your experiences of stigma/discrimination make you feel about yourself? Has it changed the way you think or feel about yourself?

5. **Emotional responses:** How does stigma make you feel? Have you experienced any difficult emotions over the past month as a result of stigma?

6. **Safety behaviours/Avoidance:** Do you think stigma has impacted upon your daily life? How so? Does it stop you from doing things?

7. **Impacts on relationships:** Do you think that your experiences of stigma have affected your relationships with others?

8. **Impacts on experiences of <psychosis> (positive symptoms):** Have your experiences of stigma impacted on your _____/ experiences of psychosis? Has it made your <experiences of psychosis> worse?

9. **Impacts on Treatment and accessing services:** Has stigma affected you accessing mental health services? Has it affected your relationships with mental health professionals /services? Has it impacted upon your treatment?

10. **Positive impacts of stigma:** Has stigma had any positive impacts on your day to day life?

11. **Recovery:** What are your hopes for the future/recovery? What are your recovery goals? Do you think experiences of stigma have impacted on your recovery? In what way / what aspects?