The SSRMI scale: development and validation of a self-stigma measure for first-degree relatives of people with mental illness

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ABSTRACT

Background: Serious mental illnesses (SMIs) are profoundly stigmatized, such that even relatives of people with SMI are impacted.

Aims: To develop/validate a scale to comprehensively measure self-stigma among first-degree relatives of individuals with SMI.

Methods: We conducted group interviews focusing on self-stigma with first-degree relatives (*n*=20) of people with SMI, from which 74 representative quotations were reframed as Likert-type items. Cognitive interviews with relatives (*n*=11) identified 30 items for the Self-Stigma in Relatives of people with Mental Illness (SSRMI) scale. Relatives (*n*=195) completed the scale twice, a month apart, together with four external correlate scales.

Results: The 30-item SSRMI was reliable, with scores stable over time. Its single factor structure allowed generation of a 10-item version. Construct validity of 30- and 10-item versions was supported by expected relationships with external correlates.

Conclusions: Both versions of the SSRMI scale are valid and reliable instruments appropriate for use in clinical/research contexts.

Declaration of interest: All authors declare no conflicts.

Key words: psychometrics, internalized, relatives, psychiatric illness, schizophrenia, schizoaffective disorder, bipolar disorder

INTRODUCTION:

Mental illnesses are highly stigmatized conditions. For those with mental illnesses such as schizophrenia, symptoms have a dramatic impact on language, thought, affect, perception, and sense of self (1). Even still, for some, the burden of stigma actually outweighs that of the illness (2). Not only do individuals with mental illness experience stigma, but their family members report feeling stigmatized too (3- 5). Stigma is a complex, multifaceted process that operates at several levels, including: institutions and structures (6), society (or the public) (7), and at the level of the individual. Self-stigma, also known as internalized stigma, operates at the level of the individual, and can be conceptualized as "a process whereby affected individuals endorse stereotypes […], anticipate social rejection, consider stereotypes to be self-relevant, and believe they are devalued members of society" (8). Self-stigma has been conceptualized as a counterpoint to constructs such as empowerment (9) and self-efficacy (8). Self-stigma grows from experiences and perceptions of discrimination (8), and has been postulated to be central to the psychological harm caused by stigma (8, 10-11).

Studies show that stigma is experienced (12), perceived (13) and internalized by family members of people with mental illness. This phenomenon has been dubbed "courtesy stigma" (3) or "stigma by association". Research suggests that self-stigma is as damaging for relatives as it is for people with mental illness themselves (14), causing psychological distress, suicidal thoughts (14) and decreased quality of life (15); however, it is postulated to be amenable to change (9). In order to evaluate the effectiveness of any interventions designed to mitigate self-stigma among relatives of people with mental illness, robust instruments with which to measure it are required.

While the Internalized Stigma Mental Illness scale (ISMI) was developed and validated to measure self/internalized stigma in people with lived experience of mental illness (16), no scales have been purpose-built to specifically and comprehensively measure self/internalized stigma amongst first-degree family members of individuals with mental illness. For example, of the scales that exist for measuring stigma among family members, two (17,18) were designed for relatives who are providing care for their affected family member (and are therefore not applicable to relatives who are not directly involved with caregiving). Further, one of these instruments includes only a five-item stigma subscale (18), and the other (17) omits a core content area (culpability) that is conceptually important in self/internalized stigma (19). An adaptation of the ISMI has been developed for use with parents of individuals with mental illness (20), and while this has good psychometric properties, it was not developed and purpose-designed for family members, and addresses only one kind of relative – parents. Last, the Devaluation of Consumers and Consumer families scale has also been used, but this was originally developed to measure family members' *perceived* social stigma/social stereotype endorsement rather than focusing specifically on self/internalized stigma (21). Importantly, it appears that the existing scales that have been used to assess self/internalized stigma amongst relatives have been founded on the implicit assumption that it is associated with social proximity/caregiving (16,18), whereas clinical experience and research suggests an important role for biological relatedness in self/internalized stigma (5).

Tools with which to measure self-stigma in family members of people with mental illness are needed to allow the rigorous assessment of the effectiveness of interventions that may be applied to tackle it.

Thus, we aimed to develop and validate a psychometric instrument with which to specifically and comprehensively measure self-stigma amongst relatives of people with serious mental illness (specifically, schizophrenia, schizoaffective disorder or bipolar disorder), founding our work on the idea that biological relatedness is important in self-stigma (5).

METHODS

Scale development overview

We adopted a structured process that involved both inductive and deductive components that unfolded over several phases. In Phase I, we used an inductive group interview-based approach with first-degree family members (biological parents, siblings, and children) of people with mental illness to generate a broad array of potential scale items. In Phase II we deductively appraised potential scale items in light of the theoretical construction of stigma, to select items for a first draft of a scale. In Phase III, we used feedback gathered from cognitive interviews with first-degree relatives of people with mental illness to reduce the number of scale items. Finally, in Phase IV, the resulting 30-item scale was validated in a cohort of 195 first-degree relatives of individuals with mental illness.

In all phases, participants were first-degree relatives of people with schizophrenia, schizoaffective disorder or bipolar disorder whom we purposively sampled from family support groups, advocacy agencies and email lists. We confirmed participants' relatives' psychiatric diagnoses using the Family Interview for Genetic Studies (22), administered via telephone (see Table I). For ecological validity, participants were not excluded if they had a personal history of mental illness, but were asked to consider the influence of a single, specific index family member's diagnosis for activities involved in

study participation. The entire study was carried out in accordance with the declaration of Helsinki, and approved by the research ethics board at the University of British Columbia. All participants provided informed consent.

Phase I: Item generation (group interviews)

We conducted six group interviews with participants, including three for relatives of people with schizophrenia/schizoaffective disorder (one each for parents, siblings, and adult children), and three for relatives of people with bipolar disorder (again, one each for parents, siblings and adult children) (See Table 1). Group interviews (each ~2 hours in length) were semi-structured in format, with discussion focused on stigma and feelings of self-stigma due to having a family member with a mental illness (See Supplemental Data, Interview Guide).

The interviews were audio recorded, transcribed verbatim and checked for accuracy. Two team members carefully and independently reviewed each transcript to identify quotations that seemed representative of, or particularly meaningful to, the group in which they occurred. An inclusive, consensus-based approach used by the reviewers led to the identification of 130 quotations to be considered for use as potential scale items.

Phase II: Item selection (expert input, deductive phase)

Six members of the team reviewed each of the 130 quotations identified as potential scale items. Each quotation was categorised by group consensus to one of the five core theoretical content areas of self-stigma identified from the literature (19) (see Table 2). We reached consensus that no additional core

content areas were present in the interviews, and that no important topics were missing, and guided by the existing literature, operationalized our concept of self-stigma in relatives of individuals with mental illness and its core components (see Table 2). To produce a first draft of a scale, we selected 74 quotations that collectively covered all five core content areas of self-stigma, and ensured that all interview groups were represented. Last, we carefully reframed the 74 quotations such that they could be answered using a Likert scale response (using the following anchors: 1=strongly disagree, 2=disagree, 3=neither agree nor disagree, 4=agree, 5=strongly agree), and modified the wording of items to clarify meaning, and to ensure that some items would be reverse coded, thus generating our first draft of the scale (see Supplemental Data, Table 1).

Phase III: Item reduction (cognitive interviews)

We conducted cognitive interviews with 11 first-degree relatives of people with SMI (see Table 1) during which participants talked through their process of answering each of the 74 draft scale items and provided feedback on their understandability and pertinence. Interviews were audio recorded and participants' comments on each item were transcribed. Again, six team members collaboratively reviewed the data from the cognitive interviews and removed or revised those items identified by interviewees as lower priority, problematic or redundant, whilst ensuring that all of the five core conceptual domains of stigma were still well represented. Through this process, the 74 items were reduced to a scale composed of 30 items that was piloted in the validation phase of the study.

Phase IV – validation

Overview

SSRMI Development and Validation

Since full psychometric validation of scales requires 5-10 participants per item (23), and the draft SSRMI had 30 items, we aimed to recruit approximately 200 participants. Participants were asked to complete a demographic information questionnaire as well as the 30-item SSRMI scale (for scoring and participant instructions, see Supplemental Data, Table 1), along with four other validated questionnaires to assess construct validity. This set of scales was administered to participants twice to establish test retest reliability: at baseline (T1) and 1 month later (T2).

Psychometric analysis

Data from the validation phase (Phase IV) were screened for missing values. Randomly missing values were replaced at the item level using maximum likelihood interpolation for SSRMI at T1 and T2. The data were then screened for multivariate outliers.

Tests for normal distribution including Bartlett's test of sphericity and Kaiser-Meyer-Olkin measure of sampling adequacy were also performed. For establishing internal consistency, Cronbach's alphas for the SSRMI as a whole, and for each of the five individual core conceptual content areas were calculated. Test-retest reliability was calculated for the SSRMI scale as a whole and for each of the content areas.

Exploratory factor analysis

The T1 data were used to explore the factor structure of the SSRMI. Factor analyses were completed with scree plot tests, the Kaiser criterion, parallel analysis, and Velicer's MAP test. Because the

nominal structure of the instrument involved five core conceptual content areas, a maximum likelihood extraction set to extract five factors with an oblique rotation (Direct Oblimin) was then performed. Subsequent tests involving two, three and four factors were also conducted. A final exploratory factor analysis was conducted to investigate a one-factor structure for the items, based on the results from the scree plot test (see Supplemental Data, Figure 1).

Construct validation

The selection of our external correlates was informed by the psychometric validation of the ISMI (16). We selected: the Centre for Epidemiological Studies Depression Scale (CES-D) to measure depressive symptoms (24), the Devaluation of Consumer and Consumer Families Scale (DCCF, 21) to measure perceived stigma, the Rosenberg Self Esteem Scale (RSE) (25) to measure self esteem, and a subset of participants also completed a measure of empowerment (ES, 26). We expected the CES-D and DCCF scores to have moderate positive correlations with SSRMI, and the RSE and ES to have moderate negative correlations with SSRMI. Correlations between the SSRMI and the CES-D, RSE, DCCF, and ES were calculated.

Developing the 10-item SSRMI

Given that exploratory factor analysis suggested a single factor latent structure for the instrument, we also developed a 10-item version of the SSRMI. To ensure breadth of content was retained, we identified two items from each of the five conceptual content areas that best captured the core of each domain, according to group consensus. Each selected item had a significant loading on the single-factor

solution to the original 30-item exploratory factor analysis. Psychometrics analyses were conducted for the 10-item version.

RESULTS – Phase IV, Validation

Participant characteristics are described in Table 1. For the 30-item SSRMI, 26% of participants had scores at the midpoint or higher at T1.

Data preparation

A total of n = 195 participants participated in the validation phase. Two participants' data exceeded the critical value for multivariate outliers and were excluded from the factor analyses, leaving n = 193 for factor analysis. Twenty four participants did not respond to any SSRMI at T2 and were included in analyses involving only T1 data, but excluded from analyses requiring T2 data. We used a multiple imputation procedure (27) to replace random missing values (107 at T1, and 20 at T2).

30-item scale

Data from the SSRMI were approximately normally distributed. Significant intercorrelations were found between the variables according to Bartlett's test of sphericity (χ^2 (435) = 2573.96, p < .001) and the Kaiser-Meyer-Olkin measure of sampling adequacy (0.87).

Internal reliability

SSRMI Development and Validation

Cronbach's alpha for the 30-item scale was excellent (α = .90). Reliability of the Stereotyping (α = .62), and Status Loss and Discrimination (α = .41) core conceptual content areas were inadequate against the accepted criterion for Cronbach's alpha of .70. Reliability of the Separation content area (α = .76) Culpability content area (α = .77) and Devaluation content area were adequate (α = .77).

Test-retest reliability

Strong test-retest reliability over a one-month period was demonstrated for the 30-item SSRMI as a whole ($r = .90$, $p < .001$), as well as for the core conceptual content areas individually: Status Loss and Discrimination ($r = .78$, $p < .001$), Separation ($r = .81$, $p < .001$), Stereotyping ($r = .78$, $p < .001$), Culpability ($r = .80$, $p < .001$) and Devaluation ($r = .84$, $p < .001$).

Relationships with demographic variables

Investigation of groups in the data by ANOVA found that the SSRMI scores were unrelated to family member's diagnosis, sex, relationship to family member with mental illness, or presence/absence of a personal history of SMI (see Table 3).

The SSRMI 30-item scale had statistically significant correlations in the expected directions with the CES-D, DCCF, RSE, and ES (Table 4).

Exploratory factor analysis

The number of factors to be retained for analysis differed across the various methods applied: The scree plot (Figure 1) suggested a one factor solution (explaining 27.5% of the variance), Kaisers criterion suggested seven, parallel analysis suggested four factors and Velicer's MAP test suggested five. The results from maximum likelihood extraction established that the five components accounted for 44.57% of the total available variance. However, the five components extracted did not align closely with the theoretically-derived surface structure of the instrument, and subsequent analyses with two, three and four factors extracted and subject to oblique rotation did not provide any further support for the five subscales. The final exploratory factor analysis was conducted to investigate the items as having a one-factor structure showed that a single extracted factor explained 29.57% of the variance, with 26 of the 30 items having significant loadings on this factor. All five subscales were well-represented.

10-item Scale

At T1, 23% of participants had scores at midpoint or higher on the 10-item SSRMI. Internal reliability of the 10-item short-form SSRMI was very good ($\alpha = .82$), and Cronbach's alpha could not be improved by removing any of the items. Test-retest reliability was also good ($r = .86$, $p < .001$).

Investigation of groups in the data by ANOVA found that the 10-item SSRMI scores were unrelated to sex, relationship to family member with mental illness, family member's diagnosis, or presence/absence of a personal history of SMI (see Table 3). The 10-item short-form SSRMI had meaningful associations with the CES-D, DCCF, RSE, and ES (Table 4). In sum, the pattern of

associations between the 30- and 10-item SSRMI is identical; this confirms the utility of the abbreviated version of the scale.

DISCUSSION

We developed a novel, comprehensive measure of internalised stigma amongst first-degree family members of people diagnosed with SMI. Using a mixed methods approach, we developed a 30-item measure with excellent internal reliability, and appropriate test-retest reliability, for which we found evidence in support of construct validity. Contrary to expectations, psychometric analyses did not provide support for five subscales in the instrument. Rather, across analyses it seemed appropriate to infer that the new scale is best understood as tapping a single overarching construct. A pragmatic consequence of this conclusion was the possibility of developing a brief version of the instrument – the 10-item SSRMI retained the broad content coverage of the full instrument and demonstrated comparable psychometric features. As the two versions of the scale are comparable in terms of psychometric features, to ease response burden for participants, the 10-item SSRMI may be preferable to the 30-item version in many settings.

We note that analyses of Ritscher et al.'s ISMI generated a similar pattern of findings to those described here (16), with exploratory analyses suggesting that self-stigma due to a personal diagnosis (while theoretically referring to a number of psychosocial processes) is best measured in a single construct and as a single scale score.

SSRMI Development and Validation

Scores above midpoint on the ISMI have been used to define proportions of studied groups of individuals with mental illness as having "high stigma" (28). Our finding that approximately a quarter of participants scored at or above midpoint on the SSRMI is broadly comparable to proportions of individuals with mental illness who score above midpoint on the ISMI (28). Though it is not possible to draw direct comparisons between the two sets of data, it does suggest support for the concept that self-stigma is an important issue for family members of people with SMI (3, 14, 15), and that there may be a need for the development of interventions (e.g. psychoeducation (29), genetic counselling (30, 31)) designed to reduce self-stigma in this population (3, 32, 33).

Limitations

Some participants in our study also self-reported a personal history of mental illness, which could potentially be seen as a limitation of our study group. We decided against excluding participants with a personal history of mental illness in the interests of ecological validity, and explicitly instructed participants to focus on their experience as a family member. Our approach was supported by the finding that having a personal diagnosis did not relate to SSRMI scores. Further, our data suggest that perhaps self-stigma due to a family member's diagnosis could be different from self-stigma related to a personal diagnosis.

We did not assess the utility of the scale among family members other than first-degree biological relatives, its potential applicability for second degree and non-biological family members remains to be assessed.

Conclusion

While other instruments have been used to measure stigma in relatives of people with mental illness (17, 18, 20, 21), the SSRMI is the first and only self-stigma measure to be developed with direct input from family members to specifically and comprehensively measure self/internalized stigma amongst first-degree family members of individuals with mental illness. Robust analyses demonstrate that it has strong psychometric properties. The SSRMI has numerous applications in both clinical and research settings to measure self-stigma and to serve as a useful tool to measure the impact of interventions designed to improve outcomes in relatives of people with mental illness.

Acknowledgements

The authors would like to thank all participants who participated in each phase of the scale's development, as well as all members of the Translational Psychiatric Genetics Group for their ongoing support. The development of the scale was made possible by funding from UBC's Hampton Grant program, and JA was supported by the Michael Smith Foundation for Health Research, the Canadian Institutes of Health Research, BC Mental Health and Addictions Services, and the Canada Research Chairs program.

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Table 1: Demographics of participants in phases I, III, and IV.

Characteristic	Mean (S.D.) or *n* (%)		
	PHASE I *n*=20	PHASE III *n*=11	PHASE IV *n*=195
Age	51.0 (14.6)	47.6 (10.7)	50.8 (13.5)
Sex Male Female Unknown	 6 (30.0) 14 (70.0)	 5 (45.5) 6 (54.5)	 28 (14.4) 166 (85.1) 1 (0.5)
Primary Caregiver	9 (45.0)	4 (36.4)	40 (20.5)[a]
Personal experience with mental illness ^	6 (30.0)	3 (27.2)	22 (11.3)
Index Relative with Mental Illness Parent Child Sibling	 5 (25.0) 9 (45.0) 6 (30.0)	 3 (27.3) 4 (36.4) 4 (36.4)	 50 (25.6) 79 (40.5) 66 (33.8)
Psychiatric Diagnosis* of Index Relative Schizophrenia Schizoaffective disorder Bipolar disorder	 6 (30.0) 6 (30.0) 8 (40.0)	 4 (36.4) 2 (18.2) 5 (45.5)	 55 (28.2) 36 (18.5) 104 (53.3)
Years since onset of psychiatric illness in index relative	18.1 (13.3)	18.2 (16.0)	15.2 (15.1)
Total number of relatives with mental illness+	1.7 (1.1)	1.7 (0.8)	2.8 (1.0)

Legend: *Diagnoses were confirmed using the Family Interview for Genetics Studies (FIGS, 22), with the exception of one participant in phase I, in which diagnosis was self-reported. +. In phase III and IV,

when the participants had more than one first degree relative with a mental illness of interest, we administered the FIGS regarding the individual for whom they had the most knowledge of symptoms and diagnosis to confirm the participant's eligibility – this became their "index relative". ^Whether the participant had personal experience with mental illness (in Phases I and III included all mental illnesses, e.g. depression, anxiety, Phase IV was restricted to SMI), based on self-report. [a]Participants who reported living with the index relative with SMI at the time of enrolment.

Table 2: Operational definitions of self-stigma and its core components.

Overarching concept: Self-stigma in first-degree relatives of people with serious mental illness *Operational Definition: a process of* ***stereotyping****,* ***separation****,* ***devaluation****,* ***culpability****,* ***status loss and discrimination*** *(19) that is expected, experienced, or shared by a family member due to their biological relatedness (5) and/or their role as a first-degree relative of someone with SMI (19).*	
Core component of overarching concept	**Operational Definition**
Stereotyping	Collectively held undesirable characteristics, which are assumed to be shared by persons in a stigmatized group, and are endorsed and internalized by family members.
Separation	Family members view themselves and their loved ones as distinctly different from other people (e.g., rejection, exclusion, isolation, withdrawal).
Devaluation	Emotional reactions and responses to feeling less valuable, or that one's worth has been depreciated (e.g., feelings of shame, embarrassment, anger, anxiety, pity, fear).
Culpability	Feelings of being responsible for their family member's SMI (e.g., blame, guilt).
Status loss/ discrimination	Family members' feelings of having been moved in a downward direction on the status hierarchy, leading to forms of inequality

Table 3: Mean SSRMI scores for the 30-item and 10-item scales.

	30-item scale mean score (SD)	*p*	10-item scale mean score (SD)	*p*
Sex:				
Male	2.62 (0.76)	0.35	2.54 (0.93)	0.27
Female	2.51 (0.60)		2.29 (1.13)	
Personal History of SMI:				
Personal history	2.63 (0.73)	0.44	2.51 (0.85)	0.42
No history	2.52 (0.62)		2.30 (1.14)	
Relative with SMI:				
Parent	2.56 (0.67)	.55	2.45 (0.71)	0.10
Child	2.57 (0.68)		2.46 (0.82)	
Sibling	2.46 (0.62)		2.10 (1.51)	
Relative's Diagnosis:				
Schizophrenia	2.44 (0.62)	0.31	2.34 (0.79)	.93
Schizoaffective	2.64 (0.59)		2.27 (1.99)	
Bipolar Disorder	2.53 (0.64)		2.35 (0.78)	

Table 4: Correlations of the SSRMI 30-item and 10-item scales with external correlates (Center for Epidemiology Scale for Depression = CES-D, Devaluation of Consumer and Consumer Families Scale = DCCF, Rosenberg Self-Esteem Scale = RSE, and the Empowerment Scale = ES).

External Correlates	SSRMI (30 items) *r* (*p*)	SSRMI (10 items) *r* (*p*)
CES-D	.38 (<.001)	.36 (<.001)
DCCF	.44 (<.001)	.41 (<.001)
RSE	-.30 (<.001)	-.28 (<.001)
ES	-.23 (.018)	-.23 (.021)