

# The Development of a Questionnaire to Explore Stigma from the Perspective of Individuals With Serious Mental Illness

Carrie Gibbons, Sacha Dubois, and Kelly Morris  
*St. Joseph's Care Group*

Barbara Parker  
*Lakehead University*

Hillary Maxwell  
*St. Joseph's Care Group*

Michel Bédard  
*Centre for Research on Safe Driving, Lakehead University,  
Northern Ontario School of Medicine, and St. Joseph's Care Group*

---

Carrie Gibbons, research coordinator, St. Joseph's Care Group, Thunder Bay, Ontario; Sacha Dubois, research statistician, St. Joseph's Care Group, Thunder Bay, Ontario; Kelly Morris, manager, Research Ethics/Research Services, St. Joseph's Care Group, Thunder Bay, Ontario; Barbara Parker, PhD candidate, Lakehead University, Thunder Bay, Ontario; Hillary Maxwell, research coordinator, St. Joseph's Care Group, Thunder Bay, Ontario; Michel Bédard, director, Centre for Research on Safe Driving, Lakehead University, associate professor, Northern Ontario School of Medicine, and scientific director, St. Joseph's Care Group, Thunder Bay, Ontario.

Michel Bédard is a Canada Research Chair in Aging and Health; he acknowledges the support of this program ([www.chairs.gc.ca](http://www.chairs.gc.ca)).

This project would not have been possible without the participants who shared their experiences. Many thanks are extended to the interviewers; the staff at People Advocating for Change Through Empowerment; the Canadian Mental Health Association – Thunder Bay Branch; and the Mental Health Outpatient Programs at St. Joseph's Care Group.

Correspondence concerning this article should be addressed to Carrie Gibbons, Research Department, St. Joseph's Care Group, 580 North Algoma Street, Thunder Bay ON P7B 5G4. Email: [gibbonsc@tbh.net](mailto:gibbonsc@tbh.net)

## ABSTRACT

The stigma associated with mental illness impacts individuals with serious mental illness (SMI). We developed a questionnaire to explore stigma from the perspective of individuals with SMI. In the first of two studies, we examined content validity, internal consistency, and convergent validity. In Study 2 we explored test-retest reliability, interrater reliability, and concurrent validity. Internal consistency reliability was high (Cronbach's  $\alpha = 0.852$ ), convergent validity ( $p < 0.001$ ) and test-retest reliability (ICC = 0.75) were demonstrated, while analyses of concurrent validity were in the expected direction ( $p < 0.01$ ). The final questionnaire is short with good psychometric properties.

**Keywords:** stigma, serious mental illness, questionnaire

The stigma associated with serious mental illness (SMI) is a major barrier to diagnosis, treatment, and community integration (Health Canada, 2002). Stigma includes perceived stigma (i.e., one's awareness of negative attitudes), internalized stigma (i.e., how stigma impacts self-esteem), and external or enacted stigma (e.g., discrimination in hiring practices; Van Brakel, 2006). Experiences include shunning, harassment, and victimization as well as feelings of shame, discouragement, anger, and alienation (Boydell, Gladstone, Crawford, & Trainor, 1999; Corrigan, Watson, & Barr, 2006; Kelly & McKenna, 1997; Vellenga & Christenson, 1994; Wright, Gronfein, & Owens, 2000). Consequently, stigmatized individuals report lower life satisfaction, poorer social outcomes, and lower self-esteem and quality of life (Link, 1987; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Markowitz, 2001). Stigma negatively impacts social interactions (Kiefer, 2001), community participation (Prince & Prince, 2002), housing (Alisky & Iczkowski, 1990; Walker & Seasons, 2002), and employment (Dalgin & Gilbride, 2003; Marwaha & Johnson, 2004; Sundar & Ochocka, 2004). It impedes mental health treatment (Hinshaw & Cicchetti, 2000; James et al., 2002), drug therapy adherence (Sirey et al., 2001), and recovery (Yanos, Roe, Markus, & Lysaker, 2008).

Most research on stigma has focused on the general public views (Link, Yang, Phelan, & Collins, 2004); individuals with mental illness are viewed with fear and often face discrimination (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000; Angermeyer & Matschinger, 2003). In Canada, while members of the general public are knowledgeable about schizophrenia, they view individuals with schizophrenia as dangerous and wish to avoid close personal contact (Stuart & Arboleda-Flórez, 2001; Thompson et al., 2002). There have been a number of anti-stigma-related activities in Canada since the 1950s (Stuart, 2005), mostly surveys of public attitudes and anti-stigma interventions targeted to community groups. While these studies are important, few validated quantitative surveys focus explicitly on the perspective of people with SMI; at the time we developed our questionnaire only three were available.

The first was a series of scales to examine various aspects associated with labelling and stigma (Link et al., 2001; Link et al., 2004; Link, Mirotznik, & Cullen, 1991; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2002). Although Link's scales are widely cited, only the Rejection Experiences scale (Link et al., 1997; Link et al., 2002; Link et al., 2004) explores stigma experiences. This scale, based on a dichotomous scale (yes/no) that may be less sensitive to the range of experiences, includes questions related to drug use.

Link and colleagues (2004) recommended the Consumers' Experience of Stigma Questionnaire (CESQ; Wahl, 1999), which they identified as a more complete measure of discrimination experiences. However, the CESQ presents limitations for Canadian jurisdictions because some questions relate to private health insurance. A further limitation is that information on the CESQ's psychometric properties has not been published.

A third survey from an unpublished thesis (Roman-Smith, 2000) was available, but it is relatively untested. Additional questionnaires have been developed since our project began. They include the Internalized Stigma of Mental Illness scale (ISMI; Ritsher, Otilingam, & Grajales, 2003), the Standardized Stigmatization Questionnaire (Haghighat, 2005), the Inventory of Stigmatizing Experiences (Stuart, Milev, & Koller, 2005), the Self-Stigma of Mental Illness Scale (Corrigan et al., 2006), the Stigma Scale (King et al., 2007), Day's Mental Illness Stigma Scale (Day, Edgren, & Eshleman, 2007), and most recently the Discrimination and Stigma Scale (DISC; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009).

We aimed to develop and validate a short survey tool for use in Canada to explore stigma experiences from the perspective of individuals with SMI. In the first study we examined content validity, internal consistency, and convergent validity. Study 2 comprised a reproducibility analysis and analysis of concurrent validity.

## METHOD

### Participants and Procedure

Study 1 and Study 2 received research ethics board approval from Lakehead Psychiatric Hospital and St. Joseph's Care Group. Study 1 comprised participants recruited from two main sources. Participants were selected from an outpatient program for individuals with SMI ( $n = 89$ ). The list of clients was stratified by age, sex, and length of time with the program. A representative sample was selected for contact by their key mental health workers and invited to participate in the project. Those who declined were replaced with a matched individual from the list. A convenience sample of individuals was also recruited from a housing program ( $n = 10$ ), a consumer/survivor organization ( $n = 5$ ), and an emergency shelter ( $n = 9$ ). Participants in Study 2 were a convenience sample recruited from a consumer/survivor organization and a voluntary mental health organization ( $n = 33$ ).

Study 1 data were obtained by interviewers who attended a training session where they were instructed on the administration of the questionnaire and on obtaining informed consent. For Study 2, two interviewers received similar training and administered the questionnaires to 16 and 17 participants, respectively, at baseline. Two weeks later, the interviewers administered the questionnaires again, but this time to the participants they had not interviewed at baseline ( $n = 17$  and  $n = 13$ , respectively; there were 3 dropouts).<sup>1</sup> In each study, participants were paid \$10 per completed interview; interviewers received \$15 per completed interview. Interviews were conducted in a space most comfortable for the participant.

### Questionnaire Development

We reviewed numerous sources specifically looking for domain areas pertaining to stigma; material examined included (a) relevant literature, (b) existing stigma surveys, (c) reports produced by a local consumer/survivor agency, and (d) reports from working groups of a government task force on mental health

reform. Fifteen different domains of stigma were identified: general public, media, psychiatric hospital, employment, accessing money, secrecy, social/recreational, legal/police, government services, housing, education, treatment by mental health professionals, relationships, self-stigma, and religion.

A working group (comprising mental health clients and clinicians) was asked to review these domains to indicate relevance and identify missing domains. The working group defined important stigma issues through a consensus process, to ensure that comments from members were given equal consideration. Next, questions were developed by the researchers, which each group member reviewed and commented on. The working group again reviewed all the comments and selected the final questions. As certain issues matched questions on the CESQ, modified versions of these questions were included in the questionnaire. The original version of our questionnaire included 24 questions with responses scored on a Likert scale from 1 (*never*) to 5 (*very often*), based on the respondent's experiences in the past year.

After administration in Study 1, the psychometric properties of the questionnaire were examined, including content validity, internal consistency, and convergent validity. The questionnaire was revised to a 15-item version (see Appendix for the final questionnaire). Study 2 was conducted to examine the test-retest reliability, interrater reliability, and concurrent validity.

## Measures

In addition to demographic information, we asked participants two questions about delays in seeking mental health services. Study 1 participants completed the original version of the stigma questionnaire. Study 2 participants completed the revised stigma questionnaire, the ISMI (Ritsher et al., 2003; Ritsher & Phelan, 2004), the Center for Epidemiological Studies – Depression Scale (CES-D; Radloff, 1977), and the Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1989). Study 2 participants also completed the revised stigma questionnaire and the ISMI a second time, approximately two weeks after the first interview.

The ISMI is a 29-item questionnaire developed to examine internalized stigma experienced by individuals with mental illness. It has five subscales: Alienation (feeling out of place), Stereotype Endorsement (agreement with common stereotypes), Discrimination Experience (treatment by others), Social Withdrawal (reducing social contacts), and Stigma Resistance (resisting internalized stigma). Because the ISMI and the revised stigma questionnaire both measure the same construct (stigma), we hypothesized they would be positively correlated.

Depressive symptoms are associated with stigma (Link et al., 1997), and these symptoms as identified on the CES-D have been used to examine the psychometric properties of other stigma questionnaires (Ritsher et al., 2003). The CES-D assesses four factors: Depressed Affect (e.g., sadness and crying), Positive Affect (e.g., happy), Somatic and Retarded Activity (e.g., poor sleep), and Interpersonal Difficulties (e.g., perception of dislike from others). We anticipated the stigma questionnaire would be positively correlated with the CES-D.

The RSES has been used to examine the validity of other stigma questionnaires (King et al., 2007; Ritsher et al., 2003; Werner, Aviv, & Barak, 2008). Higher levels of stigma are associated with low self-esteem (Kahng & Mowbray, 2005; Link et al., 1997; Link et al., 2001; Werner et al., 2008; Yanos et al.,

2008). We expected individuals who scored lower on the RSES (indicating low self-esteem) would have higher levels of stigma.

### Statistical Analysis

In Study 1, we reversed the results from the positively worded questions on the stigma questionnaire (questions 8, 9, 13, 15, 16, and 24) so that higher values indicated greater stigma for all questions. The relevance of each question was first measured by examining the number of responses. Next, we calculated kurtosis and skewness to identify questions with distributions that may not distinguish between individuals. We measured internal consistency of remaining items using Cronbach's  $\alpha$ . We assessed convergent validity with independent  $t$ -tests to compare the mean responses of individuals who had not delayed seeking mental health services to those who indicated that they had because they were concerned about what others might think. To examine stability over time for Study 2 (i.e., test-retest reliability and interrater reliability), we calculated an intraclass correlation coefficient (ICC). We computed Pearson  $r$ 's to examine the correlations between the stigma questionnaire baseline scores and the ISMI, the CES-D, and the RSES. We scored all questions on the CES-D so that higher scores indicated greater depression symptoms. We scored questions on the RSES so that higher scores indicated more self-esteem. Statistical significance was set at  $p = .05$ . All analyses were conducting using SPSS Version 15.0.

## RESULTS

### Study 1

**Demographics.** In Study 1, most participants were female (59.3%) with a mean age of 46 ( $SD = 12.0$ ). Further demographic details can be found in Table 1.

**Content validity.** Results for all questions in Study 1 are presented in Table 2. We used a two-step process to eliminate questions before further analysis. First, questions with low response rates were removed ( $< 90$  responses per question) as they were deemed irrelevant to participants; this included questions 17 (being turned down for a job) and 19 (problems during legal proceedings). Second, we removed questions with uneven distributions (i.e., heavily skewed) and/or a mean of less than 2, both of which indicated the majority of respondents "never" or "seldom" experienced stigma in these areas. Although the number of responses was high, we removed the following questions: 10 (shunned/discriminated against by others), 13 (treatment by mental health professionals), 18 (excluded from volunteering), 20 (difficulty renting), 21 (denied educational opportunities), 22 (denied permits), and 23 (difficulty accessing money).

We made exceptions for three questions: 15 (treatment by law enforcement), 16 (treatment by coworkers/supervisors), and 24 (treatment by religious community). Although the number of responses was low ( $n = 57$ ,  $n = 57$ ,  $n = 84$ , respectively), the high mean for each question ( $M = 3.71$ ,  $SD = 1.51$ ;  $M = 3.02$ ,  $SD = 1.38$ ;  $M = 3.06$ ,  $SD = 1.53$ , respectively) indicated areas of considerable stigma; the mean and distribution of responses for these questions matches those of other retained questions. Because there were fewer responses to these three questions, psychometric analyses were conducted on the 12 remaining items.

**Table 1**  
**Demographic Information *n* (%)**

Characteristic	Study 1 ( <i>n</i> = 123)	Study 2 ( <i>n</i> = 33)
Sex		
Male	50 (40.7)	17 (51.5)
Female	73 (59.3)	16 (48.5)
Age - Mean ( <i>SD</i> )	45.7 (12.0)	46.9 (16.7)
Living arrangements*		
Parents/other relatives	16 (19.5)	1 (3.0)
Spouse	40 (32.5)	9 (27.3)
Children	25 (20.3)	1 (3.0)
Unrelated persons	6 (4.9)	2 (6.1)
Alone	56 (45.5)	20 (60.6)
Living location		
House/apartment	109 (88.6)	30 (90.9)
Rooming/boarding house	3 (2.4)	2 (6.0)
Group home	1 (0.8)	0
Shelter/hostel	10 (8.1)	1 (3.0)
1 or more moves (past year)	31 (25.2)	13 (39.4)
Currently employed	32 (26.1)	6 (18.2)
Currently volunteer	57 (46.3)	25 (75.8)
Currently in school	18 (14.7)	6 (18.2)
Highest level of education		
Elementary school	12 (9.8)	2 (6.1)
Some/complete high school	45 (36.6)	13 (39.4)
Some/complete post-secondary	66 (53.7)	18 (54.6)
Main source of income		
Social assistance/pension	80 (65.0)	28 (84.9)
Insurance	9 (7.3)	3 (9.1)
Employment earnings	16 (13.0)	0
Family/other	18 (14.6)	2 (6.0)
Racial/cultural background		
White	94 (76.4)	22 (66.7)
Aboriginal/Métis	25 (20.4)	10 (30.3)
Other/refused	4 (3.2)	1 (3.0)
Delayed seeking services	65 (53.3)	21 (63.6)
If yes, in past six months	10 (15.6)	8 (38.1)

*Note.* \*Percentages may not equal 100 as more than one response was possible.

**Internal consistency.** Cronbach's  $\alpha$  for the 12 items was .852. Only deletion of questions 4 and 9 increased the internal consistency, but negligibly (Cronbach's  $\alpha$  if deleted was .853 and .856, respectively).

**Convergent validity.** Using the 12-item version of the questionnaire, participants who delayed seeking services ( $M = 36.90$ ,  $SD = 8.47$ ) had a higher mean total score than participants who did not ( $M = 29.86$ ,  $SD = 8.98$ ,  $t(120) = -4.45$ ,  $p < 0.001$ ). This represents a 24% higher reported stigma for those who delayed. When we reintroduced the three questions that had been removed due to low response rate, the analysis showed a 19% difference between respondents who delayed ( $M = 46.17$ ,  $SD = 9.89$ ) and those who did not ( $M = 38.68$ ,  $SD = 10.69$ ,  $t(119) = -4.00$ ,  $p < 0.001$ ). We examined question 11 further (discomfort with "going places where mental health services are provided"). Respondents who delayed seeking services ( $M = 2.78$ ,  $SD = 1.25$ ) scored higher on this question compared to those who did not ( $M = 2.00$ ,  $SD = 1.18$ ),  $t(118) = -3.51$ ,  $p = 0.001$ ).

## Study 2

**Demographics.** We interviewed 33 individuals at baseline and re-interviewed 30 approximately two weeks later (demographic information is based on baseline data). The gender distribution was equivalent and the mean age approached 47. See Table 1 for further demographic information.

**Test-retest (and interrater reliability).** An average of 14.7 days ( $SD = 2.2$ ) separated the administration of the questionnaires. For the 12-item questionnaire, the baseline total mean was 35.9 ( $SD = 6.4$ ); it was 37.1 ( $SD = 6.2$ ) at the second interview. The ICC was 0.75 (95% CI = 0.51 to 0.88). ISMI analyses provided a mean score of 60.2 ( $SD = 13.6$ ) at baseline and 62.8 ( $SD = 13.6$ ) at follow-up. The ICC was 0.87 (95% CI = 0.74 to 0.94).

**Concurrent validity.** Using baseline data, the 12-item questionnaire total was positively correlated with the ISMI total ( $r = 0.56$ ,  $p = 0.001$ ), the Discrimination subscale ( $r = 0.71$ ,  $p < 0.001$ ), the Social Withdrawal subscale ( $r = 0.53$ ,  $p = 0.002$ ) and the Alienation subscale ( $r = 0.47$ ,  $p = 0.008$ ) but not the other subscales. We found statistically significant correlations between individual questions and the ISMI (see Table 3).

The stigma questionnaire was not correlated with the CES-D total ( $r = 0.17$ ,  $p = 0.37$ ). However, the stigma questionnaire and the Interpersonal Difficulties subscale were correlated ( $r = 0.53$ ,  $p = 0.002$ ). We found statistically significant correlations between several stigma questionnaire items and the Interpersonal Difficulties subscale. Full results can be found in Table 4.

The correlation between the stigma questionnaire and the RSES approached statistical significance ( $r = -0.33$ ,  $p = 0.07$ ). We computed further correlation coefficients for the individual stigma questions and the RSES total. We found several statistically significant negative correlations between individual stigma questions and the RSES total (see Table 5).

**Table 2**  
**Results of the Stigma Questionnaire (Study 1)**

	<i>n</i>	Mean ( <i>SD</i> )	Skewness ( <i>SE</i> )	Kurtosis ( <i>SE</i> )
Questions that were retained				
1. View unfavourably	123	3.0 (1.28)	-0.12 (0.22)	-0.94 (0.43)
2. Heard unfavourable	123	3.34 (1.22)	-0.33 (0.22)	-0.62 (0.43)
3. Mass media	121	2.87 (1.25)	0.13 (0.22)	-1.0 (0.44)
4. Avoid telling others	123	3.36 (1.40)	-0.50 (0.22)	-0.98 (0.43)
5. Treated as less competent	123	2.75 (1.25)	0.08 (0.22)	-0.93 (0.43)
6. Shunned/avoided	121	2.17 (1.22)	0.65 (0.22)	-0.60 (0.44)
7. Lower life expectations	122	2.25 (1.35)	0.70 (0.22)	-0.74 (0.44)
R8. Treated fairly by others	121	2.41 (1.06)	0.21 (0.22)	-0.84 (0.44)
R9. Friends supportive	122	2.30 (1.15)	0.88 (0.22)	0.26 (0.44)
11. Mental health places	121	2.40 (1.28)	0.25 (0.22)	-1.24 (0.44)
12. Felt bad about self	121	3.43 (1.28)	-0.49 (0.22)	-0.63 (0.44)
14. Written applications	116	3.28 (1.69)	-0.27 (0.23)	-1.64 (0.45)
Additional questions that were retained				
R15. Law enforcement kind	57	3.71 (1.51)	-0.73 (0.32)	-0.99 (0.62)
R16. Work supportive	57	3.02 (1.38)	.05 (0.32)	-1.15 (0.62)
R24. Religious supportive	84	3.06 (1.53)	.04 (0.26)	-1.46 (0.52)
Questions that were excluded				
10. Shunned/avoided others	123	1.70 (0.98)	1.22 (0.22)	0.72 (0.43)
R13. MH workers respectful	121	1.74 (0.83)	0.80 (0.22)	-0.36 (0.44)
17. Turned down for job	58	1.93 (1.32)	1.12 (0.31)	-.08 (0.62)
18. Excluded volunteer	116	1.34 (0.81)	2.58 (0.23)	6.14 (0.45)
19. Legal proceedings	79	1.75 (1.39)	1.52 (0.27)	0.63 (0.54)
20. Difficulty renting	99	1.47 (1.08)	2.31 (0.24)	4.28 (0.48)
21. Denied education	90	1.14 (0.65)	5.23 (0.25)	28.36 (0.50)
22. Denied permits	92	1.16 (0.67)	4.79 (0.25)	23.96 (0.50)
23. Difficulty with financial	115	1.25 (0.79)	3.70 (0.23)	13.72 (0.45)

*Note.* “R” before a question number indicates a question that is “reversed” compared to the other questions (i.e., R questions are positively worded while the other questions are negatively worded).



Table 3  
Correlation Between Stigma Questionnaire and ISMI (Study 2)

	Alienation		Stereotype endorsement		Discrimination experience		Social withdrawal		Stigma resistance		ISMI total	
	r	p	r	p	r	p	r	p	r	p	r	p
1. Viewed unfavourably	0.22	0.22	0.24	0.18	0.45	0.009	0.37	0.04	0.27	0.12	0.40	0.02
2. Heard unfavourable	-0.35	0.04	-0.18	0.31	0.28	0.12	-0.07	0.71	-0.35	0.05	-0.17	0.34
3. Mass media	-0.25	0.16	0.09	0.63	0.26	0.15	0.08	0.68	-0.27	0.13	-0.02	0.91
4. Avoid telling others	0.17	0.34	-0.09	0.60	0.16	0.37	0.12	0.51	-0.14	0.43	0.08	0.68
5. Less competent	0.44	0.01	0.25	0.16	0.58	<0.001	0.44	0.01	0.20	0.26	0.50	0.003
6. Shunned/avoided	0.14	0.44	0.29	0.10	0.61	<0.001	0.41	0.02	-0.04	0.83	0.37	0.03
7. Lower expectations	0.50	0.003	0.51	0.002	0.37	0.03	0.39	0.03	0.35	0.05	0.54	.001
8. Treated fairly	0.56	0.001	0.37	0.04	0.49	0.004	0.52	0.002	0.24	0.17	0.58	<.001
9. Friends supportive	0.38	0.03	0.25	0.16	0.20	0.26	0.28	0.12	0.23	0.19	0.35	0.05
10. Mental health places	0.18	0.32	0.12	0.51	0.38	0.03	0.26	0.14	-0.11	0.54	0.23	0.20
11. Felt bad about self	0.70	<.001	0.35	0.05	0.36	0.04	0.39	0.02	0.47	0.006	0.59	<0.001
12. Written applications	0.18	0.33	0.01	0.97	0.38	0.04	0.22	0.24	-0.07	0.72	0.20	0.29
Stigma questionnaire total	0.47	0.008	0.35	0.06	0.71	<0.001	0.53	0.002	0.07	0.72	0.56	0.001

Note. ISMI = Internalized Stigma of Mental Illness scale.

**Table 4**  
**Correlation Between Stigma Questionnaire and CES-D (Study 2)**

	Somatic & retarded activity		Depressed affect		Positive affect		Interpersonal difficulties		CES-D total	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
1. Viewed unfavourably	0.11	0.56	0.24	0.18	0.07	0.70	0.28	0.11	0.17	0.35
2. Heard unfavourable	-0.17	0.36	-0.14	0.44	-0.30	0.09	0.16	0.39	-0.20	0.28
3. Mass media	0.13	0.49	0.12	0.51	-0.25	0.16	0.30	0.09	0.06	0.74
4. Avoid telling others	0.02	0.92	0.11	0.56	0.05	0.78	0.20	0.26	0.09	0.63
5. Less competent	-0.07	0.69	-0.02	0.92	0.13	0.48	0.22	0.23	0.02	0.93
6. Shunned/avoided	0.11	0.54	0.20	0.26	-0.07	0.69	0.53	.002	0.15	0.40
7. Lower expectations	0.21	0.25	0.20	0.28	0.28	0.12	0.38	0.03	0.27	0.14
8. Treated fairly	0.20	0.26	0.26	0.15	0.45	.008	0.34	0.06	0.34	0.06
9. Friends supportive	0.25	0.17	0.12	0.50	0.45	.009	-0.02	0.92	0.27	0.13
10. Mental health places	0.08	0.67	0.32	0.08	-0.14	0.43	0.49	.004	0.18	0.32
11. Felt bad about self	0.13	0.48	0.16	0.40	0.29	0.10	0.19	0.30	0.19	0.29
12. Written applications	-0.13	0.50	-0.001	1.00	-0.04	0.84	0.23	0.22	-0.04	0.85
Stigma Questionnaire total	0.04	0.83	0.22	0.25	0.06	0.76	0.53	.002	0.17	0.37

*Note.* CES-D = Center for Epidemiological Studies – Depression Scale.

**Table 5**  
**Correlation Between Stigma Questionnaire and RSES (Study 2)**

	RSES total	
	<i>r</i>	<i>p</i>
1. Viewed unfavourably	-0.32	.08
2. Heard unfavourable	0.27	0.14
3. Mass media	0.16	0.39
4. Avoid telling others	-0.06	0.75
5. Less competent	-0.31	.09
6. Shunned/avoided	-0.11	0.55
7. Lower expectations	-0.45	.01
8. Treated fairly	-0.50	.003
9. Friends supportive	-0.33	.06
10. Mental health places	-0.07	0.71
11. Felt bad about self	-0.57	.001
12. Written applications	-0.05	0.81
Stigma Questionnaire Total	-0.33	.07

*Note.* RSES = Rosenberg Self-Esteem Scale.

## DISCUSSION

This project resulted in a tool to document the stigma experienced by individuals with SMI. The items in the scale are drawn from key areas with input from mental health professionals and, importantly, users of mental health services. The original questionnaire contained 24 items, but not all items were relevant to participants. It could be that many individuals did not answer a question or responded “never” because they simply had not engaged in these types of activities (such as finding housing) within the previous year—although the CESQ, where questions are not framed within a specific time period, has also yielded a poorly distributed response to questions regarding similar events (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002; Lundberg, Hansson, Wentz, & Bjorkman, 2007; Wahl, 1999). However, three questions (interactions with law enforcement, support from coworkers/supervisors, and relationships with one’s religious community) with low response rates were retained for the final 15-item alternate version of our questionnaire as the high scores obtained on each demonstrated considerable stigma. To accommodate this issue in future use of our questionnaire, each of these three questions will be preceded by a qualifying question; should respondents indicate that they have had such experiences within the past year, they will be prompted to respond to the corresponding stigma question.

Our tool has good psychometric properties, including internal consistency and reproducibility. We supported the questionnaire's content validity through extensive research into the literature, surveys and reports from mental health agencies and government sources, combined with consultation from mental health clients and professionals. Individuals who delayed seeking of treatment reported greater stigma, a sign of convergent validity. Correlation between the ISMI, a measure of internalized stigma, and the stigma questionnaire was strong. The correlation between the CES-D total score and the stigma questionnaire was in the expected direction but did not achieve statistical significance. The stigma questionnaire did, however, correlate significantly with some of the CES-D subscales. Similarly, correlation between self-esteem and the stigma questionnaire was in the anticipated direction and achieved statistical significance on three of the stigma questionnaire items.

Our proposed stigma questionnaire represents an important addition to the field. It is short and contains questions that are applicable in the Canadian context. While the Inventory of Stigma Experiences (Stuart et al., 2005; Stuart, Koller, & Milev, 2008) was developed in Canada, more work is necessary to further explore its psychometric properties. Other stigma surveys (Day et al., 2007; Haghighat, 2005) do not report the range of psychometric properties we examined. Further, unlike other stigma questionnaires, ours does not require the use of hypothetical situations or vignettes, which have been identified as problematic (Thornicroft et al., 2009). Finally, our stigma questionnaire addresses a number of stigma experiences (such as interactions with one's religious community or support from friends) not assessed by others (Corrigan et al., 2006; King et al., 2007; Ritsher et al., 2003).

While our stigma questionnaire is comprehensive and has good indications of reliability and validity, it also has limitations. Generalizability could be an issue. While attempts were made in Study 1 to obtain a representative sample of users from the outpatient program, the final response rate reflects a smaller sample, and participants from the community agencies in both studies represent convenience samples. The psychiatric diagnosis of all participants is unknown as this information was not collected by any of the programs participating in the study. Future use of the stigma questionnaire should include representative groups of individuals with serious mental illness (e.g., schizophrenia, mood disorders, concurrent disorders) to fully understand its applicability. Finally, due to sample size limitations, we were unable to conduct analyses on the three additional items on the questionnaire; more remains to be done with these questions. Nevertheless, these analyses represent important first steps in the creation of this stigma questionnaire.

## CONCLUSIONS

A validated stigma instrument will prove useful in the clinical context. Researchers reported they need instruments to explore stigma from the individuals' perspective (Stuart & Arboleda-Flórez, 2001; Van Brakel, 2006) to develop targeted client interventions. Such interventions are an essential means to reduce stigma (Heijnders & Van Der, 2006; Prince & Prince, 2002; Schulze, 2009; Thornicroft, 2007; Yanos et al., 2008).

## NOTE

1. By administering the questionnaires twice, we obtained a measure of test-retest reliability (intrarater). Because different interviewers completed the questionnaires, this measure can also be interpreted as interrater reliability.

## RÉSUMÉ

Le stigmatisme associé à la maladie mentale impacte sur les gens ayant une maladie mentale sérieuse (MMS). Nous avons développé un questionnaire pour explorer le stigmatisme de la perspective des gens ayant une MMS. Dans la première de deux études, nous avons évalué la validité du contenu, la cohérence interne, et la validité convergente. Dans la deuxième étude nous avons évalué la fiabilité test-retest, la fiabilité inter-évaluateur, et la validité concomitante. La cohérence interne a été démontrée par la forte valeur du alpha standardisé (test de Cronbach = 0,852). La validité convergente ( $p < 0.001$ ) et un coefficient de fiabilité test-retest de 0.75 ont été démontrés et les analyses de la validité concomitante ont été dans la direction prévue ( $p < 0.01$ ). Le questionnaire final est court et possède d'excellentes propriétés psychométriques.

**Mots clés :** stigmatisme, maladie mentale sévère, questionnaire

## REFERENCES

- Alisky, J. M., & Iczkowski, K. A. (1990). Barriers to housing for deinstitutionalized psychotic patients. *Hospital and Community Psychiatry, 41*(1), 93-95.
- Angermeyer, M. C., & Matschinger, H. (2003). The stigma of mental illness: Effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatrica Scandinavica, 108*(4), 304-309. doi:10.1034/j.1600-0447.2003.00150.x
- Boydell, K. M., Gladstone, B. M., Crawford, E., & Trainor, J. (1999). Making do on the outside: Everyday life in the neighborhoods of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal, 23*(1), 11-18. Retrieved from <http://www.bu.edu/cpr/prj/>
- Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology, 25*(8), 875-884. doi:10.1521/jscp.2006.25.8.875
- Crisp, A. H., Gelder, M. G., Rix, S., Meltzer, H. I., & Rowlands, O. J. (2000). Stigmatisation of people with mental illnesses. *British Journal of Psychiatry, 177*, 4-7. doi:10.1192/bjp.177.1.4
- Dalgin, R. S., & Gilbride, D. (2003). Perspectives of people with psychiatric disabilities on employment disclosure. *Psychiatric Rehabilitation Journal, 26*(3), 306-310. doi:10.2975/26.2003.306.310
- Day, E. N., Edgren, K., & Eshleman, A. (2007). Measuring stigma toward mental illness: Development and application of the Mental Illness Stigma Scale. *Journal of Applied Social Psychology, 37*(10), 2191-2219. doi:10.1111/j.1559-1816.2007.00255.x
- Dickerson, F. B., Sommerville, J., Origoni, A. E., Ringel, N. B., & Parente, F. (2002). Experiences of stigma among outpatients with schizophrenia. *Schizophrenia Bulletin, 28*(1), 143-154. Retrieved from <http://schizophrenia.bulletin.oxfordjournals.org/>
- Haghighat, R. (2005). The development of an instrument to measure stigmatization: Factor analysis and origin of stigmatization. *European Journal of Psychiatry, 19*(3), 144-154. doi:10.4321/S0213-61632005000300002
- Health Canada. (2002). *A report on mental illnesses in Canada*. Ottawa, ON.
- Heijnders, M., & Van Der, M. S. (2006). The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health & Medicine, 11*(3), 353-363. doi:10.1080/13548500600595327
- Hinshaw, S. P., & Cicchetti, D. (2000). Stigma and mental disorder: Conceptions of illness, public attitudes, personal disclosure, and social policy. *Development and Psychopathology, 12*(4), 555-598. doi:10.1017/S0954579400004028
- James, S., Chisholm, D., Murthy, R. S., Kumar, K. K., Sekar, K., Saeed, K., ... Mubbashar, M. (2002). Demand for, access to and use of community mental health care: Lessons from a demonstration project in India and Pakistan. *International Journal of Social Psychiatry, 48*, 163-176. doi:10.1177/002076402128783217
- Kahng, S. K., & Mowbray, C. T. (2005). What affects self-esteem of persons with psychiatric disabilities: The role of causal attributions of mental illnesses. *Psychiatric Rehabilitation Journal, 28*(4), 354-361. doi:10.2975/28.2005.354.360
- Kelly, L. S., & McKenna, H. P. (1997). Victimization of people with enduring mental illness in the community. *Journal of Psychiatric and Mental Health Nursing, 4*, 185-191. doi:10.1046/j.1365-2850.1997.00054.x
- Kiefer, C. A. (2001). Out of the closet: Escaping the stigma. *Psychiatric Rehabilitation Journal, 24*, 303-304. Retrieved from <http://www.bu.edu/cpr/prj/>

- King, M., Dinos, S., Shaw, J., Watson, R., Stevens, S., Passetti, F., . . . Serafy, M. (2007). The Stigma Scale: Development of a standardised measure of the stigma of mental illness. *British Journal of Psychiatry*, 190(3), 248-254. doi:10.1192/bjp.bp.106.024638
- Link, B. G. (1987). Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American Sociological Review*, 52(1), 96-112. doi: 10.2307/2095395
- Link, B. G., Mirotznik, J., & Cullen, T. F. (1991). The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided? *Journal of Health and Social Behavior*, 32(3), 302-320. doi: 10.2307/2136810
- Link, B. G., Struening, E., Neese-Todd, S., Asmussen, S., & Phelan, J. C. (2001). Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services*, 52(12), 1621-1626. doi: 10.1176/appi.ps.52.12.1621
- Link, B. G., Struening, E. L., Neese-Todd, S., Asmussen, S., & Phelan, J. C. (2002). On describing and seeking to change the experience of stigma. *Psychiatric Rehabilitation Skills*, 6(2), 201-231. doi:10.1080/10973430208408433
- Link, B. G., Struening, E., Rahav, M., Phelan, J. C., & Nuttbrock, L. (1997). On stigma and its consequences: Evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behavior*, 38(2), 177-190. doi:10.2307/2955424
- Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, 30(3), 511-541. Retrieved from <http://schizophreniabulletin.oxfordjournals.org/>
- Lundberg, B., Hansson, L., Wentz, E., & Bjorkman, T. (2007). Sociodemographic and clinical factors related to devaluation/discrimination and rejection experiences among users of mental health services. *Social Psychiatry and Psychiatric Epidemiology*, 42(4), 295-300. doi:10.1007/s00127-007-0160-9
- Markowitz, F. E. (2001). Modeling processes in recovery from mental illness: Relationships between symptoms, life satisfaction, and self-concept. *Journal of Health and Social Behavior*, 42(1), 64-79. doi: 10.2307/3090227
- Marwaha, S., & Johnson, S. (2004). Schizophrenia and employment – a review. *Social Psychiatry and Psychiatric Epidemiology*, 39(5), 337-349. doi: 10.1007/s00127-004-0762-4
- Prince, P. N., & Prince, C. R. (2002). Perceived stigma and community integration among clients of assertive community treatment. *Psychiatric Rehabilitation Journal*, 25(4), 323-331. Retrieved from <http://www.bu.edu/cpr/prj/>
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385-401. doi:10.1177/014662167700100306
- Ritsher, J. B., Otilingam, P. G., & Grajales, M. (2003). Internalized stigma of mental illness: Psychometric properties of a new measure. *Psychiatry Research*, 121(1), 31-49. doi:10.1016/j.psychres.2003.08.008
- Ritsher, J. B., & Phelan, J. C. (2004). Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry Research*, 129(3), 257-265. doi:10.1016/j.psychres.2004.08.003
- Roman-Smith, H. M. (1999). *The development of a self-report scale for the assessment of stigma and discrimination as experienced by individuals with schizophrenia* (Unpublished master's thesis). University of Calgary, Canada.
- Rosenberg, M. (1989). *Society and the adolescent self-image* (Rev. ed.). Middletown, CT: Wesleyan University Press.
- Schulze, B. (2009). Mental-health stigma: Expanding the focus, joining forces. *Lancet*, 373(9661), 362-363. doi:10.1016/S0140-6736(08)61818-8
- Sirey, J., Bruce, M. L., Alexopoulos, G. S., Perlick, D., Friedman, S. J., & Meyers, B. S. (2001). Perceived stigma and patient-rated severity of illness as predictors of antidepressant drug adherence. *Psychiatric Services*, 52(12), 1615-1620. doi: 10.1176/appi.ps.52.12.1615
- Stuart, H. (2005). Fighting stigma and discrimination is fighting for mental health. *Canadian Public Policy*, 31(Suppl. 1), 21-28. Retrieved from <http://economics.ca/cgi/jab?journal=cpp&view=v31s1/CPpv31s1p021.pdf>
- Stuart, H., & Arboleda-Flórez, J. (2001). Community attitudes toward people with schizophrenia. *Canadian Journal of Psychiatry*, 46(3), 245-252. Retrieved from <http://publications.cpa-apc.org/browse/sections/0>
- Stuart, H., Koller, M., & Milev, R. (2008). Appendix: Inventories to measure the scope and impact of stigma experiences from the perspective of those who are stigmatized – consumer and family versions. In J. Arboleda-Flórez & N. Sartorius (Eds.), *Understanding the stigma of mental illness: Theory and interventions* (pp. 193-204). West Sussex, England: John Wiley & Sons.
- Stuart, H., Milev, R., & Koller, M. (2005). The Inventory of Stigmatizing Experiences: Its development and reliability. *World Psychiatry*, 4, 35-39. Retrieved from [http://www.wpanet.org/detail.php?section\\_id=10&content\\_id=421](http://www.wpanet.org/detail.php?section_id=10&content_id=421)

# QUESTIONNAIRE TO EXPLORE STIGMA

- Sundar, P., & Ochocka, J. (2004). Bridging the gap between dreams and realities related to employment and mental health: Implications for policy and practice. *Canadian Journal of Community Mental Health*, 23(1), 75-89. Retrieved from <http://www.cjcmh.com/>
- Thompson, A. H., Stuart, H., Bland, R. C., Arboleda-Florez, J., Warner, R., & Dickson, R. A. (2002). Attitudes about schizophrenia from the pilot site of the WPA worldwide campaign against the stigma of schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 37(10), 475-482. doi:10.1007/s00127-002-0583-2
- Thornicroft, G. (2007). *Shunned: Discrimination against people with mental illness*. Oxford: Oxford University Press.
- Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., & Leese, M. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia: A cross-sectional survey. *Lancet*, 373 (9661), 408-415. doi:10.1016/S0140-6736(08)61817-6
- Van Brakel, W. H. (2006). Measuring health-related stigma—a literature review. *Psychology, Health & Medicine*, 11(3), 307-334. doi:10.1080/13548500600595160
- Vellenga, B. A., & Christenson, J. (1994). Persistent and severely mentally ill clients' perceptions of their mental illness. *Issues in Mental Health Nursing*, 15(4), 359-371. doi:10.3109/01612849409006914
- Wahl, O. F. (1999). Mental health consumers' experience of stigma. *Schizophrenia Bulletin*, 25, 467-478. Retrieved from <http://schizophreniabulletin.oxfordjournals.org/>
- Walker, R., & Seasons, M. (2002). Supported housing for people with serious mental illness: Resident perspectives on housing. *Canadian Journal of Community Mental Health*, 21(1), 137-151. Retrieved from <http://www.cjcmh.com/>
- Werner, P., Aviv, A., & Barak, Y. (2008). Self-stigma, self-esteem and age in persons with schizophrenia. *International Psychogeriatrics*, 20(1), 174-187. doi:10.1017/S1041610207005340
- Wright, E. R., Gronfein, W. P., & Owens, T. J. (2000). Deinstitutionalization, social rejection, and the self-esteem of former mental patients. *Journal of Health and Social Behavior*, 41(1), 68-90. doi: 10.2307/2676361
- Yanos, P. T., Roe, D., Markus, K., & Lysaker, P. H. (2008). Pathways between internalized stigma and outcomes related to recovery in schizophrenia spectrum disorders. *Psychiatric Services*, 59(12), 1437-1442. doi: 10.1176/appi.ps.59.12.1437

## APPENDIX

### 15-Item Stigma Questionnaire

Please indicate (by circling the most appropriate response) the extent to which you have experienced any of the following in the *past year*. Remember to base your answers on your own personal experience. For each question, please mark (1) for Never, (2) for Seldom, (3) for Sometimes, (4) for Often and (5) for Very Often.

1. I have felt that others will view me unfavourably because I have or had a mental illness.	1	2	3	4	5
2. I have been in situations where I have heard others say unfavourable things about people who have or had a mental illness.	1	2	3	4	5
3. I have seen or read things in the mass media (e.g., television, movies, books) about people who have or had mental illnesses that I find hurtful or offensive.	1	2	3	4	5
4. I have avoided telling others outside my immediate family that I have or had a mental illness.	1	2	3	4	5
5. I have been treated as less competent by others when they learned that I have or had a mental illness.	1	2	3	4	5
6. I have been shunned or avoided when it was revealed that I use or have used mental health services.	1	2	3	4	5
7. I have been advised to lower my expectations in life because I have or had a mental illness.	1	2	3	4	5
8. I have been treated fairly by others who know I have or had a mental illness.	1	2	3	4	5
9. Friends who learned that I use or have used mental health services have been supportive and understanding.	1	2	3	4	5
10. I have felt uncomfortable going to places that provide mental health services because I was afraid of what other people might think about me.	1	2	3	4	5
11. I have felt bad about myself because I have or had a mental illness.	1	2	3	4	5
12. I have avoided indicating on written applications (for jobs, licenses, housing, school, etc.) that I have or had a mental illness for fear that this information will be used against me.	1	2	3	4	5
<b>In the past year, have you had any interaction with law enforcement officers?</b>	Yes		No		
<b>If yes, please answer the following question:</b>					
13. I have been treated with kindness and sympathy by law enforcement officers when they learned that I have or had a mental illness.	1	2	3	4	5
<b>In the past year, have you been employed or had coworkers or supervisors at work?</b>	Yes		No		
<b>If yes, please answer the following question:</b>					
14. Coworkers or supervisors at work were supportive and accommodating when they learned I have or had a mental illness.	1	2	3	4	5
<b>In the past year, have you been part of a religious community?</b>	Yes		No		
<b>If yes, please answer the following question:</b>					
15. People in my religious community have been supportive and understanding when they learned that I have or had a mental illness.	1	2	3	4	5