

Empirical Studies of Self-Stigma Reduction Strategies: A Critical Review of the Literature

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Objective: The purpose of this article was to comprehensively review published literature about strategies to reduce self-stigma among people with mental illness. Recommendations and implications for research also are discussed. **Methods:** The electronic databases of Ovid, PubMed, and PsycINFO were searched for peer-reviewed articles published between January 2000 and August 2011 by using the key words “self-stigma,” “internalized stigma,” “perceived stigma,” and “stigma intervention.” The search was further narrowed to studies that described a detailed intervention and that used self-stigma as a primary or secondary outcome, tested the intervention among individuals with a psychiatric illness, and analyzed data quantitatively with acceptable statistical tools. **Results:** Fourteen articles met inclusion criteria, and eight reported significant improvement in self-stigma outcomes. Participants predominantly had schizophrenia and related disorders or depression. Six self-stigma reduction strategies were identified. Psychoeducation was the most frequently tested intervention. Self-stigma definitions, measurements, and conceptual frameworks varied considerably across these studies. Several studies lacked a theoretical framework for their intervention. Six different scales were used to measure self-stigma. **Conclusions:** Two prominent approaches for self-stigma reduction emerged from our review: one, interventions that attempt to alter the stigmatizing beliefs and attitudes of the individual; and two, interventions that enhance skills for coping with self-stigma through improvements in self-esteem, empowerment, and help-seeking behavior. The second approach seems to have gained traction among stigma experts. Targeting high-risk groups to preempt self-stigma appears to be a promising area for future research. (*Psychiatric Services* 63:974–981, 2012; doi: 10.1176/appi.ps.201100459)

People with mental illness, such as schizophrenia, may internalize negative stereotypes about mental illness and respond by self-stigmatization (1–6). High levels of

self-stigma are associated with low levels of hope (7), self-esteem (8–10), self-efficacy (11), and quality of life (12). Self-stigma may undermine adherence to treatment recommendations

(13–15) and decrease help-seeking behavior (16,17). It also may interfere with rehabilitation goals, such as pursuing employment (18), independent living, and having a full social life (7,8,19).

The concept of self-stigma has been described by various terms, including internalized stigma, perceived stigma, and enacted stigma. Using a sociological perspective, Link and Phelan (2) postulated that perceived stigma consists of five elements (labeling, stereotyping, separation, status loss, and discrimination). These elements unfold when a less powerful, stigmatized group encounters a more powerful, stigmatizing group. On the basis of this conceptualization, they developed the 12-item Perceived Devaluation and Discrimination (PDD) Scale and Link's Perceived Stigma Questionnaire (LPSQ), a 29-item scale (20–22). Although the PDD is the most frequently used measure of self-stigma, 14 other scales are also used to assess the personal experience of stigma related to mental illness (23).

Corrigan and Watson (1,4,6,24) expanded Link and Phelan's (2) conceptualization of self-stigma into a hierarchy of “three As”: awareness, agreement, and application. To experience self-stigma, one must not only be aware of the stereotype or stereotypes that describe a stigmatized group—for example, people with mental illness are weak and, therefore, are responsible for their disorder—but also agree with the stereotype. In addition, one must also apply the stereotype to oneself (“I am weak and

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have mental illness, so I must be responsible for my disorder”) (4).

Some authors have defined self-stigma relative to the barriers it may create (namely decreased help seeking, shame, and negative appraisal). For example, according to Vogel and others (16), self-stigma is defined as “the perception of oneself as inadequate or weak if one were to seek professional help.” Luoma and others (25) defined self-stigma as “shame, evaluative thoughts, and fear of enacted stigma that results from individuals’ identification with a stigmatized group that serves as a barrier to the pursuit of valued life goals.”

Development of interventions to decrease self-stigma is a relatively new area of research. A recent review by Heijnders and Van Der Meij (26) highlighted multiple target levels for antistigma programs related mostly to physical illnesses such as HIV/AIDS, leprosy, tuberculosis, and epilepsy. The authors identified key strategies, including counseling, cognitive-behavioral therapy (CBT), empowerment, self help, and support groups. Far less is known about the role of these strategies for reducing self-stigma related to mental illness. This article reviews published literature that describes empirical strategies for reduction of self-stigma related to mental illness and discusses implications for research.

Methods

We searched the electronic databases of Ovid, PubMed, and PsycINFO for peer-reviewed journal articles published in the English language by using the terms “self-stigma,” “internalized stigma,” “perceived stigma,” and “stigma intervention.” We chose these terms because of their common usage in self-stigma reduction initiatives. Although the terms “self-stigma” and “internalized stigma” are used interchangeably, the term “perceived stigma” relates to the individual’s expectation of devaluation and discriminatory attitudes by the general public (stereotype awareness).

For the initial review, we selected articles that contained these terms in the title or abstract and were published between January 2000 and August 2011 (N=3,501). We then

screened abstracts to identify intervention studies with self-stigma as an outcome measure and completed a full-text review of such articles (N=87). We included articles that described or cited in an accessible source a detailed intervention, included an intervention targeting self-stigma as a primary or secondary outcome, tested the intervention among individuals with an existing psychiatric illness (for example, schizophrenia, bipolar disorder, substance use disorder, depression, and posttraumatic stress disorder) or in a high-risk group (for example, individuals exposed to traumatic life events), and analyzed data quantitatively with acceptable statistical tools to determine the effectiveness of the interventions. We excluded case reports, qualitative studies, interventions that targeted the general public, and studies focusing on general medical illness.

This article is a systematic narrative review of articles that met our selection criteria. We analyzed articles for the demographic profile of participants; target disorders; self-stigma definition; conceptual basis; scale or measures used; type, length, and content of intervention; mode of delivery; study design; and self-stigma outcomes and effect sizes.

Results

Fourteen articles were identified by our search. Table 1 describes the articles in terms of sample size, population studied, design, and research setting. In general, the studies were small. Six had sample sizes of 50 persons or fewer, four had sample sizes between 50 and 100, and only four had sample sizes larger than 100. Eight studies focused on persons with schizophrenia or serious mental illness, three on persons with depression, one on persons with substance use disorders, and two on groups at risk to develop a mental disorder (college students with symptoms of depression or anxiety and veterans in postdeployment transition). The race of the participants varied considerably across studies. Only half of the studies were conducted in the United States. All but two were conducted predominantly in outpatient clinical

settings. The methodological design employed by the studies varied: ten were randomized controlled trials, one had a wait-list control group, and three used a pretest-posttest design.

Table 2 presents details about the content, design, measurement, and outcomes of the self-stigma interventions. Six articles (27–32) did not clearly describe a stigma definition or a conceptual framework, three (33–35) alluded to Corrigan and Watson’s self-stigma conceptualization (1,4,6), and two (36,37) referred to Link and others’ sociological perspective of stigma (2,22). The remaining three articles (25,38,39) offered only contextual definitions with no theoretical framework. Only five articles (25,33,36–38) developed an intervention that was based on a conceptual model. Of the 14 articles, nine articles (25,30,31,33–38) described an intervention targeting self-stigma as a primary outcome and five (27–29,32,39) described interventions with self-stigma as a secondary outcome.

Types and content of intervention strategies

The most common type of intervention strategy was psychoeducation or psychoeducation combined with cognitive restructuring. Some investigators examined the effect of printed material only, such as brochures (31,39), or of materials on the Internet (30), and others examined educational sessions delivered by a trainer or a therapist. These psychoeducational interventions were most often conducted in a group format. The number of educational sessions ranged from one to 23. The content and processes used for the educational interventions varied widely. For example, Link and others (37) evaluated an intervention in which a trainer stressed the effects and consequences of stigma and encouraged participants to share personal experiences and discuss behavioral strategies. McCay and colleagues’ (36) intervention sought to educate participants to interpret the illness experience, minimize self-stigmatizing attitudes, develop hope, and pursue meaningful life goals. Shin and Lukens (32) utilized a more medically oriented approach, educating participants about illness, medication

Table 1

Demographic profile of participants in studies of self-stigma reduction strategies

					Participants						
Author and year	N	Country	Predominant diagnosis	Age (M years)	Males		Females		Predominant race-ethnicity	Setting	
					N	%	N	%			
Luoma et al., 2008 (25)	88	U.S.	Substance use disorder	36	41	47	47	53	White	Residential	
Link et al., 2002 (37)	88	U.S.	Schizophrenia	41	54	61	34	39	White	Clubhouse	
McCay et al., 2007 (36)	67	Canada	Schizophrenia	26	48	72	19	28	—	Outpatient	
Shin and Lukens, 2002 (32)	48	U.S.	Schizophrenia	37	20	42	28	58	Korean American	Outpatient	
Alvidrez et al., 2009 (31)	42	U.S.	Depression and anxiety disorders	45	13	31	29	69	Black	Outpatient	
Hammer and Vogel, 2010 (39)	1,397	U.S.	Depression	29	1,397	100	0	—	White	Outpatient	
Griffiths et al., 2004 (30)	525	Australia	Depression	36	150	26	375	74	White	Outpatient	
MacInnes and Lewis, 2008 (38)	20	United Kingdom	Serious mental illness	32	20	100	0	—	—	Inpatient	
Knight et al., 2006 (28)	21	United Kingdom	Schizophrenia	39	11	52	10	48	White	Outpatient and inpatient	
Aho-Mustonen et al., 2011 (29)	39	Finland	Schizophrenia	40	35	90	4	10	—	Prison	
Fung et al., 2011 (33)	66	China	Schizophrenia	45	37	56	29	44	Chinese	Outpatient	
Luckstead et al., 2011 (34)	50	U.S.	Schizophrenia	53	41	81	9	19	Black	Outpatient	
Wade et al., 2011 (35)	263	U.S.	Depression and anxiety symptoms	19	119	45	144	55	White	Outpatient	
Adler et al., 2009 (27)	2,297	U.S.	At-risk combat veterans	—	2,202	96	95	4	—	Outpatient	

effects, stigma, relapse prevention, crisis management, communication and stress-management skills, self help, and community resource utilization. They also used visual aids, such as charts and handouts, to reinforce didactic materials. Alvidrez and others (31) evaluated an intervention tailored for African-American adults, including use of a psychoeducational booklet, "Getting Mental Health Treatment: Advice From People Who've Been There." Information included experiences and advice of black mental health consumers on treatment engagement, challenges in seeking mental health treatment, and strategies to overcome those challenges.

One study (25) evaluated the effect of acceptance and commitment therapy, a contemporary behavioral analytic theory of language and cognition (40) in which participants are instructed to watch their thoughts mindfully and feel their feelings completely. Participants

were also taught to respond to their stigmatizing attitudes and behaviors by applying principles such as "acceptance," "diffusion," and "contact."

Three studies (28,29,38) evaluated interventions that combined psychoeducation with elements of CBT. MacInnes and Lewis (38) encouraged participants to share illness experiences and educated them about symptoms, stress, coping, self help, and stigma and its impact. Principles of self-acceptance and CBT challenged specific beliefs about stigma. Knight and others (28), using cognitive-behavioral elements, tested an intervention to improve self-esteem by increasing stigma awareness. Participants also received psychoeducation about stigma and myths and realities about mental illness. Aho-Mustonen and others (29) indirectly targeted self-stigma through improving self-esteem. Their intervention included education about schizophrenia and its

symptoms, epidemiology, and course of illness as well as stress and medication effects. Participants received homework that was based on cognitive-behavioral principles.

Finally, three studies used even more complex multimodal interventions. Fung and others (33) created an intervention that combined five intervention strategies, including psychoeducation, CBT, motivational interviewing, social skills training, and goal attainment. Lucksted and others (34) developed Ending Self-Stigma, a program that involved a combination of cognitive-behavioral exercises, discussion, sharing of experiences, group support, skills training, and problem solving. Adler and others (27) described the effectiveness of Battlemind debriefing and Battlemind training, a strategy that combines cognitive and skills-based approaches to educate returning military personnel about their postdeployment transition.

Measures

The articles reviewed used six different scales to measure changes in individuals' personal experience of stigma (Table 2). The PDD-LPSQ (20,21) was the most commonly used measure. Even though all six scales presented information on their psychometric properties (23), only three scales—the PDD-LPSQ, the Internalized Stigma of Mental Illness (ISMI) Scale, and the Self-Stigma of Mental Illness Scale (SSMIS)—were grounded by a conceptual framework.

Outcomes and effect sizes

Eight studies (25,27,30,32,34,35,38,39) reported a significant decrease post-intervention in self-stigma levels. Only two of the seven studies involving patients with schizophrenia or a psychotic disorder reported significant improvement postintervention (32,34). Effect sizes (Cohen's *d* [41]), were mostly small (.2) to medium (.5) (Table 2). Large effect sizes, 8.03 and .95, were reported by only two studies (32,38). If actual effect sizes (Cohen's *d*) were not reported, they were calculated by using the formula described by Thalheimer and Cook (42). Because most of these studies were randomized controlled trials with small sample sizes, effect sizes should be interpreted with caution.

Discussion

Our review identified six different strategies for intervention to decrease self-stigma related to mental illness. Interventions ranged from psychoeducation alone to psychoeducation combined with cognitive restructuring and more complex or multimodal interventions. Most interventions involved patients with schizophrenia and psychotic spectrum disorders or depression and gave little attention to stigma related to other psychiatric disorders. In addition, most of the studies reviewed were exploratory or pilot investigations with significant limitations, such as small sample size, lack of randomization, or no control group. Almost all studies reported only immediate postintervention outcomes and did not measure any follow-up outcomes to assess sustainability of the effect. None of the studies

controlled for mediating variables, such as level of symptoms, severity of illness, functional status, and changes in self-esteem, empowerment, or coping skills. Many of the studies were unique and not directly comparable, and none have been replicated.

Given that the development of self-stigma interventions research is in its nascent stages, such limitations are understandable. Even though these limitations preclude drawing firm conclusions, it is encouraging to find some promising interventions that merit further evaluation. The effect sizes provided in Table 2 may serve as a resource to test these interventions with more rigorous study designs and larger representative sample sizes.

Apart from these methodological limitations, our review identified several developmental issues in the emerging research that warrant careful scrutiny. To a large extent, the articles reviewed used different definitions of self-stigma, often alluding to multiple conceptualizations. Conceptual clarity in the definitions of stigma has been an issue for quite some time (2,43–45). In a recent review article, Livingston and Boyd (5) concluded, "Conceptual overlap is evident in leading definitions of internalized stigma. . . . Measurement overlap is apparent in several items and subscales that are contained within instruments that are designed to measure internalized stigma. . . . Perhaps the difficulty of compartmentalizing psychosocial variables into neat categories reflects the messy and entangled nature of people's lived experiences." Moreover, the term "self-stigma" is used interchangeably with "internalized stigma," "perceived stigma," "enacted stigma," "internal stigma," and "personal stigma." Clearly, a consensus on the definition and conceptualization of self-stigma and related terminology would benefit this field of research and could guide measurement.

Our review also found that the PDD was the scale used most commonly to measure self-stigma. However, some authors (25,29,36) expressed reservations about its appropriateness to detect changes in self-stigma levels. In our review, eight studies used this scale, and only two

recorded significant improvement in self-stigma outcomes (32,38). The PDD measures an individual's awareness of public attitudes, beliefs, and perceptions toward the stigmatized group (20). However, awareness of stereotypes itself is not sufficient to cause self-stigma. Accepting and applying these stereotypes are also necessary (4). The PDD does not detect changes in these two key constructs (acceptance and application). Further, an increased awareness of the public's stigmatizing views has been associated with the decreased likelihood that public stereotypes are perceived as legitimate (4). As such, decreasing perceived stigma (stereotype awareness) alone may not be an efficient approach to reduce self-stigma. The conceptualization of Watson and colleagues (4) may more comprehensively capture an individual's experience of self-stigma. The ISMI and SSMIS (46,47) likely represent the best measures to evaluate self-stigma. In our review, studies that measured self-stigma with the ISMI, the Self-Stigma of Seeking Help Scale, or the Depression Stigma Scale reported significant improvements more frequently (25,30,34,35,39). It is possible that these scales were more sensitive to change in self-stigma.

Another key issue that emerged from our review was the scarcity of a conceptual basis for self-stigma interventions. Only five articles (25,33,36–38) developed an intervention that was based on a conceptual model. Selecting and describing a conceptual framework that underpins an intervention allow one to understand the specific targets and promote anticipation of desired changes in the targeted construct. We recommend that in order to further systematic research that targets self-stigma, future studies should clearly identify and adopt a theoretical framework for self-stigma interventions. Early evidence from our review suggests that CBT techniques have the potential to combat self-stigma (33,34,38). In a recent article, Roe and others (48) reported positive outcomes of narrative-enhancement cognitive therapy among persons with severe mental illness. Participants showed improvements in six domains (experiential learning, positive change

Table 2

Intervention strategies targeting self-stigma among individuals with existing psychiatric illness or in high-risk groups

Strategy and author and year of study	Manual or protocol	Delivery format	Principal targets	Scale ^a	Effect size ^b	Significant improvement
Existing psychiatric illness						
Acceptance and commitment therapy						
Luoma et al., 2008 (25)	Yes	2 to 3 group sessions	Stigmatizing thoughts and behaviors	ISMI and PDD	.67 ^c ; .27 ^d	Yes
Psychoeducation (face to face)						
Link et al., 2002 (37) ^e	Yes	16 group sessions	Effects and consequences of stigma, sharing personal experiences	LPSQ	—	No
McCay et al., 2007 (36) ^e	Yes	12 group sessions	Illness experience, engulfment, and hope	LPSQ	—	No
Shin and Lukens, 2002 (32) ^e	Yes	10 group sessions	Cultural sensitivities, crisis management, communication, and stress management skills	PDD	8.03	Yes
Psychoeducation booklet or brochure						
Alvidrez et al., 2009 (31) ^f	Yes	1 individual session	Seeking treatment and engagement	PDD	.13	No
Hammer and Vogel, 2010 (39) ^f	Yes	1 individual session	Male sensitivities, illness and its epidemiology	SSOSH	.18	Yes
Psychoeducation (BluePages Web site) versus CBT (MoodGym Web site)						
Griffiths et al., 2004 (30) ^f	Yes	Five individual modules	Illness, symptoms, and treatment	DSS (personal and perceived stigma)	.11 (personal stigma) and 0 (perceived stigma) (BluePages); .10 (personal and perceived stigma) (MoodGym)	Yes
Psychoeducation with cognitive-behavioral therapy						
MacInnes and Lewis, 2008 (38)	No	6 group sessions	Stigmatizing beliefs, stress, and coping	PDD	.95	Yes
Knight et al., 2006 (28)	Yes	6 group sessions	Low self-esteem, stigma-myths, and reality	PDD	.01	No
Aho-Mustonen et al., 2011 (29) ^e	Yes	8 group sessions	Illness, symptoms, and epidemiology	LPSQ	.59	No
Multimodal strategies						
Fung et al., 2011(33) ^e	Yes	12 group and 4 individual sessions	Goal attainment and treatment adherence	CSSMI	.147	No
Lucksted et al., 2011 (34)	Yes	9 group sessions	Stigma myths and reality, community integration	ISMI	.57	Yes

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Table 2*Continued from previous page*

Strategy and author and year of study	Manual or protocol	Delivery format	Principal targets	Scale ^a	Effect size ^b	Significant improvement
High-risk group Counselor self-disclosure						
Wade et al., 2011 (35) ^{e,g}	No	One group session	Help seeking	SSOSH	.51	No
Battlemind training						
Adler et al., 2009 (27) ^f	Yes	23 group sessions	Postdeployment transition	Hoge Stigma Scale	.13	Yes

^a ISMI, Internalized Stigma of Mental Illness Scale; PDD, Perceived Devaluation and Discrimination Scale; LPSQ, Link's Perceived Stigma Questionnaire; SSOSH, Self-Stigma of Seeking Help Scale; DSS, Depression Stigma Scale; CSSMIS, Chinese Self-Stigma of Mental Illness Scale

^b If actual effect sizes (Cohen's *d*) were not reported, they were calculated by using the formula described by Thalheimer and Cook (42).

^c Effect size for ISMI

^d Effect size for PDD

^e The study was a randomized comparative effectiveness trial.

^f The study was a randomized controlled trial.

^g Group counseling itself had a significant positive effect on self-stigma levels.

in experience of self, acquiring cognitive skills, enhanced hope, improved coping, and emotional change). According to Watson and colleagues' social-cognitive model (4), internalization (acceptance and application) of awareness of stigmatizing stereotypes results in the "Why try?" effect, in which individuals question why they should even try treatment, given their belief that it won't work for people like them (49). The CBT interventions may be effective in changing these overgeneralizations. To increase cost-effectiveness, CBT-based antistigma initiatives could be incorporated into the CBT interventions routinely offered to patients with schizophrenia (50–54).

We identified two contrasting self-stigma reduction approaches: first, interventions that attempt to alter stigmatizing beliefs and attitudes, and second, interventions that encourage participants to accept the existence of stigmatizing stereotypes without challenging them and that enhance stigma-coping skills through improvements in self-esteem, empowerment, and help-seeking behavior. The latter approach seems to have gained traction among stigma experts (25,28,31,33,55). Although the approach needs further empirical exploration, it appears to have some theoretical support. In a recent review of self-stigma, Corrigan

and others (49) conceptualized self-stigma, empowerment, and self-esteem as part of a continuum: "Personal empowerment is a parallel positive phenomenon conceived as a mediator between self-stigma and behaviors related to goal attainment." Whereas empowerment anchored one end of a self-stigma continuum, self-esteem and self-efficacy anchored the other end (49).

Brohan and others (56) found a strong inverse relationship between empowerment and self-stigma. The authors opined that a focus on empowerment may result in self-stigma reduction. Knight and others (28) attempted to improve self-esteem outcomes by educating clients about stigma and myths and realities about mental illness. Their intervention did not try to alter stigma levels. Instead, the authors used education to increase awareness of and coping with stigma and self-esteem levels. These conceptual frameworks and the preliminary empirical evidence suggest that both self-esteem and empowerment could be independently targeted to reduce self-stigma.

Our review revealed a striking paucity of research on the reduction of self-stigma related to anxiety disorders, such as posttraumatic stress disorder. Individuals with these disorders experience not only the devastating effects of the

illness but also self-stigmatization (57,58). We recommend that future research target these disorders. Additionally, targeting high-risk groups to preempt self-stigma is a promising area for future research. Public stigma campaigns have employed a similar approach (59). Our review identified two studies that targeted high-risk groups (college students with psychological symptoms [35] and returning military personnel during postdeployment transition [27]). Further research could involve other high-risk groups, such as victims of natural disasters or other traumatic life events. Moreover, it would also be prudent to identify the best time to target such individuals with antistigma interventions. In our review, most studies did not indicate the duration of illness at the time of the intervention. Although it may seem logical that early intervention would be best, this expectation needs empirical validation.

Conclusions

We recommend that researchers evaluating self-stigma interventions pay greater attention to self-stigma conceptualization, measurement tools, and theoretical frameworks. An approach that involves cognitive restructuring merits further evaluation. Last, because we limited our review to articles

published in the English language, it is possible that we have missed self-stigma work done in other languages.

Acknowledgments and disclosures

This work was supported, in part, by grant IIR 08-086 to Dr. Sullivan from the Department of Veterans Affairs Office of Research and Development. Dr. Mittal was supported by the Veterans Integrated Service Network 16 Mental Illness Research and Education and Clinical Center, Central Arkansas Veterans Healthcare System, and the Center of Excellence for Mental Health Outcomes, both in Little Rock. The authors acknowledge Mary K. Bartnik, M.A., Shane Russell, B.A., Amanda Lunsford, M.A., and Valerie Shue, B.A., for help with the literature search and research and editorial assistance.

The authors report no competing interests.

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