

# The relationship between self-stigma and quality of life among people with mental illness who participated in a community program

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**Objective:** The aim of this study was to investigate the relationship between self-stigma and quality of life (QoL) in people with mental illness who participate in a community program. **Methods:** Using medical records, data including 28 people with mental illness who participated in a community program in 2014 were analyzed. All participants were classified into either a community program group (CG; n=17) or a non-community program group (NCG; n=11). The classification was based on when the participant engaged in the community program: The CG participated since January, 2014, while NCG participated since October, 2014. Scores for the Self-Stigma Scale-Short (SSS-S) and the WHO questionnaire on the Quality of Life, Brief Form (WHOQOL-BREF) measured in October, 2014 were converted into Rasch scores and analyzed. **Results:** SSS-S domain scores of Affect and Behavior for the CG were negatively correlated with all WHOQOL-BREF domain scores ( $r = -0.634$  to  $-0.741$ ,  $p < 0.01$ ). In contrast, the SSS-S Cognitive scores were not correlated to any WHOQOL-BREF domain score in either group. In addition, the SSS-S domain scores for Affect and Behavior in the NCG were negatively and moderately correlated with all WHOQOL-BREF domain scores ( $r = -0.438$  to  $-0.685$ ) although only the  $r$  between the SSS-S Behavior domain score and the WHOQOL-BREF Psychological domain score was significant. **Conclusions:** Cognitive self-stigma may not impact the QoL of patients with mental illness; however, affect and behavioral self-stigma are very likely to jeopardize their QoL. The effects of self-stigma on QoL were more obvious in the people who participated in the community program than in those in participants who did not. It is suggested that mental healthcare providers put additional effort into reducing self-stigma in people with mental illness. *Journal of Nature and Science*, 1(7):e135, 2015.

community program | mental illness | occupational therapy | self-stigma | quality of life

Self-stigma, one of the most painful stigmas with destructive effects [1], may negatively impact the treatment effects for people with mental illness. It is suggested that self-stigma contains three components, cognition, affect, and behavior, that respectively corresponding to stereotype, prejudice, and discrimination in public stigma [2, 3]. Moreover, both Mak and Cheung [4] and Corrigan and Watson [3] agreed that the development of self-stigma begins from cognition, followed by affect and behavior. Therefore, self-stigma could be the consequence of public stigma, and additionally impact patients' ability to positively confront their mental illness. For example, patients who self-stigmatize themselves are likely to feel embarrassed, guilty, and inferior as compared to their healthy counterparts [5,6], to internalize prejudice, stereotypes, and discrimination toward themselves [3,4], and to tend to lose their motivation to receive any medical and/or health care [7-9]. Therefore, these patients may experience worsening of their symptoms, which results in enormous social problems for a community. For these reasons, there is growing interest in detecting self-stigma in people with mental illness [10-12], and interventions are recommended to integrate both reducing self-stigma and controlling the symptoms of this illness [13,14].

In addition to reducing the treatment effects, many studies [e.g., 11,15,16] have found that self-stigma has substantial negative impacts on the quality of life (QoL) of patients. QoL contains

multidimensional underlying concepts (physical, psychological, social, and environment) and is useful to help healthcare providers acquire a holistic view of an individual's health condition [17,18]. Therefore, understanding the relationship between self-stigma and QoL may provide healthcare providers insights through which to foster effective intervention, e.g., they may want to pay additional attention to the component of the self-stigma that correlates with the QoL the most in order to design appropriate intervention programs.

The main intervention for self-stigma includes macro and micro aspects. The macro aspect focuses on public stigma and uses education, contact, and protest to reduce public stigma [19,20]. Through decreased public stigma, self-stigma may also decline [21-23]. While public stigma is based on societal factors and may be difficult to change [23], reducing self-stigma from the micro perspective could be a potential alternative. Therefore, a variety of programs have been designed for people with mental illness to help them deal with their self-stigma. For examples, effects of cognitive-behavioral therapy (CBT) [24,25], psychoeducation [26,27], and programs combined using CBT and psychoeducation [14,28] on self-stigma reduction have been found.

However, to the best of our knowledge, no studies have examined the effects of occupational therapy, a commonly used rehabilitation program, with regard to its effects on people with mental illness [29] as it relates to reducing self-stigma. Because occupational therapy uses different programs that integrate with a community to help people with mental illness build up their self-esteem and levels of achievement, we hypothesized that occupational therapy might reduce self-stigma. Specifically, occupational therapy helps people with mental illness gain contact with the community and induces interaction with the residents of these communities, and *vice versa*. Through successful contact with the community, both community residents and people with mental illness can begin to acknowledge that mental illness is not a threat, which may reduce the self-stigma characteristics of people with mental illness. Therefore, we suggested that occupational therapy should also be considered when helping patients reduce their self-stigma. Moreover, the relationship between self-stigma and QoL is not clear in patients with mental illness who receive occupational therapy. Therefore, there is a need to further investigate the above issues.

This study had two purposes: (1) to examine the intervention effect of one community service program designed by occupational therapists (OTs) on the self-stigma of people with mental illness; (2) to investigate the associations between self-stigma and QoL in people engaged in the program and those not in the program, respectively.

## Methods

The study was approved by the Hospital Ethics Committee of the Jianan Psychiatric Center, and all data were retrieved from medical records.

Conflict of interest: No conflicts declared.

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**Table 1.** Participants' characteristics, SSS-S and WHOQOL-BREF scores

	CG (n=17)		NCG (n=11)		<i>t</i>	<i>p</i>
	Mean or (n)	SD or (%)	Mean or (n)	SD or (%)		
Participants' characteristics						
Age (year)	41.53	10.56	37.37	11.97	0.968	0.342
Onset age (year)	23.35	8.14	20.36	5.63	1.062	0.298
Gender (male)	(13)	(76.5%)	(9)	(81.8%)	-- <sup>a</sup>	1.00 <sup>a</sup>
Education (≤junior high)	(5)	(29.4%)	(3)	(27.3%)	-- <sup>a</sup>	1.00 <sup>a</sup>
Diagnosis					-- <sup>a</sup>	1.00 <sup>a</sup>
Organic mental disorder	(2)	(11.8%)	(1)	(9.1%)		
Bipolar disorder	(1)	(5.9%)	(0)	(0.0%)		
Schizophrenia	(14)	(82.3%)	(10)	(90.9%)		
SSS-S						
Cognition (logit)	-2.41	2.68	-1.47	2.23	0.959	0.346
Affect (logit)	-1.52	4.24	-2.07	4.58	0.328	0.746
Behavior (logit)	-1.25	2.54	-1.68	2.81	0.422	0.677
WHOQOL-BREF						
Physical (logit)	0.51	1.63	0.71	1.28	0.341	0.736
Psychological (logit)	0.67	1.72	0.43	1.18	0.407	0.687
Social (logit)	1.26	2.84	0.85	1.28	0.519	0.609
Environment (logit)	0.60	1.76	0.69	1.00	0.173	0.864

SSS-S: Self-Stigma Scale-Short; WHOQOL-BREF: The WHO questionnaire on the Quality of Life, Brief Form; CG: community program group; NCG: non-community program group. <sup>a</sup>Tests using Fisher's Exact Test.

**Community service program.** A program aimed to benefit and help the community was designed by several OTs, and the program also increased social participation for participants with mental illness. Although it was designed by OTs, the program was led by the participants themselves, and all the participants were empowered. The community services included cleaning the community and the city (e.g., parks, beaches, and campuses) and accompanying elderly community members. The frequency of the community service was once per week with each time around 60 minutes. After the community service, the participants had a meeting that included feedback and member support. In addition, all members assembled at the beginning of each month to discuss the community service planned for the month. Afterward, each participant worked on his/her assigned preparations for the community service. Through the program, participants are able to interact well with the community, can become prepared for change, and can gain confidence, which might help them to reduce self-stigma.

**Participants.** Data for 28 participants who engaged in the community program during the calendar year of 2014 were retrieved; however, 11 of them participated after October, 2014. Therefore, we classified the participants as community program group (CG; n=17) and non-community program group (NCG; n=11) for the following analyses. Because our primary outcome measures (i.e., self-stigma and QoL) were examined in October, it was reasonable to assign the patients who participated in the program after October as the non-community program group. Moreover, both self-stigma data and QoL were collected once in October, and the CG was used for the post-intervention tests, while the NCG was used for the pre-intervention test. The characteristics of the two groups are summarized in Table 1. In addition, all participants had a Disability Card and a Catastrophic Illness Card.

**Self-Stigma Scale-Short (SSS-S).** The SSS-S was originally developed in Hong Kong [4] with only 9 items, and it was recently used in Taiwan. Although Hong Kong and Taiwan share almost the same characters in their written language, the items in the SSS-S have been worded and validated in a Taiwanese sample, and its psychometric properties were found to be satisfactory [30]. A 4-point Likert scale is used for the SSS-S, and each item is scored from 1 (=the lowest level of self-stigma) to 4 (=the highest level of self-stigma). In addition, the SSS-S has three domains: Cognition, Affect, and Behavior.

**The WHO questionnaire on the Quality of Life, Brief Form (WHOQOL-BREF).** The WHOQOL-BREF developed by the WHO [31] originally contained 26 items, and 2 additional items (viz., "eat" and "respect") were added in the Taiwan version [32,33]. The

current study used the WHOQOL-BREF Taiwan version, which has been evidenced to be reliable and valid across many different populations (e.g., heroin-dependent patients [34] and patients with schizophrenia [35]). A 5-point Likert scale is used for the WHOQOL-BREF, and each item is scored from 1 (=the worse condition) to 5 (=the best condition) in addition to 3 reversely coded items (viz., "Pain and discomfort," "Medication," and "Negative feelings"). Hence, higher scores represent better QoL. In addition, the WHOQOL-BREF includes four domains: Physical, Psychological, Social, and Environment.

**Data analysis.** Both SSS-S and WHOQOL-BREF scores were converted from a Likert scale into a continuous Rasch score [36,37] for all the following analyses; SSS-S and WHOQOL-BREF scores hereafter mean the converted Rasch scores. In brief, the Rasch score uses a *logit* unit, which means a continuously underlying self-stigma and/or QoL level of a person persists. A Rasch score of 0 on self-stigma/QoL means the person's self-stigma/QoL level makes up 50% of the population; a Rasch score of 1 and -1 means the subject's self-stigma/QoL level are 33% and 67% of the population, respectively. The differences in participant characteristics and those of the SSS-S and WHOQOL-BREF scores between the two groups were analyzed using independent *t* tests. In addition, a Cohen's *d* was calculated as the mean difference between the two groups ([SSS-S or WHOQOL-BREF domain scores of CG] - [SSS-S or WHOQOL-BREF domain scores of NCG]) divided by their mean standard deviation [38,39]. A negative *d* value indicates that the CG had lower score than did the NCG, and a  $|d| > 0.2$  suggests substantial differences between the two groups [40,41]. The relationship between the SSS-S score and WHOQOL-BREF score was analyzed using Pearson correlation coefficients for the two groups, respectively, and an  $|r| > 0.3$  suggests moderate effect [42]. With the exception that the conversion was transformed using Winsteps software [43], and *d* was calculated using Microsoft EXCEL 2011, all other analyses were done using SPSS software, version 17.0 (SPSS Inc., Chicago, IL).

## Results

The mean (SD) age was 41.53 (10.56) years for the CG and 37.37 (11.97) years for the NCG, and the onset age was 23.35 (8.14) years for the CG and 20.36 (5.63) years for the NCG. In addition, most CG and NCG participants were male ( $n = 13$  [76.5%] and 9 [81.8%], respectively), had an educational level higher than junior high ( $n = 12$  [70.6%] for the CG and 8 [72.7%] for the NCG), and had a diagnosis of schizophrenia ( $n = 14$  [82.3%] for the CG and 10 [90.9%] for the NCG). No significant differences were found in all the above demographics.

**Table 2.** Correlation between SSS-S domain scores and WHOQOL-BREF scores stratified by whether participating in the community program

SSS-S domain score	WHOQOL-BREF domain score			
	Physical	Psychological	Social	Environment
CG (n=17)				
Cognition	0.004	-0.165	-0.036	-0.041
Affect	-0.693**	-0.760**	-0.699**	-0.703**
Behavior	-0.634**	-0.704**	-0.741**	-0.655**
NCG (n=11)				
Cognition	0.030	0.064	0.203	0.088
Affect	-0.507	-0.644	-0.438	-0.526
Behavior	-0.513	-0.685*	-0.484	-0.592

SSS-S: Self-Stigma Scale-Short; WHOQOL-BREF: The WHO questionnaire on the Quality of Life, Brief Form; CG: community program group; NCG: non-community program group. \* $p < 0.05$ ; \*\* $p < 0.01$

The mean (SD) Rasch scores for the SSS-S were -2.41 (2.68) for Cognition in the CG and -1.47 (2.23) in the NCG, -1.52 (4.24) for Affect in the CG and -2.07 (4.58) in the NCG, and -1.25 (2.54) in the CG and -1.68 (2.81) in the NCG. In addition, the mean (SD) Rasch scores for the WHOQOL-BREF were 0.51 (1.63) for Physical in the CG and 0.71 (1.28) in the NCG, 0.67 (1.72) for Psychological in the CG and 0.43 (1.18) in the NCG, 1.26 (2.84) for Social in the CG and 0.85 (1.28) in the NCG, and 0.60 (1.76) for Environment in the CG and 0.69 (1.00) in the NCG. However, no significant differences were found in the SSS-S and WHOQOL-BREF scores between the two groups. In addition, except for the fact that the SSS-S Cognition domain score had substantial difference between the two groups ( $d = -0.38$ ), the  $|d|$  for all other domain scores in the SSS-S and WHOQOL-BREF were small (0.13-0.18), respectively.

Negatively and moderately significant correlations were found between the SSS-S Affect and Behavior domain scores and all WHOQOL-BREF domain scores ( $r = -0.634$  to  $-0.741$ ,  $p < 0.01$ ) in the CG, while no significant correlations were found between the SSS-S Cognition domain score and all of the WHOQOL-BREF domain scores. As for the NCG, only one significant correlation was found (SSS-S Behavior domain score and WHOQOL-BREF Psychological domain score). Although no other significant correlations between the SSS-S Affect and Behavior scores and the WHOQOL-BREF domain scores were found, their effects were moderate (Table 2).

## Discussion

In this study, the effects of a community service program designed by OTs on the self-stigma reduction of people with mental illness were examined. Although no significant effects were found, our results still shed some light on how to foster an intervention program on self-stigma reduction for people with mental illness for healthcare providers. Moreover, we also demonstrated a negative relationship between self-stigma and QoL in people with mental illness who participated in the community program under consideration.

Only the self-stigma Cognition domain exhibited a substantial difference between the two groups, and the CG group had lower self-stigma as compared with its NCG counterparts. All other domains of self-stigma and all domains of QoL were not different between the two groups, and we proposed potential reasons as follows: First, cognition is suggested to be the first developed self-stigma among the three components (i.e., cognition, affect, and behavior), and it seems to be reasonable to be declined earlier than affect and behavior when the patient receives an intervention [3,4]. Moreover, QoL is impacted by self-stigma [11,15,16], and the effects of intervention on QoL are very likely to be slower than those on self-stigma. That is, the effects of the community program may occur only in the beginning as the intervention effects were only detected for the very first area (i.e., self-stigma in cognition). Therefore, engagement in a one-year program may not be enough for such patients, and a longer period is warranted. Second, the intensity of the program may be insufficient. The treatment effects were diminished because the frequency of the program was low

(once to twice per week), and the engagement of each patient was not persistent (patients were allowed to freely drop any service). In addition, the self-stigma and QoL were measured in October, while the community program aimed to last for a whole year; thus the magnitude of the community program on the CG participants may be insufficient.

Third, the research design of our study may have influenced the outcomes. Because we only measured post-intervention tests for the CG and pre-intervention tests for the NCG, the baseline scores for the SSS-S and WHOQOL-BREF were not assessed (i.e., the scores in January, 2014). In addition, we were unable to ensure that both groups had the same scores at the beginning of the program. Therefore, the nonsignificant results may be due to unadjusted baseline scores. Fourth, potential confounders such as medication, depression, social support, mental state, employment status, self-esteem, and treatment adherence [e.g., 44-46], were not controlled in this study. As a result, the effects of our program may be diminished because of the lack of controlling confounders. Finally, the sample size of this study was small, which may have resulted in little power by which to detect any significant difference.

The association between self-stigma and QoL was in our expectations and corresponded to previous studies [11,15,16]. In addition, our findings suggested that the CG had a stronger relationship between self-stigma and QoL than did the NCG. A possible cause is that the two groups had different levels of insight. When people with mental illness have good insight, they are prone to have low QoL [47] and high levels of self-stigma [48]. Moreover, it is reasonable to assume that those who were engaged in the program had better insight than did those who did not participate in the program. As a result, a much more clear relationship between self-stigma and QoL was found in the CG patients than in the NCG patients. Nonetheless, healthcare providers should put additional effort toward reducing self-stigma in patients with mental illness to improve their QoL based on our results indicating a negative relationship between self-stigma and QoL.

The study has some limitations. First, although the community program persisted up to one year, and its effect on self-stigma and QoL could be causal, self-stigma and QoL were measured at the same time, and their relationship was cross-sectional. A longitudinal study for self-stigma and QoL may help us to further understand the causal relationship between self-stigma and QoL. Second, we did not have the baseline data for the two groups, and thus, the comparisons of the SSS-S and WHOQOL-BREF scores may be biased because we were unable to adjust for their baseline scores. Third, the participants were not randomly selected, which limits the generalizability of our study to the entire population. Fourth, the study sample size of this study was relatively small, and future studies using a large sample size are warranted.

In conclusion, a community service program could be a potential intervention for healthcare providers to reduce self-stigma in patients with mental illness. However, the program should persist long enough to achieve intervention effects, and potential confounders should also be considered when designing such a program. Moreover, the self-stigma reduction may also be beneficial for improving the QoL of people with mental illness.

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