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Long-term effect of a name change for schizophrenia on reducing stigma

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Abstract

Background   A name change for schizophrenia was first implemented in Japan for reducing stigma in 2002; however, little is known of its long-term impact.

Methods   Total 259 students from 20 universities answered an anonymous self-administered questionnaire about their mental health-related experiences, and stigma scales including feasible knowledge and negative stereotypes for four specific diseases, including schizophrenia (old and new names), depression, and diabetes mellitus. We also asked to choose the old and new names of schizophrenia and dementia among ten names for mental and physical illnesses and conditions.

Results   The participants had more feasible knowledge and fewer negative stereotypes for the new name of schizophrenia than the old name, but were still significantly worse than for depression and diabetes mellitus ($p < 0.01$). Direct contact experiences with those who have mental health problems were associated with feasible knowledge for schizophrenia but not negative stereotypes ($\beta = 0.13$, $p = 0.020$). The rate of correct responses for the old and new names of schizophrenia was significantly lower than that of dementia (41 vs. 87 %, $p < 0.001$). Mental health-related experience from media was associated with the recognition of name change for schizophrenia ($p = 0.008$), which was associated with less feasible knowledge for new name of schizophrenia.

Discussion   The name change of schizophrenia has reduced stigma since 12 years have passed. More effective campaigns, educational curricula, and policy making are needed to reduce stigma toward schizophrenia.

Keywords   Stigma · Schizophrenia · Stereotyping · Name change · Terminology

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Introduction

A number of studies have indicated that around 20 % of the population experience mental illnesses in their lives [1, 2], and for three-fourths of all mental illnesses, the onset occurs by the age of 24 [1, 2]. However, public stigma toward mental illness is still persistent and considerably reduces help-seeking intentions and mental health service utilization among young people, and the negative attitudes for

treatment and recovery in people with mental illness and their family members [3–6].

A lack of knowledge about mental illness is associated with stereotyped beliefs and negative attitudes toward mental illness, which contribute to actual discriminatory behavior [7]. The experience of social contact with those who have mental health problems and well-qualified mental health lectures appear to reduce stigmatizing beliefs [8–10]. Since recent clinical strategies for mental illness place more emphasis on a positive view of personal recovery [11, 12], a recent review proposed that mental health-related knowledge can be divided into positive and evidence-based aspect (feasible knowledge), and negative and stereotyped aspect (negative stereotypes) [13]. One study showed that feasible knowledge was associated with the intention to seek help and disclose, but negative stereotypes was not [14].

Changing the name of a mental illness is another effective strategy to reduce stigma. In Japan, the name of schizophrenia was changed in 2002 for the purposes of stigma reduction, from "Seishin-Bunretsu-Byo" (mind-split disease) to "Togo-Shitcho-Sho" (integration disorder) [15]. Although the new name, "Togo-Shitcho-Sho" (integration disorder), may not fully reflect the present symptomatic and biological basis of the disorder [16], several studies have reported that the name change effects on reducing stigma because of leading to realistic optimism of patients and their family members [15, 17–20]. This pioneering approach led to a name change for dementia in Japan, from "Chiho" (idiocy and stupidity) to "Ninchisho" (cognition disorder) in 2004. Today, the movement to change the name of schizophrenia has spread to other Asian countries [21, 22], and several new names have been proposed for "schizophrenia" [23–25]. However, the long-term effect on the name change has yet to be investigated. Our preliminary survey showed that 58 % of university students, who were approximately 12 years old at the time of the name change, knew the new name of schizophrenia whereas only 42 % knew the old name [18]. Interestingly, some reported that they were not aware that the old and new names of schizophrenia referred to the same condition, although they had heard of both names [18]. These results suggest that young people understand the old and new names of schizophrenia as different conditions, and that the effect of name change may differ between the short and long terms. However, there has been no study that investigates the long-term effect of name change for schizophrenia in general young adults [19].

The current study investigated whether the name change for schizophrenia would be associated with more feasible knowledge and less negative stereotypes in young adults, who experienced the name change when they were 8 years old. We also investigated whether the recognition of name change was associated with mental health-related experiences and knowledge toward schizophrenia.

Methods

Participants

A total of 259 undergraduate and graduate students from 20 colleges and universities in Tokyo participated in this study (male = 150, mean age 20.0, SD 1.2; Table 1). The survey was conducted between November 2013 and July 2014. Participants were recruited via an authorized job recruitment board or internet site at each college or university, without providing any information about the mental health survey. Exclusion criteria were not having graduated from junior high school and high school in Japan and not planning to be a student in Japan 1 year later, as these data were derived from a baseline survey in a randomized controlled trial for 1 year (trial number: UMIN000012239). For avoiding the influence of experiences of specialized lectures from the survey, those registered in year 3 or higher in the department of medicine or psychology at the time of entry were also excluded into the study. This study was approved by the Research Ethics Committee at the Office for Life Science Research Ethics and Safety, the University of Tokyo (approval No. 13-104 and 13-142), and all participants gave written informed consent after a full explanation of this study.

Measurements

Participants answered an anonymous self-administered questionnaire in a room in a university, which took 20 min to complete. The questionnaire consisted of socio-demographic variables, mental health-related experiences (their own mental health problem, direct contact with those who have mental health problems, lectures, and media), and two types of knowledge (feasible knowledge and negative stereotypes) for four specific diseases, including schizophrenia (old and new names), depression, and diabetes mellitus (DM). We also asked participants to select the old and new names of schizophrenia and dementia from among ten names for mental and physical illnesses and conditions.

Mental health-related experiences

The questionnaire contained six dichotomous questions regarding participants' mental health-related experiences. These included one question each regarding their own experiences of mental health problems ("Have you ever had any mental health problem yourself?"), their

Table 1 Demographic characteristics for the study participants

	Total ($n = 259$) Mean (SD)	Male ($n = 150$) Mean (SD)	Female ($n = 109$) Mean (SD)	Gender difference[a] p value
Age at survey, years	20.0 (1.2)	20.0 (1.2)	20.0 (1.3)	0.85
Mental health-related experiences				
Their own mental health problems, % (n)	16 % (41)	13 % (20)	19 % (21)	0.20
Direct contact, % (n)	37 % (96)	29 % (44)	48 % (52)	0.003
Lectures, % (n)	50 % (129)	45 % (68)	56 % (61)	0.091
Media, % (n)	84 % (218)	86 % (129)	82 % (89)	0.34
MIDUS-SR				
Old name of schizophrenia	6.4 (2.9)	6.6 (2.9)	6.2 (2.7)	0.34
New name of schizophrenia	5.2 (2.4)	5.3 (2.6)	5.1 (2.1)	0.50
Depression	3.4 (2.2)	3.5 (2.2)	3.3 (2.1)	0.33
DM	2.1 (2.1)	1.9 (1.9)	2.3 (2.3)	0.087
OS				
Old name of schizophrenia	19.1 (3.9)	18.7 (3.7)	20.0 (4.2)	0.057
New name of schizophrenia	**19.8 (3.3)**	**19.4 (3.1)**	**20.3 (3.6)**	**0.029**
Depression	22.2 (3.7)	22.3 (3.9)	22.0 (3.3)	0.53
DM	27.7 (3.4)	27.7 (3.5)	27.7 (3.3)	0.93
Correct rate for schizophrenia, % (n)	41 % (154)	43 % (65)	37 % (40)	0.28
Correct rate for dementia, % (n)	87 % (226)	87 % (130)	88 % (96)	0.74

Bold values indicate significant gender difference ($p < 0.05$)

MIDUS-SR Social Recognition of Illness subscale of the Mental Illness and Disorder Understanding Scale, *DM* diabetes mellitus, *OS* the omnibus survey, *SDSJ* the Japanese version of Social Distance Scale

[a] Gender differences were tested using t test for continuous variables and using Chi-square test for categorical variables

experiences of lectures ("Have you ever taken any lecture or course related to mental health?"), and their experiences through the media ("Have you ever watched a television program or read an article in the newspaper or on the internet about those who have mental health problems?"). The participants also answered three questions about their direct contact with those who have mental health problems ("Are you currently living with, or have you ever lived with, someone with a mental health problem?", "Do you currently have, or have you ever had, a neighbor with a mental health problem?", and "Do you currently have, or have you ever had, a close friend with a mental health problem?"). Participants who had one or more experiences were defined as having direct contact experience.

Feasible knowledge

For feasible knowledge, participants were asked four questions from the Mental Illness and Disorder Understanding Scale (MIDUS) [26]. The original MIDUS was made and validated in Japanese, and consists of 15 items rated on a 5-point Likert scale (range 0–60, a lower score representing more knowledge). The factor analysis revealed three factors in the MIDUS: Treatability of illness (e.g., "mental illness is treatable"), efficacy of medication (e.g., "medication is

effective in improving symptoms"), and social recognition of illness (e.g., "mental illnesses are very common"); all of which ask about positive and feasible knowledge for mental illness [26]. In this study, the MIDUS social recognition of illness subscale (MIDUS-SR, four items, range 0–16) was used for four specific disease names [old and new names of schizophrenia, depression, and diabetes mellitus (DM); e.g., "Togo-Shitcho-Sho is very common"].

Negative stereotypes

The Office for National Statistics in the UK carried out the Omnibus Survey (OS) as part of the mental illness and addiction stigma campaign conducted by the Royal College of Psychiatrists between 1998 and 2003 [27]. In this survey, participants responded to the questionnaire consisting of 8 items rated on a 5-point Likert scale (range 8–40, a higher score representing less stereotypes) regarding negative and stereotyped knowledge for the specific conditions (e.g., "patients with schizophrenia are a danger to others"). In this study, we applied the questions for four specific disease names. The reliability and validity of the scale were originally ascertained for the study (Supplementary materials), and we used 7-item version of the OS scale for each disease (range 7–35) to further analysis.

Recognition of old and new names as the same condition

We asked the participants to identify the old and new names of schizophrenia and dementia ("Seishin-Bunretsu-Byo" and "Togo-Shitcho-Sho", and "Chiho" and "Ninchi-sho") from among ten names for mental and physical illnesses and conditions (bipolar disorder, depression, mental retardation, diabetes mellitus, hyperprolactinemia, and hypertension). The two correct answers were the accurate new and old name pairs for schizophrenia and dementia.

Statistical analysis

We employed a one-way repeated measures analysis of variance (ANOVA) using Name as the within-subjects factor (schizophrenia old/schizophrenia new/depression/DM) for MIDUS-SR and OS. Multiple regression analyses were performed using knowledge (MIDUS-SR or OS scores) for the new name of schizophrenia as a dependent variable and each experience as independent variables. The difference in demographic characteristics between participants who correctly and incorrectly answered the pair for schizophrenia was tested using t test. Then, we employed a two-way repeated measures ANOVA using Name as the within-subjects factor (schizophrenia old/schizophrenia new) and Answer as the between-subjects factor (correct/incorrect responses for schizophrenia). All analyses were carried out using SPSS 20.0J (IBM Inc., New York, USA).

Results

The socio-demographic characteristics of the study sample are shown in Table 1. Female participants had more direct contact experience (48 vs. 29 %, $p = 0.003$), and fewer negative stereotypes (OS) toward the new name of schizophrenia than male participants (mean ± SD 19.4 ± 3.1 vs. 20.3 ± 3.6, $p = 0.029$). Older participants had more experience through the media (mean age 20.1 ± 1.2 vs. 19.6 ± 1.0, $p = 0.034$), and more feasible knowledge (MIDUS-SR) for the new name of schizophrenia and for depression than younger participants (schizophrenia new: $r = -0.13$, $p = 0.045$; depression: $r = -0.13$, $p = 0.036$).

Effect of the name change for schizophrenia

A one-way repeated measures ANOVA for MIDUS-SR showed a significant main effect for name ($F = 2.9 \times 10^2$, $p < 0.001$). Post hoc Tukey tests showed significant differences between all pairs (all $p < 0.001$; Fig. 1). For OS,
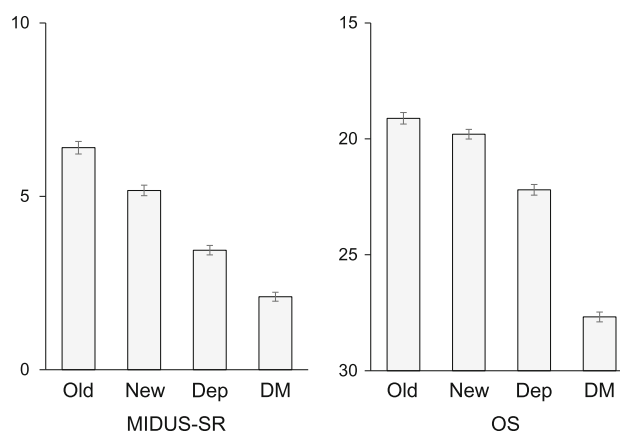
Fig. 1 The differences of stigma among four specific diseases. The two graphs illustrate the differences in feasible knowledge (MIDUS-SR) and negative stereotypes (OS) among four diseases. The reverse axis is applied for the OS to show that the *lower bar* is the smaller stigma. Post hoc Tukey tests for the name showed significant differences in all pairs ($p < 0.001$ for all pairs except in negative stereotype between the old and new names of schizophrenia, $p = 0.003$). *Old* old name of schizophrenia, *New* new name of schizophrenia, *Dep* depression, *DM* diabetes mellitus

there was also a significant main effect for Name ($F = 3.1 \times 10^2$, $p < 0.001$). Post hoc Tukey tests showed significant differences between all pairs (all $p < 0.001$ except for $p = 0.003$ between old and new names of schizophrenia; Fig. 1). This means that the participants had more feasible knowledge and fewer negative stereotypes for new name of schizophrenia than the old name, but still worse than those for depression and DM.

Univariate regression analyses showed that three experiences of their own mental health problems, direct contact with people with a mental illness, and lecture attendance were associated with MIDUS-SR scores for the new name of schizophrenia (own experience: $\beta = 0.14$, $t = 2.3$, $p = 0.021$; direct contact: $\beta = 0.15$, $t = 2.4$, $p = 0.017$; lectures: $\beta = 0.17$, $t = 2.7$, $p = 0.008$; Table 2). After adjusting for all confounding variables, direct contact experience was associated with feasible knowledge ($\beta = 0.13$, $t = 2.3$, $p = 0.020$; Table 2). However, there was no significant association between experience and negative stereotypes ($p > 0.05$) (Table 2).

Recognition of name change for schizophrenia

The rate of correct responses for the old and new names for schizophrenia was significantly lower than that of dementia (41 vs. 87 %, McNemar $\chi^2 = 1.0 \times 10^2$, $p < 0.001$; Table 1). The respondents who correctly selected the old and new names of schizophrenia had more experience through the media than incorrect respondents (91 vs. 79 %, $p = 0.008$; Table 3). The correct respondents for dementia

Table 2 Multiple regression analysis for knowledge with past experiences

Dependent variables[a]	Independent variables	Crude model			Adjusted model 1[b]			Adjusted model 2[c]			Adjusted model 3[d]		
		β	t	p	β	t	p	β	t	p	β	t	p
Evidence-based knowledge	Own experiences	**0.14**	**2.3**	**0.021**	**0.13**	**2.0**	**0.044**	0.084	1.3	0.20	0.048	0.84	0.40
	Direct contact	**0.15**	**2.4**	**0.017**	**0.14**	**2.2**	**0.029**	0.11	1.6	0.10	**0.13**	**2.3**	**0.020**
	Lectures	**0.17**	**2.7**	**0.008**	**0.16**	**2.5**	**0.012**	**0.14**	**2.1**	**0.036**	0.11	1.8	0.067
	Media	0.044	0.70	0.48	0.030	0.47	0.64	−0.033	−0.51	0.61	−0.007	−0.13	0.90
Negative stereotype	Own experiences	−0.73	−1.3	0.20	−0.65	−1.2	0.25	−0.73	−1.2	0.22	−0.38	−0.72	0.47
	Direct contact	−0.05	−0.11	0.91	−0.23	−0.53	0.59	−0.33	−0.74	0.46	−0.67	−1.7	0.098
	Lectures	−0.43	−1.0	0.30	−0.34	−0.82	0.41	−0.43	−0.97	0.33	0.00	−0.01	0.99
	Media	0.59	1.0	0.30	0.52	0.90	0.37	0.69	1.2	0.25	0.55	1.0	0.31

Bold values indicate significant gender difference ($p < 0.05$)

[a] The MIDUS-SR for new name of schizophrenia was used as evidence-based knowledge and OS as negative stereotype

[b] Adjusted by age and sex

[c] Adjusted by age, sex, and remained three experiences (rest of own experiences, direct contact, lectures, and media)

[d] Adjusted by age, sex, and remained three experiences, and remained knowledge score (OS or MIDUS-SR)

Table 3 Difference between participants who correctly and incorrectly answered the pair for schizophrenia

	Total ($n = 259$) Mean (SD)	Correct ($n = 105$) Mean (SD)	Incorrect ($n = 154$) Mean (SD)	Group difference[a] p value
Age at survey, years	20.0 (1.2)	20.1 (1.3)	19.9 (1.2)	0.27
Mental health-related experiences				
Their own mental health problems, % (n)	16 % (41)	16 % (17)	16 % (24)	0.90
Direct contact, % (n)	37 % (96)	59 % (62)	48 % (52)	0.29
Lectures, % (n)	50 % (129)	53 % (56)	66 % (101)	0.35
Media, % (n)	**84 % (218)**	**91 % (96)**	**79 % (122)**	**0.008**
MIDUS-SR				
Old name of schizophrenia	6.4 (2.9)	6.0 (3.0)	6.7 (2.7)	0.074
New name of schizophrenia	5.2 (2.4)	5.4 (2.5)	5.0 (2.4)	0.21
Depression	3.4 (2.2)	3.6 (2.3)	3.3 (2.1)	0.30
DM	2.1 (2.1)	2.0 (1.8)	2.1 (2.2)	0.727
OS				
Old name of schizophrenia	19.1 (3.9)	19.0 (4.2)	19.2 (3.6)	0.71
New name of schizophrenia	19.8 (3.3)	19.9 (3.3)	19.6 (3.4)	0.43
Depression	22.2 (3.7)	22.0 (3.9)	22.5 (3.4)	0.32
DM	27.7 (3.4)	27.6 (3.4)	27.9 (3.3)	0.41

Bold values indicate significant group difference ($p < 0.05$)

MIDUS-SR Social Recognition of Illness subscale of the Mental Illness and Disorder Understanding Scale, *DM* diabetes mellitus, *OS* the omnibus survey

[a] Group differences were tested using t test for continuous variables and using Chi-square test for categorical variables

were older than the incorrect respondents (20.1 ± 1.2 vs. 19.6 ± 0.9, $p = 0.041$).

A two-way repeated measures ANOVA for feasible knowledge showed a significant main effect for Name ($F = 75$, $p < 0.001$) and a significant Name × Answer interaction ($F = 16$, $p < 0.001$), but no significant main effect for Answer ($F = 0.16$, $p = 0.69$; Fig. 2). This means that those who correctly responded the pair of schizophrenia had more similar MIDUS-SR scores for old and new names of schizophrenia than those who incorrectly responded (Fig. 2). With respect to negative stereotypes (OS), there was a significant main effect for Name
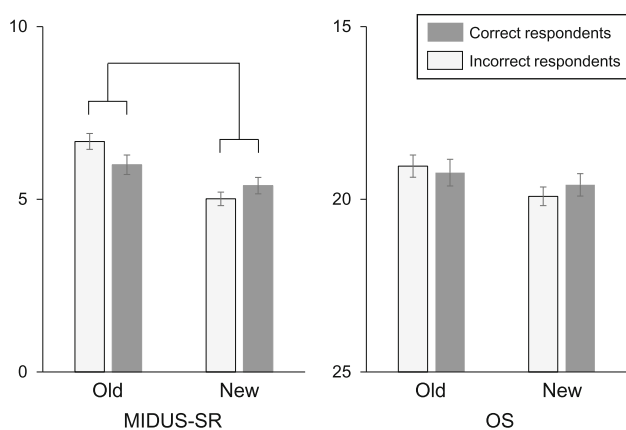
Fig. 2 The differences of stigma by the recognition of name change for schizophrenia. The two graphs illustrate the differences in feasible knowledge (MIDUS-SR) and negative stereotypes (OS) for the old and new names of schizophrenia among respondents who correctly or incorrectly paired these names. The reverse axis is applied for the OS to show that the *lower bar* is the smaller stigma. A two-way repeated measures ANOVA for MIDUS-SR showed that those who correctly responded the pair of schizophrenia had more similar scores for old and new names of schizophrenia than those who incorrectly responded. *Old* old name of schizophrenia, *New* new name of schizophrenia

($F = 10.0$, $p = 0.002$), but no significant main effect for Answer ($F = 0.029$, $p = 0.86$), nor a significant name × answer interaction ($F = 1.8$, $p = 0.18$).

Discussion

The present study investigated whether the name change for schizophrenia had improved stigma (feasible knowledge and negative stereotypes) in 259 general students from 20 universities and colleges. The participants had more feasible knowledge and fewer negative stereotypes for new name of schizophrenia than the old name, but still worse than those for depression and DM. Mental health-related experiences were associated only with feasible knowledge for schizophrenia but not with negative stereotypes. Only 41 % of participants recognized the old and new names of schizophrenia as the same condition, while 87 % were aware of the name change for dementia. The recognition of name change for schizophrenia was associated with mental health-related experiences from media and could effect on less feasible knowledge for new name of schizophrenia. To the best of our knowledge, this is the first study to explore the 12-year impact of name change for schizophrenia on stigma in general young adults.

The findings suggest that the name change reduces stigma toward schizophrenia, similar to the results of previous studies [15, 17–20]. However, the results also suggest

that new name of schizophrenia is still highly stigmatized compared to depression and DM among young adults. One reason is that the public image for old name of schizophrenia (mind-split disease) could be a stigmatizing term itself even whether they recognize the name and the condition of schizophrenia or not. Second, the official educational curricula in Japanese schools had not included mental health issues until only recently, and even today only cover mental health in general, without mentioning any specific psychiatric diseases [28]. As such, students tend to have little awareness of mental health and lose opportunity of appropriate care when they encounter a mental health problem [6, 29]. Third, major depression has become a greater issue of concern as the number of people who received treatment has increased 2.4-folded from 1999 to 2008 in Japan [30]. Therefore, television and newspapers have still covered schizophrenia fewer than these illnesses. Fourth, media reports have a tendency to link schizophrenia to negative impacts, such as criminal acts, dangerous behavior, and bizarre cases [31], which would be expected to strengthen negative stereotypes [31]. This is in line with our results that experience through the media had little positive effect on stigma reduction, even in unadjusted analyses, compared to the three other types of experience. Mass media interventions and improvements in educational systems are necessary to reduce stigma [32].

With respect to the relationship among experiences and stigma, three types of experiences were associated with feasible knowledge; these included participants' own mental health problems, direct contact, and lectures. One survey has suggested that knowledge of positive aspects would affect the intention to seek help and disclose [14], while several randomized controlled trials have shown that social contact with those who have mental health problems and well-qualified mental health lectures contributes to reducing the desire for social distance from people who have mental health problems [8–10]. On the other hand, social contact and lectures without any quality control may sometimes strengthen negative beliefs and attitudes [9, 33]. Biological knowledge for schizophrenia and depression could have rather negative impact toward the diseases [34]. As our survey did not include any assessment of the quality and intensity of the experiences, future studies are needed to examine whether qualified social contact and lectures affect knowledge and attitude regarding both the positive and negative aspects for schizophrenia.

Only 41 % of participants recognized the new and old names of schizophrenia as the same condition, whereas 87 % knew both names of dementia. Similar to the increased number of patients with depression, there was a 2.6-fold increase in the number of people with diagnosis of dementia over the past decade in Japan [30]. Second, as referred to the new name of dementia (cognition disorder),

the symptoms of dementia have been focused more on cognitive impairment and related behavioral problems than psychiatric symptoms. It is the possibility that the public image for the new name of dementia was less influenced by the stigma for psychiatric disorders.

Those who correctly answered the old and new name pair for schizophrenia had more similar feasible knowledge for both names than those who incorrectly answered, suggesting that the recognition of name change would effect on less feasible knowledge for new name of schizophrenia. The name change for schizophrenia was implemented in 2002 when the study participants were 8 years old. As there is little experience and needs to obtain the information of name change for schizophrenia in their childhood, the incorrect respondents seemed to think the old and new names for schizophrenia as different conditions, which may be a long-term effect of the name change for schizophrenia [18]. As correct respondents had more likely to receive mental health-related experiences from media, more appropriate media program toward mental illness should be broadcasted for young people.

This study had several methodological limitations. First, although the study participants were recruited from 20 universities and colleges using the authorized recruitment board that most of the students used, a potential selection bias should be considered. Second, as the questionnaire used dichotomous questions about mental health-related experiences, the quality and intensity of the experiences were not measured. Third, as pointed out in previous studies [13, 35, 36], the social desirability bias may have influenced the results. Future studies should use less biased measurement methods, such as the implicit association test [13, 20]. Fourth, the MIDUS and OS scales were not fully validated for stigma among different diseases and conditions. Further studies for developing well-validated and feasible scale assessing stigma for a variety of health conditions are needed. Finally, this study was a cross-sectional survey that is unable to figure out causal relationships among experiences and knowledge, as well as actual behavior changes.

In conclusion, we investigated the long-term effects of the name change on stigma toward schizophrenia, including feasible knowledge and negative stereotypes. The results suggest that the name change successfully reduced stigma toward schizophrenia among general university students, and that the effects of the name change may differ in the long term, because more people think the old and new names as different conditions. However, as stigma toward schizophrenia is still stronger than that toward depression and DM and the recognition of name change for schizophrenia would worsen stigma, more effective stigma-reduction campaigns, educational curricula, and policy making are needed to improve stigma toward schizophrenia.

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