Perceived stigmatisation of patients with mental illness and its psychosocial correlates: a prospective cohort study

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KEY MESSAGES

1. Perceived stigmatisation of patients with severe mental illness (SMI) was moderate and increased significantly over 1 year.

2. Patients' perceptions of stigmatisation and their re-hospitalisation, together with mediating factors (eg patients' functioning and self-esteem at recruitment, mental state, and family expressed emotion at 1-year follow-up) can predict illness relapse.

3. Development of community-based mental health care for SMI patients and their families is recommended.

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Introduction

People with mental illness have been stigmatised by the public as dangerous, violent, and unpredictable. Stigma is defined as social devaluation of people because of their personal attributes, leading to disgrace and social isolation.[1] This biased attribution of misbehaviour and disgrace to people with mental illness is over-generalised.

According to the attribution model and self-stigmatising hypothesis, the severity of the stigmatisation perceived by patients may lead to self-esteem decrement and at times predict illness relapse.[2] Nonetheless, systematic assessment of the experiences of people with severe mental illness (SMI) and studies of stigma from the perspective of families and health professionals are limited. This study assessed patients' perceived stigmatisation and its association with clinical, psychosocial, and psycho-pathological factors over 1 year.

According to the stigmatising self-hypothesis,[2] two hypotheses on the relationships between patients' perceived stigmatisation, re-hospitalisation rate, and other clinical and psychosocial factors were tested: (1) patients' perceived stigmatisation correlates with family and health professionals' attitudes toward SMI, their psychosocial health, and re-hospitalisation rate; (2) patients' perceived stigmatisation predicts their re-hospitalisation after 1 year, as mediated by their psychosocial and clinical variables and the families' and professionals' attitudes toward them.

Methods

This prospective cohort study was conducted from April 2010 to January 2012. Three groups of subjects: (1) randomly selected eligible adult patients, (2) the main family caregivers of the patients, and (3) mental health professionals of two public hospitals were invited to complete a questionnaire at the beginning and after 1 year.

Adult outpatients with SMI (schizophrenia, other psychotic disorders, and mood disorders for <5 years) were randomly selected, as were their main family caregivers. Assuming an attrition rate of 15%, a sample of 270 patients could achieve 90% power and an $\alpha=0.01$ to detect a moderate effect size (mean difference/standard deviation) of 0.34 and was adequate for multiple linear regression (104+ total number of covariates).[3] A total of 62 mental health professionals were recruited, including 18 nurses, eight psychiatrists, three occupational therapists, and two medical social workers.

Primary outcome measures included the 18-item Discrimination and Devaluation Scale (DDS), Specific Level of Functioning Scale, Chinese Rosenberg Self-Esteem Scale, Brief Psychiatric Rating Scale, and number and days of re-hospitalisations over the past 6 months. Secondary outcome measures consisted of the Chinese versions of Perceived Self-Efficacy Scale, Level of Expressed Emotion Scale, Family Burden Interview Schedule, Community Support Services Index, and professionals' Stereotype and Restriction Scale.[2,4] All scales demonstrated satisfactory internal consistency and construct validity.[2,4]

A qualitative, exploratory approach was used to elicit patients', family members' and health professionals' views on stigmatisation using focus group interviews. Six focus group interviews were

conducted with selected patients, family caregivers, and professionals independently (5-8 participants/ group) after the first assessment. Selection was made from those with the highest, median, and lowest DDS or Stereotype and Restriction Scale scores (2-3 from each level).

The correlations of the mean DDS scores of patients with other variables were examined. Chi-square/Fisher's exact test and independent T test were used to compare the mean DDS scores between categorical variables and changes in mean DDS scores and other continuous variables over 1 year, respectively. Multivariate regression and structural equation modelling technique were used to evaluate factors influencing the DDS scores and the hypothetical model predicting re-hospitalisations at the 1-year follow-up, respectively. Focus group interviews were transcribed and cross-checked for accuracy, followed by content analysis within and between groups by two independent assessors, contrasting the coding schemes and checking for inter-assessor agreement or reliability.

Results

Of 270 patients (and their family caregivers) who completed the questionnaire at the beginning (response rate, 84.4%), 238 completed the questionnaire at 1 year (attrition rate, 11.9%). Characteristics of patients and their caregivers were comparable between the 238 participants and the 32 dropouts and between the two recruitment sites (Table 1). Of 62 health professionals, 32 (51.6%) had undertaken at least one community psychiatric care course; 52 (83.3%) had a bachelor/master degree, with a mean±standard deviation (SD) community care experience of 6.57±4.54 years.

The mean DDS score was 55.03 (SD, 8.49; range 37-78; possible range, 18-90) at the beginning and 60.53 (SD, 9.17; range, 38-79) at 1 year, indicating a moderate level of stigmatisation perceived by patients and the level increased significantly after 1 year. Patients significantly deteriorated in terms of functioning (196.60±21.79 vs 169.56±22.97), self-esteem (25.98±6.17 vs 22.13±5.01), length of re-hospitalisation (22.13±5.01 vs 12.48±7.08 days/6 months), positive symptoms (2.90±2.17 vs 3.45±2.30), overall burden (0.88±0.39 vs 0.95±0.32), and need for support services (2.99±3.29 vs 3.49±2.51) [P=0.01-0.05]. Health professionals' attitudes toward patients were slightly negative at the beginning and increased non-significantly at 1 year (3.44±0.36 vs 3.52±0.57 for stereotype and 2.43±0.44 vs 2.56±0.62 for restriction).

The mean DDS scores at two time points correlated with most of the psychosocial variables, patient age, duration of illness, and number of psychiatric treatment received at the beginning (r/ rs=0.20-0.29, P=0.05-0.001). Similar levels of mean DDS scores were found among different types of SMI (P>0.1).

Multiple regression analyses indicated that patients' self-esteem, age, mental state, functioning, number of psychiatric treatments received (or length of re-hospitalisations at 1 year), and duration of illness (or expressed emotion at 1 year) accounted for 60.0% [F(10,235)=40.72, P<0.001; Cohen's effect size f^2=1.56] and 57.0% [F(10,235)=38.78 and P<0.002; Cohen's f^2=1.38] of the total variance in the perceived stigmatisation (large effect)[3], respectively (Table 2). Of these variables, patients' self-esteem, mental state, and age made the largest contributions. Different linear regression models were also tested. The best models indicated a large effect size (adjusted R^2=0.50-0.72; large effect sizes with Cohen's f^2=0.67-0.92).

Structural modelling using maximum likelihood estimation supported the study hypothesis that patients' DDS could predict the length of re-hospitalisations at 1 year, mediated by patients' age, functioning, self-esteem, and number of psychiatric treatments received at the beginning, and by their mental state and family expressed emotions at 1 year (Fig).

Content analyses of the six focus group interviews resulted in four themes, including common emotional and behavioural responses towards SMI patients, possible reasons for stigmatisation, negative feelings about stigmatised experiences, and effective coping methods. Important messages on stigmatisation included: (1) the patients believed that stigmatisation occurred anytime and anywhere with negative verbal and behavioural expressions; (2) the main reasons for stigmatisation perceived by patients and professionals were very similar, including inadequate knowledge of mental illness, ineffective communication, and misunderstanding about their illness mostly learnt from relatives and the mass media; and (3) most patients expressed inferior and stressful feelings regarding recent experiences of stigmatisation; and (4) their effective ways of coping, including compliance with medication and regular follow-up, ignoring negative thoughts, explaining more to people about their illness, establishing better social support, and managing their emotions.

Discussion

In this study, the total DDS and self-esteem scores were relatively higher than those reported in a 2-year study of 88 psychiatric patients in the US.[2] Nonetheless, our patients' secrecy and withdrawal were relatively lower and caused less harm secondary to further social isolation and reinforcement of internalised stigmatisation.[1,2,5] Hong Kong patients demonstrated greater efforts to cope with stigmatisation of mental illness such as positively seeking social support from people, openly

TABLE 1. Characteristics of patients and family caregivers at baseline*

Characteristics	Those who completed two assessments			Those who dropped out at 1-year follow-up		
	Site A (n=118)	Site B (n=120)	Total (n=238)	Site A (n=14)	Site B (n=18)	Total (n=32)
Patients						
Female	72 (61.0)	78 (65.0)	150 (63.0)	9 (64.3)	11 (61.1)	20 (62.5)
Male	46 (39.0)	42 (35.0)	88 (37.0)	5 (35.7)	7 (38.9)	12 (37.5)
Age (years)	38.12±9.81	37.31±9.32	37.72±9.81	37.23±10.32	36.81±9.62	36.90±9.32
Education level						
Primary school or below	16 (15.5)	15 (12.5)	31 (13.0)	2 (14.3)	3 (16.7)	5 (15.6)
Secondary school	88 (74.6)	89 (74.2)	177 (74.4)	10 (71.4)	13 (72.2)	23 (71.9)
Tertiary	14 (11.9)	16 (13.3)	30 (12.6)	2 (14.3)	2 (11.1)	4 (12.5)
Duration of mental illness (months)	33.2±14.23	31.83±12.02	32.31±12.82	31.84±12.02	32.31±13.52	31.81±14.02
Primary psychiatric diagnosis						
Bipolar affective disorders	13 (11.0)	12 (10.0)	25 (10.5)	1 (7.1)	2 (11.1)	3 (9.4)
Psychotic disorders	23 (19.5)	24 (20.0)	47 (19.7)	3 (21.4)	4 (22.2)	7 (21.9)
Schizophrenia	44 (37.3)	46 (38.3)	90 (37.8)	5 (35.7)	6 (33.3)	11 (34.4)
Unipolar affective disorders (eg major depression)	28 (23.7)	26 (21.7)	54 (22.7)	3 (21.4)	4 (22.2)	7 (21.9)
Others (eg dual diagnoses)	10 (8.5)	12 (10.0)	22 (9.2)	2 (14.3)	2 (11.1)	4 (12.5)
No. of medical diseases	0.52±0.60 (0-4)	0.63±0.70 (0-5)	0.60±0.78 (0-5)	0.61±0.79 (0-3)	0.68±0.80 (0-4)	0.64±0.87 (0-4)
No. of family members living with patient	2.32±0.93 (0-4)	2.13±0.98 (0-5)	2.24±0.97 (0-5)	2.62±1.29 (1-5)	2.12±1.74 (0-5)	2.45±0.89 (0-5)
Psychiatric medications						
Anti-depressants	36	40	76 (31.9)	3 (21.4)	5 (27.8)	8 (25.0)
Anti-convulsants	3	3	6 (2.5)	1 (7.1)	1 (5.6)	2 (6.3)
Atypical anti-psychotics	24	24	48 (20.2)	3 (21.4)	4 (22.2)	7 (21.9)
Conventional anti-psychotics	19	18	37 (15.5)	2 (14.3)	3 (16.7)	5 (15.6)
Lithium salts	3	3	6 (2.5)	1 (7.1)	1 (5.6)	2 (6.3)
Both anti-depressants and anti-psychotics	28	32	60 (25.2)	3 (21.4)	4 (22.2)	7 (21.9)
None	2	3	5 (2.1)	1 (7.1)	0 (0.0)	1 (3.1)
Re-hospitalisation in the past 6 months						
No.	0.49±0.41	0.51±0.37	0.50±0.48	0.50±0.42	0.54±0.37	0.52±0.45
Length (days)	9.12±4.18	10.08±5.33	9.82±6.88	8.51±5.78	9.48±3.77	8.90±3.15
No. of default follow-up in the past 6 months	0.20±0.24	0.28±0.27	0.22±0.25	0.22±0.29	0.29±0.36	0.25±0.31
No. of contact hours with caregivers per week	35.45±10.24	33.13±8.81	32.85±9.87	32.26±13.33	36.31±9.98	35.10±12.36
Psychiatric treatments						
CPN visits and education	60 (50.8)	63 (52.5)	123 (51.7)	8 (57.1)	10 (55.6)	18 (56.3)
Family therapy/education	4 (3.4)	5 (4.2)	9 (3.8)	1 (7.1)	1 (5.6)	2 (6.3)
Medication compliance management	70 (59.3)	72 (61.0)	142 (59.7)	8 (57.1)	11 (61.1)	19 (59.4)
Psycho-education	80 (67.8)	78 (65.0)	158 (66.4)	9 (64.3)	9 (64.3)	18 (56.3)
Social and work skills training	41 (34.7)	44 (36.7)	85 (35.7)	5 (35.7)	5 (35.7)	10 (31.3)
Others (relaxation and self-regulation)	25 (21.2)	28 (23.3)	53 (22.6)	4 (28.6)	4 (28.6)	8 (25.0)
Family caregivers						
Female	65 (55.6)	68 (57.1)	133 (56.4)	9 (60.0)	11 (57.9)	20 (58.8)
Male	52 (44.4)	51 (42.9)	103 (43.6)	6 (40.0)	8 (42.1)	14 (41.2)
Age (years)	45.21±10.02	47.45±9.77	46.78±12.23	40.53±10.55	48.05±11.56	46.90±10.96
Education level						
Primary school or below	25 (21.4)	20 (16.8)	45 (19.1)	2 (13.3)	4 (21.1)	6 (17.7)
Secondary school	70 (59.8)	73 (61.3)	143 (60.6)	10 (66.7)	12 (63.2)	22 (64.6)
Tertiary	22 (18.8)	26 (21.9)	46 (19.5)	3 (20.03)	3 (15.8)	6 (17.7)
Relationship with patient						
Child	25 (21.4)	23 (19.3)	48 (20.3)	3 (20.0)	4 (21.1)	7 (20.6)
Parent	38 (32.5)	39 (32.8)	77 (32.6)	5 (33.3)	5 (26.3)	10 (29.4)
Sibling	9 (7.7)	10 (8.4)	19 (8.1)	1 (6.7)	2 (10.5)	3 (8.8)
Spouse	41 (35.0)	43 (36.1)	84 (35.6)	5 (33.3)	7 (36.9)	12 (35.3)
Others	4 (3.4)	4 (3.4)	8 (3.4)	1 (6.7)	1 (5.3)	2 (5.9)
Monthly household income (HK$)						
≤5000	6 (5.1)	7 (5.9)	13 (5.5)	1 (6.7)	2 (10.5)	3 (8.8)
5001-10 000	26 (22.2)	25 (21.0)	51 (21.6)	3 (20.0)	4 (21.1)	7 (20.6)
10 001-20 000	45 (38.5)	48 (40.3)	93 (39.4)	6 (40.0)	7 (36.8)	13 (38.2)
20 001-30 000	28 (23.9)	26 (21.8)	54 (22.9)	3 (20.0)	4 (21.1)	7 (20.6)
>30 000	12 (10.3)	13 (10.9)	25 (10.6)	2 (13.3)	2 (10.5)	4 (11.8)

* Data are presented as mean±SD or No. (%)

TABLE 2. Multiple regression analyses using the Discrimination and Devaluation Scale as the dependent variable

| Variable	β	T	df	P value
Baseline				
Rosenberg Self-Esteem Scale	-0.17	-3.54	236	0.0008
Patient age	0.14	3.09	236	0.001
Brief Psychiatric Rating Scale	0.14	3.01	235	0.001
No. of psychiatric treatments received	0.13	2.49	235	0.005
Specific Level of Functioning Scale	-0.12	-2.38	236	0.008
Duration of illness	0.11	2.26	236	0.01
Model summary: R^2=0.82, adjusted R^2=0.81, F=40.72, P<0.001				
1 year				
Rosenberg Self-Esteem Scale	-0.18	-3.49	236	0.001
Brief Psychiatric Rating Scale	0.16	3.15	235	0.002
Length of re-hospitalisation	0.15	3.02	236	0.001
Specific Level of Functioning Scale	-0.15	-3.00	235	0.001
Patient age	0.14	2.69	236	0.004
Level of Expressed Emotion Scale	0.12	2.25	236	0.01
Model summary: R2=0.81, adjusted R2=0.80, F=38.78, P<0.001				
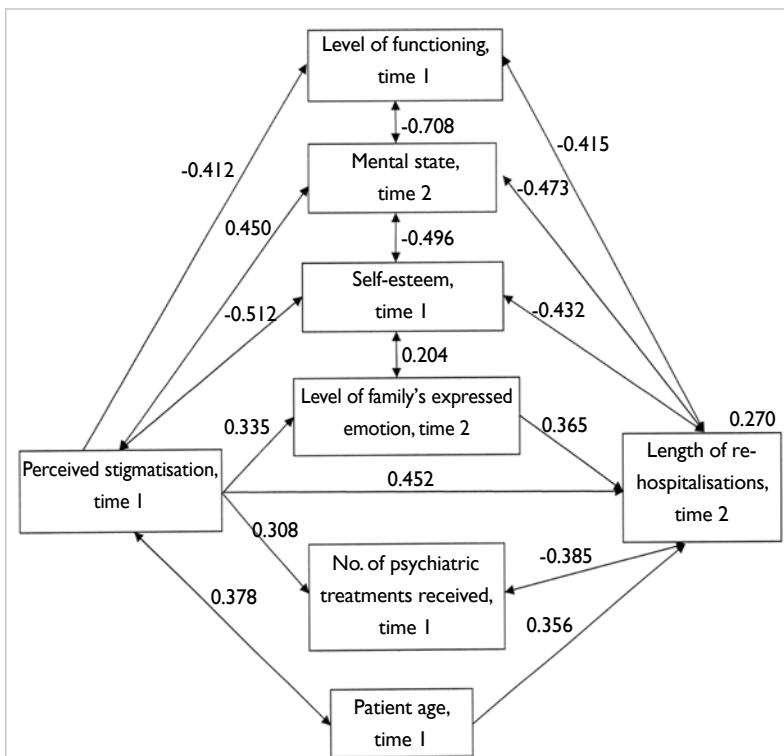
FIG. Path diagram of perceived stigmatisation of patients with severe mental illness in predicting the length of re-hospitalisation at 1 year and mediating factors*
* With maximum likelihood estimation, the Discrimination and Devaluation Scale predicts the length of re-hospitalisation at 1 year: goodness-of-fit index CMIN/df=1.529, df=412, P=0.0005, Tucker Lewis Index=0.916 (P>0.9), Comparative Fit Index=0.925 (P>0.9), Normed Fit Index=0.904 (P>0.9), and Root Mean Square Error of Approximation=0.047 (P<0.05) with 90% CI of 0.040-0.054

talking about the illness, and facing up to potentially stigmatising situations.

Patients' functioning, mental state, and self-esteem were significantly worsened and their family's overall caregiving burden, needs for community support services, and length of re-hospitalisations were significantly increased over 1 year. Mental health care providers should be aware of the negative longer-term effects of this perceived stigmatisation on community-dwelling SMI patients. Fortunately, the local health professionals' stereotypes and restrictions toward these patients were lower than those in western studies and not correlated to the patients' perceived stigmatisation. The mental health professionals in Hong Kong reported a high rate of acceptance of those with SMI.[6] Perception of responsibility for a mental illness, together with myths of dangerousness and violence in people with SMI, may be culture-related and require further investigation.

Patients' symptom severity, psychosocial functioning, self-esteem, and duration of illness and family expressed emotions are associated with their own perceived stigmatisation.[1,2] As indicated by the focus group interviews, the behavioural consequences of stigma (eg rejection and avoidance by others) affected most patients with SMI. Perceived stigma produced negative changes in feelings, attitudes, and behaviours for both the patients and family members at 1 year. High expressed emotion was associated with reported effects of perceived stigma in both patients

and their families (such as lowered self-esteem and increased family burden), which is consistent with the perceived effect of stigma on schizophrenic patients and families in China.[7] Perceived stigma of patients strongly affected their levels of perceived expressed emotion by family members. Therefore, directly addressing the perceived stigma and the destructive internalisation of negative self-images can decrease family members' expressed emotion and in turn reduce patients' relapse rates. The more chronic the course of the illness, the higher the patients' perceived stigmatisation and thus the more they need treatments/services. Early educational intervention may minimise long-term undesirable effects in both patients and their families.

Patients' perceived stigmatisation was associated with the length of re-hospitalisation after 1 year, as mediated by patients' self-esteem and families' expressed emotion. This is consistent with the key assumption of the modified labelling theory, namely that the stigma induced by being diagnosed/labelled with a mental illness results in a spoiled identity,[2] which is linked to negative psychosocial outcomes in terms of employment, self-esteem, and psychosocial functioning. Such negative consequences affect patients' mental condition and contribute to their illness relapse.[1,2] In addition, the patients' mental state (or symptom severity) and self-esteem were associated with both the level of their perceived stigmatisation and re-hospitalisation at both time points. These two patient factors also affect the level of perceived stigmatisation and the course of illness.[1]

Stigmatised patients may be denied access to important social roles.[8] Nonetheless, in the focus group interviews, many patients were able to envisage stigma-coping strategies and avenues for positive change (such as good drug compliance and emotion management and establishing a better social support network). These strategies can help patients develop a sense of empowerment and enhance their self-esteem and ability to manage their daily lives.

A few limitations of this study are worth noting. First, the study samples were recruited from two outpatient settings only and might not be representative. Second, the sample consisted of a high proportion of females (63%) in the two major illness groups (58% in schizophrenia and other psychotic disorders and 35% in affective disorders) and psychiatric nurses (60%) and thus could not fully reflect the gender patterns of these mental disorders[8,12] or the composition of community mental health care teams in Hong Kong. Third, only important patient, family, and staff factors were selected for model testing; many potential confounders (such as medication compliance and social support) should have been included. Lastly, the illness relapse could have been measured by changes in symptom severity and non-adherence to treatment, not just by number and length of psychiatric re-hospitalisations.

Patients' perceived stigmatisation and number of re-hospitalisations can predict illness relapse of SMI patients. Development of valid measurement and design of effective interventions is needed.

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