

Stigma and expressed emotion: a study of people with schizophrenia and their family members in China[†]

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Background The most damaging effect of stigma is the internalisation of others' negative valuations.

Aims To explore the factors that mediate patients' emotional and cognitive responses to stigma.

Method Based on responses to 10 open-ended questions about stigma appended to the Chinese version of the Camberwell Family Interview, trained coders rated the effect of stigma on both patients and family members in 1491 interviews conducted with 952 family members of 608 patients with schizophrenia at 5 sites around China from 1990 to 2000.

Results Family members reported that stigma had had a moderate to severe effect on the lives of patients over the previous 3 months in 60% of the interviews, and on the lives of other family members in 26% of the interviews. The effect of stigma on patients and family members was significantly greater if the respondent had a high level of expressed emotion, if the patient had more severe positive symptoms, if the respondent was highly educated and if the family lived in a highly urbanised area.

Conclusions Clinicians should assess the effect of stigma as part of the standard work-up for patients with mental illness, and help patients and family members reduce the effect of stigma on their lives.

Declaration of interest None.

Persons suffering from schizophrenia and their close family members are such frequent targets of stigma that the World Psychiatric Association has initiated an international campaign to combat the stigma and discrimination associated with this illness (Sartorius, 1997). Stigma is usually conceptualised as a malevolent influence existing in the external environment, that wreaks havoc with the lives of those who are the object of it. In this conceptualisation, the targets are seen as passive receivers of other people's ill will. However, the most damaging effect of stigma and discrimination is the subjective internalisation of these negative valuations, a cognitive process that can be resisted and altered. Campaigns to combat stigma typically focus on how its objective levels can be reduced, but the results are less than impressive. Changing how patients and their families respond to negativity is a much more realistic goal for clinicians to achieve. To do this, clinicians first need a greater understanding of the factors that mediate the emotional and cognitive responses to stigma and discrimination. One such factor is the level of expressed emotion in the family.

METHOD

The work reported in this paper was conducted at the Beijing Hui Long Guan Hospital, the Anding Hospital in Beijing, the Guangji Hospital in Suzhou, the Jilin Provincial Neuropsychiatric Hospital in Siping and the Jingzhou City Psychiatric Hospital.

Definition

The overall effect of stigma and discrimination on the lives of patients and their family members was operationally defined as the combined effects of four stigma-related experiences:

- the frequency and intensity of devaluing statements and behaviours by others, experienced by the patient and the patient's family members;
- the degree of unjustified external restrictions (as judged by the respondent) on the activities of the patient and the patient's family members;
- the level of self-restriction of activities by the patient and the patient's family members due to fear of stigma and discrimination;
- the intensity of patients' and family members' emotional reactions to actual or feared stigma and discrimination.

Including self-restriction of activities and fear of stigma makes it possible to assess the effect of stigma even when the illness has been kept a secret (a common situation in China).

Questions

Based on this definition, 10 open-ended questions (see Appendix) were added to the Chinese version of the Camberwell Family Interview (CFI-CV) (Phillips & Xiong, 1995). The CFI-CV is a 90-minute interview administered to family members of patients with schizophrenia, that obtains detailed information about their responses to the patient's illness over the previous 3 months. The questions on stigma and discrimination typically took 5-8 minutes, near the end of the interview; interviewers probed for further detail if they felt this necessary. The audiotaped interviews were transcribed and then coded by trained coders according to the instructions in a detailed coding manual.

Answers

Based on respondents' answers to the 10 questions (and other information spontaneously provided about stigma in the earlier parts of the interview), coders rated the overall magnitude of the effect of stigma and discrimination in the previous 3 months on the life of the patient and, separately, on the lives of the patient's family members. This rating was made on a 4-point scale (0=no effect, 1=mild effect, 2=moderate effect, 3=severe effect). If the respondent stated that the effects of stigma on different family members differed, the effect on the most severely affected family member was coded.

[†]See editorial, pp. 466-467, this issue.

Interviews

A total of 1491 interviews conducted with 952 family members of 605 patients with schizophrenia were included in this study. Respondents' perceptions of patient and family discrimination often change with the severity and duration of the patient's illness, so it was important to include assessments taken at different points in the course of the illness. Of the interviews, 61% ($n=903$) were conducted at the time of the patient's admission to hospital (641 of these were at the first admission); the remainder were follow-up interviews conducted while the patient was in remission, 12 to 60 months after the index admission. These interviews come from a number of completed and ongoing projects:

- (a) a completed family intervention project in Jingzhou, Hubei Province ($n=69$);
- (b) two completed projects that assessed the predictive power of the CFI-CV in Siping, Jilin Province ($n=61$) and Suzhou Jiangsu Province ($n=264$);
- (c) an ongoing project comparing clozapine and chlorpromazine in first-episode patients at Beijing Hui Long Guan Hospital ($n=670$);
- (d) an ongoing project on the effectiveness of family counselling at Anding Hospital in Beijing ($n=427$).

Among the 1240 CFI-CV interviews that were independently rated by two coders, the intraclass correlation coefficients (ICCs) for the magnitude of the effect of stigma and discrimination on patients and on family members were 0.68 and 0.67, respectively. In cases where two coders independently rated the effect of stigma and discrimination, the mean of the two scores was employed in subsequent analyses.

Rating scales

These five studies also obtained detailed demographic information on the patients, their family members and the respondents to the CFI-CV interview. Chinese versions of the 18-item Brief Psychiatric Rating Scale (BPRS) (Phillips *et al.*, 1990), the Scale for the Assessment of Negative Symptoms (SANS-CV) (Phillips *et al.*, 1991) and the Global Assessment of Functioning (GAF) (Wu & Wang, 1990) were administered at the same time as the CFI-CV interviews. At all sites, the interviews and coding were conducted by attending-level psychiatrists or senior psychiatric nurses who were

extensively trained by the first author in the use of the scales. All of the studies obtained written informed consent from both patients and family members.

Characteristics of the family member respondents

Of the 952 family member respondents, 50% (478) were male; 635 (66.7%) were parents, 222 (23.3%) were spouses and 95 (10.0%) were other relatives. At the time of the examination, respondents' mean (s.d.) age was 49.5 (12.1) years, mean duration of formal schooling was 8.8 (4.4) years, and mean face-to-face contact time with the patient was 40.9 (29.8) hours per week; 93% of respondents lived with the patient.

Characteristics of patients

Of the 608 patients, 52% (317) were male. Their mean (s.d.) age of onset was 26.4 (7.6) years. At the time of the CFI-CV interview, patients' mean (s.d.) age was 28.8 (7.5) years; mean duration of schooling 11.0 (2.9) years; median (interquartile range) duration of illness 2.9 (1.5–4.3) years; mean (s.d.) BPRS total score 34.4 (12.4); mean SANS-CV total score 18.3 (15.1); mean GAF score 48.0 (22.3); 72.6% had had only one hospital admission; 60.1% had never married; 60.8% lived in urban centres, 19.2% in suburban areas, 4.6% in county towns and 16.4% in rural villages; the mean (s.d.) per capita family income as a proportion of the national urban per capita income (adjusted for changing income levels in different years) was 83% (68%).

Statistical methods

There were substantial differences in the characteristics of subjects and some differences in coding practices across sites (the assessed effect of stigma on patients and family members at Anding Hospital was significantly higher than that reported at the other four sites), so all results were adjusted for differences between the sites. The relationship of patient and respondent characteristics to the reported magnitude of the effect of stigma on patients and family members was assessed using *F*-tests for categorical characteristics and partial ranked correlation coefficients for continuous characteristics. High expressed emotion was considered present in CFI-CV interviews in which six or more critical comments, hostility, or at least a moderate

level of emotional overinvolvement were coded; the ICC for the determination of high *v.* low expressed emotion was 0.82.

To identify factors independently related to the effect of stigma on patients and family members, two multiple regression equations were constructed that adjusted for the effect of the five study locations (by entering four dummy variables) and simultaneously considered 13 potential predictors: respondents' age, gender, duration of schooling and level of expressed emotion (low *v.* high); patients' gender, duration of schooling and marital status (never married *v.* ever married); age at onset of the illness, duration of the illness (using a log transformation) and severity of positive and negative symptoms at the time of the CFI-CV interview; the mean per capita income of family members (adjusted for year, log transformation); and the level of urbanisation of the location of residence (inner city, suburbs, town or village). Patient age was not included in the regression models because it overlapped with age at onset and duration of illness; GAF score, time of the examination (at admission or after discharge) and type of respondent (parent, spouse or other) were excluded because they were highly correlated with other variables (i.e. multicollinearity). The final models included data from all 1491 examinations.

RESULTS

Family members' reports indicated that stigma had a moderate to severe effect on the lives of patients in 60% (899/1491) of the interviews, and a moderate to severe effect on the lives of healthy family members in 28% (418/1491) of the interviews (Table 1). The mean (s.d.) level of effect (on the 0–3 point scale) was 1.49 (0.93) for patients and 0.78 (0.87) for family members.

Univariate results

A wide variety of patient and respondent characteristics was significantly related to the reported effect of stigma on both patients and family members (Tables 2 and 3). Female respondents, respondents with a higher social status (i.e. high mean family income and higher educational level), respondents from more densely populated city districts, respondents interviewed at the time of the patient's hospital admission and respondents with high

Table 1 Effect of stigma and discrimination on the lives of patients with schizophrenia and their family members over the previous 3 months as reported in 1491 separate CFI–CV examinations at five study sites in four cities in China from 1990 to 2000

	Effect of stigma on patients		Effect of stigma on family members	
	n	%	n	%
None	254	17.0	681	45.7
Mild	338	22.7	392	26.3
Moderate	606	40.6	333	22.3
Severe	293	19.7	85	5.7

CFI–CV, Chinese version of Camberwell Family Interview.

expressed emotion (particularly high emotional overinvolvement with the patient) reported greater effects of stigma and discrimination on the lives of both patients

and their family members. As expected, the severity of patients’ positive and negative symptoms and the patients’ overall level of functioning at the time of the CFI–CV interview were positively correlated with the effect of stigma on patients and on family members. Stigma and discrimination have a greater effect on younger patients who have an earlier age at onset, on unmarried patients, on well-educated patients and on male patients.

Multivariate results

After adjusting for location and the 13 potential predictive factors (Table 4), 7 factors remained significantly related to the reported effect of stigma on the lives of patients in the 3 months before the interview. The reported effect was higher if: the respondent had high expressed emotion, was more educated or was female; and if the patient had an early age of onset, severe positive symptoms, lived in a more

urbanised location or was male. Five factors were independently related to the reported effect of stigma on family members: high expressed emotion and higher education in the respondent; and more severe positive symptoms, living in a more urbanised location, and a longer duration of illness in the patient.

DISCUSSION

Stigma experienced by individuals with mental illness and their families in China

Schizophrenia, because of its distinctive symptoms, disruptive behaviour and perceived dangerousness (Link *et al*, 1987), is a particular target for stigma and discrimination. In the Chinese setting, aetiological beliefs about mental illnesses intensify the stigma focused on patients with schizophrenia and their family members. The Chinese ‘moral view’ (Lin & Lin, 1980) considers mental illness a punishment for

Table 2 Relationship of patient and respondent characteristics to level of effect of stigma and discrimination on lives of patients with schizophrenia and family members over the previous 3 months (n=1491; adjusted for five study sites)

Characteristic	n	Level of effect of stigma and discrimination on the patient				Level of effect of stigma and discrimination on family			
		Adjusted mean	s.e.	F	P	Adjusted mean	s.e.	F	P
Patient gender									
Female	690	1.32	0.043			0.72	0.038		
Male	801	1.56	0.043	25.24	<0.001	0.78	0.037	2.46	0.117
Patient marital status									
Never married	896	1.66	0.042			0.78	0.038		
Ever married	595	1.26	0.042	87.41	<0.001	0.73	0.038	1.34	0.248
Hospital admissions									
Single	1082	1.42	0.043			0.74	0.038		
Multiple	409	1.49	0.049	1.48	0.224	0.78	0.043	0.65	0.422
Respondent type									
Parent	1000	1.57	0.039			0.75	0.036		
Spouse	345	1.16	0.053	28.50	<0.001	0.82	0.048	5.74	0.003
Other ¹	146	1.34	0.080			0.55	0.072		
Respondent gender									
Female	735	1.54	0.042			0.81	0.037		
Male	756	1.35	0.043	16.91	<0.001	0.70	0.038	7.68	0.006
Time of examination									
At admission	903	1.57	0.041			0.84	0.036		
After discharge	588	1.20	0.053	5.66	<0.001	0.57	0.047	29.30	<0.001
Expressed emotion²									
Low	957	1.25	0.039			0.59	0.035		
High	534	1.76	0.045	110.90	<0.001	1.00	0.040	90.08	<0.001

1. ‘Other’ includes 105 siblings, 14 children, 5 grandparents and 22 in-laws. *Post-hoc* tests (Tukey) found that the reported effect of stigma on patients was significantly different across the three groups; the effect of stigma on family members reported by spouses and parents was not significantly different, but the effect on these two groups was significantly greater than that reported by other types of respondents.

2. Based on the results of the Chinese version of the Camberwell Family Interview.

Table 3 Adjusted rank correlation between patient and respondent characteristics and level of effect of stigma and discrimination on the lives of patients with schizophrenia and their family members over the previous 3 months ($n=1491$; adjusted for five study sites)

Characteristic	Effect of stigma on patient (partial correlation)	Effect of stigma on family (partial correlation)
Patient characteristics		
Age	-0.2268***	-0.0168
Years of schooling	0.1241***	0.0356
Age of onset of illness	-0.2109***	-0.0275
Duration of illness	-0.0821	-0.0293
BPRS score at time of CFI-CV examination	0.2015***	0.2915***
SANS-CV score at time of CFI-CV examination	0.1272***	0.2689***
GAF score at time of CFI-CV examination ¹	-0.2153***	-0.2859***
Level of urbanisation of residence (1=village, 2=town, 3=suburbs, 4=city)	0.1828***	0.3049***
Per capita income of family (adjusted for year)	0.1692***	0.1625***
Respondent characteristics		
Age	0.0537	-0.0290
Years of schooling	0.1454***	0.1021***
Level of emotional overinvolvement with the patient ²	0.3501***	0.3761***
Level of criticism of the patient ²	0.1902***	0.2558***

CFI-CV, Chinese version of Camberwell Family Interview; BPRS, Brief Psychiatric Rating Scale; SANS-CV, Chinese version of Scale for Assessment of Negative Symptoms; GAF, Global Assessment of Functioning.

1. $n=1486$ because GAF data were missing in five cases.

2. Assessed as part of the CFI-CV exam.

***Two-tailed $P < 0.001$.

an ancestor's misbehaviour or for the family's current misconduct. In rural areas, the frequent association of mental illness with malevolent spiritual forces induces many families with a member with mental illness to seek help from shamans (Li & Phillips, 1990; Pearson, 1993). In urban areas psychosocial factors, especially breakdown of family relationships, are the most frequent folk explanations of schizophrenia (Phillips *et al*, 2000), and beliefs about the genetic transmission of the illness (Lee, 1986) lead to discrimination of patients' family members. Each of these aetiological beliefs implies that there is something pathogenic about the family, whether it lies in their ancestors' behaviour, in their own behaviour, in their 'fate', in their ways of conducting relationships or in their biological make-up.

The current study found that in China several factors were independently related to the perceived magnitude of the effect of stigma on both the patient and the family. The perceived effect of stigma was greater if the patient had more prominent positive symptoms, if the respondent had a relatively high educational level and if the family lived in a highly urbanised location. Patients who were more acutely ill probably generated more negative responses from their associates and the community

Table 4 Results of multiple regression analyses to identify patient and respondent characteristics that are independently related to the severity of the effect of stigma and discrimination on the lives of patients with schizophrenia and their family members ($n=1491$)¹

Characteristic	Effect of stigma on patients			Effect of stigma on family members		
	Beta	t	P	Beta	t	P
Patient characteristics						
Patient's gender (1=female, 2=male)	0.071	2.86	0.004	0.034	1.36	0.174
Patient's marital status (0=never married, 1=ever married)	-0.064	-1.85	0.065	0.014	0.41	0.681
Patient's years of schooling	0.024	0.86	0.391	-0.007	-0.25	0.806
Level of urbanisation of residence (1=village, 2=town, 3=suburbs, 4=city)	0.089	2.98	0.003	0.124	4.19	<0.001
Per capita income of family members (adjusted for year, log transformation)	0.050	1.83	0.068	0.026	0.97	0.332
Age of onset of illness	-0.160	-5.13	<0.001	-0.038	-1.23	0.221
Duration of illness (log transformation)	-0.023	-0.86	0.391	0.056	2.12	0.034
Severity of positive symptoms (BPRS score at time of CFI-CV examination)	0.133	4.34	<0.001	0.173	5.73	<0.001
Severity of negative symptoms (SANS-CV score at time of CFI-CV examination)	-0.031	-1.01	0.313	0.003	0.09	0.926
Respondent characteristics						
Respondent's gender (1=female, 2=male)	-0.058	-2.34	0.019	-0.038	-1.55	0.122
Respondent's age	0.037	1.35	0.177	-0.027	-1.02	0.310
Respondent's years of schooling	0.122	4.16	<0.001	0.083	2.86	0.004
Respondent's level of expressed emotion (from CFI-CV examination; 0=low, 1=high)	0.211	8.47	<0.001	0.184	7.49	<0.001

CFI-CV, Chinese version of Camberwell Family Interview; BPRS, Brief Psychiatric Rating Scale; SANS-CV, Chinese version of Scale for Assessment of Negative Symptoms.

1. Results are simultaneously adjusted for all variables included in the table and for location (five study sites).

at large; in China such negative responses are often directed at the family because the family is morally and legally responsible for controlling the behaviour of its members. The finding that better-educated family members had an increased sensitivity to stigma is consistent with previous findings (Angermeyer *et al*, 1987; Phelan *et al*, 1998); such family members may feel that they have more to lose. The relationship of perceived stigma with level of urbanisation may be due to a higher level of external supervision of patients' behaviour in the more densely populated urban districts, or a lack of close (supportive) ties in high-rise urban environments where neighbours are frequently strangers.

The effect of stigma on the lives of patients was greater for male patients and for patients with a younger age at onset of the illness. In China, urban patients with schizophrenia who fall ill earlier are less likely to obtain satisfactory (government-sponsored) employment and have much greater difficulty finding a spouse, so they are considered socially inferior because they often never achieve these minimal requirements of 'adult' status. Moreover, the social expectations for men are greater than for women, so the effect of stigma is greater on men: women who marry but do not work are in the acceptable role of 'housewife', but men must be both married and family breadwinner to attain social status. Female respondents reported greater effects of stigma on patients than male respondents; mothers and wives are more attuned to the negative consequences of stigma on the emotional and social lives of their family members with mental illness than are fathers and husbands.

The effect of stigma on healthy family members was also greater in families in which the patient had a longer duration of illness. The longer the illness persisted, the more difficult it was for families to keep the 'family secret'; as more community members became aware of the illness, the negative social consequences for the family (both feared and actual) increased.

Links between expressed emotion and stigma

The work on expressed emotion assumes that high expressed emotion about the patient among family members reflects a pattern of interaction within the family that is stressful for the patient (Leff *et al*, 1983; Koenigsberg & Handley, 1986; Kavanagh,

1992). Expressed emotion has been investigated primarily as a construct predicting patient relapse; its links to other constructs, such as stigma, have not yet been explored. Stigma, as a negative societal attitude directed towards the individual and family, may further stress relationships in the family system and thus magnify high levels of expressed emotion in the family (Greenley, 1986). Conversely, family members' levels of expressed emotion could influence their perception and response to stigma and discrimination. For example, relatives with low expressed emotion, who are not over-anxious in their response to the patient's illness (Vaughn & Leff, 1981), may tend to perceive stigma in ways that are less threatening and harmful to the patient or the family; relatives with high expressed emotion, who respond to the patient's illness in a highly anxious and fearful manner, may experience stigma more acutely.

The most remarkable finding of this study was the extremely strong relationship between high expressed emotion and the reported effect of stigma on both the patient and the family. After controlling for a wide range of predictive variables, the level of expressed emotion of the respondent remained the most important predictor of the perceived magnitude of the effect of stigma on the lives of patients and other family members. Given the correlational nature of the study, it is impossible to ascertain the causal link between these two variables or to identify a common precursor condition for both factors, but we hypothesise that high expressed emotion and enhanced sensitivity to the effects of stigma are mutually reinforcing. Interventions that aim to reduce family members' levels of expressed emotion may also reduce perceived stigma, and thus the destructive internalisation of negative self-images. Conversely, directly addressing the cognitive processes that facilitate the internalisation of stigmatised valuations could decrease family members' high expressed emotion and, potentially, patients' relapse rates. One report on patients with depression (Sirey *et al*, 2001) suggests that clinical interventions aimed at addressing patients' perceived stigma could improve treatment adherence and outcomes.

Combating stigma

These results highlight an important point that has not been emphasised in traditional anti-stigma campaigns: namely, that stigma

and discrimination are usually experienced and interpreted at the level of the individual patient and at the level of the family unit, not at the level of the community. Individuals and family units respond differently to actual or feared stigma and discrimination, depending on their internal characteristics and personal history. Interventions aimed at reducing the negative effects of stigma must, therefore, include components that are specifically focused on patients and patients' family members. Health professionals have the most direct contact with patients and their families, so they are the appropriate group to provide these interventions. Health professionals should openly discuss the problem of stigma with patients and families, assess the ways in which it is affecting their self-esteem and quality of life and encourage them to externalise stigma as society's ignorance rather than internalising it. They may also encourage patients and families to join with others in a similar situation to find mutual support, affirmation and, possibly, to become active in the consumer movement. Any and all of these measures would help patients and families find alternative identities to overcome society's negative labelling.

APPENDIX

Open-ended questions about stigma and discrimination added to the Chinese version of the Camberwell Family Interview (CFI-CV) (translation from the Chinese)

1. Do others know about the mental illness? (If so) how did they find out?
2. Do you think it is better to keep it a secret? Why?
3. If others knew about the mental illness, what do you think they would think?
4. Do you think mental illness is disgraceful? Why?
5. Has the patient been looked down on, discriminated against, or unfairly restricted because of the illness?
6. Is the patient worried about being discriminated against?
7. Has the discrimination or fear of discrimination affected the patient's feelings, work, study, ability to find a spouse, self-respect or social activities?
8. Are other family members concerned about discrimination against the patient? Has this concern affected their work, social activities or feelings?
9. Have other family members been concerned about being discriminated against themselves or have they actually been discriminated against because there is a person with a mental illness in the home?

10. Has this concern about discrimination or actual discrimination of healthy family members affected their work, social functioning, ability to find a spouse or feelings?

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CLINICAL IMPLICATIONS

- Stigma and the fear of potential stigma have a major effect on the quality of life of patients with schizophrenia and their family members; clinicians should assess the effect of stigma as part of the standard work-up for patients, and help patients and family members reduce the negative effects of stigma on their lives.
- Stigma has a more profound effect on patients and family members when the patient is more severely ill and when the family has a high socio-economic status.
- The close relationship between high expressed emotion and the perceived effect of stigma suggest that interventions aimed at either problem might relieve both.

LIMITATIONS

- Cultural factors mould both the experience of stigma and the response to stigma, so it is uncertain to what extent these Chinese results will hold true in other cultures.
- We have depended on family members' reports of the effect of stigma on the lives of patients; the patients themselves may have different ideas about the effect of stigma.
- In combining data from five studies in four Chinese cities over a period of 10 years, that include evaluations both at the time of admission and during remission, we introduced a number of potential confounding variables that had to be adjusted by statistical methods.