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Experience of stigma among Chinese mental health patients in Hong Kong

AIMS AND METHOD

The study was intended to rectify the lack of data on how Chinese people experience the stigma of mental illness. A questionnaire on perceived stigmatisation, experiences of rejection and ways of coping with stigma was completed by 193 persons attending a psychiatric out-patient clinic in Hong Kong.

RESULTS

Most of the participants were aware of the stigma associated with mental illness, but experiences of rejection were relatively less frequent. Eleven per cent of the respondents indicated that they were neglected by health care professionals and 8% had been avoided by family members. The most frequently reported coping method was maintaining secrecy about the illness.

CLINICAL IMPLICATIONS

In China, people with mental health problems experience stigma in various degrees. However, some of the people surveyed expressed feelings of relief that others were supportive and sympathetic towards their illness. Mental health professionals should maintain optimism in helping their patients to cope with the stigma.

The stigma attached to a label of 'mental illness' can have a lasting impact on the person so labelled. The expectation and actual experience of stigmatisation can result in lowering of self-esteem (Link *et al*, 2001) and quality of life (Rosenfield, 1997), persistent depression (Link *et al*, 1997), impairment in social relationships (Perlick *et al*, 2001) and early treatment discontinuation (Sirey *et al*, 2001). Coping with the stigma by avoidance, withdrawal and secrecy is common, but may result in demoralisation, social isolation and lost opportunities for education, employment and housing (Link *et al*, 1991).

Clausen (1981) saw stigma as 'a buzz word that aroused emotionalism'. Based on the results of a long-term study of mental health service users and their families, Clausen concluded that,

'the patient's fear of rejection, coupled with uncertainty about ability to function in everyday roles, is a far more significant barrier to full social participation than is anything appropriately called stigma' (Clausen, 1981).

First-person accounts showed that some people developed coping strategies to deal with the stigma of mental illness and were able to lead a satisfactory life (Lundin, 1998; Camp *et al*, 2002).

We conducted a cross-sectional survey on the perception and experience of stigmatisation among Chinese people receiving mental health care in the community.

Method

The survey took place at the out-patient clinic of the Department of Psychiatry at the University of Hong Kong. The first 200 out-patients who met the following criteria were recruited:

- (a) the patient was literate and gave informed consent;
- (b) the patient was aged 18–60 years;

- (c) based on assessment by the authors, the patient was in remission or not severely ill.

The authors reviewed the psychiatric record to establish the primary DSM-IV Axis I diagnosis (American Psychiatric Association, 1994).

A self-report questionnaire assessed beliefs about discrimination against individuals with mental illness, rejection experiences and ways of coping with stigma, characterised as secrecy, avoidance and withdrawal, and advocacy and confrontation. The questionnaire (in Chinese) was modified from versions previously used in Western studies (Link *et al*, 1991, 1997; Wahl, 1999). We included items that were relevant in a Chinese society, and modified the wording and sentence structures to make the questions easy to understand. This questionnaire had earlier been piloted with the help of 10 out-patients whose mental illness was in remission.

Participants rated the section on perceived stigmatisation using a four-point response scale (Table 1). Items assessing rejection experiences (see Table 2) and coping strategies (see Table 3) asked whether the respondents 'ever' experienced the form of rejection or employed the coping strategy described. Participants answered using a yes/no response, and were advised to answer 'don't know' if they had not encountered the relevant situation, to avoid overestimating negative responses.

Results

Sample characteristics

Seven eligible patients did not complete their questionnaire, and hence data from 193 respondents were used for further analysis. There were 97 women and 96 men in the final sample. The mean age was 39 years (range 20–58 years). Most of these participants were single (62%),

**Table 1. Perceptions of stigmatisation (n=193)**

Item ¹	Strongly disagree n (%)	Slightly disagree n (%)	Slightly agree n (%)	Strongly agree n (%)
Most people believe that someone with a previous mental illness is untrustworthy	30 (15.5)	46 (23.8)	88 (45.6)	29 (15.0)
Most people would not marry someone who has a history of mental illness	17 (8.8)	49 (25.4)	75 (38.9)	52 (26.9)
Most people believe that someone with a previous mental illness is dangerous	24 (12.4)	39 (20.2)	85 (44.0)	45 (23.3)
Most people would take the opinion of someone with a previous mental illness less seriously	28 (14.5)	37 (19.2)	86 (44.6)	42 (21.8)
Most people look down on people who have a history of mental illness	22 (11.4)	30 (15.5)	79 (40.9)	62 (32.1)
Most people think that someone with a previous mental illness is less intelligent than the average person	35 (18.1)	56 (29.0)	65 (33.7)	37 (19.2)
Most employers would not hire a person who has a history of mental illness	22 (11.4)	25 (13.0)	82 (42.5)	64 (33.2)
Most people avoid someone who has a history of mental illness	23 (11.9)	43 (22.3)	81 (42.0)	46 (23.8)
Most people would not accept someone with previous mental illness as a close friend	22 (11.4)	63 (32.6)	68 (35.2)	40 (20.7)
Most people believe that receiving psychiatric treatment is a sign of personal failure	36 (18.7)	73 (37.8)	48 (24.9)	36 (18.7)

1. English translation of the Chinese questionnaire.

29% were married, 8% divorced and 1% widowed. Nearly half were employed full-time (43%), 35% were unemployed, 8% were employed part-time, 8% were home-makers and 7% worked in sheltered workshops or supported employment. A majority lived with family members (79%), 14% lived independently and 8% lived in supervised hostels. Three-quarters of the sample had had a previous admission to a psychiatric unit: 22% of the 193 participants on one occasion, 36% two to four times and 17% more than four times. Nearly half of the sample had a diagnosis of schizophrenia or another psychotic disorder (48%), 21% had bipolar affective disorder, 13% major depression and 14% anxiety disorder.

Responses to the questionnaire items

Most respondents felt that people with a history of mental illness were discriminated against in various ways (Table 1). Three-quarters of them agreed that 'most employers would not hire a person who has a history of mental illness'.

The most common rejection experience was an encounter with a hurtful or offensive media portrayal of mental illness, reported by half the sample (Table 2). Actual rejection was less frequently experienced. The majority of the respondents (85%) affirmed that they had not been rejected by their family members, and 71% answered that they had not been neglected by health care professionals. Disclosure of the respondents' mental illness history to friends did not in most cases lead to rejection: 28% of the respondents reported that their friends treated them differently after they knew about

the history of mental illness, but 47% of the sample did not experience such rejection. The item generating the greatest proportion of 'don't know' responses (54%) was that enquiring about rejection experiences at job interview. Possibly, the respondents had kept their history of mental illness a secret, or were not required to reveal their state of health at the interview.

The use of secrecy was the most frequently endorsed way of coping with stigma, followed by the use of confrontation and avoidance (Table 3). However, few respondents hid their mental illness history from health care professionals (16%) or avoided making new friends after receiving psychiatric treatment (11%). More than half of the sample said that they attempted to correct their friends who held negative views about people with mental illness (62%).

We used the chi-squared test to compare the stigma experiences of those with a psychotic disorder and of those with another psychiatric diagnosis. There was no significant difference between the two groups, except for one item: a greater proportion of people with a psychotic disorder replied that they had been turned down for a job for which they were qualified because of their psychiatric history (29% v. 12%, $\chi^2=11.1$, d.f.=2, $P=0.004$).

Discussion

Our survey indicates that many mental health care patients feel that they have experienced stigma and discrimination. On the other hand, some respondents were not unfairly treated when their mental illness history



Item	No n (%)	Don't know ¹ n (%)	Yes n (%)
Have some of your friends ever treated you differently after they knew you had a history of mental illness?	90 (46.6)	49 (25.4)	54 (28.0)
Have some of your neighbours, colleagues and relatives ever avoided you because they knew you had a history of mental illness?	97 (50.3)	61 (31.6)	35 (18.1)
Have your family members ever avoided you because of your previous mental illness?	163 (84.5)	15 (7.8)	15 (7.8)
Have people used the fact that you have a history of mental illness to hurt your feelings?	103 (53.4)	41 (21.2)	49 (25.4)
Have you ever seen or read anything in the mass media (e.g. magazines, newspapers, television and radio broadcasting and advertisements) about persons with mental illness that you found hurtful or offensive?	65 (33.7)	33 (17.1)	95 (49.2)
Have you ever been turned down for a job for which you were qualified when your history of mental illness was revealed?	50 (25.9)	104 (53.9)	39 (20.2)
Have you ever been treated as less competent by others when they learnt you had a history of mental illness?	63 (32.6)	64 (33.2)	66 (34.2)
Have you ever experienced the break-up of a love relationship because of your history of mental illness?	83 (43.0)	82 (42.5)	28 (14.5)
Have you ever been asked to resign by your employer because of your history of mental illness?	102 (52.8)	73 (37.8)	18 (9.3)
Have you ever been neglected by a health care professional because of your history of mental illness?	137 (71.0)	35 (18.1)	21 (10.9)

1. Participants were advised to answer 'don't know' for experiences they had not encountered.

Item	No n (%)	Don't know ¹ n (%)	Yes n (%)
Secrecy			
Do you try your best to hide the fact that you have a history of mental illness?	62 (32.1)	22 (11.4)	109 (56.5)
Do you think it is a good idea to keep a history of mental illness secret?	46 (23.8)	23 (11.9)	124 (64.2)
Would you advise a close relative or friend who had been a patient with mental illness not to tell anyone about it?	60 (31.1)	37 (19.2)	96 (49.7)
Do you wait until you know a person well before you tell them you have a history of mental illness?	44 (22.8)	21 (10.9)	128 (66.3)
Do you try to prevent your colleagues and employers knowing that you have had a mental health problem?	57 (29.5)	27 (14.0)	109 (56.5)
Do you avoid telling the health care professionals that you have had a history of mental illness?	147 (76.2)	15 (7.8)	31 (16.1)
You are given an application form that requires you to provide information of your history of mental illness: do you leave that item out or reply that you have no history of mental illness?	50 (25.9)	42 (21.8)	101 (52.3)
Avoidance and withdrawal			
Do you avoid applying for a job if you know the employer does not like to hire people with previous mental illness?	59 (30.6)	29 (15.0)	105 (54.4)
Do you resign from a job if you know the employer does not like to hire people with previous mental illness?	114 (59.1)	31 (16.1)	48 (24.9)
Do you avoid dating and setting up a family because you have a history of mental illness?	113 (58.5)	40 (20.7)	40 (20.7)
Do you prefer to make friends with patients with previous mental illness?	72 (37.3)	58 (30.1)	63 (32.6)
After receiving psychiatric treatment, do you avoid making new friends?	150 (77.7)	22 (11.4)	21 (10.9)
After receiving psychiatric treatment, do you avoid going out with friends?	147 (76.2)	18 (9.3)	28 (14.5)
Do you avoid a friend because you know he or she will look down on someone with a previous mental illness?	66 (34.2)	31 (16.1)	96 (49.7)
Advocacy and confrontation			
Do you attempt to correct your friends if they hold negative views on people with mental illness?	41 (21.2)	33 (17.1)	119 (61.7)
Do you fight for equality (e.g. speak up, write to newspapers, complain to urban/legislative councillors) if you or other patients with previous mental illness are unfairly treated?	81 (42.0)	42 (21.8)	70 (36.3)
Do you complain to or seek help from self-help organisations for people with mental illness if you or other patients with previous mental illness are unfairly treated?	62 (32.1)	60 (31.1)	71 (36.8)
Do you participate in some social activities related to mental illness (e.g. educating the general public about mental illness)?	76 (39.4)	56 (29.0)	61 (31.6)
Do you refuse to resign from a job if you are asked to do so because of a history of mental illness?	63 (32.6)	49 (25.4)	81 (42.0)

1. Participants were advised to answer 'don't know' for experiences they had not encountered.



was disclosed. A survey conducted in the USA among people with schizophrenia receiving out-patient treatment found that stigma experiences were common, but actual discrimination was relatively less frequent (Dickerson *et al*, 2002). Half of those surveyed replied to the item 'Have you been treated as less competent by others when they learned you had received psychiatric treatment?' as occurring 'sometimes', 'often' or 'very often'. The proportions who similarly endorsed the items on being turned down for a job, difficulty in renting an apartment, denial of educational opportunities and exclusion from voluntary activities were 24%, 16%, 5% and 9%, respectively. These respondents indicated that they were generally treated fairly by others. This contrasts with a report, based on responses from 556 UK mental health care users, which showed that 56% experienced discrimination within the family, 51% from friends, 47% in the workforce and 44% from general practitioners (Mental Health Foundation, 2000). It is noteworthy that the UK survey had a relatively low return rate of 13%, which might have resulted in a self-selected bias. In our survey, the high level of functioning might partly account for the infrequent experience of rejection. Another explanation is that the respondents had avoided disclosing their mental illness history until they were confident of acceptance. A significant proportion of our sample said they coped with the stigma by advocacy and confrontation; however, their replies did not necessarily indicate actual behaviour.

Interpretation of the findings of our study is limited by its non-random sampling method. Personal experiences of stigma might have influenced study participation. It was our impression that very few of those eligible refused to participate, although the precise proportion could not be determined. We cannot exclude the possibility that the relatively infrequent report of actual rejection was due to the respondents' denial. The use of a self-report questionnaire in this study avoided the risk that the interpersonal setting of an interview might have limited the disclosure of experiences that were emotionally distressing; on the other hand, an interview might facilitate the emotional expression and reporting of stigma experiences. Another limitation is that our findings cannot be extrapolated to Chinese mental health users in other countries because of differences in societal attitudes towards both Chinese people and people with mental illness.

Our findings agree with published research that people with mental illness are faced with problems of stigma and struggle to cope with it every day (Wahl, 1999; Camp *et al*, 2002; Dickerson *et al*, 2002; Schulze & Angermeyer, 2003). However, we talked with some of the study participants after they had completed the questionnaire, and were encouraged by hearing of a few examples of cordial acceptance following disclosure of the participant's mental illness history. One person reported,

'I had never imagined my senior to be so supportive! One of my colleagues knew of my mental illness and looked down on me. During my recent admission to hospital, I told my senior about my illness. Not only did my senior accept my illness, my senior talked with the colleague who looked down on me and asked the colleague not to discriminate against people with mental illness.'

Many psychiatrists avoid telling patients with schizophrenia their diagnosis (Ono *et al*, 1999; Clafferty *et al*, 2001). This reluctance to impart the diagnosis may come from psychiatrists' paternalistic concern that the subsequent labelling could seriously harm the patient. Avoiding discussion of the diagnosis cannot help in tackling the problems related to psychiatric stigma. A major implication of our study is that mental health professionals can present a less gloomy picture of the public reaction towards people with mental illness. Patients should be given hope and advice on coping with the stigma. Cognitive-behavioural therapies and fostering empowerment are strategies that can assist individuals dealing with the self-stigma and social stigma of mental illness (Dickerson, 1998; Holmes & River, 1998).

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