

The Perceptions and Experiences of Discrimination of People with Mental Illness in Hong Kong

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**Equal Opportunities Commission
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Phase 1: Survey

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|----------------------|--|
| Questionnaire | 4 focus groups conducted according to an open-ended interview guide to formulate a conceptual framework and locally relevant items for the survey |
| Sample | <ul style="list-style-type: none">❖ Respondents came from 28 halfway houses and a public psychiatric outpatient clinic❖ A convenience sample of respondents receiving treatment for diabetes mellitus at a public diabetic center served as a control group |

Phase 1: Survey

Data collection

- ❖ The research assistant read out the questionnaire to groups of about 20 halfway house residents
- ❖ Respondents in the outpatient clinics completed the questionnaire in a quiet room by themselves

Period of study

June to July, 2001

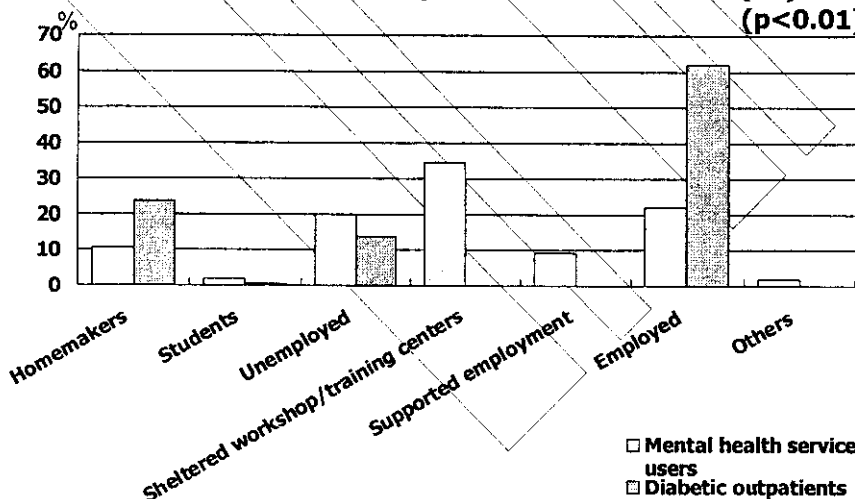
No. of valid questionnaires: 917

Phase 1: Survey

	Mental health service users	Diabetic outpatients
No. of respondents	757	160
Sex ratio	Male 53.5% (405) Female 46.5% (352)	Male 48.8% (78) Female 51.3% (82)
Age	39.7 (17-67)	41.0 (17-55)
Duration of illness	10.7 years (1-51)	7.9 years (1-26)

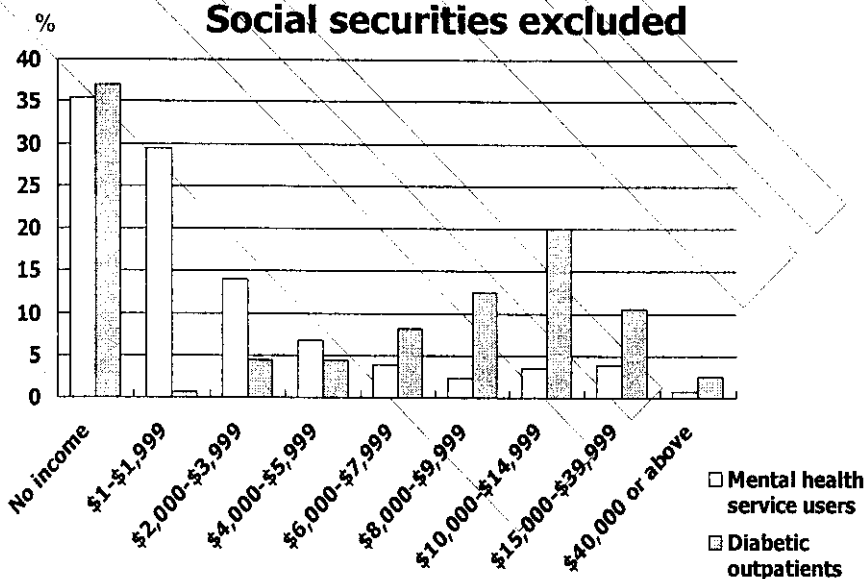
Employment status

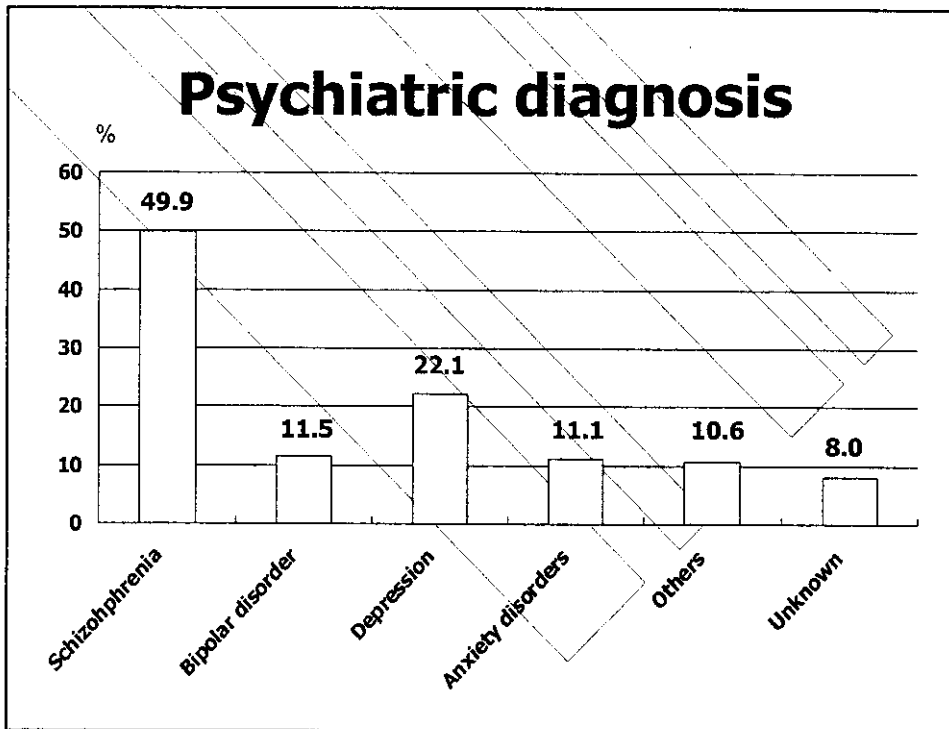
Employed Mental health service users 22.0% (165)
 Diabetic outpatients 61.9% (99)
 (p<0.01)



Personal monthly income

Social securities excluded





Phase 2: Case studies

Interviewees were recruited

Sample

- (1) from survey respondents who indicated a willingness to be interviewed after completion of the questionnaire
- (2) during the research assistant's additional visits to halfway houses
- (3) from a self-help organization for people with mental illness

Phase 2: Case studies

Interviewees were asked

- Method**
- to describe in detail one or more discriminatory experiences
 - explain how those adverse experiences affected their lives
 - what methods they used to cope with them
 - to make recommendations for improvement

Phase 2: Case studies

- Method**
- ❖ Each interview lasted about an hour
 - ❖ Interviews written up by the research assistant and principal investigator as a summary that contained narrative accounts of discrimination

Period of study October 2001 to March 2002

No. of interviewees: 50

Phase 2: Case studies

Mental health service users

No. of interviewees	50
Sex ratio	Male 50.0% (25) Female 50.0% (25)
Age	37.6 (19-57)
Duration of illness	14.1 years (2-39)

The experience of medical treatment

Did NOT know about the right of appealing to judge during compulsory admission

Mental health service users **83.7% (364)**

The experience of medical treatment

Having been referred to psychiatrists by non-psychiatric medical specialties for physical diseases

Mental health service users 21.3% (124)

Felt unreasonably tied up, injected medications, or locked up during non-psychiatric hospitalization

Mental health service users 21.9% (78)

The experience of medical treatment

(Results from phase 2)

Internal bleeding (later diagnosed as von Willebrand's disease) regarded as suicidal

Ms. E was infuriated and tried to explain to them, "If I attempted suicide, why did I come to the hospital by myself?" But the nurses didn't listen to her at all and replied, "How can you explain the bleeding in the esophagus if you only had a bowl of noodles? It's not unusual for a mental patient like you to attempt suicide. Perhaps you simply couldn't bear the pain and so you came to the hospital!"

Impacts of drug treatment

Having not been offered a job owing to the side effects of psychotropic drugs

Mental health service users 37.4% (133)

Work performance being impaired by the side effects of psychotropic drugs

Mental health service users 51.1% (206)

Impacts of drug treatment

Having been laughed at by colleagues/schoolmates owing to the side effects of psychotropic drugs

Mental health service users 37.7% (139)

Having been mistaken as lazy by the employer owing to the side effects of psychotropic drugs

Mental health service users 44.4% (154)

Impacts of drug treatment

Having been blamed by family members owing to the side effects of psychotropic drugs

Mental health service users 56.7% (207)

Impacts of drug treatment

Reduced the amount of / stopped taking psychotropic drugs owing to their side effects

Mental health service users 45.7% (199)

Did not attend psychiatric clinics owing to the side effects of psychotropic drugs

Mental health service users 25.9% (111)

Impacts of drug treatment

Relapse of mental illness because of not taking psychotropic drugs

Mental health service users 39.0% (164)

Impacts of drug treatment

Medical staff did NOT explain side effects to respondents when injecting psychotropic medications during psychiatric hospitalization

Mental health service users 76.8% (294)

Medical staff did NOT explain side effects to respondents when prescribing oral medications during psychiatric hospitalization

Mental health service users 64.8% (283)

Impacts of drug treatment

Had no right to choose drug treatment

**Mental health
service users** 66.6% (297)

Impacts of drug treatment (Results from phase 2)

" My limbs were rigid after I was given an injection of psychotropic medicines in the hospital. I was like a robot; I couldn't work well. My boss told me that my salary was halved because of my poor work performance. Also, the colleagues became rude and criticized me for being incompetent," Mr. F said.

Impacts of drug treatment (Results from phase 2)

"Often I felt drowsy and could hardly open my eyes. I was very uncomfortable after taking the drugs so that I needed a day off for rest sometimes," she recalled. It seemed to her that the drugs made her feel worse than the illness itself. As a result, she did not take the drugs when she felt she had no problem any more. "Doctors could hardly understand my feelings but kept asking me to comply with the prescription." Ms. S was eventually hospitalized in a mental hospital.

Employment

Having not been offered a job after illness was revealed

Mental health service users	45.1%	(180)
Diabetic outpatients	25.0%	(16)

Employment

Having been laid off after illness was revealed

Mental health service users	33.6%	(149)
Diabetic outpatients	4.9%	(4)

Work

Attitudes of co-workers / schoolmates deteriorated after illness was revealed

Mental health service users	36.9%	(197)
Diabetic outpatients	5.2%	(5)

Work (Results from phase 2)

Negative comments from colleagues

"It's like having a time bomb right beside me, and you have no idea when it'll explode!"

"How come you get so nervous over minor things! You should take more of your pills!"

"Oh yes, I think you should stay in the hospital, you're so sick! Just quit the job and take a rest there! Had some people not claimed that patients with mental illness could work normally, I'd never had hired you in the first place!"

Social relationships (family members and friends)

Disliked by family members and friends because of their illness

Mental health service users 35.7% (234)

Diabetic outpatients 3.9% (6)

**Social relationships
(family members and friends)**

**Received negative comments
from family members and friends during
relapse of illness**

**Mental health
service users** 60.0% (306)

**Family members and friends considered
respondents highly violent**

**Mental health
service users** 53.0% (275)

**Social relationships
(family members and friends)**

**Family members and friends
disliked others knowing about
respondents' illness**

**Mental health
service users** 68.8% (367)

Social relationships (family members and friends)

**Girl/boyfriend broke up with respondents
because of illness**

Mental health service users 29.2% (57)

Having been divorced because of illness

Mental health service users 36.7% (54)

Having been isolated by friends because of illness

Mental health service users 40.3% (151)

Social relationships (Results from phase 2)

To Mr. Z's great astonishment, his wife sent him a letter demanding divorce only a few months subsequent to the onset of his illness. Mr. Z was heart-broken. "I called my wife but she didn't answer the phone. She also didn't let my daughters talk to me on the phone. Later the social worker and I went to see her several times. But she refused to open the door and let me see my children. She just replied that there was no such person."

Media

The media should improve news reporting on mental illness

Mental health service users 50.8% (383)

Unwilling to be interviewed by the media

Mental health service users 60.4% (457)

Emotional reactions to discrimination

Felt second-class 47.5% (215)

Felt unworthy of living 36.1% (164)

Felt it was their own fault to have mental illness 34.0% (256)

Reluctant to develop close relationship with people 39.6% (180)

Felt bad about concealing mental illness 43.8% (262)

Limitations

The findings might not be generalizable to individuals who

- had milder mental illnesses
- came from a higher social class background
- sought private mental health service
- were well cared for by their family members (60% of subjects for the survey recruited from halfway houses)

Limitations

- Respondents' subjective report of the experience of prejudicial attitudes and/or unfair treatment rather than objectively or legally substantiated instances of discrimination may be subject to bias
- Lack of staff resources could have contributed to the insufficient explanation of treatment during brief outpatient visits, and the possible over-use of chemical or physical restraints relative to psychosocial interventions in mental hospitals

Limitations

- Anticipated discrimination was subjective and not equivalent to discrimination that already happened
- Further research must examine the context, impact, and validity of these forms of anticipated discrimination

Limitations

- Because of the low-income background and low marriage rate of the respondents, unfair treatment pertaining to medical insurance coverage, application of tourist visa, driving license and child custody could have been underestimated
- The findings might not reflect the most current situation as new measures have been taken by service providers, but do give a general picture of the experience of psychiatric discrimination in modern Hong Kong

Recommendations

- ❖ Inter-sectoral, systematic, sustained efforts should be instilled into channels of knowledge transmission to reduce discrimination and empower individuals with mental illness
- ❖ Government and other major social institutions should fund further studies and public awareness campaigns on psychiatric discrimination targeted at all levels of society using a multi-media approach

Recommendations

- ❖ Unfair recruitment practices and other work related discrimination should be urgently reviewed and rectified
- ❖ The condition requiring the absence of particular illness among jobholders should be assessed in light of the inherent job requirement
- ❖ The Government should take the lead to remove unjustified medical requirements imposed on job applicants

Recommendations

- ❖ The media should take the lead in forming a multi-sectoral working group (including the government, patient groups, and other stakeholders) to examine the role of the media in reducing the formation of prejudicial attitudes and acts toward persons with mental illness

Recommendations

- ❖ Major review of the adequacy of the present public and private psychiatric services in meeting the needs of people with mental illness in Hong Kong
- ❖ Involving patients and their families should be taken as an important policy initiative and any attempt to realize it, through formal and informal, government and non-government ways

Recommendations

- ❖ Formation of a Mental Health Council (including representatives from all major areas of mental health and primary care, patients and family) that advises the government on, and coordinates the implementation of, mental health policy, collects and analyzes mental health data, and safeguards patients' rights

Recommendations

- ❖ Review the need for medications that cause fewer side effects and have better efficacy in enhancing patients' well-being, using the professional standard of treatment in other similarly developed countries as a benchmark
- ❖ Provide more information on the clinical guidelines for drug prescription and the side effects of drug treatment to patients and family members

Recommendations

- ❖ Evaluate the adequacy and effectiveness of the 2,500 offers of new medications with respect to clinical efficacy, patients' well-being, and total cost of illness
- ❖ Evaluate whether the current process of informing patients about their basic rights pertaining to compulsory hospitalization has been implemented

Recommendations

- ❖ Integrate the client-base focus at all levels of training for staff involved in the treatment and rehabilitation of people with mental illness
- ❖ Built-in active elicitation of information on actual or anticipated discrimination in clinical evaluation
- ❖ Adverse impacts of psychiatric discrimination in planning community services should be considered to facilitate rapport building, promote patients' treatment adherence and enhance their sense of dignity

Recommendations

- ❖ More mental health services operate with flexible hours based in the community, primary care, and general hospitals
- ❖ Because private general practitioners constitute about 90% of the primary care medical service in Hong Kong and can facilitate destigmatization, flexible hours of service, and feasibility of early intervention, they should be provided with adequate training to deal with common mental disorders such as anxiety, depression and some of the early and more self-limiting psychotic disorders to help relieve the burden of mental health problems

Recommendations

- ❖ More programs should be developed for educating and empowering family members in the knowledge and skills of caring for individuals with mental illness
- ❖ One way of empowering them is to provide opportunities of consultation and participation in the formulation of policies and service provisions that are relevant to mental health issues

Recommendations

- ❖ Provide respite services (family members who cannot provide care temporarily due to work or other commitment) to help ease off unnecessary tension between the patients and family members