

Help-seeking Pathways for In-patients with First-episode Psychosis in Hospital Kuala Lumpur

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ABSTRACT

Introduction: Help-seeking pathway in psychiatry is the important link between the onset of a mental disorder and mental health service provision. Understanding of the help-seeking pathway can help us to devise more effective strategies for early detection and treatment. **Objectives:** To determine the help-seeking pathways and treatment delaying factors of in-patients with first-episode psychosis in Hospital Kuala Lumpur (HKL). **Methods:** This is a hospital-based cross-sectional descriptive study of 50 in-patients with first-episode psychosis in HKL. Structured Clinical Interview for DSM-IV - Clinical Version for Axis I Disorders (SCID-CV) was used for establishing diagnosis. Socio-demographic data, information on help-seeking pathways, and treatment delaying factors were determined through face-to-face interview and semi-structured questionnaires. **Results:** The number of non-psychiatric help-seeking contacts prior to first consultation with psychiatric service ranged from 0 to 10. The mean (\pm SD) number of contacts was 2.3 (\pm 2.6), and median was 1 (IQR = 0 to 3). About a third of them (32%) had three or more non-psychiatric contacts. The most common point of first non-psychiatric contact was with traditional healer 24 (48%), followed by general practitioners 12 (24%), and only 14 (28%) of them sought help directly from psychiatric service. The most common reason reported for delay in seeking psychiatric treatment was, "not aware that changes were related to mental illness" (74%). **Conclusions:** History of contacts with traditional healers was common among in-patients with first episode psychosis in HKL. Treatment delay was mainly contributed by factors related to lack of awareness on psychosis. More strategic mental health education program is needed for early detection and treatment of psychosis.

Keywords: Help-seeking pathway, first-episode psychosis, traditional healer

INTRODUCTION

Help-seeking pathway in psychiatry is an important link between the onset of a mental disorder and mental health service provision. Understanding of the help-seeking pathway can help us to devise strategies to improve detection and treatment of psychiatric disorder. The pathway to care commonly involves a progression from non-psychiatric services or even non-medical services to psychiatric services, with general practitioners having a potentially important role in the early recognition and referral of individuals with early psychosis. The pathways to care are variable, depending on the nature of the health care system and its financial and structural characteristics. There is a significant prevalence of 'never-treated psychosis' particularly in developing countries ^[1].

In a pathway to care study of 86 patients with schizophrenia spectrum disorders in Canada, a total of 194 contacts were made. The mean number of contacts per person was 2.3 and the range of contacts was from 1 to 6. The majority of contacts were made to emergency services (32.5%) and family physicians (22.7%). The majority of contacts were initiated by the patient (44%) and the family (34%). Health care professionals initiated 12% and friends, police and teachers accounted for the remaining 10%. The number of contacts it took to receive appropriate treatment varied. 33 were successful after one contact, 31 after two contacts, 18 after three contacts, eight after four contacts, 1 after five contacts and 3 after six contacts. The most common contact that resulted in successful treatment was emergency services (52%). Others were family physicians (18%), psychiatrists (18%), psychologist (8%) and family and friends (4%). The family most often initiated successful contacts (44%) followed by patients themselves (25%) and health care professionals (20%). Friends, teachers and the police accounted for the remaining 11% ^[2].

The pathways to appropriate care following the onset of a psychotic episode can be long, indirect and inefficient.

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A study in United Kingdom examined the pathways into the hospital system for people experiencing a first psychotic episode from a family's perspectives. It was found that: i) Appropriate services were not available to relatives when they were required, ii) Multiple contacts were made prior to admission, iii) Relatives usually made appropriate contacts initially but when these proved unsuccessful, they were forced to turn to more unusual contacts, and iv) Police contact was distressing for relatives but they were grateful when it led to hospital admission ^[3].

In a first-episode psychosis study in Australia ^[1], it was found that: i) The mean number of helping contacts with a variety of professionals and non-professionals prior to referral to a specialist center was 4.9 (range 1-17), ii) 55% of people had 4-6 contacts, iii) 16% had more than 6 helper contacts, iv) 36% of initial help seeking contacts were with a general practitioner (primary care physician) and 50% had seen a general practitioner at some stage prior to referral to the specialist center, and v) 50% were probably psychotic by the time they first sought help and another 37% were either manic or depressed.

In a pathway to care study of 182 patients with first-episode psychosis referred to early intervention for psychosis service in New Zealand, an average of 3.87 (SD = 6.81) attempts at help-seeking behavior were made in the 6 months prior to referral (range = 0-42). The majority (70%) of the sample had contact with a general practitioner or psychiatric outpatient clinic in the 6 months prior to referral. But these services were low sources of referral (7.7% and 16%, respectively). Most referrals (64%) came from inpatient services ^[4].

In a study at All India Institute of Medical Sciences (AIIMS) in New Delhi on patients with acute psychosis ^[5], data gathered from the outpatient psychiatric clinic showed that the first contact with helping agent was with traditional or religious healers (70%). Only 10% first sought help from the psychiatric service. The main reason for current consultation was onset or exacerbation of odd or threatening behavior (86%). The mean time interval between onset of these behaviors and treatment seeking was 14 days. Campion & Bhugra ^[6] studied the treatment methods and rituals performed by religious healers who were consulted by 45% of psychiatric patients before presenting to a psychiatric outpatient clinic in southern India, and noted that the medical literature seldom mentions traditional healers despite their importance as the first line of treatment in developing countries.

In a pathway to care study of patients with first-episode schizophrenia in 2 hospitals in Japan, Keio University Hospital (54 patients) and Oizumi Mental Hospital (29 patients), the referral pathways were compared. 40 patients (74.1%) came to the university hospital and 12 patients (41.4%) came to the mental hospital. At the mental hospital, nine patients (31.0%) had been admitted because of a legal obligation, and six (20.7%) had been referred through public health centers. None of the patients had been referred to either of the services by general practitioners. The main reason for seeking treatment was psychiatric symptom aggravation (59.3%) at the university hospital and acting out (64.3%) at the mental hospital ^[7].

In a study of pathway to psychiatric care for 35 patients with first-episode psychosis in Hong Kong ^[8], the mean number of help-seeking contacts before treatment was 1.06. Majorities were initiated by parents (24.3%) and patients themselves (29.7%). The most frequent first contact was through social workers (27.0%) and primary care physicians (27.3%). For the second contact, the most frequent choices were social workers (33.3%) and private psychiatrists (33.3%). The most common reason given for delay in seeking treatment was lack of knowledge about psychosis (74.3% in patients and 54.3% in family members).

In a pathway study of 5 East Asian countries (China, Japan, Korea, Malaysia and the Philippines) involving patients with schizophrenia ^[9], most Japanese subjects sought care in western medicine. Subject from Korea and China alternated between western medicine and magico-religious therapies or traditional herbal medicine. In the Philippines and Malaysia, the majority of the subjects sought magico-religious therapies first followed by western psychiatric care.

In a pathway to care study in Bali, 54 consecutive patients with no prior psychiatric treatment were investigated. Subjects who had sought help from traditional healers were asked to evaluate treatment effect retrospectively according to a 5-point scale. The pathway to psychiatric care was dominated by traditional healers. Of the patients, 47 (87.0%) consulted a healer (mean number 2.9) before visiting the mental hospital. Consultation with the healers was associated with treatment delay. However, of the 137 traditional healers on the pathway, 11 (8.0%) recommended that the subjects go to a mental hospital, and all of them immediately followed the advice. Of the 47 subjects, 14 (29.8%) evaluated the treatment effect as much improved by at least one traditional healer on the pathway, although they ultimately attended the mental hospital. Subjects without psychotic symptoms tended to evaluate the treatment effect as much improved more often than psychotic subjects. Traditional healers function not only as a barrier to reaching psychiatric care, but as either an effective provider of care or a decision-making support for seeking help from psychiatric care for some mental patients in Bali ^[10].

As for Singapore ^[11], 24% of the patients with first-episode psychosis had sought consultation with a traditional healer prior to consulting a psychiatrist. A study among Malays in Kelantan, a rural state of Malaysia showed that more than 80% of patients with mental disorders had consulted a traditional healer who also dissuaded these patients from seeking western medical treatment ^[12].

In a Kuala Lumpur pathway to care study by Koh^[13] in University Malaya Medical Center (UMMC), from the 100 patients with first-episode psychosis interviewed, 58% had never sought any form of treatment prior to coming to hospital. 9% had sought help from general practitioners, 14% from traditional healers, 10% from religious mediums and 6% from primary care/specialist clinics. Among those who did not seek any form of treatment prior to coming to hospital, 34% were male patients and 24% were female patients. Traditional healers or religious mediums were the preferred choice for both male (8%) and female (16%) patients. They were also the preferred choice of treatment for Malays (11%), Chinese (6%) and Indians (7%).

There was another local pathway to care study of first-episode psychosis and epilepsy among Malays by Razali & Salleh^[14] in Hospital Kubang Kerian, Kelantan. From the 120 out-patients with first-episode psychosis interviewed, 15% sought help directly from the hospital. 10% had sought help from general practitioners, 61.7% from traditional healers and 3.3% from other sources. There was significant treatment delay in patients with first-episode psychosis compared to those with epilepsy.

The objectives of this study are to determine the help-seeking pathways and treatment delaying factors of inpatients with first-episode psychosis in HKL. This has implication in designing better mental health services for early detection and treatment of patients with first-episode psychosis in Kuala Lumpur. This study is unique as it is conducted in a hospital that provides services in a highly urbanized area (i.e. Kuala Lumpur, the capital city of Malaysia), and is gazetted for involuntary psychiatric admissions. Furthermore, psychiatric admissions are totally free of charge as it is fully funded by the government.

METHODOLOGY

Location of study:

This is cross-sectional descriptive study conducted in the Department of Psychiatry & Mental Health, Hospital Kuala Lumpur (HKL). HKL is the largest hospital in the country and Kuala Lumpur is the capital city of Malaysia. HKL offers specialist psychiatric service, and is gazetted for compulsory psychiatric admission. Ethical approval for the study was obtained from the Medical Research & Ethics Committee, National University of Malaysia (UKM). Permission to conduct the study was obtained from HKL, and the study was registered with National Medical Research Registry (NMRR).

Sample:

A convenient sampling was conducted twice a week to identify newly diagnosed in-patients with first-episode psychosis. Patients with first-episode psychosis were those suffering from psychosis for the first time, and sought help for their psychosis from psychiatric service for the first time. The sampling period was a consecutive period of 4 months. The inclusion criteria were all in-patients with first-episode psychosis, including substance-induced psychosis and other organic psychosis. Those with language barrier, no family members around to verify history, and refused consent were excluded. Altogether 50 in-patients were recruited for the study.

Assessment:

The diagnosis of psychosis and different types of psychosis were based on all available clinical information and using the Structured Clinical Interview for DSM-IV Axis I Disorders – Clinical Version (SCID-CV). SCID-CV is a semi-structured interview for making the major Diagnostic & Statistical Manual of Mental Disorders, 4th edition (DSM-IV) Axis I diagnoses^[15].

Socio-demographic data, information on help-seeking pathways, and treatment delaying factors were determined through face-to-face interview and semi-structured questionnaire. In order to get more accurate history, the key friend or family members caring for patient prior to psychiatric contact were identified for interview. The researcher was conversant in English, Bahasa Malaysia, Cantonese and Mandarin. The language that was most comfortable to patients and family members was used for the interview and data collection.

Help-seeking pathway variables that were included in the study were: i) Number of non-psychiatric help-seeking contacts, ii) Most frequent point of first non-psychiatric help-seeking contact (i.e. traditional healers, general practitioners, clinical psychologist, counselors, social worker, telephone helpline etc.), iii) Number of help-seeking contacts with traditional healers (i.e. 'bomoh', monk, priest, ayurvedic or homeopathy practitioner, others.), v) The person who initiated the first non-psychiatric and psychiatric help-seeking contact (i.e. patient, friends, family members, employer, others), and iv) Adverse help-seeking pathway experience (i.e. those involving police, violent behavior and compulsory admission).

Factors contributing to delay in seeking psychiatric treatment that were assessed are: i) Not aware that behavioral changes were related to mental illness, ii) Believed that a doctor cannot help the condition, iii) Lack of knowledge about where or how to get help, iv) Lack of financial resources (i.e. for transport, consultation, medicine etc.),

v) Lack of time or nobody is free to accompany patient for treatment, vi) Concern about language barrier in communicating problem to doctor, vii) Concern about stigmatization (i.e. people will laugh or discriminate), viii) Concern about treatment (e.g. pain, side effects or confinement), ix) Considered that symptoms were not serious enough for treatment, x) Believed that symptoms would improve spontaneously, xi) Conflicting opinion with patient (i.e. patient refused to get help), and xii) Conflicting opinion with family members (i.e. family members disagreed to seek help).

Data analysis:

The data was analyzed using the Statistical Package for the Social Sciences (SPSS) version 12. Descriptive and non-parametric statistical tests were used for analysis. Statistical significance was set at $\alpha < 0.05$.

RESULTS

Socio-demographic data:

The age of the patients ranged from 15 to 70 years old. The mean (\pm SD) age was 33.1 (\pm 14.1) years old. Most of the patients fell into the age group of 21-30 years old (40%). As for gender, 31 (62%) were males, and 19 (38%) females. Most of them were Malay (22, 44.0%) followed by Chinese (14, 28.0%), Indian (6, 12.0%) and others (8, 16.0%). Only seventeen (34.0%) of them were married. As for the pre-hospitalization living arrangement, 48 (92.0%) of them were living with others, and 4 (8.0%) were living alone. Less than half (23, 46.0%) of the patients were employed.

Diagnosis:

Table 1 shows the DSM-IV diagnostic categories of the patients. When regrouped, 19 (38%) of the patients had Schizophrenia Spectrum Disorder (Schizophrenia & Schizophreniform Disorder), 6 (12%) had Mood Disorder (Bipolar I Disorder or Major Depressive Disorder) with psychotic features, 13 (26%) had Substance-Induced Psychosis, and 12 (24%) had other types of psychosis (Brief Psychotic Disorder and other organic psychosis). Three (6%) of the patients had a dual diagnosis of either Schizophrenia Spectrum Disorder or Bipolar I Disorder with substance abuse.

Table 1: DSM-IV Diagnostic categories of patients with first-episode psychosis

| Diagnosis | (N = 50) | (%) |
|--|----------|-----|
| Schizophrenia | 15 | 30% |
| Schizophreniform Disorder | 4 | 8% |
| Bipolar I Disorder with psychosis | 2 | 4% |
| Major Depressive Disorder with psychosis | 4 | 8% |
| Brief Psychotic Disorder | 6 | 12% |
| Delusional Disorder | 1 | 2% |
| Substance-Induced Psychosis | 13 | 26% |
| Other psychotic disorder | 5 | 10% |

Help-seeking pathway:

The number of non-psychiatric help-seeking contacts prior to first consultation with psychiatric service ranged from 0 to 10. The mean (\pm SD) number of contacts was 2.3 (\pm 2.6), and median was 1 (IQR = 0 to 3). About a third of them (32%) had three or more non-psychiatric contacts. The most common point of first non-psychiatric contact in help-seeking pathway was with traditional healer 24 (48%), 12 (24%) was with general practitioner, and only 14 (28%) of the patients sought help directly from psychiatric service. All the patients were admitted involuntarily under Form A. 23 (46%) of the patients were admitted with police assistance and 27 (54%) had violent behavior on admission. Figure 1 summarizes the key findings on help-seeking pathway of the patients.

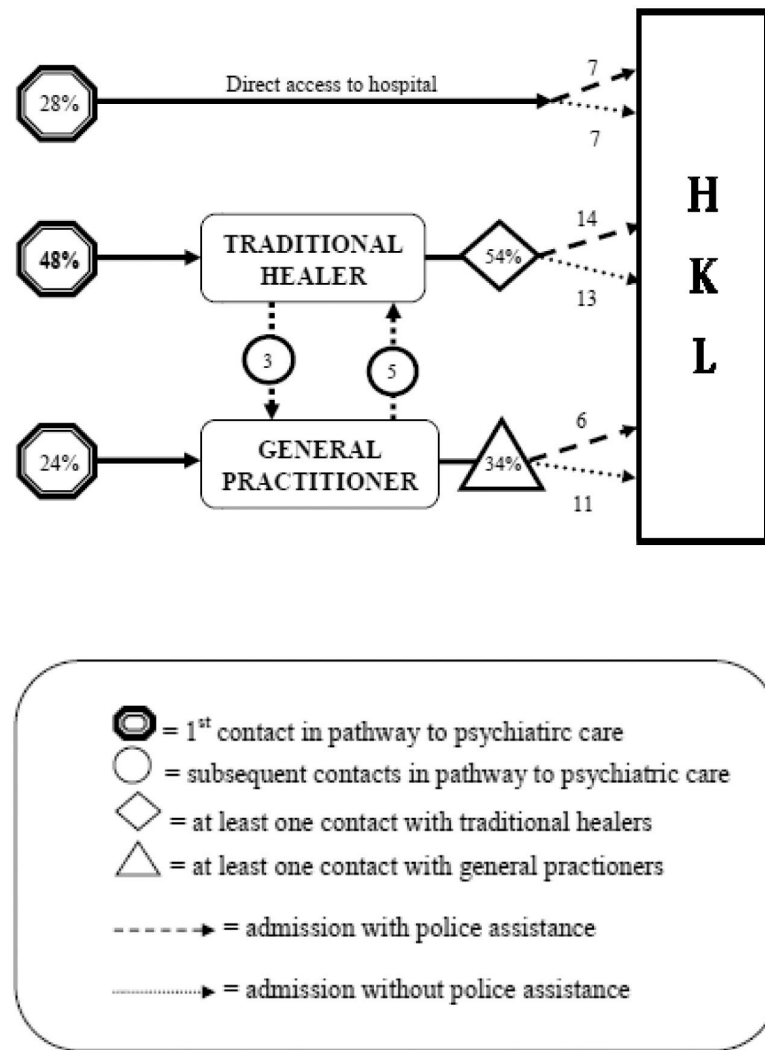


Figure 1: A summary of pathway to psychiatric care in Hospital Kuala Lumpur

Overall, 27 (54%) of the patients had at least one contact with traditional healer prior to their first consultation with psychiatric service. About a quarter of them (24%) had 3 or more contacts with traditional healers prior to consulting psychiatric service. History of contact with traditional healer was not found to be associated with age, gender, ethnic and education level ($P < 0.05$).

Most of the first non-psychiatric contacts in the help-seeking pathway were initiated by patients' family members (35, 70%), followed by public (7, 14%), employer (5, 10%), friend (2, 4%), and patients themselves (1, 2%). As for the first psychiatric contact, most were also initiated by family members (29, 58%), followed by public (14, 28%), employer (4, 8%), patient themselves (2, 4%) and friend (1, 2%). More public initiated first psychiatric contacts compared to first non-psychiatric contacts (28% vs. 14%).

Delay in seeking psychiatric treatment:

Reasons reported by family members for delay in seeking psychiatric treatment are summarized in Table 2. The top 5 reasons reported were, "not aware that changes were related to mental illness" (74%), "conflicting opinion with patient i.e. patient refused to seek psychiatric help" (72%), "believed that symptoms would improve spontaneously" (66%), "considered that symptoms were not serious enough for treatment" (56%), and "believed that a doctor cannot help the condition" (42%). "Conflicting opinion with patient" was significantly associated with history of contacting traditional healer (OR = 4.42, 95% CI = 1.15 to 16.96), and violent behavior on admission ($\chi^2_{1df} = 8.305, P = 0.004, OR = 7.33, 95% CI = 1.71 to 31.34$).

Table 2: Reasons reported by family member for delay in seeking help from psychiatric service

| Reasons for delay* | N (%) |
|---|-----------|
| 1. Not aware that changes were related to mental illness. | 37 (74%) |
| 2. Believed that a doctor cannot help the condition. | 21 (42%) |
| 3. Lack of knowledge about where or how to get help. | 2 (4%) |
| 4. Lack of financial resources for transport, consultation, medicine etc. | 5 (10%) |
| 5. Lack of time or nobody is free to accompany patient for treatment. | 4 (8%) |
| 6. Concern about language barrier in communicating problem to doctor. | 3 (6%) |
| 7. Concern about stigmatization – people will laugh or discriminate. | 8 (16%) |
| 8. Concern about treatment e.g. pain, side effects or confinement. | 13 (26%) |
| 9. Considered that symptoms were not serious enough for treatment. | 28 (56%) |
| 10. Believed that symptoms would improve spontaneously. | 33 (66%) |
| 11. Conflicting opinion with patient i.e. patient refused to seek help | 36 (72 %) |
| 12. Conflicting opinion among family members i.e. other family members disagreed with getting help. | 8 (16 %) |

* Can be more than one reason

DISCUSSION

In this study, 54% of the respondents had at least one contact with traditional healer prior to first contact with psychiatric service, with about a quarter of them (24%) having 3 or more contacts. In fact, traditional healers were the most popular choice of first non-psychiatric contact (48%). This is in contrast to a local study by Koh in the same city, whereby only 24% of the respondents had sought help from traditional healers prior to contact with psychiatric service [13]. A study in Singapore also showed that only 24% of the respondents had sought help from traditional healer before consulting psychiatrist service [11]. This may be explained by the relatively lower socio-economic status of respondents in this study, and therefore possibly their greater faith in traditional treatments. In-patient psychiatric service in HKL is completely subsidized by the government, thus may naturally attract more patients from the lower socio-economic group. Further studies are needed to validate this association.

Besides that, the relatively more hostile patients in this study could also possibly contribute to this; 54% of the patients were violent, 68% were verbally abusive, and all patients were admitted involuntarily under 'Form A'. So, family members could have difficulty in bringing patients to psychiatric service. In fact this study has shown that history of consulting traditional healer was significantly associated with refusal in seeking psychiatric help. Consulting traditional healers was much easier, as some of the healers were willing to do home visit or even consultation by proxy to offer treatments. This is of course much more convenient, and acceptable to patients and family members. Hence, consulting traditional healers was a more popular choice of first help-seeking contact (48%) as compared to general practitioners (24%) or psychiatric service (28%).

Local studies, [12, 14, 16] and several studies in other Asian countries such as Bali [10], the Philippines [9], and India [5, 6] has evidently supported the popularity of traditional treatments among patients as first line of option for treating mental illness. Mental health services in Malaysia often face competition from traditional healers. All three main ethnic groups in Malaysia have their own version of traditional healers; 'bomoh' for the Malays, 'vaidya' (ayurvedic physician) for the Indians, and 'sinseh' for the Chinese. Typical traditional treatments include the use of holy waters, prayers, religious rituals, herbs, massage etc. The popularity of traditional treatments could be influenced by the social stigma associated with mental illness, and cultural beliefs that accommodate the role of evil spirits, charms and other magico-religious factors in causing mental illness [19]. This is also understandable due to the relative lack of mental health resources and awareness in these countries. This is different from the pathways to care pattern observed in developed countries such as Japan [7], Canada [2], New Zealand [4] and United Kingdom [3] whereby health or social agencies are the more popular point of contacts prior to contact with psychiatric service.

In a developing country like Malaysia, whereby mental health professionals are very limited, we should consider having meaningful collaboration with traditional healers. This is in keeping with the Ministry of Health's policy to integrate traditional and complementary medicine in government hospitals. This had been started in 3 local hospitals; Kepala Batas Hospital in Pulau Pinang, Sultan Ismail Hospital in Johor Bharu, and Putrajaya Hospital for non-psychiatric disorders [17]. Some traditional healers may be helpful to formulate a more holistic concept of psychosis by integrating psycho-spiritual principles. The alternative neo-concept of psychosis may be more easily understandable

and acceptable for patients and family members, especially those from the lower socio-economic background.

Some studies have suggested that traditional treatments can be effective for treating neurosis among patients with mental disorders ^[12, 18]. Therefore, there can be mutual benefits when traditional healers and psychiatrists consent to collaborate with one another, even for psychotic disorders. Traditional healers can refer psychotic patients for acute management. On the other hand, psychiatrists can refer certain patients after a period of acute psychosis e.g. those with drug induced psychosis to traditional healers for follow-up and psycho-spiritual counseling. This may be better in terms of accessibilities and acceptance of treatment. In this way, workload of psychiatrists may also be reduced, without compromising on the effective care of patients with psychosis.

Direct access to psychiatric service (28%) was only the second most popular help-seeking pathway in this study after consultation with traditional healers (48%). The 3rd common pathway was through private general practitioners or government doctors in primary care clinics (24%). Overall, 34% of the respondents had seen at least one general practitioner prior to contact with psychiatric service. This is more or less similar to those reported in local and developing Asian countries e.g. University Malaya Medical Centre (UMMC), Kuala Lumpur, Malaysia (15%) ^[13], Hospital Kubang Kerian, Kelantan, Malaysia (10%), Singapore (26%) ^[11], Bali, Indonesia (18%) ^[10], Hong Kong (27%) ^[9], and India (20%). This is in contrast to those reported in more developed countries e.g. Australia (50%) ^[1], New Zealand (70%) ^[4], France (70%) ^[20], and Germany (66%) ^[21], whereby awareness on mental illness is better.

As concluded in many other studies, this provides further support that general practitioners and family physicians are important gatekeepers to direct patients with psychosis to psychiatric care. Therefore, the ongoing programs for educating general practitioners on psychosis should be encouraged and strengthened. Besides recognition of psychosis, emphasis should also be on how to skillfully negotiate with patients with psychosis to seek psychiatric help.

The most common reason reported by family members for the delay in seeking psychiatric treatment was “not aware that changes were related to mental illness” (74%). This is consistent with the study in Hong Kong ^[8] whereby “lack of knowledge about psychosis” was the reason given by 74.3% of patients, and 54.3% of family members. The second most common reason was, “conflicting opinion with patient i.e. patient refused to seek help” (72%). Related to that, 54% of the patients were physically violent, and 68% were verbally abusive on admission; 46% of the patients had to be admitted with police assistance, and all hospitalizations were involuntary admissions. Other common reasons reported were, “believed that symptoms would improve spontaneously” (66%), “considered that symptoms were not serious enough for treatment” (56%), and “believed that a doctor cannot help the condition.” (42%). These reasons are more or less similar to those reported earlier by Chiang in Hong Kong ^[8]. These notable findings suggest that factors related to lack of awareness on psychosis are central reasons for the delay in seeking psychiatric treatment.

These findings on treatment delay have several implications. First, family members need to be educated on recognizing psychosis at an early stage (when it is more easy to manage), and taught skillful ways of negotiating with patients to seek early psychiatric treatments. Second, they also need to know that seeking police help to bring patient for psychiatric treatment when other means have failed, is a wise option in long term, and they do not have to feel guilty about it. Third, dialogue between police officers and psychiatrists should be encouraged to highlight and appreciate the role of police officers in helping patients with psychosis, especially among those with violent behavior.

This study has several limitations. The sample size was small. It involved only in-patients in a highly urbanized area, many patients had substance-induced psychosis (26%), and all patients were admitted involuntarily. Therefore, the findings cannot be generalized to patients in other settings.

CONCLUSION

Contacts with traditional healers prior to consultation with psychiatric service were common among in-patients with first-episode psychosis in HKL. Treatment delay was mainly contributed by factors associated with lack of awareness on psychosis. More strategic mental health education program is needed for early detection and treatment of psychosis.

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