

Pathway to Care for Patients with First-episode Psychosis in Hong Kong

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Abstract

Objective: To describe the pathway to care for patients with first-episode psychosis in Hong Kong.

Patients and Methods: Thirty five consecutive patients attending the Early Assessment Service for Young People with First-episode Psychosis at Queen Mary Hospital were recruited. All patients were systematically interviewed about the issues relating to the help-seeking pathway before receiving treatment.

Results: A longer duration of untreated psychosis was associated with more clinical symptomatology than a shorter duration of untreated psychosis. A significant proportion of patients accessed the early assessment service directly. The most frequently reported first contact was a primary care physician or a social worker.

Conclusion: This exploratory study underlines the importance of engaging patients with first-episode psychosis and their relatives with primary care physicians and/or social workers for early intervention.

Key words: Hong Kong, Psychotic disorders

Introduction

Empirical studies have shown that the duration of untreated psychosis (DUP) of individuals with psychosis averages 1 to 2 years.¹⁻⁴ It has also been demonstrated that a longer DUP is associated with poorer outcome in terms of symptoms, functioning, and relapse.⁵⁻⁷ There are various potential obstacles to receiving prompt treatment, including patients' lack of insight, relatives' lack of information, fear of stigmatisation, withdrawal and poor social network, and accessibility of services.⁶⁻⁸ However, the majority of studies are based on western patients and few data are available for non-western groups.

Drake et al suggested that the help-seeking pathway is the critical link between the onset of a psychiatric disorder and service provision.⁶ The formulation of a help-seeking pathway model will enhance the understanding of psychiatric services, and suggest possible measures of improvement.⁹ For example, the Calgary pathway to care study examined the number of attempts patients with first-episode psychosis (FEP) made to obtain treatment before their arrival at the Early Psychosis Program.¹⁰ The mean number of contacts per person was 2.3, and patients sought help from emergency services (32.5%), primary care physicians (22.7%), psychologists (10.8%), psychiatrists (10.3%), and friends (5.2%). From this study, the investigators concluded that by improving the public and primary care professionals' recognition of early psychotic symptoms, the DUP could be shortened.

In Hong Kong, with a population of approximately 7 million, the Early Assessment Service for Young People with First-episode Psychosis (EASY) programme was established in 2001. The EASY programme accepts referrals of patients with FEP aged between 15 and 25 years. The service aims to improve the outcome for patients with early psychosis by the following approaches: media and public education about psychosis to enhance early detection (e.g., using posters, pamphlets, exhibition boards, and videos); early referral and assessment, open referral from medical professionals, or self-referral via a telephone helpline and the Internet; and comprehensive pharmacological and psychosocial management for identified patients and their carers.

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To date, no study performed in Hong Kong has examined the pathway to care for patients with FEP. This study reviewed the help-seeking pathways for patients with FEP and systematically explored the reasons for delay in seeking treatment for a consecutive group of patients attending the EASY programme.

Patients and Methods

Patients were recruited from the EASY programme at Queen Mary Hospital (QMH), which covers the catchment area of Hong Kong Island and East Kowloon. The catchment area population is approximately 1.9 million or 28% of the population of Hong Kong.¹¹ The study was approved by the ethics committee at QMH.

Patients

Consecutive patients assessed to be suitable for the EASY programme were recruited into the study. All patients were experiencing a first episode of psychiatric illnesses with psychotic symptoms. Patients with diagnoses of psychiatric illnesses caused by brain damage and dysfunction or physical diseases, or who had psychiatric disorders caused by psychoactive substance use were excluded from the study. A consensus diagnosis was made for each patient according to the *Diagnostic and Statistical Manual of Mental Disorders DSM-IV*¹² following interviews with the patients and their relatives, and relevant clinical information. Of 50 patients who satisfied the entry criteria, 35 gave informed consent and completed the interviews and assessments.

Assessment of Pathway to Care

The pathway to care was assessed by a semi-structured interview conducted by 2 of the investigators. The help-seeking pathway interview examined the duration of delay, reasons for delay, route to the first approach to the psychiatric service, reasons for the first consultation, and psychosocial assessment. The help-seeking behaviour section examined the alternative help that was sought before the approach for formal medical care; alternative help included Chinese medicine, self-prescribed herbal medicine, acupuncture, Qi-kung, massage, and religious help. The duration of these help-seeking behaviours and who had initiated each method were explored. The reasons for not approaching a psychiatrist at the first presentation of the symptoms were investigated.

The assessment instrument was developed by a panel of 2 psychiatrists, 2 psychologists, and 2 medical students. The instrument was tested and refined, and a final version was developed. At least 1 family member was present during the interview to confirm the information given by the patients.

Clinical Data

Clinical variables were assessed by the investigators using the Positive and Negative Syndrome Scale (PANSS),¹³ the Scale for Assessment of Positive Symptoms,¹⁴ and the

Montgomery and Asberg Depression Rating Scale.¹⁵ The side effects of treatment were assessed according to the Simpson-Angus Scale,¹⁶ the Abnormal Involuntary Movement Scale (AIMS),¹⁷ and the Barnes Akathisia Rating Scale (BARNES).¹⁸ The Interview for the Retrospective Assessment for the Onset of Schizophrenia¹⁹ was used to assess early symptoms and signs of schizophrenia. The quality of life of patients was evaluated by administering the Chinese version of the Short Form 36 Health Survey Questionnaire²⁰ and the Hong Kong Cantonese version of the World Health Organization Quality of Life Measure (WHOQOL-BREF [HK]).²¹

Statistical Analysis

The data were analysed using the Statistical Package for the Social Sciences. Descriptive statistics were used to portray the reasons for delayed treatment and the differential patterns of pathway to care were also described. In this study, patients were divided into 2 groups of long and short DUP using the median split of the DUP. Non-parametric U-test was conducted to compare the associated factors for delay in seeking help between the 2 groups.

Results

Of the 35 patients who completed the interview and clinical measurements, 14 (40%) were men and 21 (60%) were women. The mean age was 22.2 years (range, 16 to 30 years). Seven patients (20%) had a family history of psychiatric disorder. Eighteen patients (51.4%) had religious beliefs; 7 were Buddhist (20.0%), 7 were Christian (20.0%), and 4 were Catholic (11.4%). Eleven patients (31.4%) were students, 11 were unemployed (31.4%), and 13 (37.1%) were employed.

Pathways to Care

The mean number of help-seeking contacts before treatment in the EASY programme was 1.06. Thirteen patients (37.1%) made no help-seeking contacts, 10 (28.6%) made 1 contact, 9 (25.7%) made 2 contacts, and 3 (8.6%) made 3 contacts. Among the 35 patients, 11 contacts were initiated by parents (24.3%), 9 by the patients (29.7%), 4 by the school (10.8%), 3 by siblings (8.1%), 3 by friends (8.1%), 3 by non-psychiatric clinicians (8.1%), and 2 by community nurses (5.4%). Patients most frequently sought assistance from social workers (n = 10; 27.0%), followed by primary care physicians (n = 7; 18.9%), and private psychiatrists (n = 6; 16.2%). The most frequent points of first contact were social workers (n = 7; 31.8%) and primary care physicians (n = 5; 27.3%). For the second contact, the most frequent choices were private psychiatrists (n = 4; 33.3%) and social workers (n = 4; 33.3%). Most of the referrals to the EASY programme were made via the telephone helpline (n = 15; 42.9%), followed by referral from an accident and emergency department (n = 10; 25.7%), primary care physicians and private psychiatrists (n = 8; 22.9%), and the Internet (n = 2; 5.7%).

Figure 1. Pathways to care identified by the Early Assessment Service for Young People with First-episode Psychosis programme

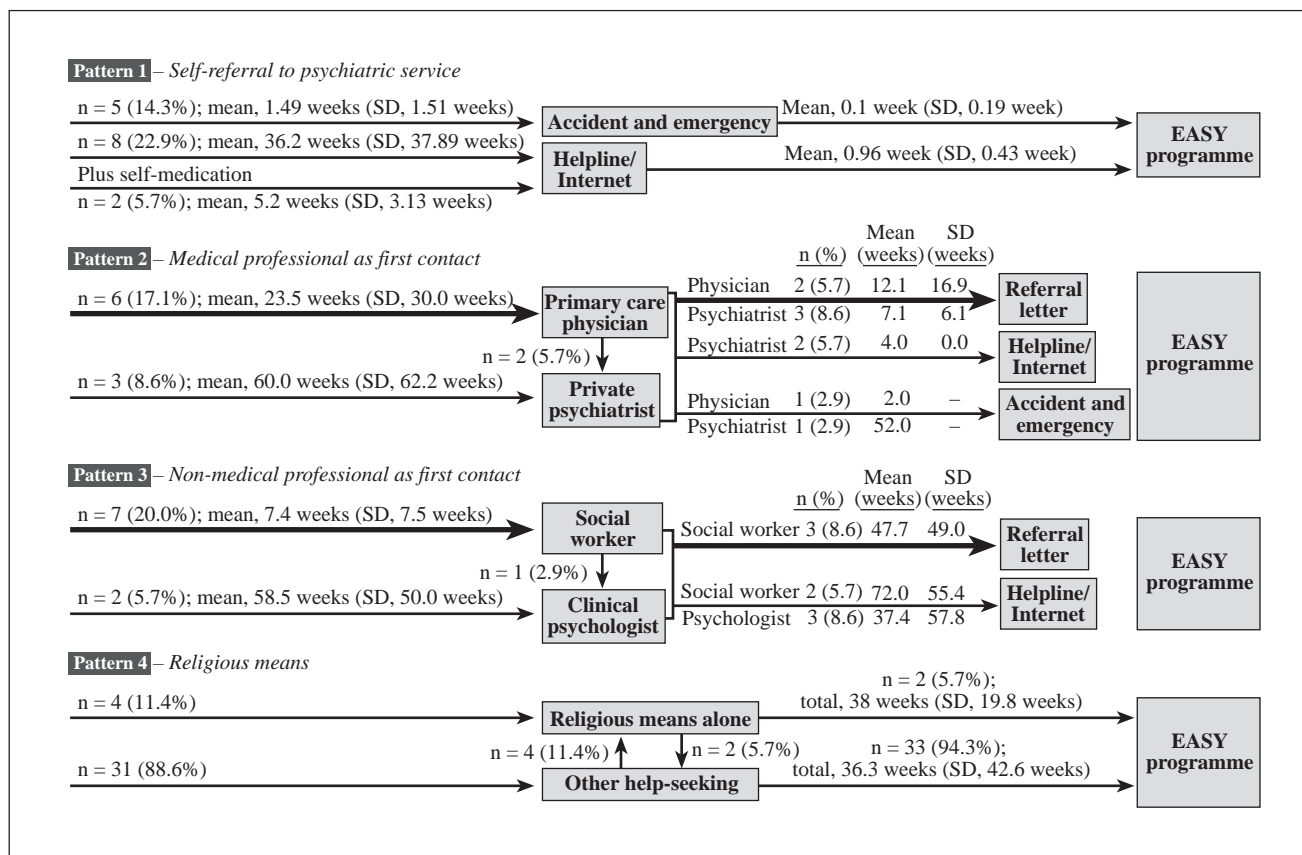


Figure 1 further illustrates the patterns of the pathway taken by patients to the EASY programme. Four different pathways were identified: self-referral, referral by a medical professional, referral by a non-medical professional, and referral via a religious source.

There were 2 main sources for self-referral to the EASY programme: through an accident and emergency department (n = 5; 14.3%) and via the telephone helpline or Internet service (n = 10; 28.6%). For those patients referred from an accident and emergency department, the mean DUP was approximately 1.49 weeks (SD, 1.51 weeks). Patients referred via this route took approximately 0.1 week (SD, 0.19 week) to receive initial service at the EASY programme.

Patients who accessed the service through the helpline or Internet could be further divided into medication-naïve (n = 8) and self-medicated patients (n = 2). The mean DUP for medication-naïve patients was 36.2 weeks (SD, 37.89 weeks) and that for self-medicated patients was 5.2 weeks (SD, 3.13 weeks). Patients referred via this route took approximately 0.96 weeks (SD, 0.43) to receive initial service at the EASY programme.

Patients referred by medical professionals had initially approached a primary care physician (n = 6; 17.1%) or private psychiatrist (n = 3; 8.6%). The mean DUPs for approaches to a general practitioner or private psychiatrist were 23.5 weeks (SD, 30.0 weeks) and 60.0 weeks (SD, 62.2 weeks), respectively. After their initial contact with the medical professionals, 5 patients (14.3%) were directly

referred to the EASY programme, 2 (5.7%) were given further information from the telephone helpline/Internet service, and the remaining 2 (5.7%) attended the accident and emergency department before being referred to the EASY programme. The DUP for patients attending a private psychiatrist was the longest at 60.0 weeks, followed by self-referral via the telephone helpline/Internet (36.2 weeks), referral via a general practitioner (30.0 weeks), and self-referral via the accident and emergency department (1.49 weeks).

Seven patients (20.0%) approached a social worker and 2 (5.7%) approached a clinical psychologist as first-line help for psychotic symptoms. The mean DUP for approaching a social worker was 7.4 weeks (SD, 7.5 weeks) and that for approaching a clinical psychologist was 58.5 weeks (SD, 50.0 weeks). Not all patients using this approach were referred directly to the EASY programme for intervention. These approaches resulted in the longest referral time to the EASY programme. Four patients (11.4%) sought help through religious means alone, whereas the other 31 (88.6%) received other means of local rituals. All of these patients finally accessed the EASY programme via the telephone helpline.

Reasons for Delay in Seeking Help

Reasons offered by patients and relatives for the delay in seeking help are summarised in Table 1. The most common reason given by patients for the delay was “lack of knowledge

about psychosis" (74.3%). This was also the most common reason given by the family member for the patient's delay in seeking help (54.3%). Other reasons given by the patients for the delay in seeking help included "did not consider that the changes were related to mental illness" (40.0%), "symptoms were not serious" (37.1%), and "symptoms would improve spontaneously" (31.4%). This was different

Table 1. Reasons given by patients (n = 35) and family members for the delay in seeking treatment.

Reason for delay*	Patients	Family members
Lack of knowledge about psychosis	26 (74.3%)	19 (54.3%)
Belief that a doctor cannot help the condition	5 (14.3%)	2 (5.7%)
Did not consider that the changes were related to mental illness	14 (40.0%)	7 (20.0%)
Lack of knowledge about how to seek help	7 (20.0%)	3 (8.6%)
Lack of financial resources	2 (5.7%)	2 (5.7%)
Lack of time	3 (8.6%)	1 (2.9%)
Felt help-seeking was too troublesome	3 (8.6%)	0 (0.0%)
Concern about stigmatisation	6 (17.1%)	1 (2.9%)
Concern about receiving treatment	6 (17.4%)	N/A
Considered that symptoms were not serious	13 (37.1%)	5 (14.3%)
Believed that symptoms would improve spontaneously	11 (31.4%)	1 (2.9%)
Presence of comorbid illness	2 (5.7%)	N/A
Conflicting opinion with patient	N/A	6 (17.1%)
Conflicting opinion with other family members	N/A	2 (5.7%)
Not aware of patient's symptoms	N/A	7 (20.0%)
Others	3 (8.6%)	5 (14.3%)

* Some patients had more than 1 reason. Some questions were relevant only for the patients and some were only relevant for the family member.

from the perspectives of family members for the delay in seeking help. For example, the majority of reasons given by family member for the delay in seeking help included "did not consider that the changes were related to mental illness" (20.0%), "not aware of patients' symptoms" (20.0%), and "conflicting opinion with other family members" (17.1%).

Duration of Untreated Psychosis

The mean DUP in this group of patients was 393.41 days (SD, 751.04 days; range, 0 to 3504 days; median, 122 days). There were no significant correlations between DUP with age of onset, sex, or symptom scores (PANSS, AIMS, BARNES, WHOQOL-BREF [HK]). In a further analysis, patients were divided into 2 groups depending on the DUP; the median DUP of 122 days was used as the cut-off value. Patients with a DUP of up to 122 days were defined as short DUP (n = 17), and patients with a DUP of more than 122 days were defined as long DUP (n = 18). There were significant differences for PANSS positive and PANSS social impulsivity scores between the 2 groups, as shown in Table 2. High levels of positive symptomatology and impulsivity were associated with a short DUP; the effect sizes for the 2 scores were in the moderate and high range, respectively. Table 3 summarises the main reasons for psychiatric consultation for these patients. The most frequently reported reasons for psychiatric consultation were open self-referral capability and bizarre behaviours. This finding suggests that the EASY programme creates an accessible channel for patients with psychosis to seek early professional help.

Discussion

This study analysed the help-seeking pathways for FEP in Hong Kong. There are several notable findings. Firstly, the results show that a significant proportion of patients directly access the EASY programme. This open-referral pathway is an innovative feature of the service and the data confirm that it has been used effectively by patients. Among the patients who seek help from other contact points prior to their referral to the EASY programme, the most frequent first contact is through family physicians and social workers. This finding is different from the observations of the Calgary study, which showed that the most frequent first contacts

Table 2. Comparison of clinical symptoms between patients with short and long duration of untreated psychosis.

Clinical symptom	Short duration of untreated psychosis		Long duration of untreated psychosis		p Value	Effect size
	Mean (SD)	Median (range)	Mean (SD)	Median (range)		
PANSS positive	23.57 (6.54)	24.00 (13.00-38.00)	18.43 (5.56)	17.50 (9.00-27.00)	0.04	0.85
PANSS negative	20.71 (6.06)	19.00 (11.00-31.00)	17.29 (4.78)	16.00 (8.00-25.00)	0.11	0.63
PANSS global psychopathology	42.57 (19.94)	40.00 (18.00-81.00)	37.07 (10.06)	37.50 (21.00-54.00)	0.64	0.37
PANSS social impulsivity	7.21 (3.53)	6.50 (3.00-13.00)	3.71 (1.07)	3.00 (3.00-6.00)	0.01	1.52
PANSS total	94.07 (32.36)	95.50 (50.00-150.00)	76.50 (18.67)	75.00 (45.00-109.00)	0.23	0.69

Abbreviation: PANSS = Positive and Negative Syndrome Scale.

Table 3. Factors that led to engagement with early intervention service

Reason*	Number (%)
Accessible self-referral means	18 (51.4%)
Unacceptable behaviour	12 (34.3%)
Insomnia	12 (34.3%)
Advised by family	10 (28.6%)
Depression/anxiety	9 (25.7%)
Self-harm	6 (17.1%)
Advised by friend	5 (14.3%)
Advised by doctor/clinical psychologist/ social worker	5 (14.3%)
Suicide risk	4 (11.4%)
Violence	3 (8.6%)
Severe impairment in functioning	3 (8.6%)
Alternative help ineffective	2 (5.7%)
Burden to family	2 (5.7%)
Unemployment	2 (5.7%)

* Some patients had more than 1 reason.

were through family physicians and emergency services.¹⁰ This finding highlights the importance of social workers as gatekeepers for patients with early psychosis in Hong Kong. This is particularly important for patients still in the education system as most of the secondary schools in Hong Kong have a social worker on campus. Educational efforts directed towards social workers should constitute an important component in further efforts to achieve a reduction in DUP. Another important finding from this study is that patients with FEP with positive symptoms tend to have a short DUP. This agrees with many studies that have reported that successful contacts are influenced by symptoms, particularly positive symptoms and suicidal ideas/attempts.¹⁴

There are a number of limitations to this study. Firstly, although a systematic approach with the use of standardised instruments and a semi-structured interview was adopted, the pathway data are based on patients' descriptions and are subject to recall bias. To enhance validity, all the data were confirmed by at least 1 family member who was present during the interview. Secondly, the sample size was modest and further study with a larger group of patients would be beneficial. Nevertheless, the current findings are important for guiding the formulation of early detection strategies.

The findings highlight the role of relatives and patients in seeking help. Continued public education about psychosis, thereby improving the knowledge of potential patients and their relatives, would be an important component in an overall strategy to achieve early detection of psychosis. This study also identified social workers and general practitioners as the key gatekeepers for patients with psychosis in the community. It is important for these professionals to recognise the early symptoms of FEP and effect prompt referral. Lastly, the data provide an account of improved

access through the telephone helpline. It is noteworthy that a number of patients identified improved access as a factor that facilitated their presentation. Service design should therefore aim to reduce logistic and administrative barriers to seeking medical care for FEP.

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