THE PATHWAYS TO HEALTH CARE
A Comparison Between Psychotic Illness And Epilepsy

DR MOHD AZHAR BIN MOHD YASIN

Dissertation Submitted In Partial Fulfillment Of The Requirements For The Degree Of Master Of Medicine (Psychiatry)

UNIVERSITI SAINS MALAYSIA
2006

DEDICATION

A special dedication goes to

My dear wife, Dr Noor Suryani Mohd Ashari

Who gives a full support during the course and during the preparation of this

Dissertation, and my beloved children Nurul Ain Aqilah, Nurul Alya Atiqah

And Muhammad Amir Syauqi for

Their loved and patience.

ACKNOWLEDGEMENTS

In the name of God, Most Gracious, Most Merciful

I would like to acknowledge Prof. (Dr) Hj. Mohd Razali Salleh, my supervisor for his close and expert supervision throughout my study and the preparation of this draft. My sincere appreciation goes to Ass. Prof. Hjjh Hasanah Che Ismail, head of psychiatric Department, Hospital Universiti Sains Malaysia for her guidance and concern before and during my study.

I would like to thank the research assistants, Ms Rosnani Salleh and Ms. Norlizawati Mahmood@Ismail for their hard working and to the lecturers, colleagues, staffs and others who involve either direct or indirectly in helping me to complete this dissertation.

I am also thankful to Pn. Nurul Bariah Hassan for her permission to use the questionnaires on patients' satisfaction, and to Ass Prof. Dr. Syed Hatim Noor and Dr Kamarul Imran Musa (Lecturers in Medical Statistic) and Dr Ismail Ibrahim (Lecturer in Community Medicine) for helping me in statistical analysis.

Last but not least to patients and their relatives, thank you for your participation and cooperation.

TABLE OF CONTENT

Acknowledgements		III
Table of contents		IV
List of diagrams, figures and tables		VI
List of abbreviations		VII
Abstract	: English	VIII
	Bahasa Malaysia	XI

1. Introduction and Literature review

1.1 An overview of psychotic illness and epilepsy	1
1.2 Mental health services in Malaysia	9
1.3 The concept of Pathway to care	26
1.4 Studies on pathways to care among psychiatric patients	32
1.5 Studies on pathways to care among epileptic patients	37
1.6 Traditional, complementary and alternative medicine in Malaysia	39

2. Objective

2.1 General objective	55
2.2 Specific objective	55
2.3 Hypothesis	56
2.4 Flow chart	58

3. Methodology

3.1 Study population 59

3.2 Research Design and sample size calculation 59

3.3 Study period and setting 61

3.4 Sampling technique 61

3.5 Inclusion criteria 61

3.6 Exclusion criteria 62

3.7 Definitions 62

3.8 Procedure 65

3.9 Instruments 65

3.10 Statistical analysis 68

4. Results 69

5. Discussion 86

6. Conclusion 96

7. Limitation 98

8. Recommendation 100

9. References 103

10. Appendices 116

Appendix A Semi-structured Questionnaires
Appendix B Structured Clinical Interview for DSM-IV
Appendix C DSM-IV criteria for Schizophrenia
Appendix D DSM-IV criteria for Schizophreniform disorder
Appendix E Map of Kelantan State
Appendix F Consent Form

LIST OF DIAGRAMS, FIGURES AND TABLES

CHAPTER 2	Page
Diagram 2.1, Hypothetical pathway	56
Flow chart	58
CHAPTER 4	
Table 4.1, Sociodemographic variables of psychotic and epileptic patients	69
Figure 4.1, Distribution of patients and type of pathways	72
Diagram 4.1, Summary of pathways to health care	74
Table 4.2, Sociodemographic characteristic and pathways	76
Table 4.3 (a), Consultation of traditional/alternative healers and diagnosis	77
Table 4.3 (b), Consultation of traditional/alternative healers and diagnosis	78
Table 4.4, Sociodemographic variables of decision makers	79
Table 4.5, Factors that influenced the consultation of traditional/alternative healers	81
Table 4.6, Contact Delay (CD) and Treatment Delay (TD) of psychotic patients	82
Table 4.7, Contact Delay (CD) and Treatment Delay (TD) of epileptic patients	83
Table 4.8, CD and TD of epileptic and psychotic patients who had consulted traditional/alternative healers	84
Table 4.9, CD and TD of epileptic and psychotic patients who had not consulted traditional/alternative healers	85

LIST OF ABBREVIATIONS

HUSM	Hospital Universiti Sains Malaysia
HKB	Hospital Kota Bahru
CP	Contact Point
TP	Treatment Point
DUP	Duration of untreated psychosis
DUI	Duration of untreated illness
CI	Confidence interval
OR	Odd Ratio
SD	Standard deviation
Med	median
SPSS	Statistic Package for social Sciences
e.g	'exempli gratis' / example
i.e	that is to say
et al	and the rest
etc.	'et cetera' / others

ABSTRACT

INTRODUCTION: Identifying the pathways which patients take to reach health care is important, as patients' experience of the first pathway to care may determine their future compliance and progression of the illness. Understanding the type of pathways, which patients take and the associated factors that influence the selection are crucial information for future intervention to improve the quality of health care. Studies on pathways to care were sparse and pathways to care among local psychiatric patients had not been explored.

AIM: The aim of the study was to describe the pathways to health care of psychotic patients (schizophrenia and schizophreniform disorder) to the tertiary health center (psychiatry and medical specialized clinics in HUSM); and to examine the demographic, social, clinical and other factors influencing the pathway to care. Similar assessments were done in epilepsy patients for comparison.

METHOD: The number and type of previous healers (modern and traditional) visited by patients since onset of illness were assessed using multiple sources of information in 60 psychotic (schizophrenia and schizophreniform disorder) and 60 epileptic patients attending the respective specialist clinics for the first time during the study period. The pathways taken by the patients before reaching the clinics were explored by using semi-structured interview questionnaires and charted on a common diagram. Patients' sociodemographic data, details of the illness, and information regarding the decision makers were also gathered during the interview from patients, and family members

RESULTS: Sixty patients in each psychotic and epileptic group entered the study; all of them were Malays. Schizophreniform disorder formed the majority (76.7%) of the psychotic patients. Four types of pathways were identified from the studied population. The pathway involving consultation of traditional and/or alternative healers was the most popular (44.3%) and was significantly higher in psychotic than epileptic patients. 61.7 % and 26.7 % of the psychotic and epileptic patients consulted traditional and/or alternative healers respectively. Most of them consulted Malay traditional healers (bomoh) and only 2 patients consulted homeopathic practitioners in addition to bomoh. Other pathways were direct access (24.2%), which was the second most popular, followed by private General Practitioner (18.3%), and other government's doctors (13.3 %). Direct pathway was equally represented by patients from both groups, while General practitioner and other doctors pathways were predominated by epileptic patients. The demographic variables between those who had consulted traditional and/or alternative healers and those who did not were not significantly different. Belief in supernatural caused of mental illness and availability of traditional and/or alternative healers were the factors that significantly influenced the decision of seeing traditional and/or alternative healers. There was no significant different in contact delay between the diagnostic groups. There was significant difference in treatment delay between epileptic and psychotic patients regardless whether they had consulted or not consulted traditional and/or alternative healers.

CONCLUSION: Epileptic and psychotic illness such as schizophrenia and schizophreniform disorder have a slight different pathway in help seeking behavior. A

significant higher number of psychotic than epileptic patients consulted traditional/alternative healers. As a complementary treatment in Malay society, bomoh is more popular than the well-established alternative medicine in treating such illness. The author concluded that the study of pathway to health care could provide a framework for better understanding of health services utilization and the associated factors that affect the services utilization. The effects of socio-cultural belief on the studied population were not much different as compared to the findings from the earlier studies. Hence there is a need for further understanding about traditional, complementary and alternative medicine and collaboration between traditional/alternative and modern health services.

ABSTRAK

PENGENALAN : Mengenalpasti langkah yang diambil oleh pesakit untuk mendapatkan rawatan kesihatan adalah penting kerana pengalaman pertama pesakit terhadap rawatan boleh menentukan pematuhan dan perkembangan penyakit mereka. Memahami jenis langkah yang diambil dan faktor berkaitan yang mempengaruhi pemilihan mereka adalah maklumat penting dalam campur tangan untuk meningkatkan kualiti rawatan kesihatan. Kajian mengenai langkah-langkah untuk mendapatkan rawatan amat sedikit dan langkah untuk rawatan dikalangan pesakit psikiatri masih belum diselidiki.

TUJUAN : Tujuan kajian ini dijalankan untuk menerangkan langkah-langkah mendapatkan rawatan kesihatan oleh pesakit psikotik (skizofrenia dan ganguan skizofreniform) di pusat kesihatan tinggi (klinik pakar perubatan dan psikiatri di HUSM) ; dan untuk menilai data demografi, sosial, klinikal dan faktor-faktor lain yang mempengaruhi langkah mendapatkan rawatan. Sebagai kajian perbandingan, penilaian sama dilakukan ke atas pesakit epilesi.

KAEDAH : Bilangan dan jenis pengamal perubatan (moden dan tradisional) yang dikunjungi oleh pesakit sejak mula mendapat penyakit dinilai menggunakan pelbagai sumber maklumat dari 60 pesakit psikotik (skizofrenia dan skizofreniform) dan 60 pesakit epilepsi yang mendapatkan rawatan di klinik pakar masing-masing pada lawatan pertama semasa dalam tempoh kajian.

Langkah yang diambil oleh pesakit sebelum sampai ke klinik diselidiki menggunakan soalan soal-selidik separa struktur dan di cartakan dalam bentuk diagram am. Data sosiodemografi pesakit, butir-butir penyakit, dan maklumat mengenai penanda keputusan juga dikumpul semasa pesakit dan ahli keluarganya ditemuramah, maklumat mengenai penanda keputusan juga dikumpulkan semasa temuduga dijalankan ke atas pesakit dan ahli keluarga.

KEPUTUSAN : Kesemua enam puluh pesakit dalam setiap kumpulan psikotik dan epileptik yang menyertai kajian ini adalah Melayu. Majoriti pesakit psikotik (76.7%) adalah pesakit ganggguan skizoreniform. Empat jenis langkah dikenalpasti dari populasi kajian, jenis langkah yang diambil melibatkan merujuk dengan pengamal perubatan tradisional dan /atau alternatif, adalah yang paling popular (44.3%) dan lebih tinggi secara signifikan bagi pesakit psikotik berbanding psikiatri epileptik (61.7%) daripada pesakit psikotik dan (26.7%) pesakit epileptik berjumpa dengan pengamal perubatan Melayu (bomoh) Kebanyakan mereka merujuk pengamal perubatan Melayu (bomoh) dan hanya dua orang merujuk kepada pengamal homeopati selain dari bomoh. Langkah-langkah lain adalah berhubung terus (24.2%), kedua popular diikuti oleh yang melibatkan Pengamal Perubatan Swasta (18.3%) dan langkah lain melibatkan doctor kerajaan (13.3%) Kedua-dua kumpulan mempunyai persamaan dlam langkah berhubung terus, sementara itu, langkah untuk berjumpa pengamal perubatan am dan doktor-doktor lain lebih kepada kumpulan pesakit epileptic. Pemboleh ubah demografi antara mereka yang merujuk pengamal perubatan tradisional dan /atau alternatif dengan mereka yang tidak merujuk kepada mereka tidak menunjukkan perbezaan yang signifikan.

Kepercayaan mengenai fenomena ghaib sebagai punca penyakit mental dan ketersedia ada pengamal perubatan tradisional dan alternatif ini menjadi faktor penting mempengaruhi keputusan untuk merujuk kepada pengamal prubatan tadisional dan alternatif ini. Tiada perbezaan yang signifikan bagi kumpulan diagnostik dalam langkah lambat berhubung. Terdapat perbezaan signifikan dalam lambat mendapat rawatan antara pesakit epileptic dan psikotik tanpa menghiraukan samada mereka merujuk atau tidak pengamal perubatan tradisional /alternatif.

KESIMPULAN: Penyakit epileptic dan psikotik seperti skizofrenia dan gangguan skizofreniform mempunyai sedikit pewbezaan dalam langkah yang diambil untuk mendapatkan bantuan. Bilangan pesakit epileptik dan psikotik ayng merujuk pengamal tadisional/alternatif lebih tinggi secara signifikan. Bomoh popular dikalangan masyarakat Melayu sebagai rawatan sampingan untuk mengubati penyakit berbanding perubatan altrnatif yang lebih terkenal. Penyelidik menyimpul bahawa kajian mengenai langkah mendapakan rawatan kesihatan boleh menyediakan satu rangka kerja untuk lebih memahami penggunaan seris kesihatan dan faktor sodio-budaya yang mempengaruhi perkhidmatan tersebut. Kesan kepercayaan sosio-budaya dalam pupulasi kajian tidak berbeza dibandingkan dengan penemuan dari kajian awal. Oleh itu, pemahaman yang lebih mendalam mengenai peubatan tradisional, sampingan dan alternatif dan juga kerjasama antara perkhidmatan tradisional/alfternatif dan kesihatan moden amat diperlukan.

CHAPTER 1

1. INTRODUCTION

The study of pathway to care is important. Various studies in different population, ethnic and countries have noted wide variation in pathway to care, factors that contributed to the variation and delay. The information gathered from the study is useful to improve the health system delivery and promote early intervention. Malaysia as a multi racial country has a diversity of traditional healers practicing beside the modern medicine practitioners. Local studies (Razali, 1989; Razali & Najib, 2000) revealed that psychiatric and even medical patients consulted traditional healers before came to the hospital and this resulted in delay in visiting the hospital. Development of mental health services had its impact on our country, such as introduction to community psychiatry services since 1980s and emergence of newer drugs. Pathway study at the present time would enable us to appreciate and assess the effectiveness of the psychiatric services development. The present study also include epilepsy patients as a comparison group due to the fact that this illness was associated with stigma and involvement of traditional healers in the pathway of care.

1.1 An overview of psychotic illness and epilepsy.

Psychotic illness (such as Schizophrenia and schizophreniform disorder) and epilepsy have many common features, chronically disabling and relapsing characterized both natural course. Even though their clinical features were difference but layman

knowledge, attitudes, and perceptions about epilepsy and psychotic illness were influenced by cultural believes.

Schizophrenia

Schizophrenia is a major psychiatric disorder characterized by a disruption in affective, cognitive and social domains, resulting in a compromised ability to adapt to a changing environment and function adequately in the community. The point prevalence, expressed as number of cases per 1000 persons at risk, is estimated at between 1.4 and 1.6 and the lifetime prevalence ranges from 0.5% to 1.0% of the population (Jablensky, 1995). In addition to association with severe functional impairment, the disorder is associated with significant morbidity and mortality; approximately 10% of patients will die by suicide (Drake & Cotton, 1986).

According to the current neurodevelopment models of schizophrenia, the disorder may already begin during prenatal development despite the usual psychotic manifestation between the ages of 18 to 25.

The male onset preceded the female for about five years; the incidence in men peaks during the age of 20 to 25 while the peak incidence in women occurs between 25 and 35 years. However its effects on men and women is in equal frequency.

It is hypothesized that a failure occurs during the period of cell migration, leading to non-optimal connections between brain areas. The onset of the psychotic symptoms is so

much later, when the affected part of the brain matures (Weinberger, 1987). The onset of the psychotic episode may be abrupt or insidious, but the majority of individual display some type of prodromal phase manifested by the slow and gradual development of a variety of signs and symptoms (e.g., social withdrawal, loss of interest in school or work, deterioration of hygiene and grooming, unusual behavior, outburst of anger) eventually a symptoms characteristic of active phase appears, marking the disturbance as schizophrenia. Before a patient in the stable phase relapse, there is usually a prodromal period in which there may be nonpsychotic dysphoric symptoms, attenuated form of positive symptoms, or idiosyncratic behaviors. This prodromal period usually lasts for several days to a few weeks but may last for several months (Heinrichs & Carpenter, 1985; Subotnik & Nuechterlein, 1988).

Rates of employment, marriage, and independent living are significantly lower among schizophrenia patients as compared to general population, which reflecting the functional impairments they experience (Loranger, 1984). Several first-episode studies of schizophrenia suggest that many patients experience psychotic symptoms for a long time before receiving appropriate treatment.

The symptoms of schizophrenia are often classified as positive and negative (Andreasen and Olsen 1982). Both types of symptoms can cause special problems in social functioning and contribute to the stigma because of schizophrenia. In most patients with schizophrenia, positive and negative symptoms are present in different proportions at different periods of the illness.

Most longitudinal studies of schizophrenia suggest that its course is variable, with some individual free of further episodes, the majority displaying exacerbations and remissions, and a small proportion remaining chronically severely psychotic (Harding et al, 1987; Tsuang et al, 1981). Inter-episode residual symptoms are common, majority of patients alternate between acute psychotic episodes and stable phases, with full or partial remission. The complexity of clinical presentation, course, and severity of schizophrenia makes its treatment and long-term management particularly challenging. For patients presenting with their first episode of schizophrenia, prompt diagnosis and intervention may be critical in optimizing long terms of symptoms remission, time to psychotic relapse, and prevention of psychosocial deterioration.

Lieberman (1993) suggested that schizophrenia could be regarded as progressive encephalopathy, such that the longer patients experience the symptoms the more likely they are to suffer lasting impairment. Indeed Mc Glashan and Fenton (1993) suggested that the process that makes schizophrenia a lifelong disorder might be most active during the early stages of the illness.

A number of prospective studies in which patients were followed up to 11 years after the initial onset of their illness found that, after an initial phase of deterioration, patients tended to stabilize (Duke et al, 1984; McGlashan, 1984; Carpenter & Straus, 1991). In fact majority of the deterioration is likely to take place in the early stages of their illness – during the first 5 to 10 years, emphasizing the importance of early intervention.

Schizophreniform disorder

Gabriel Langfeldt first coined the term in 1939 to classify a group of psychotic patients with good prognosis. It represented an attempt to classify patients who had been described as schizophrenic but who did not display deterioration in overall functioning. Schizophreniform disorder was not included in Diagnostic and Statistical Manual (DSM) I or II. It was first included in DSM -III (1980). DSM-IV defines schizophreniform disorder as identical to schizophrenia with the prime exceptions of duration of illness and the requirement for deterioration in social or occupational functioning. During the acute episode, psychotic symptoms including delusion, hallucination, disorganized thinking, and catatonic behavior may all be present, as in schizophrenia, but the total episode of disturbance including prodromal, active, and residual phases is defined as between one and six months duration.

Community studies have reported a lifetime prevalence of schizophreniform disorder of approximately 0.2 percent and one year prevalence of 0.1 percent. The age of onset is similar to schizophrenia (adolescence and early adulthood), while little information is available concerning sex, race or social class distribution.

Of the existing hypotheses concerning the pathophysiological mechanism of schizophreniform disorder, dopamine receptor supersensitivity is probably the leading candidates. Biological and laboratory markers validating the presence of schizophreniform disorder and distinguishing it from other forms of psychiatric illness

have not appeared. In several studies computed tomography (CT) scans failed to detect significant differences between patients with schizophreniform disorder and those with schizophrenia although both types of patients displayed increased ventricular brain ratio. When patients are actively hallucinating and delusional, antipsychotic medications are the psychopharmacological agents of choice, while benzodiazepines may be used as an adjunct for anxious and agitated state. Studies showed that patients with Schizophreniform disorder responded faster than schizophrenic to antipsychotic medication. Many studies show that more than half of schizophreniform disorder patients are reclassified at follow up as suffering from schizophrenia and according to the American Psychiatric Association, approximately two thirds of patients diagnosed with schizophreniform disorder progress to a diagnosis of schizophrenia.

Epilepsy

Epilepsy is the most common serious neurological disorder worldwide, affecting about 50 million people. In most people with epilepsy, the disorder is clinically benign. However, because of the stigma associated with having epilepsy, which is common to many cultures, there can be a negative effect on the social identity of people with the disorder, particularly for those living in resource-poor countries (Jacoby et al, 2005).

The incidence of epilepsy in general is between 11 and 49 per 100,000 people. The prevalence of epilepsy is about 9%, or one in eleven individuals. The prevalence of recurrent seizures or epilepsy is one in two hundred or .5%. The incidence of epilepsy is greatest during the first year of life. The second peak begins at about age 55.

The motor manifestations can consist of rhythmic jerking movements, stiffening of limbs, loss of postural control or falling. Sensory manifestations can consist of sensory hallucinations, tingling feelings, feelings of numbness in the limbs or the face. The psychological manifestations can be bonafide hallucinations, they can be olfactory hallucinations, the smell of burning rubber tires or rotten apples, or it can be a pleasant olfactory experience.

There are two systems of classifying epilepsies. The most commonly used system is the International Classification of Epileptic Seizures. The International Classification of Epileptic Seizures distinguishes between partial seizures and generalized seizures, partial seizures involve only a portion of the brain at the onset. They can be further divided into two types; simple partial, in which consciousness is not impaired and complex partial, in which consciousness is impaired. Both types of partial seizures can spread resulting in secondarily generalized tonic-clonic seizures. Generalized seizures are those in which the first clinical changes indicate that both hemispheres are initially involved. Consciousness usually is impaired during generalized seizures, although some seizures, such as the myoclonic type, may be so brief that impairment of consciousness cannot be assessed.

The first step in diagnosing epilepsy is through careful, detailed history taken from the patient, or from witnesses, family members and friends. The next step in diagnosing epilepsy is to get an EEG, a brain wave test. The EEG pattern will help us define what we suspect clinically

In children, idiopathic seizures constitute 45 - 55% of seizures. In adults, 15- 24 % of epilepsies are idiopathic. In children, the cause or etiology of the seizures can be due to perinatal injuries. This if followed by events related to prematurity, metabolic conditions that occur in newborns, genetic factors, metabolic disorders and finally, trauma. In adults, strokes, brain tumors, dementias, brain degeneration and trauma comprise the etiologies of symptomatic epilepsies

In addition to injury and status epilepticus, the concern was about the embarrassment of those that have seizures. Patients with epilepsy are at higher risk for certain types of psychiatric disorders and behavioral symptoms. People with epilepsies are still discriminated against both in terms of obtaining insurance and keeping a job. Many people cannot afford to have a seizure. They could lose their source of income, and their ability to support a family. Basic goal in treatment of epilepsy is to prevent seizures, but not with that goal only in mind, because it is not enough to just suppress seizure activity. Treatment also has to focus on quality of life. Medications that are so sedating would interfere with one's ability to process information and work and they feel awful all the time. That just doesn't make sense. The treatment aimed to effectively control the seizures and to maintain the individual quality of life that they want.

According to study by Pal et al in 2002 worldwide 85–94% of people with epilepsy are not in treatment with antiepileptic drugs (AEDs) This statistic, known as the treatment gap, varies across countries of Asia, Africa, and the Americas. Each region faces, now or in the future, its own problems in assessing the public health impact of the condition, the

needs of people with epilepsy, effective ways to meet these needs, the reform of discriminatory legislation, and so on.

A crude statistic such as the treatment gap conceals many possible explanations for non-treatment, ranging from difficulty in access to personal preference. In general terms, a high treatment gap in a particular region might be explained by one or more of three scenarios: (a) No AED treatment is available; b) Treatment is available but difficult to access, because of cost, geographic, cultural, or knowledge barriers; or (c) AED treatment is accessible but people prefer other types of treatment, or even prefer no treatment. It has been suggested recently, although without supporting evidence, that the existence of indigenous practitioners will retard efforts to close the treatment gap by using allopathic treatment.

The evaluation and understanding of pattern of consultation exists (pathways to health care), to identify healers, and associated factors are important basis for planning appropriate intervention for these illnesses.

1.2 Mental health services in Malaysia

Malaysia is a tropical country in the heart of South East Asia with a population of 24 million people of diverse ethnic, cultural and religious backgrounds living in harmony in 330,000 km^2 of land on the Asian mainland and Borneo. Malaysia, which lies on the crossroads of trade between east and west Asia, has an ancient history as a center of trading attracting commerce between Europe, west Asia, India and China. It has had

influences from major powers that dominated the region throughout its history. Today the country, after independence in 1957, has embarked on an ambitious development project to make it a developed country by 2020.

In this effort the economy has changed from one producing raw material to one manufacturing consumer goods and services and the colonial health system has been overhauled and social systems strengthened to provide better services for its people. The per capita income, which was under 1,000 US dollars at independence, has now passed 4,000 US dollars and continues to grow, with the economy largely based on strong exports that amount to over 100 billion US dollars.

The earliest mentioned of mental health services in Malaysia was made by Wad and Grant (1830) in a report, which mentioned the presence of lunatic asylum near the regiment hospital, Penang. Before 1952, the Central Mental Hospital in Tanjung Rambutan, Perak was the only mental health service catering for the whole country. In 1957 the mental health service was based on institutional care in four mental hospitals throughout the country (Razali, 2004).

Since the implementation of community psychiatric service there is now a healthy development of mental health services. This is being supplemented by a newly established primary care mental health service that covers community mental health by integrating mental health into primary health care. The first project to extend mental health care to the community was started in 1976 with the formation of the Community

Health Unit in the Ministry of Health. The processes began with psychiatric team from the psychiatric unit of general hospital run clinic at the district hospital. The mobile teams provided the medications and follow-up of discharged patients.

The progress was slow and the status remained the same 10 years later. The situation was the government to appoint a foreign consultant to study the magnitude of the problem. In 1987 the World Health Organization (WHO) consultant in mental health, Dr. Alen German was invited to study the status of psychiatric services in the country. In his report which is not officially released to the public; Dr German highlighted that mental health was not given a priority and lagged behind other health services as compared to other developing countries. There was not enough decentralization and psychiatric units were segregated away from mainstream of the general health care delivery system. Psychiatrist was still not part of health care team and it remained esoteric and misunderstood (Razali, 2004).

Although the report did not specifically comment about community psychiatric services, it was obvious that community psychiatric services were at the infancy stage and lack of integration of the services into primary (general) health care system. The view is shared by Nordin a mental health personnel in Hospital Bahagia, the largest mental institution in the country. Observing the data from Hospital Bahagia with an increasing number of patients being discharged from the hospital; he questioned to what extent that these patients would get appropriate care from health workers or even mental health personnel (Razali, 2004).

Consolidation of the psychiatric services

As a follow-up to Dr German's report, the Ministry of Health studied various models on decentralization of mental health program into the primary health care system. The process involved upgrading the psychiatric services, restructured the function of primary health care services and legislatively drafting a new Mental Health Policy. In term of training, a practical approach would be to plan strategies and equip primary health care workers with knowledge and skill of mental health management.

In upgrading the psychiatric units, priority was given to improve the rehabilitation and community services facilities such as renovation of day care centre. Other than conducting peripheral clinic for new and followed up of old cases, the unit also started basic community and rehabilitation programs such as conducting carer support groups, home services, health education and promoting day care centre. In major psychiatric units, they have sheltered workshop and run advanced community services. In a general hospital in the southern part of peninsular for instance, the community services is too advance to the extent that it does not require psychiatric ward; majority of the patients were managed in the community. Recently the Ministry of Health was conducted a pilot project to study the feasibility of setting-up day care centre in the rural area.

In term of training, more numbers of professional in mental health field and paramedical groups were sent for further training in this sub-specialty. The primary health care service is an integral part of the country's health systems and forms the first level of contact of

people with health care system. The system which has been developed since independence was a two-tier system which consists of a health centre and rural (community) clinic. The integration of mental health care into primary health care services means that mental health components are incorporated into the work of primary health workers in health centre, peripheral clinic and hospital. They would be also involved in the management of psychiatric patients at all level.

The integration involved two major processes: to impart mental health skills to the primary skills to the primary care workers and restructured the function of primary care facilities to deal with psychiatric patients more effectively. Recently the government has introduced a postgraduate program in Family Medicine in the local university and recognized it as a specialist qualification. Under the new organization of the primary health care services, a family medicine specialist will be in-charge of the health center; before that it was headed by a medical officer (medical graduate without post-graduate qualification) the family medicine specialist because they had enough psychiatric exposure in their four-year training program. The health center now would receive new psychiatric patients as well as old patients for follow-up. Previously new psychiatric case was considered as alien and quickly referred to a nearby psychiatric unit; while follow-up cases will be seen by the visiting psychiatric at a selected district hospital only.

The integration also will reduce stigmatization because psychiatric patients could mix together with other patients and shared the same facility with them.

In a related development, the Parliament of Malaysia recently passed the Mental Health Act 2001 to replace Mental Health Ordinance 1952 and similar ordinances operating in East Malaysia. The new act which emphasized on community psychiatry rather than institutional care are also incorporated measures to improve the quality of psychiatric services, protect the right of citizens from forced psychiatric admission and prevent the abuse of mentally disordered person.

Current situation

Like many other countries, primary care setting has been the first-line provider for health services in Malaysia. In advanced healthcare systems, primary care also has become central to our mental health needs. This has been in line with the introduction of community psychiatric services and the move towards decentralization of psychiatric services. The decentralization "of mental health services implies that mental health care should be made available at the community, district, and regional levels through psychiatric in- and out-patient units linked to the general medical facilities. Integration of mental health care into the general health service means that the mental health component should be incorporated into the work of the primary health worker, the community health centre, district and regional health centres and hospitals." (WHO, 1975).

The deinstitutionalization witnessed a large number of patients with chronic mental disorders returning to their family and the psychiatric units of general hospitals become overcrowded. The families look after the vast majority of mentally ill patients who return home because no other centre is available for them. At present there is no private

psychiatric hospital in Malaysia. Although a limited number of half-way houses run by non-government organizations (NGO) for temporary settlement available, they are not a viable alternative to cater for the increasing number of chronic schizophrenia in the community.

Deinstitutionalization shifted much the burden of care of chronic schizophrenia from the mental institution to the family. Acceptance of the mentally ill is believed to be good on the whole and is considered a great source of support for the overstretched psychiatric services in Malaysia. Some family members suffered considerable stress in looking after their chronically mentally ill relatives. Despite their burden, they did not complaint about it; they did their best to cope with patients' disturbed behavior.

In an earlier study among the carers of Malay schizophrenic patients, it was found that about 23% of them developed neurotic disorders resulting from the stress; nearly half of them neurotic depression. The stress is closely related to the product of active psychosis and they were generally able to tolerate negative symptoms of schizophrenia.

Some of the family members outrightly rejected their mentally ill relatives or fabricate the story of their failure in managing them in order to get sympathy from mental health workers. Since no other alternative available, the rejected patients ended up wandering in the street. Some of them were admitted to the Old Persons' Home of the Ministry of Welfare and Social Development for protection. Most of them ended in frequent admissions and discharge that contributes to the revolving door syndrome. In a related

study, the author found that 73% of the inmates of the Old Persons' Home in the country were not in geriatric age group; 27.5% of them were suffering from psychiatric illnesses that need treatment and the other 15.3% were chronic schizophrenia. More than 95% of them had mental illness prior to the admission.

The two related problems demonstrate the failure of deinstitutionalization processes and community management. The Old Persons' Home should not be a dumping ground for rejected schizophrenic patients. The accumulation of schizophrenic patients in Old Persons' Home is described as the phenomenon of transinstitutionalization: the replacement of one custodial institution, the psychiatric hospital with another. Lamb and Shaner (1993) described the same phenomenon in USA involving psychiatric patients admission to prison.

The planning of community services should satisfy the needs of this group of schizophrenic patients. The greatest oversight of deinstitutionalization is failure to provide a therapeutic living environment. Poorly integrates program will expose discharge patients to disadvantages. Managing chronic schizophrenia in the community is a great challenge to the government in health care reforms.

The deinstitutionalization was flawed because the shift from institutional to community based living was not associated with clear systemic planning or adequate placed support system in the community. Although the decentralization of the psychiatric services in the country had been implemented more than 40 years, facilities for rehabilitation and

community management of discharged chronic mental patients are still lacking. Most of the discharged patients went back home without going through rehabilitation process or transitional living units. Majority of the relatives did not receive advice from health professionals on the management of difficult behavior at home. Both the patients and their families were not prepared for community management. The patients are forced to stay with their families whether they like it or not and the family members have no other choices, they should accept them. Lack of rehabilitation and community cares facilities and inadequate staff in all the categories was the root of the problem. The difficulties faced by psychiatric patients to access to psychiatric services due to lack of integration between the psychiatric and primary health care system aggravated the problem.

There are several factors that contribute to barriers to diagnosis and treatment of psychiatric disorder in primary care settings (Geringer, 2004).

A. Patient factors

1. A patient may present with a somatic complaint and minimize the mood component of the illness. For example, a chronic pain patient who states, "I'm depressed because of my pain. Wouldn't you be?"
2. A concurrent medical illness often obscures psychiatric symptoms. Examples include anorexia in a depressed cancer patients and anxiety in a patient with cardiac arrhythmia.
3. Denial of psychiatric issues or their mood symptoms may occur. A patient may present with a full complement of depressive symptoms but deny feeling sad.

4. Stigma and shame leads to fear of a mental health diagnosis or treatment.
5. The belief that psychiatric referral will lead to abandonment by the primary care provider.
6. The belief that psychiatric illness is untreatable
7. The belief that psychiatric drugs are mind-altering and/or addictive is common.
8. The belief that treatment will be too expensive is also common.

B. Physician factors

1. Often there is a lack of time to make an accurate diagnosis during an appointment.
2. Fear of being embarrassed and inadvertently stigmatising a patient, especially if that patient becomes emotional and upset.
3. There often is uncertainty about when and how to make an appropriate referral for psychiatric services.
4. There may be fear that the patient will have an illness that is unresponsive to treatment.
5. The physician may have had prior negative experiences in which psychiatric doctors were seen as unavailable, uncommunicative, or unresponsive.
6. There may be a lack of knowledge about the appropriate diagnosis, drugs, and duration of treatment.

The stigma towards mental illness is still common in developing countries including our country. Most public are reluctant to visit the psychiatrist for fear of being labelled as 'mad'. This is due to the common belief among the public that psychiatrists only treat people with severe mental illness (Razali, 1998).

Some preferred to seek traditional treatment rather than consulting a psychiatrist because of their belief that mental illness is caused by supernatural power. By studying the community's attitude towards mental illness, it can give us the idea on the seriousness of the problem (Razali, 1998).

Razali et al (1996) had studied the concept of aetiology of mental illness in 134 Malay patients in Kelantan, Malaysia. About 53% of the patients attributed their illnesses to supernatural agents whereby witchcraft and possession by evil spirits were regarded as the common causes. This belief was not significantly associated with age, gender, and level of education or occupation of the patients. The number of patients who believed in supernatural causes of their mental illness was significantly higher among those who had consulted 'bomoh' (traditional healer) than among those who had not consulted them. The patients who believed in supernatural causes of their mental illnesses were also found to show poor drug compliance.

The belief that mental illness is caused by evil spirits and witchcraft has also been observed in other cultures and religions. Pfeiffer (1994) had conducted a study on 343 mainly Protestant outpatients of a psychiatric clinic in Switzerland and reported that

37.6% of them believed that influence of evil spirit could be the possible cause of their problems, labelling this as 'occult bondage' or 'possession'. Exploration of patients' belief in demonic forces showed primarily a desire to explain their symptomatology in terms of their subcultural and religious values. Patients with schizophrenia frequently explained auditory hallucinations or delusions of being influenced as the work of demonic forces, whereby the depressed patients interpreted their lack of interest and joy in religious activities as a sign of demonic influence. He also reported that 30.3% of them sought help through ritual prayers and exorcism.

In Singapore, Kua et al (1993) studied the illness behaviour of 100 Chinese psychiatric patients. He reported that 22% of the patients believed that they were possessed by spirit. The patients sometimes explained possession as due to a charm cast on them or having stepped on a spirit accidentally or "on something dirty". This belief was held more in women than men, and is not related to educational background. He also found that 36% of the patients had consulted a traditional healer before coming to hospital, even those who did not believe in possession.

Joel et al (2003) had done a study on community health workers in South India using a case vignette and reported that a significant proportion of them did not recognize chronic psychosis as a disease condition, believing that it was caused by black magic, evil spirits and poverty, and felt that doctors could not help.

Negative attitudes towards mental illness will not only influence the treatment-seeking behaviour, but will also interfere with the implementation of community-based care in our country. With the shift towards deinstitutionalization and community-based psychiatric care, the general public is coming into increasing contact with the mentally ill and their attitudes will influence on the acceptance of the mentally ill and their social integration into the community (Wolff et al, 1996).

A popular belief among the public is that the mentally ill people are aggressive. Therefore, the family or caregivers would insist for the patient to be admitted to the ward. These are the people who would be difficult to be convinced of the availability of acute home-based treatment by the community psychiatric staff. If this problem persist, then it would be difficult for our country to move towards the deinstitutionalization as in the developed country.

In this study, patients attending the psychiatric and medical specialist clinics of Hospital Sains Malaysia in Kubang Kerian, Kelantan were studied to determine the pattern of pathway to health care and to examine the factors that associated with the selection of the pathways. The findings obtained could be used to help in planning the psychiatric services at primary care level and also in identifying to whom and which aspect of mental illness that should be emphasized in awareness or educational program.

Hospital Universiti Sains Malaysia, Kelantan

Kelantan is situated in north-east of penisula Malaysia, between Thailand in north and states of Terengganu, Pahang, and Perak . Its covers a land of 14,922 square kilometers. Kelantan consists of ten districts namely Kota Bahru, Bachok, Machang, Pasir Puteh, Tanah Merah, Tumpat, Kuala Kerai, Jeli and Gua Musang. Kota Bahru is the state capital, which located at the bank of Kelantan river.

The total population is more than 1.5 million (1,522200) and the distribution of the population differs from one district to another with 86% of the population living in the northern districts (except Kuala Krai and Gua Musang), which contribute only about 26% of total land area. Kota Bharu is the most densely populated area (about half million population)

The Malays form the main ethnic group that is 94.1% (approximately one million) with Islam as the main religion. Chinese constitutes of 4.6%, Indian about 0.5% and other races 0.8%. (Jabatan Kes. Neg. Kelantan, 2003)

An extended family set-up is still common phenomenon in most area in Kelantan. The main sources of income are from the palm oil plantation, agriculture product and fishing. The rural handicrafts such as 'batek', jewellery and silver products are considered as major industries, which some of the attraction for the local and international tourists.

There are two tertiary health centers in Kelantan that providing the main psychiatric services, i.e., Hospital Kota Bharu (HKB) and Hospital Universiti Sains Malaysia (HUSM). Both are located in Kota Bharu. This study was done in HUSM.

In local context, the management of serious mental disorder, such as schizophrenia, has been an interest of the psychiatric service in the Hospital Universiti Sains Malaysia (HUSM). The department of psychiatry has been part of the HUSM since its inception in 1983. The HUSM, which is the training hospital for the School of Medical Science of the Universiti Sains Malaysia, was opened in Kelantan when the school was transferred from its main campus in Penang to its Kubang Kerian branch in 1984.

The psychiatric services in HUSM started as an outpatient clinic in October 1983. In August 1987, the psychiatric services took a step forward with the opening of its own psychiatric inpatient ward with the capacity of 16 beds for both female and male patients. It was further upgraded into separate male and female ward in July 1999 with a total capacity of 36 beds.

The psychiatric services in HUSM aimed to cover three broad functions. Firstly, it provides standard psychiatric care for patients from the nearby areas, such as, Kota Bharu, Bachok, Pasir Puteh and Jerteh.

Secondly, it functions as part of a teaching institution in providing adequate psychiatric training and research for the undergraduate medical students and post-graduates

candidates in psychiatry. Its post-graduate course in psychiatry (Master in Medicine (Psychiatry)), which started in June 1996, produced 13 psychiatrists nationwide. Thirdly, to promote mental health through seminars, public forums and advocacy groups. The concept of advocacy was adopted in the form of PERSIKOL (Persatuan Psikologi Kelantan), an active non-governmental organization established in 1998, with its base in HUSM. It has organized many public forums, seminars and convention at the state to the national level since its inception, including the Fifth Malaysian Mental Health Convention in August 2001 and the National Symposium of Mental Health in October 2003.

Currently, the department offers Standard psychiatric outpatient service (3 days per week), Inpatient psychiatric ward (36 beds, 18 beds for each gender), Child and Adolescent Guidance Clinic (each Monday and Tuesday), Psychological assessment and psychotherapy clinic (every Saturday, Tuesday and Thursday), Community Psychiatric Unit and Liaison-consultation psychiatry service.

These services can be accessed either by self referral or referral from inside (from the casualty, out patient clinic or inter department) or from outside the hospital (General practitioner, government and private hospital or other agencies). Utilizations of these services have multiplied over the years.