

The National Mental Health Registry (NMHR)

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SUMMARY

The National Mental Health Registry (NMHR) collects information about patients with mental disorder in Malaysia. This information allows us to estimate the incidence of selected mental disorders, and to evaluate risk factors and treatment in the country. The National Mental Health Registry (NMHR) presented its first report in 2004, a year after its establishment. The report focused on schizophrenia as a pioneer project for the National Mental Health Registry. The development of the registry has progressed with data collected from government-based facilities, the academia and the private sector. The 2003-2005 report was recently published and distributed. Since then the registry has progressed to include suicides and other mental illnesses such as depression. The NMHR Report 2003-2005 provides detailed information about the profile of persons with Schizophrenia who presented for the first time to various psychiatry and mental health providers throughout Malaysia. More detailed description regarding pharmacotherapy is reported and few cross tabulations done in an effort to provide better understanding and more clinically meaningful reports.

KEY WORDS:

Schizophrenia, Mental Health, Registry

INTRODUCTION

The decision to develop this registry is to ensure that accurate information is readily available and accessible in a timely manner within the mental health sector. With this information, a clear and coherent strategy can be implemented to improve mental health services and reduce the burden of mental health disorders in this country.

Based on the World Health Organization's recommendations (WHO, 2002) there is need to narrow the gap between what is urgently needed and what is currently available. The four strategies recommended by WHO are:

1. Information for better decisions;
2. Integrate policy and service development;
3. Advocacy against stigma and discrimination;
4. Enhanced research capacity.

These strategies are fundamentally inter-related, the development and existence of a registry is a prerequisite for translating policies into service needs.

Research capacity and culture are both greatly influenced by an efficient health information system.

The National Mental Health Registry (NMHR) would be addressing the first component of health information with regard to current services and clients and provide input regarding criteria for access in relation to needs of population served, intervention provided, minimum data set for individual patients and outcome data (Raphael, 2004).

The National Mental Health Registry (NMHR) collects information about patients with mental disorders in Malaysia. This information allows us to estimate the incidence of selected mental disorders, and to evaluate risk factors and treatments in the country. Such information is useful in assisting the MOH, Non - Governmental Organizations, private providers and industry in the planning and evaluation of mental health services, leading to its prevention and control.

The NMHR is co-sponsored by the following organizations of the Ministry of Health Malaysia:

- Medical Development Division, Ministry of Health;
- Public Health Department;
- Psychiatry services (Department of Psychiatry and Mental Health).

An Advisory Committee has been established to oversee the operations of the NMHR. The MOH, Universities, professional bodies, Non-Governmental Organization and private healthcare providers are represented on this committee to ensure that the NMHR stays focussed on its objectives, and to assure its continuing relevance and justification.

The objectives of the National Mental Health Registry are to:

- i. Determine the disease burden attributable to mental disorders by quantifying its morbidity, and its geographic and temporal trends in Malaysia.
- ii. Identify subgroups in the population at high risk of mental disorders to whom prevention effort should be targeted.
- iii. Identify potential risk factors involved in mental disorders.
- iv. Evaluate the treatment, control and prevention of mental disorders.
- v. Stimulate and facilitate epidemiological research on mental disorder, e.g. generating hypotheses on etiology.

MATERIALS AND METHODS

Disease Registration Methods

The National Mental Health Registry (NMHR) has established a dynamic unit named the Mental Health Registry Unit (MHRU) to systematically collect data from the registered Source Data Providers. Based in the Department of Psychiatry and Mental Health, Hospital Kuala Lumpur, MHRU manages the data collection, data entry, data analysis and data reporting. The source data providers are the Ministry of Health hospitals and health facilities, the hospitals under Ministry of Education and Private Hospitals where mental disorders are seen and treated. The data standards were established based on usefulness for the mental health registry, ease of data collection and compatibility with other data sets (e.g. DSM IV).

Two types of case record forms (CRF) are employed in data collection. The schizophrenia notification forms gather information on patient's demography, clinical history and process of care. The outcome form collects data on medical outcome, side effects, social functioning and quality of life. The CRFs are used as part of the clinical records. Regardless of age, all patients diagnosed as Schizophrenia are included in the registry. The completed forms are sent to the MHRU where data are analysed, interpreted and presented in regular reports to be disseminated to users. Participation of source data producers is entirely voluntary.

The data transferred to MHRU are kept strictly confidential with access limited only to authorized individuals working in the MHRU.

RESULTS

Coverage

In 2003 there were 29 Departments of Psychiatry under the Ministry of Health (MOH) and four from the universities. Of the public service departments, 29 were registered as source data producers from January 2003 and gave a coverage of 90.6% in the initial phase. If only the Ministry of Health Hospitals were taken into account, the coverage was 87.5%. In 2004, the number of participating source data producers increased to 73, consisting of 20 health facilities and 21 Ministry of Health Hospitals. In 2005, an one health facility was further added.

Progress

The National Mental Health Registry (NMHR) presented its first report in 2004, a year after its development. The report focused on schizophrenia as a pioneer project for the National Mental Health Registry. Since then, development of the registry has progressed, collecting data from government-based facilities, the academia and the private sector. The 2003-2005 report has recently been published and distributed. Now the registry has progressed to include suicides and other mental illness such as depression.

From the three year (2003-2005) National Mental Health Registry for Schizophrenia, the following can be concluded:

Incidence Rate

The incidence rate from this report is about five cases per 100,000 population/year. Comparing the incidence rates from other countries, rates of Schizophrenia fell within a range of 7.7 to 43.0 per 100,000¹⁴. This wide variation in incidence rate could be attributed to the diagnostic criteria used in diagnosing Schizophrenia. Other reasons that could contribute to this differences includes social cultural reason and under reporting especially in East Malaysia.

Demographic Profile shows that the majority of patients with schizophrenia in Malaysia are in the productive age of 20-40 years. Eighty percent of the patients were either single, divorced, widowed or separated. The majority of the cases had some form of education, at least have completed middle secondary level.

Unemployment

Employment data of the registered case revealed that almost 70% were never employed or unemployed at the time of registration.

Weight

Mean weight of the patients were 58-59kg with about 60% within normal BMI, with one fifth of them either overweight or obese. Based on data available from registered cases on BMI, prescribers of antipsychotics need to consider the possible associated weight gain.

Family History of Schizophrenia

Twenty three percent of cases had a positive family history of schizophrenia.

DUP

The duration of untreated illness is long; with a mean of 28.7 months (median of 12 months); the mean being longer among females.

Comorbidities

Approximately 20% suffered from some form of co-morbidity with substance abuse being the commonest (about 80%). Cannabis was found to be the most common substance abused followed by amphetamine / methamphetamine.

Care setting

More than a quarter of patients were brought into contact for treatment by their families. However more than 40% were first seen as inpatients.

Pharmacotherapy

About 75% of the registered cases registered over the three years had been given monotherapy antipsychotic treatment (Haloperidol being the most common typical agent and Risperidone the most common atypical). About 20% of cases were given atypical oral antipsychotic. Twelve percent of the new cases had been treated with more than one antipsychotic at their first contact.

DISCUSSION/CONCLUSIONS

The NMHR had provided vital information in the development of mental health services in Malaysia. Programs

on awareness and early detection of cases of schizophrenia have to be strengthened and there is a need for concerted effort from all sectors including the community. There should be a multi disciplinary team approach in managing comorbidities and medical related conditions amongst people with schizophrenia. The data from this registry had been used as a platform for further research on schizophrenia in Malaysia by postgraduate students and others.

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