

National Cancer Patient Registry- Haematology Malignancy (NCPR-HM)

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SUMMARY

Treatment option of Haematological malignancies has expanded over the last decade. The outcome of treatment is expected to be better compare to previously. However, study of treatment outcome for haematological malignancies has not been carried out in Malaysia. The goal of this study is to measure the treatment outcome in patients with haematological malignancy.

KEY WORDS:

Patient registry, Haematology malignancy

INTRODUCTION

Malignancy of Blood and Lymphatic system includes leukaemia, myelodysplasia and lymphomas. Based on Malaysian National Cancer Registry data, Leukaemia is the fourth most common cancers among peninsular Malaysia males in 2003 and seventh commonest among the females; 7.1% of all cancers in males compared to 4.0% of all cancers in females. Lymphoma accounts for 4.3% of all cancers in males living in peninsular Malaysia in the 2003 NCR report. Treatment option of Haematological malignancies has expanded over the last decade, with better understanding of disease biology and development of novel treatment modalities e.g. monoclonal antibody and refinement of transplantation besides improvement on chemotherapeutic drugs and supportive care, the outcome of treatment is expected to be better compare to previously. However, study of treatment outcome for haematological malignancies has not been carried out in Malaysia.

A system of long term follow-up and surveillance is instituted in centres treating haematological malignancy. Information on treatment and long term outcome are collected to generate meaningful data for future planning and reference.

Aims of NCPR-HM

The primary goal of NCPR-HM is to evaluate the treatment outcome of patients diagnosed with haematological malignancy. The objectives for this patient registry are:

1. Describe the natural history of haematological malignancy in Malaysia.
2. Determine effectiveness of treatment for haematological malignancy.
3. Monitor safety of products and services used in the treatment of haematological malignancy.
4. Evaluate access to and quality of treatment services for haematological malignancy.

MATERIALS AND METHODS

This is a multi-centre, prospective study which will register all patients with haematological malignancy i.e. Acute lymphoblastic leukaemia (ALL), acute myeloid leukaemia (AML), chronic lymphocytic leukaemia (CLL), chronic myeloid leukaemia (CML), myelodysplasia, plasma cell dysplasia, Hodgkin's lymphoma, Non-Hodgkin's lymphoma, aplastic anaemia and multiple myeloma, who also fit other inclusion criteria. These cases are taken from cases referred to the participating centres from 2008 – 2010. All cases will be followed up for every 3 months, 6 months and 12 months.

This database shall cover all patients with confirmed diagnosis of haematological malignancy, who are being treated in centres with clinical haematologists in MOH and private medical centre. However participation in this database is completely voluntary. All sites that satisfy the following selection criteria are invited to participate:

- Hospitals that provide care for haematological malignancy treatment in the MOH with specialised care.
- Each site has appointed a Site Coordinator (SC) who is responsible for database-related administration and data collection, and who is liaise with the registry manager.
- Accept responsibilities for data collection as well as for ensuring proper record keeping and document filing.
- Agree to comply with the registry procedures and are willing to be subjected to ongoing review of data by medical monitor or other representative of NCPR-HM office.

NCPR-HM has started to collect data using CRF in hard copy for pilot stage in March 2008 until end of July 2008. It involves MOH hospital at this moment. The government centers are Ampang Hospital, Sultanah Aminah Hospital, Ipoh Hospital, Queen Elizabeth Hospital, Tengku Ampuan Rahimah Hospital, HUKM, General Hospital Sarawak and Penang Hospital. In future more centres are expected to participate. It will eventually expand to more MOH and private medical centers.

The data will then capture electronically via a web application. Stringent information security policies are implemented to maintain confidentiality. All new cancer patients are registered on attendance at participating sites and existing patients on follow up may also be included in the registry. The patients are followed up every 3 months, 6 months and 12 months. A report will be generated for that. There are two datasets used in this registry: 1) core dataset which is essential for data analysis, 2) non core dataset which

Table I: Milestone of the Registry

February 2008	NCPR-HM steering committee meeting
March 2008 – July 2008	Pilot study started in eight participating sites
April 2008	Revised Case Report Form (CRF) to rectified the problems after one month data collection
May 2008	CRF is finalized and ready for web application development
July 2008	e-NCPR web application is ready for trial
August 2008	Official launch of e-NCPR web application

is additional data for further analysis. It is expected that a report for the haematological malignancy patients will be produced by end of this year. Milestone of the registry is shown in Table I.

Future direction

At present, cooperation of existing participating sites is fully needed to get quality data. It is hope that the data would provide useful information for the public and local research

to understand more about the treatment outcome of haematology malignancy. We also hope to get more participation from other sites to in the future.

REFERENCE

1. Gerard Lim CC, Yahya H. Second Report of the National Cancer Registry, Cancer Incidence in Malaysia. National Cancer Registry, Ministry of Health, Kuala Lumpur, 2003.