

New Registry: National Cancer Patient Registry - Colorectal Cancer

L Wendy*, M Radzi**

*Department of Medicine, Clinical Campus of UPM, Aras 9&10B, Grand Seasons Avenue, 72, Jalan Pahang, 53000 Kuala Lumpur,

**Department of Medicine, Hospital Sultanah Bahiyah, KM 6, Jalan Langgar, 05460 Alor Star, Kedah, Malaysia

SUMMARY

Colorectal cancer is emerging as one of the commonest cancers in Malaysia. Data on colorectal cancer from the National Cancer Registry is very limited. Comprehensive information on all aspects of colorectal cancer, including demographic details, pathology and treatment outcome are needed as the management of colorectal cancer has evolved rapidly over the years involving several disciplines including gastroenterology, surgery, radiology, pathology and oncology. This registry will be an important source of information that can help the development of guidelines to improve colorectal cancer care relevant to this country. The database will initially recruit all colorectal cancer cases from eight hospitals. The data will be stored on a customized web-based case report form. The database has begun collecting data from 1 October 2007 and will report on its first year findings at the end of 2008.

KEY WORDS:

Colorectal, Cancer, Registry

INTRODUCTION

Recent studies have shown an increasing incidence of colorectal cancer (CRC) in Asian populations¹. According to the Second Report of the National Cancer Registry², colorectal cancers accounted for 14.2% of male cancers and 10.1% of female cancers in Malaysia, making it the commonest cancers among men and the third most common cancer among women respectively. CRC is the third commonest cause of cancer-related mortality in Malaysia.

Management of colorectal cancer has evolved rapidly over the past decade with advances in endoscopic techniques, surgery, oncology, radiology and molecular genetics. The wealth of clinical and epidemiological evidence has allowed formulation of clear practice guidelines on the management of colorectal cancer in average risk and high risk groups by international gastroenterological, surgical and oncology societies. Management of CRC is multidisciplinary and should include selection of appropriate therapy, surveillance strategies post surgical resection, identification of high risk groups e.g. inherited colon cancer syndromes and screening of CRC in high risk groups.

At present, no such registry that dedicates itself to comprehensive reporting on all aspects of colorectal cancer

exists in Malaysia. Currently, data that is available on colorectal cancer from the National Cancer Registry in Malaysia is limited².

MATERIALS AND METHODS

Patient population

This is a multi-center project involving eight hospitals scattered throughout Malaysia. All confirmed cases of colorectal cancer from these hospitals will be recruited into the database from October 2007 to December 2010. The colorectal cancer cases are identified through the gastroenterologists, colorectal surgeons, pathologists and oncologists working in these eight centers.

The eight initial pilot sites are based at Hospital Sultanah Bahiyah (Alor Star), Hospital Sultanah Aminah (Johor Bahru), Hospital Kuala Lumpur, Hospital Serdang, Hospital Selayang, Hospital Queen Elizabeth (Kota Kinabalu), Hospital Raja Perempuan Zainab II, (Kota Bharu), Hospital Universiti Sains Malaysia (Kubang Kerian). There are plans to include one new site which is Hospital Umum Sarawak. These are large hospital centers with heavy case workloads dealing with colorectal cancer. The sources of patients are from the local population and referrals from the local surrounding hospitals.

Inclusion criteria

All histologically verified colorectal cancer cases from these eight hospitals will be reported to the colorectal cancer database (irrespective of the staging, histopathology, duration of the disease) within the study period.

Exclusion criteria

Any patient who received their treatment at participating study sites not within the study period. Anal cancers are also excluded.

Case report form (CRF)

All data on demographics, clinical history, family history, pathology and treatment details (including, surgical, oncology and palliation treatment) will be extracted from patients' medical records by research assistants under supervision by site investigators.

The data is stored on a customized web-based electronic case report form readily accessible to the source data providers from the eight initial pilot sites.

Database monitoring and data management

Database monitoring and data management will be carried out by the research assistants who are under the supervision of the principal investigators and the Clinical Research Centre, Hospital Kuala Lumpur in compliance with patient data protection.

RESULTS

One hundred and ninety seven cases of colorectal cancers have been reported to the database from the eight participating hospitals between 1st October 2007 and 29 February 2008. Data collected are as follows:

- demographic details
- family history
- concomitant medical problems
- presenting symptoms
- investigation details
- pathology staging
- therapy offered
- details of surgical and oncology therapy, including complications
- follow-up details

The registry will report on its findings at the end of 2008.

DISCUSSION

All the cancer statistics in Malaysia is derived from the National Cancer Registry. The data derived from the National Cancer Registry on colorectal cancer is rather limited. As management of colorectal cancer care advances, we need not just detailed and comprehensive demographic data, but treatment outcome data is also essential. The key areas benefiting from establishing a colorectal cancer registry are as follows:

- i. Patient care and education**
 - Identification of high risk patients for colorectal cancer by virtue of their family history.
 - Risk assessment and person contact is easier using a customized computer database.
- ii. Education of healthcare professionals**
 - Fostering collaboration with other colorectal cancer registries throughout the world.
 - Audit and review cancer treatment outcomes (surgery and oncology outcomes) in terms of disease-free survival, mortality, complications and side-effects.

iii. Research

- Provide a more accurate and refined prevalence estimates of colorectal cancer in Malaysia e.g. ethnic variations and risk, geographical variations as well as socio-cultural and socio-economic influences.
- Facilitate clinically important research on colorectal cancer from data collected in the registry. e.g. is the population of hereditary colon cancer in Malaysia similar to the Western population?
- Generate data for publication of original scientific papers.

iv. Health Policy Makers

- Help decision making on the resource allocation, need on improvement of quality control on equipments, training personnel and strengthening areas which require improvement and provide optimal care to patients.
- Provide evidence to help formulate screening and surveillance strategies that are relevant and cost-effective in the Malaysian setting.

CONCLUSION

It is hoped that the establishment of the database will further our knowledge on colorectal cancer in the Malaysian population. This database will serve as an invaluable repository of data for quality assessment of colorectal cancer management in Malaysia.

FINANCIAL SUPPORT AND ETHICS APPROVAL

The NCPR - Colorectal Cancer is supported by grants administered via the Clinical Research Centre, Kuala Lumpur. The project has been approved by the Medical Research and Ethics Committee of the Ministry of Health, Malaysia.

ACKNOWLEDGEMENT

We would like to thank the Ministry of Health and the Clinical Research Centre for the support in this project. In addition, we are grateful to the various hospitals, the source data providers and the registry manager and research assistants for their assistance in providing the data on the patients.

REFERENCES

1. Cancer incidence in five continents vol IX. <http://www.iarc>.
2. Second Report of the National Cancer Registry. <http://www.makna.org.my/NCR/>