




## RESEARCH ARTICLE

## Gaps in cancer care in a multi-ethnic population in Sarawak, Borneo: A central referral centre study

Melissa Siaw Han Lim <sup>1,2</sup>, Pei Jye Voon<sup>3</sup>, Adibah Ali<sup>4</sup>, Fitri Suraya Mohamad<sup>2,5</sup>, Lin Lin Jong<sup>2</sup>, Lee Ping Chew <sup>2,6,7</sup>, Mohamad Adam Bujang<sup>7</sup>, Yolanda Augustin <sup>1,2,8\*</sup>, Yuong Kang Cheng<sup>2</sup>

**1** Department of Paraclinical Sciences, Faculty of Medicine and Health Sciences, Universiti Malaysia Sarawak (UNIMAS), Kota Samarahan, Malaysia, **2** Society for Cancer Advocacy and Awareness Kuching, Kuching, Sarawak, Malaysia, **3** Department of Radiotherapy, Oncology and Palliative Care, Sarawak General Hospital, Ministry of Health, Kuching, Sarawak, Malaysia, **4** Department of General Surgery, Sarawak General Hospital, Ministry of Health, Kuching, Sarawak, Malaysia, **5** Department of Cognitive Sciences, Faculty of Cognitive Sciences and Human Development, Universiti Malaysia Sarawak (UNIMAS), Kota Samarahan, Malaysia, **6** Hematology Unit, Department of Medicine, Sarawak General Hospital, Ministry of Health, Kuching, Sarawak, Malaysia, **7** Clinical Research Centre, Sarawak General Hospital, Ministry of Health, Kuching, Sarawak, Malaysia, **8** St George's University of London, London, United Kingdom

\* [yaugusti@sgul.ac.uk](mailto:yaugusti@sgul.ac.uk)



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## Abstract

### Background

The state of Sarawak on the island of Borneo in East Malaysia, in working towards developing and strengthening cancer services through a holistic patient-centred approach, must focus on the comprehensive needs of cancer patients by taking into account the psychosocial, cultural and spiritual aspects of Sarawak's multi-ethnic, multi-cultural population.

### Methods

A 42-item survey questionnaire was developed and validated with a total of 443 patients. The perceived importance of information provided and level of patient satisfaction were assessed with a 5-point Likert scale in 10 domains (Diagnosis, Surgery, Radiotherapy, Systemic therapy, Clinical trials, Pain management, Treatment monitoring, Psychosocial support, Sexual care and fertility issues, and Financial support). A Spearman's rank correlation test was applied to determine the correlation between response in both item and domain categories for perceived importance and satisfaction.

### Results

Overall, patients were more satisfied with information related to cancer diagnosis, treatment and surgery but less satisfied with information pertaining to sexual aspects of care and family planning, psycho-social support and financial support. The majority of patients were satisfied with the level of treatment-related information received but preferred the information to be delivered in more easily comprehensible formats. Sexual aspects of care and family planning, psychosocial support and treatment monitoring post-discharge were perceived as

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important but seldom addressed by health care professionals due to lack of professional counsellors, social workers and clinical nurse specialists. Many patients face financial toxicity following a cancer diagnosis, particularly when diagnosed with advanced cancer requiring complex multi-modality treatment.

## Conclusion

Cancer patients in Sarawak have various unmet information needs. Written information and educational videos in local indigenous languages may be more suitable for Sarawak's multi-ethnic population. Sexual aspects of care and family planning are challenging but essential topics to discuss, in particular due to the high prevalence of breast and cervical cancer amongst young women of reproductive age in Sarawak. Financial assessment and information on support services offered by government and non-government organisations should be provided to eligible patients. A holistic needs assessment of each patient at time of diagnosis and support through their cancer journey requires a multi-disciplinary team of medical, nursing and allied health professionals including clinical nurse specialists, pharmacists, counsellors, physiotherapists, occupational therapists, speech and language therapists, dieticians and social workers.

## Introduction

Malaysia is approaching an epidemiologic transition, similar to many developing countries, where cancer diagnosis is on the rise. Sarawak is the largest state in Malaysia spanning 120,000km<sup>2</sup> with a population of 2.9 million and is equipped with only one tertiary public hospital (Sarawak General Hospital in the state capital Kuching) with cancer care facilities including surgery, chemotherapy and radiotherapy. Cancer patients from all over Sarawak are referred to Sarawak General Hospital and current facilities are inadequate to cope with the current volume of patients. Sarawak has a multi-ethnic and multi-cultural population consisting broadly of indigenous Iban, Bidayuh, Orang Ulu and Melanau ethnic groups as well as Malay, Chinese, Indian and Eurasian communities. A cancer diagnosis requires a significant level of personal adjustment for patients and their families and can have a profound effect on patient quality of life [1]. It is therefore vital to provide comprehensive patient health literacy and support services to all cancer patients. Accurate, clear and easily comprehensible patient information can alleviate some of the stress associated with a new diagnosis of cancer and empower patients to effectively navigate the cancer management pathway and improve the quality of cancer care [1]. Accurate information may also empower patients to communicate more effectively with family members to support their decision-making process [2]. A previous study reported that good communication between healthcare professionals and patients also requires patient consultation and involvement in terms of understanding patients' ideas, concerns and expectations of cancer care and available support services [3]. Although a number of initiatives have been undertaken by both government and non-government organisations (NGOs) [4] to provide patients in Sarawak with cancer and supportive care information, the effectiveness of these initiatives has not been formally assessed [5].

In supporting patient-centred care [6], each patient should undergo a needs assessment to identify needs that can be addressed by health care professionals as well as allied health professionals and social support groups. In 2011, the International Psychology Society (IPOS)