

COMMENTARY

The UK-SEA-ME Psychosocial-Cultural Cancer Research Network: Setting the Stage for Applied Qualitative Research on Cancer Health Behaviour in Southeast Asia and the Middle East

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Abstract

Psychosocial and cultural factors influencing cancer health behaviour have not been systematically investigated outside the western culture, and qualitative research is the best approach for this type of social research. The research methods employed to study health problems in Asia predominantly are quantitative techniques. The set up of the first psychosocial cancer research network in Asia marks the beginning of a collaboration to promote and spearhead applied qualitative healthcare research in cancer in the UK, Southeast Asia and the Middle East.

This paper sets out the rationale, objectives and mission for the UK-SEA-ME Psychosocial-Cultural Cancer Research Network. The UK-SEA-ME network is made up of collaborators from the University of Leeds (UK), the University of Malaya (Malaysia), the National University of Singapore (Singapore) and the University of United Arab Emirates (UAE). The network promotes applied qualitative research to investigate the psychosocial and cultural factors influencing delayed and late presentation and diagnosis for cancer (breast cancer) in partner countries, as well as advocating the use of the mixed-methods research approach. The network also offers knowledge transfer for capacity building within network universities. The mission of the network is to improve public awareness about the importance of early management and prevention of cancer through research in Asia.

Keywords: Psychosocial research network - Middle East- Southeast Asia - late presentation - cancer

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Rationale

Cancer is a health issue of increasing priority in the developing world where 70% of all the cancer deaths is occurring (WHO, 2006). A cancer epidemic is imminent in Asia as Asia accounts for over one half of the world's cancer burden and it also consists of many poor countries in the world. The APJCP dedicated Volume 10 (Supplement 2) 'Asian Pacific Cancer Epidemiology' to present the evidence of rising cancer incidences and mortality in 5 continents; these were covered in 7 reviews in the region (downloadable from (www.apocp.org)).

Late presentation and diagnosis is a common factor attributing to high cancer mortality; 40% of all cancer deaths in the developing world are preventable if the disease was diagnosed early (WHO, 2006). Richard and colleagues (1999) systematically reviewed the evidence on the influence of delayed presentation of cancer symptoms on survival, and have shown that delayed diagnosis is a major cause of poor survival. Delayed or late presentation and diagnosis for cancer also have significant public health impacts on the cost of treatment and healthcare (Groot et al., 2006) and quality of life (Unger-Suldana et al., 2009;

Kwan et al., 2010).

Cross-section, observational studies have established associations of delayed presentation for cancer with socio-economic characteristics (Ramirez et al., 1999), but we still do not understand fully the reasons and circumstances in which people presented late or delayed seeking medical help for cancer symptoms. Apart from psychological and cognitive factors, it is now widely acknowledged that social and cultural influences also play an important role in motivating health seeking decisions and behaviour for cancer. In addition, WHO (2002) highlights the importance of a broad social context in cancer prevention and control at the national level and stresses the importance of considering different factors which can impact on implementation and success of cancer control and education initiatives in low resource countries. All these factors and their impacts on individual and familial decisions and behaviours have not been systematically investigated.

Quantitative research approach has been the main method of choice of previous studies on factors influencing cancer health behaviour in both the western and non-western countries. Qualitative studies exploring late

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presentation or delayed help seeking for cancer symptoms are rare. Unlike quantitative research, qualitative research is value for its ability to provide in depth explanations and contextual information crucial to understand attitudes, decision making process, behaviours, concerns, motivations, culture or lifestyles, as well as generating ideas for new strategies, interventions or theories. In western countries, a limited number of related qualitative studies was found and in these studies, mostly White patients were recruited; only one study included African American patients. However, none of the studies included patients for other ethnic, cultural and religious background (Smith et al., 2005). While in Asia, two regional journals (Asia Pacific Journal of Public Health and Asia Pacific of Cancer Prevention) were searched and only 3 related qualitative studies were found.

To address these limitations in Asia, the first cancer behavioural science research network focusing on the psychosocial-cultural aspect of cancer was set up in August 2010 between Leeds (UK) and the Middle East and Southeast Asia regions. The network, also known as the UK-SEA-ME Psychosocial-Cultural Cancer Research Network, is funded by the Worldwide Universities Network (WUN) and co-ordinated from the University of Leeds, UK. The network serves two important functions, i.e., to promote applied qualitative research activities on delayed presentation and diagnosis for cancer and to provide knowledge transfer for capacity building in qualitative research in member universities. The network's founding members are the University of Leeds, University of Malaya, National University of Singapore and the University of the United Arab Emirates. For synergy, the network advocates the use of Mixed-Methods research approach to combine members' areas of expertise and research skills.

The network hopes to extend its membership to include individuals, researchers, academicians and practitioners who shared our interest in the Asia Pacific region. Details of the network and its founding members are found at www.leeds.ac.uk/lihs/psychiatry/staff/limwun.html.

Breast cancer is the most frequent type of female cancer globally. In 2008, there were 1.38 million new cases (23% of all cancer cases), and 458,000 deaths worldwide (GLOBOCAN, 2008). It is estimated that by 2020 there will be 20 million new cases of cancer a year (Reeler et al., 2007). If current statistics remain the same, 4.6 million of these will be breast cancer and occurring in developing countries where breast cancer incidence is rising by up to 5% a year (Anderson et al., 2006). For these reasons, breast cancer is chosen as our first disease focus, with the intention to extend future research to other type of common cancers such as colorectal cancer.

Existing observational studies in the Middle East revealed that at least 70% of breast cancer was diagnosed in regional or distant stage of the disease (advanced stage) and around 40% of women delayed their first doctor appointment for more than 3 months. In Southeast Asia, lower incidences (30 - 60%) of advanced stage breast cancer were reported in 3 urban hospitals in Malaysia, but this might not reflect the overall situation where cancer services are not evenly distributed. In Singapore, despite better healthcare and a more educated population, about 25%

of breast cancer diagnosed since 1997 were at advanced stage. Only limited studies investigating this problem can be located in these countries and even so, none are qualitative studies. Thus, to ameliorate this weakness, the network members will prioritise qualitative research to fully understand the problem, and to identify and develop appropriate and effective intervention strategies.

Objectives and Agenda

The UK-SEA-ME network brings together 3 themes:

(1) Establishing delayed presentation/diagnosis/treatment for breast cancer: Identifying the extent of the problem using existing epidemiological evidence and all related research activities in partner countries. What kind of research can be carried out? What research strategy can be employed to move forward?

(2) State responses to breast cancer burden: Review of existing public health strategies and interventions. What is missing? What intervention strategies can be proposed, piloted and implemented?

(3) Identifying research priorities, infrastructure and capacity needed: Identifying what are the gaps for future research and priorities? What are the actual and perceived barriers to achieve priorities? What type of knowledge and capacity building are needed and can be transferable between countries?

Our agenda is to be mobilised through a series of seminars/workshops and research funding applications at the national and international levels. In November 2010, the Co-ordinator hosted the first meeting and workshop in Leeds, UK, where all partners met to officially formalise the network and discussed future research and knowledge transfer activities. In the workshop, 9 papers reflecting the above themes were presented by the network partners and invited speakers. The workshop was well attended by researchers, clinicians (breast surgery and pathology), policy makers, representatives from cancer charities, cancer survivors and post graduate students.

A second network seminar is planned and to be hosted by our partners at the University of Malaya, Malaysia in Summer/Autumn 2011. To some extent, our objectives have been achieved with the publication of the 8 articles in this journal, our success in securing funding in the UAE, the submission of 3 further research applications in the UK, Malaysia and Singapore, and knowledge transfer activities in member universities.

Mission

With an increase in applied qualitative healthcare research, we hope to contribute not only to an improvement of cancer service provision and delivery in member countries, but also promoting a service and care that is patient-focused. Through our research, we also hope to improve public awareness and lay knowledge and understanding about early diagnosis and treatment for cancer.

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