



Cancer Patient's Awareness, Expectations and Carer Needs in Primary Care Settings: A Review and Implications for Brunei Darussalam

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Abstract

Background: Recognizing the symptoms to enable early diagnosis may have a significant impact on the progression of the illness, including their approach and the carers' overall wellbeing and adeptness. It is important to recognise and understand the general populations' knowledge and expectations about cancer and what unmet needs that carers encounter to enable better delivery of care.

Aim: To review current evidence of cancer awareness and knowledge among the general population as well as challenges faced by cancer carers and its relevance in Brunei Darussalam.

Design: An integrative review of literature was carried out. An expert panel framed key areas of investigation on the selected topic and a comprehensive review was undertaken to explore those keys areas in-depth. A search was performed using the key terms included in six databases, including hand search of key journals. Data was analysed using the principles of integrative review.

Findings: Data analysis revealed two themes: public awareness of cancer and unmet needs of cancer carers.

Conclusion: Cancer care can be improved with an increased awareness and understanding of the disease including addressing the needs of the carer. Further research is needed locally to identify the knowledge gaps and lacking needs of the population as patients and carers.

Key terms: Integrative Review, Cancer, Primary Care, Brunei Darussalam, General Practitioners, Public Awareness, Public Expectations, Unmet Needs, Cancer Carers.

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Introduction

Cancer is found to be the leading cause of morbidity and mortality worldwide where the incidence rate is expected to increase to about 70% over the next two decades.¹ According to the World Health Organization (WHO), it is the second leading cause of death globally whereby 8.8 million deaths in 2015 was due to cancer. More than 70% of cancer deaths occur in the low and middle income countries due to the limited or non-existent availability of resources for diagnosis, treatment and prevention of cancer.² Not excluding delays in diagnosis due to poor awareness and poor access to healthcare leading to presentation of advanced diseases where it has been shown in a study that cancer survival is related to cancer symptom awareness.³ Nonetheless, apart from posing a burden on the individual and their surrounding family and friends, the disability and death that it brings imposes a significant global economic cost where it is approximately 900 billion US dollars per year.³ This is

excluding the cost of the patient care. Hence, it is critical to identify areas for improvement in cancer care to minimize the global burden.

From the year 2009 to 2015, cancer has been the number one leading cause of mortality in Negara Brunei Darussalam.⁴ The current local healthcare system has been evolving to achieve an integrated and better cancer care and in order to achieve all aspects of an improved cancer care, raising awareness among the public to allow early identification of suspected cancer is vital as this relates to better survival.³ Better cancer care is also associated with supporting the carer as it indirectly supports the patient and have a positive influence on clinical outcomes.⁵ Thus, it should be recognized that when a person is diagnosed with cancer, they are not the only individual who has to go through the cancer journey but also those who surround close to them including family and friends. Cultural aspects, knowledge and religious beliefs may contribute to the current situation of public awareness and needs of cancer carers in Brunei Darussalam.

Review question

What evidence is available on the public awareness, expectations towards cancer

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care and unmet needs of cancer carers in Brunei Darussalam?

Review Design

The review followed the Whitemore and Knafl framework (2005) of an integrative literature review as methodological design.⁶ This allowed combining diverse methodological approaches in empirical studies (both quantitative and qualitative) that focused on evidence available on public awareness of cancer and the unmet needs of cancer carers.

Search strategy

Studies included were from 1999 to 2016 and this comprised of reports, systematic reviews, both quantitative and qualitative studies as well as other literature related to current evidence on public awareness of cancer and the unmet needs of cancer carers. We did not follow principles of systematic review. However, we undertook a comprehensive review of literature as our methodology. Key words of our search includes: Brunei Darussalam, AND Cancer, AND Awareness, AND Cancer Carers, OR Support Person, OR Informal Carer, AND Unmet Needs.

Data Analysis

We used Whitemore and Knafl principles of integrative review. The extracted data

underwent four analytic stages; data reduction, data display, data comparison and conclusion drawing and verification. In stage 1, data reduction was done by a team of primary care academicians, trainees and researchers who formed a study panel. This panel met regularly to frame key areas of investigation on the selected topic. In stage 2, data display was completed by individual members who were assigned to undertake in-depth comprehensive review to explore the keys areas whereby reports on those selected themes were then submitted. To perform stage 3, which is data comparison, we used constant comparison as a method of an iterative process of examining data to identify themes, that had similar patterns and relations. Key authors KV, SM FI, and PH met to discuss on the findings submitted by those individuals. Finally, for stage 4 that is conclusion drawing and verification, we verified patterns using primary data, identified any similarities, differences and any spurious findings. These were dealt with in order to ensure valuable information was not lost.

Results

Data analysis revealed two themes: public awareness and expectation of cancer and unmet needs of cancer carers.

Theme 1: Public awareness on cancer

Niksic M et al has shown that increased cancer awareness indicated an increase in cancer survival.³ However, a systematic review by Macdonald S. et al showed that inability to recognize the seriousness of a symptoms play a role in delayed presentation as opposed to not recognizing the symptoms itself.⁷ Furthermore, a literature review suggests that a majority of women are able to recognize the symptoms of common cancer when a list is provided but are unable to recall the symptoms when asked.⁸ Thus, there are various aspects of patient awareness that could contribute to improved cancer care which could be knowledge, awareness of the seriousness of the symptom and being able to recall the symptom. These studies also compared the level of awareness and knowledge between the different demographics of the sample population studies where it revealed that poor awareness was correlated to lower socioeconomic status, minor ethnicity, being younger and unemployed.^{3,7,8}

A similar research was carried out in Brunei Darussalam by Chong et al; which aimed to assess the level of knowledge and awareness of colorectal cancer in Brunei Darussalam.⁹ 431 patients participated in the cross sectional study, where they were

asked about the signs or symptoms, risk factors and any screening modalities that they were aware of for colorectal cancer. The study concluded that the general knowledge of colorectal cancer in Brunei Darussalam is poor. Higher scores were associated with being female, higher levels of education and non-Malay race but they were still generally poor. However, the limitations about this particular study is that it focused on only one specific cancer and the sample population comprised of participants who were either patients or their accompanying relatives attending the various outpatient clinics in a tertiary hospital.⁹ Thus, the sample was not a good representation of the general public in Brunei. Currently, cancer awareness campaign would be held sporadically in public places such as shopping malls and hospitals and the media would take opportunities during World Cancer Day to promote awareness. However, its effectiveness on the general population is unknown.

In the United Kingdom, the National Awareness and Early Diagnosis Initiative (NAEDI) consists of several work streams that was established to help ensure the delivery of cancer reform strategy, which identified the need to investigate and target all the risk factors to improve cancer

outcomes. One of these strategies focused on developing a validated measure of public awareness of cancer signs and attitude to help seeking and benchmarking current levels on a national basis against which to evaluate policy initiatives design to improve awareness.¹⁰ A study that was done by Robb et al in the United Kingdom tailed a population-based survey assessing the public awareness of cancer in Britain using a validated cancer awareness measure (CAM) tool.¹⁰ It examined the inconsistencies in relation to age, socio-economic status (SES) and ethnicity and associations between awareness, perceived barriers and anticipated delay in presentation. Thus, further research is needed locally in order to achieve the following aims: a) to assess the awareness of cancer warning signs among the general population in Brunei Darussalam; b) to examine the anticipated delay in seeking help for each of the symptoms among the general population in Brunei Darussalam; c) to identify the perceived barriers to help-seeking for cancer among general population in Brunei Darussalam; and d) to investigate the association between awareness, perceived barriers and anticipated delay in presentation among the general population in Brunei Darussalam.

Theme 2: Unmet Needs of Cancer Carers

A diagnosis of cancer not only has an impact on the patient themselves, but also on their family and friends resulting in cancer being described by Kayser (2007, cited by Ussher¹¹) as 'we-disease'. Naturally, many research and studies related to cancer have been conducted with the patient as the main subject but more studies concerning cancer carers are emerging as they have shown to play an imperative role in cancer care. Apart from delivering informal health care support at home, they also provide with social and emotional support to the patient.¹²

The term carer has no universal definition, where numerous articles have used synonymous terms. This include "caregivers", "next of kin", "family caregivers" and even as specific as "spouses/partners".^{13,14} However, a simplified description of carer is the cancer patient's "principal support person" which can be further defined as someone that they can count on and who helps them with their needs.¹³ Thus, this includes a wide scope of relationships, either related or not related, spouses or non-spousal. With the popular trend of shorter hospital stays, the carer is a valuable source of fundamental and unpaid support for the

patient and supporting the carer would indirectly support the patient and have a positive influence on clinical outcomes.¹⁴

A review on the effects of caring for a cancer patient has identified more than 200 issues and challenges that transpire with the responsibility of being a carer. These issues range from physical health and social problems such as sleep disturbance and role strain to lack of information and emotional problems such as depression and anxiety.¹² These concerns may cause further burden, which may subsequently inhibit proper care to the patient. Thus, it is vital to identify and address the challenges faced by the carer. However, it has been found that a majority of carers hesitate in seeking help from formal providers due to concerns of legitimacy of needs, patient being the focal concern, time constraint and difficulty in leaving the patient or carers not wanting to cause nuisance to formal providers.^{15,16}

Non-profit organizations (NPOs) that aid adult cancer patients and their carers such as Macmillan Support Group in the United Kingdom, American Cancer Society in the United States of America, Majlis Kanser Nasional (MAKNA) or Persatuan Kebangsaan Kanser Malaysia (National Cancer Society of Malaysia) in Malaysia,

is unheard of in Brunei apart from those that cater only to cancer patients such as the Brunei Breast Cancer Support Group.¹⁷ Thus, the dissimilarities in resources deem it essential to conduct a research on cancer carers in Brunei. Specific objectives of future research should include a) identifying the unmet needs of cancer carers in Brunei; b) exploring any issues that could hinder the carer from providing holistic care towards the patient; and c) exploring the carers' concerns in providing care to a cancer patient.

Limitations

The scope of our findings were limited due to the search methodology of using comprehensive literature review and limited studies on public awareness of cancer in Brunei Darussalam and the unmet needs of cancer carer.

Conclusion

Our review found that public awareness plays an important role in early detection of cancer and this should entail recognizing the symptoms related to cancer and the seriousness to enable recall and reduce the knowledge-recall gap.⁸ This could prevent delay in diagnosis which has proved to be key in achieving improved cancer outcomes, improved survival, better

treatment and patient satisfaction. Furthermore, improving public awareness would be beneficial to not only individuals with cancer but also to those who are looking after these individuals. Hopefully, it would improve the quality of informal care given by the carers as well as their confidence level. Nonetheless, these carers should also be looked after to ensure that the care they provide is not restrictive and their relationship is not strained. Thus, it is vital to have an indication of Brunei's public awareness about cancer in order to improve them and similarly for cancer carers, identifying knowledge gaps and unmet needs is crucial prior to addressing them. Thus, with the upcoming research of knowing the level of public awareness of cancer and identifying the unmet needs of cancer carers in Brunei, it is hoped to be a step in improving the nation's cancer care.

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