

Early diagnosis and late presentation of cancer in primary care settings: A review and implications for general practitioners of Brunei Darussalam

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Abstract

Background: Early diagnosis of cancer is evidenced to improve survival rate and quality of life for patients with cancer. In developed countries, general practitioners (GPs) play a key role in improving cancer care experiences, yet little is known about the role of GPs in cancer care in primary care settings.

Aim: To review current evidences of cancer care in primary care settings and its relevance to Brunei Darussalam.

Methods: An integrative review of literature was undertaken. An expert panel framed key areas of investigation on the selected topic where individual researchers explored those keys areas in-depth. A search was taken into five databases including hand search of key journals, using key terms included. Data was analysed using the principles of integrative review.

Findings: Data analysis revealed three themes: (i) factors leading to delayed cancer presentation at primary care settings, (ii) effect of time interval in cancer care trajectory and (iii) implications for GP learning needs on cancer care.

Conclusion: The context of patient, carer, and clinician in defined social settings seems to play a key role in improving cancer care in primary care settings. The immediate need for future research focusing on exploring and developing knowledge base on improving cancer care at primary care settings in the context of Brunei Darussalam is highly recommended.

Key terms: Integrative Review, Cancer, Primary Care, Brunei Darussalam, General Practitioners, Early Diagnosis, Delayed Presentation

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Introduction

Cancer is the leading cause of morbidity and mortality worldwide, with the incidence rates expected to increase to about 70% over the next two decades¹. The prevalence of cancer is rising worldwide and it is estimated that 14 million new cases are diagnosed in 2012¹. In 2012, it was estimated that 8.2 million people died due to cancer³. More than 70% of all cancer deaths occur in the low and middle income countries due to limited resources⁴. This rapidly growing number of cancer places a significant burden on the health system to improve cancer care in any way possible.

There are increasing studies which demonstrated the importance of general practitioner (GPs) in cancer care of patients, particularly in screening for recurrence among cancer survivors, and providing comprehensive extended follow-up care, including managing other co-morbidities^{5,6,7}. In view of the projections of shortages in the number of oncologists by 2020, there has been a shift of cancer care from secondary and tertiary to primary care⁸. Several studies have reported GPs' willingness to be more involved in cancer care of patients^{9,10}. However, GPs seem to lose track of patients who are undergoing cancer treatment resulting to a loss in the continuity of care. They may also find it difficult to take over their patients' follow up at the end of the cancer treatment if they have not seen them for some time^{11,12}. Although there has been an exponential rise in primary care cancer research in relation to the role of GPs in cancer care, little is known about how best GPs could improve cancer care at primary care settings.

Background

Brunei Darussalam is one of the countries in South East Asia, with a population of about 430 000 people¹³. Its political system is governed by the Malay Islamic Monarchy. In Brunei Darussalam, cancer is the leading cause of mortality since 2009¹⁴. Cancer accounted for 18.4% of all-

cause mortality in 2009 and this has increased to 21.1% in 2013¹⁴. The main causes of cancer deaths are attributed to cancers of the trachea, bronchus and lung; rectum and anus; and liver and intrahepatic bile ducts¹⁴. This increasing cancer mortality has thrust new demands on the current healthcare system in order to achieve an integrated cancer care. However, in Brunei Darussalam, cancer care is predominantly managed by the specialists in the hospital settings and there is little involvement of GPs apart from patients' first presentation to GPs with probable symptoms indicative of cancer.

Review question

What evidences available on early diagnosis and late presentation of cancer care in primary care settings in Brunei Darussalam and its educational implications for general practitioners?

Review Design

The review followed the Whittemore and Knafelz⁵¹ framework of an integrative literature review as methodological design. This allowed combining diverse methodological approaches in empirical studies (both quantitative and qualitative) that focused on evidences available on early diagnosis and late presentation of cancer care in primary care settings in Brunei Darussalam and its educational implications for general practitioners.

Search strategy

Studies included were from 2000 to 2015. Included studies were reports, systematic reviews, both quantitative and qualitative studies and other literature related current evidences on cancer care in primary care settings. We did not follow principles of systematic review. Yet we undertook a comprehensive review of literature as our methodology. Key words of our search includes: Brunei Darussalam, AND Cancer, AND Primary Care Settings, OR Primary Care, OR Community care, AND Family Physicians,

OR General Practitioners, AND Early Diagnosis, OR Delay Presentation, AND Patient Expectations, AND Public Preferences. Major five data bases were included in our search: MEDLINE, CINAHL, EMBASE, PsycINFO and Google Scholar. Data retrieval were conducted during October 2015-January 2016.

Data analysis

We used Whittemore and Knaff⁵¹ 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, a team of primary care academicians, trainees and researchers formed as study panel. This panel met regularly to frame key areas of investigation on the selected topic. In stage 2 data display, individual members, then were assigned to undertake in-depth comprehensive review explore those keys areas and they submitted their reports on those selected themes. To perform stage 3, 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 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. Authors met with a purpose to identify and reach a consensus on the final themes.

Results

Data analysis revealed three themes: *factors that leads to delayed cancer presentation at primary care settings, effect of time interval in cancer care trajectory and implications for GP learning needs on cancer care.*

Theme 1: Factors that leads to delayed cancer presentation at primary care settings

One of the earlier studies by Safer et al explored factors affecting delays in patients seeking treatment for the first time for a particular symptom. They categorised the delays into three chronological stage¹⁵.



Figure 1: Theoretical model of patient delay described by Safer et al¹⁵

Several studies comprehend how different factors affect the delay in cancer presentation at primary care settings. Some quantitative evidences shown inconsistent association between demographic characteristics^{16,17}. For example, studies concluded there is no association between patient delay with age, gender or socioeconomic status^{18,19,20}. On the other hand, Bish et al, Arndt et al and Ramirez et al found that there is association between age and patient delay^{21,22,23}. Many studies have also reported that patients are not aware of the symptoms, which could be indicative of cancer^{24,25,26}. Studies reported the correlation of social relations on care seeking. Burgess et al demonstrated five common factors which led to delays in

presentation at primary care settings among breast cancer patients in the United Kingdom: a) interpretation of symptoms, b) attitudes to GPs attendance, c) beliefs about consequences of cancer treatment, d) perception of competing priorities, and e) triggers to action²⁷. Another Malaysian qualitative study found that help seeking behaviour was influenced by a multifaceted interaction of cognitive, environmental, beliefs, culture, and psychosocial factors among cancer patients²⁸. Indeed, Andersen et al further developed a model of total patient delay that extended Safer's model into five stages²⁶. This model is widely used for thematic analysis by several studies that explored patient delay in care seeking.

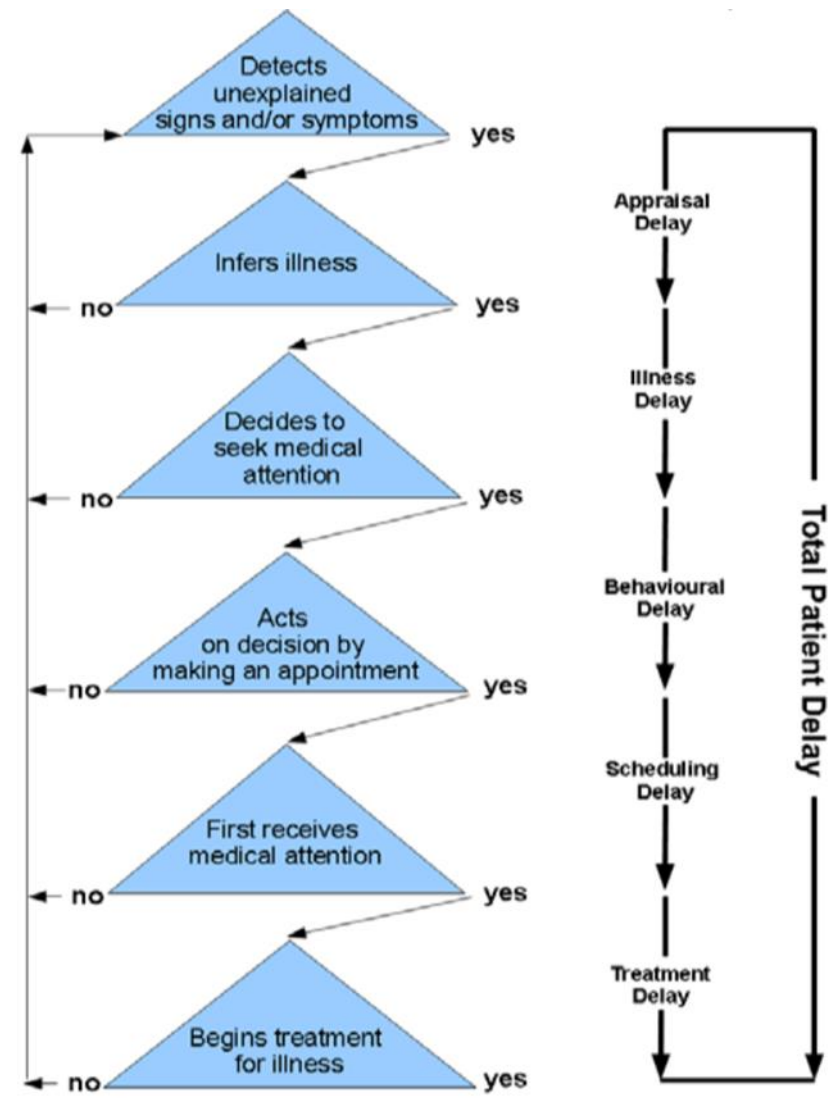


Figure 2. The General Model of Total Patient Delay as proposed by Andersen et al²⁶.

Concluding from the literature review, we can speculate that similar factors such as non-recognition or awareness of early symptoms of cancer, health behaviours such as attitudes to GPs attendance and health beliefs about cancer treatment may explain possible reasons of late presentation to health services, although there has been no study yet to explore this. Hence, future studies should a) identify personal, social, traditional, cultural, religious and economical factors that influenced the late presentation of cancer patients to health care services, b) explore the health services oriented factors which affect delay in presentation to health care services, and c) devise strategies to reduce late presentation of cancer patients to health care services.

On the other hand, GPs are the first port of call within the healthcare system for patients with suspicious cancer symptoms. For example, majority (>80%) of patients with cancer in the United Kingdom, first presents clinically to their GPs^{29,30} and proportion of patients presenting late to GPs is yet to be found. Therefore, it is important to encourage early presentation and minimise delay in reporting symptoms as late presentation may result in delayed diagnosis of cancer associated with lower survival rate.

It is pertinent for GPs to be aware of the anticipated barriers to delay in cancer presentation during the initial consultation. There have been some studies identifying risk factors for delayed presentation from patients' perspectives³¹. However, there has been no research performed looking at the reasons for delay in presentation of cancer from GPs' perspectives. Hence, this research question arises: 'What are the views of GPs towards delays in cancer presentation in Brunei Darussalam?'

Theme 2: Effect of time interval in cancer care trajectory

Late presentation of cancer patients to the health care services is likely to contribute to advance stage at diagnosis leading to poor survival³². This is due to the fact that late

presentation is correlated with bigger size of tumour, distant metastases and involvement of lymph nodes³³. There is also evidence that the route to presentation and initial management in the primary health care, are key elements of cancer patient outcomes³⁴. Hence prevention of late presentation is imperative due to its connection with survival.

There are increasing evidences that illustrated significant correlation between the onset of symptom to cancer diagnosis, and the stage at the time of diagnosis with subsequent survival^{35,36}. A systemic review by Neal et al reported longer intervals to diagnosis is associated with poorer outcomes such as mortality, disease and/or treatment related morbidity³⁷. Some studies defined delay as duration of 3 months because it is conventional and likely to represent a clinically important delay³⁸. Early detection, accurate diagnosis, and effective treatment, including pain relief and palliative care, help to increase cancer survival rates and reduce suffering³⁹.

A study by Allgar et al which compared the delay in diagnoses of six types of cancers for patients in the United Kingdom found significant delays in the diagnoses of colorectal and lung cancers¹⁷. In Denmark, a population-based cohort study of patients with colorectal cancer showed an increased risk of mortality when the diagnostic intervals are longer than 5 weeks⁴⁰. Another study in the United States of America demonstrated 40% of patients with non-small cell lung carcinoma had significant treatment delays⁴¹. Furthermore, these delays were correlated with poorer prognosis. In a small prospective British study, 20% of lung cancer patients awaiting radiotherapy for curative intent became incurable while they were on the waiting list⁴². Meanwhile, there are limited studies on the effect of treatment delay on survival rate in liver and intrahepatic bile duct cancers. A cohort study in the Netherlands showed that there is no correlation between treatment time and survival for

hepatocellular carcinoma⁴³. The morbidity and psychological outcome in cancer diagnosis may be as important as survival outcome. Similarly, reducing diagnostic delays may result in improved prognosis and increase the proportion of early stage cancers identified¹. A study by Risberg et al showed that psychological distress is positively associated with total diagnostic delay⁴⁴. Therefore, shortening diagnostic delay may not only improve survival, but may also increase the quality of life of cancer patients. On the other hand, in the United Kingdom, patients' delay in seeking consultation with health care professionals contribute significantly to the time interval in the pathway, compared to delays in referral and initiation of treatment⁴⁵. However, currently, there has been no study examining the time intervals between access to health care, diagnosis and treatment for cancer patients in Brunei.

Theme 3: Implications for GP learning needs on Cancer Care

Due to the burden from rise of cancer cases, GPs now hold a considerable responsibility, not only for diagnosis and treatment decisions but also screening, and pain management⁴⁶. Despite the extensive role of GPs in providing cancer care, little attention has been given to improve and update the knowledge of cancer in primary care⁴⁷. They reported that GPs lack familiarity with cancer treatments and sense their roles are not recognised by oncology specialists⁴⁸. Although, oncology modules are gradually incorporated for undergraduate medical students and also for postgraduate training, yet medical schools reported to provide limited teachings on cancer care⁴⁹. Studies have shown that the cancer care quality can be improved through education, hence the need to incorporate cancer education in medical trainings⁴⁹. Yet, keeping up with the recent developments of cancer care can be a challenge for GPs.

On the other hand, various open learning resources such as conferences, continuing medical education courses, online web casts and formal training opportunities are already in place to improve cancer knowledge for GPs⁴⁹. A growing number of GPs have narrowed their scope of practice to specialise in oncology, known as general practitioners in oncology (GPO). Their role includes management of cancer symptoms and pain, palliative care, supervision of systemic chemotherapy and serve as bridging the primary care and oncology specialists care systems⁴⁶.

Mode of delivery of knowledge is also vital in medical education, as different teaching methods have evolved over the years. Traditionally, didactic approach of learning was preferred whereby lectures were given by hospital consultants⁵⁰. However, this approach was suggested to be less effective and has shifted to newer methods of delivery that are more interactive and relevant with the ever evolving new cancer theories⁵¹. Internet is extensively used in most hospitals and health centres, not only for entering patients' information but also as a means of accessing medical or other information such as online journals. Hence, there have been a growing number of internet-based educational interventions that can be accessed by health professionals⁵².

Learning needs of GPs can be more focused if we know the different uncertainties which GPs find difficulty tackling when consulting patients with cancer or identifying them at an early stage. Educational methods, in the form of informal or formal training, will aid in learning, and one such available postgraduate programmes is the Masters in Science in Primary Health Care offered in the local university. This programme covers a wide area of relevant health, medical and professional topics not specifically targeting in oncology, so perhaps a specialized programme or course targeting oncology care could also be offered. In

Brunei Darussalam, there are 121 GPs who provide care in the primary care settings⁵³. Despite regular continuous medical education programs, GPs' specific education on cancer care remains limited as this is only covered very occasionally in such programs. Furthermore, little is known about educational needs of GP workforce. Future research should focus on a) explore educational needs to improve cancer care knowledge and practices among GPs b) to investigate the preferred models of delivery of cancer care education among GPs c) associate demographic variations and educational needs of GPs on cancer care and d) identify educational strategies to improve cancer care knowledge and practices among GPs.

Conclusion

Our review concludes that early diagnosis is the key factor to improve cancer outcomes such as improved survival, better treatment and patient satisfaction. Review also suggest the importance to tackle the missed opportunities that often lead to delayed presentation and screening, and poor survival rates at primary care settings. On the other hand, we also found that current initiatives to improve early diagnosis are mainly from the developed countries, where early identification of cancer often occurs at primary care settings. However, such initiatives may have less compatibility or applicability to any other local settings in

view of the differences in the social, cultural and religious backgrounds. For example, despite cancer being the leading cause of mortality and morbidity in Brunei Darussalam, little is known about interventions that could help early diagnosis in primary care. With this in mind, authors are currently undertaking a study on Improving Cancer care Outcomes at Primary care (IMCOP) in Brunei Darussalam with an aim to explore and develop knowledge base on improving cancer care at primary care setting in the context of Brunei Darussalam. In the first stage of this large IMCOP study, authors were engaged in exploring factors that leads to delayed cancer presentation at primary care settings both from patients and GPs' perspectives, the effect of time interval in cancer care trajectory and educational needs of GPs on cancer care at Brunei Darussalam.

Limitations

This study benefited from being a first review that intends to review available evidences on early diagnosis and late presentation of cancer care in primary care settings in Brunei Darussalam and its educational implications for GPs. However, the scope of our findings were limited due to the search methodology of using comprehensive literature review and limited studies on cancer care at primary settings in Brunei Darussalam.

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