

**USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINES AMONG  
CANCER PATIENTS IN PENANG, MALAYSIA: A QUALITATIVE AND  
QUANTITATIVE ASSESSMENT OF HEALTH BELIEFS, TREATMENT  
DISCLOSURE AND HEALTH RELATED QUALITY OF LIFE**

**by**

**MARYAM FAROOQUI**

**Thesis submitted in fulfilment of the requirements for the degree of  
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**UNIVERSITI SAINS MALAYSIA**

**2013**

## **DEDICATION**

This thesis is dedicated to all the cancer patients who have lost the fight and to those who believe in not to quit the fight.

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## LIST OF ABBREVIATIONS

<b>Terms</b>	<b>Abbreviation</b>
Complementary and alternative medicine	CAM
World Health Organization	WHO
Traditional and Complementary medicines	T&CM, T/CM
Evidence Based Medicine	EBM
Health Related Quality of Life	HRQoL
Treatment Decision making Process	TDP
Conventional Therapies	CT
National Cancer Registry	NCR
Age Standardized incidence Rate	ASR
Biologically Based Therapies	BBTs
Mind Body Complementary Therapies	MBCTs
Whole Medical System	WMS
Traditional Chinese Medicine	TCM
Energy Medicines	EM
Manipulative and Body Based Therapies	MBBTs
Traditional Malay Medicine	TMM
Traditional Indian medicines	TIM
Hepato-Cellular Carcinoma	HCC
American Association of Retired Persons	AARP
Quality of Life	QoL

Health Belief Model	HBM
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire	EORTC QLQ
Malaysian Ethical Research Committee	MREC
Statistical Package for Social Science	SPSS
Global Health Status	GHS

## GLOSSARY OF KEY TERMS

<b>Terms</b>	<b>Definition</b>
<b>Complementary and alternative medicine (CAM)</b>	A group of diverse medical and healthcare systems, practices, and products that are not currently part of conventional medicines
<b>Complementary medicine</b>	A diagnosis, treatment and/or prevention that complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual frameworks of medicine.
<b>Conventional Medicines</b>	Medicine as practiced by holders of M.D. (medical doctor) degree and by their allied health professionals, such as physical therapists, psychologists, and registered nurses. Other terms for conventional medicine include allopathy and allopathic medicine; Western medicine, mainstream medicine, orthodox medicine, and regular medicine; and biomedicine.
<b>Biologically/natural based therapies (BBTs)</b>	It includes various types of animal and herbal products which are commonly sold as dietary supplements.
<b>Mind body medicines/Mind body complementary therapies (MBCTs)</b>	It includes a variety of techniques to enhance the mind's capacity to affect bodily function and symptoms (meditation, yoga, hypnotherapy, yoga, qigong, tai chi, prayers and spiritual therapies, deep breathing techniques).
<b>Whole medical system (WMS)</b>	It is a complete system of theory and practice outside the conventional allopathic/ western system (Homeopathy, Traditional Chinese medicine (TCM), Ayurveda, naturopathy etc).
<b>Energy medicines (EM)</b>	It includes the use of energy fields, either the unconventional use of electro-magnetic fields, or the manipulation of energy fields that surrounds and penetrates the human body (magnetic and light therapy)

<b>Manipulative and body based therapies (MBBTs)</b>	These therapies are based on manipulation and/or movement of one or more parts of the body (chiropractic, massage therapy, spinal manipulation).
<b>Traditional and Complementary Medicine (T/CM)-Malaysia</b>	Traditional and Complementary Medicine practice together is other than practice of medicine or surgery by registered medical practitioners, as defined in Medical Act 1971, Malaysia.
<b>Health</b>	A state of complete physical, mental, and social well-being not merely the absence of disease.
<b>Quality of Life (QoL)</b>	Individuals' perceptions of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns.
<b>Health Related Quality of life (HRQoL)</b>	Patients' perspectives regarding their disease and treatment on their functional and physical symptoms.

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## LIST OF PUBLICATIONS

1. Farooqui, M., Hassali, MA., Shatar, AK., Shafie, AA., Seang, TB., Farooqui, MA. Qualitative exploration of Malaysian cancer patients' perspectives on cancer and its treatment. *BMC Public Health*, 11(1), 525. [IF:2.3]
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1. Farooqui M, Hassali MA, Knight AAS, Shafie AA, Tan BS, Farooqui MA. Cancer patients' perception towards the use of Traditional & Complementary Medicines (T&CM) for cancer treatment. A qualitative study. ISPOR 16<sup>th</sup> annual international meeting, 21-25<sup>th</sup> May, 2011, Baltimore, USA.
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A cross-sectional assessment of the quality of life of cancer patients and their complementary and alternative medicines (CAM) use. ISPOR 5<sup>th</sup> Asia pacific conference, 6<sup>th</sup>-9<sup>th</sup> September, 2012, Taipei, Taiwan.
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**PENGGUNAAN UBAT KOMPLEMENTARI DAN ALTERNATIF DALAM  
KALANGAN PESAKIT KANSER DI PULAU PINANG, MALAYSIA: PENILAIAN  
KUALITATIF DAN KUANTITATIF TERHADAP KEPERCAYAAN  
KESIHATAN, PENDEDAHAN RAWATAN DAN KESIHATAN BERKAITAN  
KUALITI HIDUP**

**ABSTRAK**

Penggunaan perubatan alternatif dan komplementari (CAM) adalah meluas untuk penjagaan kesihatan dan pengurusan gejala-gejala penyakit. Di Malaysia, terdapat bukti bahawa pelbagai CAM digunakan oleh pesakit dengan kanser. Pesakit kanser cenderung untuk menggunakan CAM dalam usaha untuk mengurangkan berulangnya kanser dan mengurangkan kesan-kesan sampingan akibat terapi konvensional. Kajian ini bermatlamat untuk menyediakan suatu penilaian yang komprehensif mengenai kepercayaan kesihatan, pendedahan rawatan dan kesihatan berkaitan kualiti hidup bagi pesakit kanser dalam konteks perubatan alternatif dan komplementari (CAM). Suatu pendekatan metodologi gabungan diadaptasi dengan menggunakan kedua-dua kaedah kualitatif dan kuantitatif. Analisis kandungan bertema mengenal pasti tiga tema utama: kepercayaan pesakit terhadap kanser dan rawatannya, persepsi pesakit terhadap penggunaan CAM bagi merawat kanser dan pendedahan tentang penggunaan CAM kepada ahli penjagaan kesihatan. Sejumlah 20 orang pesakit ditemu bual; 12 orang telah menggunakan CAM, sementara itu, hanya 4 orang mengetahuinya daripada doktor. Keberkesanan CAM yang agak lambat dan kos dinyatakan sebagai penghalang terhadap penggunaan CAM. Pesakit bersetuju bahawa pendedahan tentang CAM adalah penting untuk mengelak sebarang interaksi dengan ubat

konvensional. Tanggapan bahawa kurangnya pengetahuan dan minat dalam kalangan doktor terhadap CAM serta kebimbangan terhadap penamatan terapi oleh doktor semasa pendedahan CAM menjadi alasan mengapa CAM tidak didedahkan.

Keputusan kuantitatif menunjukkan bahawa daripada 393 orang pesakit, 184 (46.8%) dilaporkan menggunakan CAM. Dalam kalangan semua data demografi dan penyakit, penggunaan CAM secara signifikan dikaitkan dengan tahap pendidikan ( $p=0.001$ ), status pekerjaan ( $p=0.02$ ), gender ( $p=0.021$ ) dan pendapatan bulanan isi rumah ( $p<0.001$ ). Penggunaan CAM yang paling biasa adalah terapi berasaskan biologi (72.8%). Seramai 80 (43.5%) orang peserta tidak pasti jumlah yang mereka belanjakan untuk CAM setiap bulan. Sementara itu, 139 (75.5%) orang peserta mengatakan bahawa kawan-kawan dan ahli keluarga merupakan sumber maklumat utama CAM. Sikap pengguna CAM terhadap terapi CAM secara signifikan berbeza daripada sikap mereka terhadap terapi konvensional ( $p<0.05$ ). Dilaporkan bahawa pengguna CAM lebih mempercayai keberkesanan terapi konvensional daripada terapi CAM. Kadar pendedahan CAM adalah 43%, namun demikian; hanya 62 (33.7%) kes yang doktor bertanyakan tentang penggunaan CAM kepada pesakit. Dapatan bagi kajian kesihatan berkaitan kualiti hidup (HRQoL) menunjukkan bahawa peserta perempuan ( $p=0.035$ ) berbangsa Melayu ( $p=0.047$ ) yang benar-benar mengamalkan ajaran Islam ( $p=0.011$ ) didapati mempunyai skor Status Kesihatan Global (GHS) yang baik. Pesakit yang mempunyai insurans perubatan juga menunjukkan skor GHS yang baik ( $p=0.021$ ). Pesakit kanser pada tahap yang kritikal dilaporkan mempunyai skor min GHS yang rendah ( $p<0.001$ ). Dalam kalangan pengguna dan bukan pengguna CAM, skor GHS menunjukkan perbezaan yang signifikan ( $p=0.002$ ).

Sebagai kesimpulan, kajian ini mengenal pasti bahawa CAM biasanya digunakan dalam kalangan pesakit kanser di Malaysia. Penggunaan CAM yang pelbagai atau berbeza mendorong lebih banyak penyelidikan dijalankan berkaitan dengan keberkesanan terapi ini untuk rawatan kanser. Secara relatif, pendedahan tentang CAM adalah sesuatu yang baik, namun demikian perkara ini tidak dipraktikkan sebaiknya oleh para doktor. Hal ini memerlukan penyelidikan lanjut. Kanser juga dilaporkan memberi kesan terhadap kualiti hidup pesakit, dari segi fungsi dan juga emosi. Pengguna CAM dilaporkan mempunyai skor kualiti hidup yang amat rendah dibandingkan dengan bukan pengguna CAM, yang memerlukan penyelidikan lanjut tentang kesan daripada CAM yang berpotensi memberi manfaat atau yang mungkin memudaratkan kualiti hidup pesakit.

**USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINES AMONG  
CANCER PATIENTS IN PENANG, MALAYSIA: A QUALITATIVE AND  
QUANTITATIVE ASSESSMENT OF HEALTH BELIEFS, TREATMENT  
DISCLOSURE AND HEALTH RELATED QUALITY OF LIFE**

**ABSTRACT**

The use of Complementary and Alternative Medicines (CAM) is widespread for general health maintenance and management of disease symptoms. In Malaysia, there is evidence that a variety of CAM is used by patients with cancer. Cancer patients tend to use CAM in an attempt to reduce cancer recurrence and to lessen the side effects due to conventional therapies. The study aimed to provide a comprehensive evaluation of health beliefs, treatment disclosure and health related quality of life of cancer patients in the context of CAM. A mixed methodological approach using both qualitative and quantitative methods was adapted. The thematic content analysis identified three major themes: patients' beliefs towards cancer and its treatment, patients' perceptions toward the use of CAM for cancer treatment and the disclosure of CAM use to the health care providers. Twenty patients were interviewed, twelve of them reported to use CAM while only four disclosed it to the doctors. The slow progression of CAM effectiveness and cost were given as barrier to CAM use. Patients agreed that CAM disclosure is important to avoid any interaction with the conventional medicines. Perceived lack of physicians' knowledge & interest in CAM,

fear of termination of therapy by the physicians upon CAM disclosure was given as reasons of CAM non disclosure.

The quantitative results revealed that out of 393 patients, 184 (46.8%) reported to use CAM. Among all the demographic and disease variables, CAM usage was significantly associated with the level of education ( $p=0.001$ ), employment status ( $p=0.021$ ), female gender ( $p=0.021$ ) and monthly household income ( $p<0.001$ ). The most common CAM used was biologically based therapies (72.8%). Nearly half of the participants 80 (43.5%) were not sure of their monthly CAM expenditure. Friends and family members 139 (75.5%) were the most common source of CAM information. CAM users' attitudes toward CAM therapies differ significantly from their attitude towards conventional therapies ( $p<0.05$ ). CAM users reported to believe in the effectiveness of conventional therapies more than CAM therapies. CAM disclosure rate was 43%, however; only in 62 (33.7%) cases doctors had specifically asked about patients' CAM use. The HRQoL of the participants in general showed female gender ( $p=0.035$ ), Malay ethnicity ( $p=0.047$ ) and patients practicing Islam as their religion ( $p=0.011$ ) were having better Global Health Status (GHS) scores. Patients having medical insurances also showed better GHS score ( $p=0.021$ ). Patients at very advanced stages of cancer reported to have lower GHS mean scores ( $p<0.001$ ). Among the CAM users and non users only the GHS scores shows significant difference ( $p=0.002$ ).

In conclusion the study identified that CAM use is common among Malaysian cancer patients. Different types of CAM were used by the patients which welcomes more research on effectiveness of these therapies for cancer. CAM disclosure was relatively better however doctors' enquiry on patients' CAM use was very low which requires further investigation. Cancer is reported to affect patients' quality of life functionally and

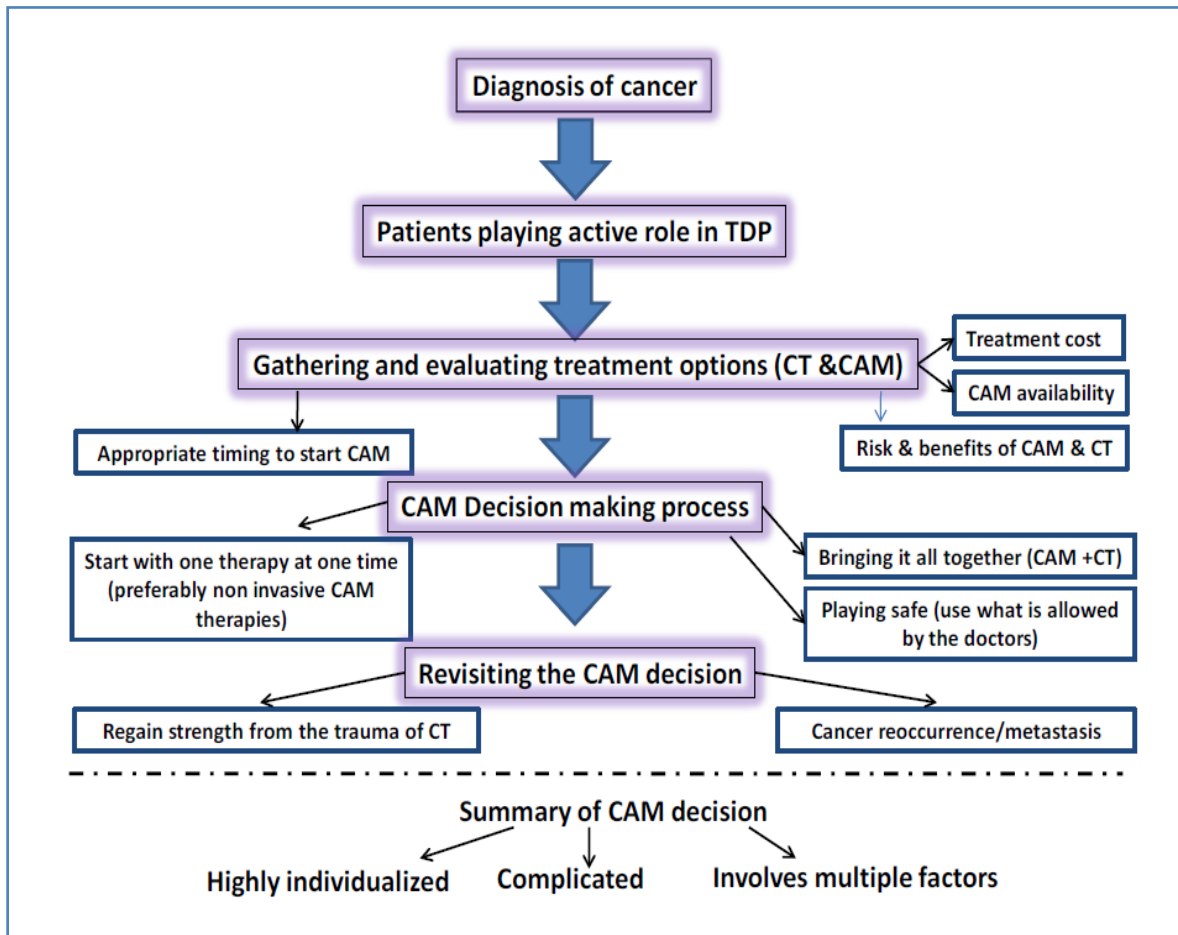
emotionally. CAM users reported to have poor quality of life scores as compare to CAM non users which requires further investigation on potential beneficial or harmful effects of CAM on patients' quality of life.



## **CHAPTER ONE: GENERAL INTRODUCTION**

## **1.1 Background to research**

The use of Complementary and Alternative Medicines (CAM) is increasing in Malaysia among healthy individuals as well as among patients with chronic diseases including cancer (Hasan et al., 2009). This demands an investigation about the frequency and patterns of CAM use among cancer patients to assess its implications in cancer care. It is evident that beside other factors such as perception of the disease and fear of cancer treatment, a strong belief in traditional modes of healings is among the factors contributed in presentation of cancer at advanced stages among Malaysian cancer patients (Taib et al., 2007). Similarly the psychological impact of cancer diagnosis contributes to problems such as depression and anxiety for patients and their care givers (Saniah & Zainal, 2010). As a consequence of these factors, cancer patients usually try different treatment options in a desperate search for a cure. Choosing CAM for cancer is a complex process. Due to the availability of a wide range of CAM the decision to use these therapies often puts patients and their care givers in a dilemma as they try to choose the best for their cancers. Figure 1.1 summarizes the steps involved in the CAM decision making process.



**Figure 1.1 Summary of CAM decision making process for cancer patients** (Note: TDP-Treatment Decision making Process, CT-Conventional Therapies, CAM-Complementary and Alternative Medicines)

Patients' decision to use CAM is highly individualized and involves multiple factors. Combining CAM therapies with conventional cancer treatments may have the potential to cause adverse effects (Boon et al., 2000). The slow progression of the effects of CAM may delay patients from seeking proven therapies for cancer. Communication between patients and health care providers may help patients to seek the right CAM at the right time. Due to these reasons it is crucial to investigate why and how people decide to use CAM for cancer. Studies that have attempted to evaluate patients' decision making processes in CAM use show that the decision to use CAM does not only depend on demographic and

disease characteristics but is also due to the perceived effectiveness of CAM and conventional treatments and experiences within health care systems (Boon et al., 1999; Boon et al., 2003). Such investigations may benefit patients and their health care providers in designing programs to educate patients on the use of Evidence Based Medicines (EBM) for cancer and the importance of CAM use discussion with health care providers.

The integration of CAM into the modern health care system is considered as an effective tool to provide a holistic approach to cancer care rather than merely focusing on a disease oriented approach (Ben-Arye et al., 2012). In the Malaysian context the concept of integrative medicine has emerged in the last two decades with an increasing recognition of the popularity of traditional medicines and the potential of combining them with evidence based medicinal CAM to offer supportive cancer care. Several integrative medicine units have been set up throughout the country to ensure patients receive proven therapies for cancer (Portal Rasmi Bahagian Perubatan Tradisional & Komplementari, 2011). However, the decision of patients to use CAM is still unexplored among Malaysian cancer patients.

The current study aimed:

- i) To determine the prevalence and types of CAM used by cancer patients, their monthly expenditure and sources of information on CAM.
- ii) To determine the beliefs of CAM users and non users towards the causes and curability of cancer.
- iii) To determine the beliefs of CAM users and non users towards the effectiveness of CAM and conventional therapies for cancer treatment.

- iv) To determine the overall CAM disclosure rate to doctors, doctor's investigations of their patients' CAM use and patients' reason of CAM non disclosure.
- v) To compare the Health Related Quality of Life (HRQoL) of cancer patients in the context of CAM.

## **1.2 Justification of the study**

In the research area, few studies have attempted to evaluate CAM use among cancer patients in Malaysia, these studies are confined to certain types and stages of cancer among specific ethnic groups only (Lua, 2011; Shaharudin et al., 2011). These studies were unable to adequately identify the ethno-cultural differences which affect the decision to use CAM. Increased incidence of cancer among Malaysians, and presentation at advanced stages, demands an in-depth investigation to identify the key issues to understanding Malaysian cancer patients' decision to use CAM. Malaysian literature is still lacking data on how cancer patients perceive the effectiveness of CAM over conventional medicines. Patient-doctor communication on cancer treatment also affects patients' treatment seeking behaviour. However, this issue is poorly explored in the Malaysian context. Issues related to monthly CAM expenditure would help to identify methods to offer some subsidies or medical coverage of CAM in the Malaysian health care system. Evaluation of Health Related Quality of Life (HRQoL) of cancer patients in general and to different types of CAM therapies specifically would help to provide better opportunities to improve the health policies on CAM.

### **1.3 Overview of the thesis**

Chapter 2 takes the form of a literature review and provides an overview of incidence of cancer in Malaysia and its impact on the Malaysian health care system. The role of CAM in the Malaysian health care system with specific reference to cancer is discussed in detail. The practice of CAM decision making processes and the factors associated with CAM use is provided in a later section of this chapter. CAM disclosure to health care providers and specifically to doctors is discussed. Lastly the chapter concludes by exploring issues related to CAM use and HRQoL of cancer patients. Chapter 3 elaborates on two different methodological approaches i.e. qualitative and quantitative methods, and how they have been adapted for this thesis. Chapter 4 presents the results from the qualitative phase of the research. This chapter presents cancer patients' beliefs in relation to cancer and its treatment, CAM use CAM decision making process and decisions of patients regarding CAM disclosure to the doctors.

Chapter 5 presents the results from the quantitative phase of the thesis. This chapter discusses the use of CAM among cancer patients, their beliefs towards the effectiveness of CAM and conventional medicines for cancer, and CAM disclosure to the doctors. Chapter 6 aims to present the Health Related Quality of Life (HRQL) of cancer patients in the context of CAM. Chapter 7 draws the thesis towards conclusion, reviewing the implications of the study findings, limitations of the approach used, and a brief section outlining recommendations for future research.

## **CHAPTER TWO: LITERATURE REVIEW**

## **2.1 Introduction**

This chapter discusses the review of literature related to prevalence of cancer in Malaysia, the common medical treatments that cancer patients undergo, the prevalence of CAM among healthy Malaysians as well as patients with chronic diseases including cancer, and the reasons for CAM use. In addition, cancer patients' CAM disclosure to doctors and the impact of CAM therapies on cancer patients' quality of life are discussed.

## **2.2 Burden of cancer world wide**

Cancer is among the leading causes of death globally (World Health Organization, 2013). In 2008, 7.6 million people were reported to have died due to cancer; whereby an estimated 30% of the cancers were preventable. Deaths from cancer worldwide are expected to rise to over 13.1 million in 2030 (World Health Organization, 2013). Middle to low income countries reported higher incidence of cancer and approximately 70% of the deaths were reported from these countries. Lung (1.37 million deaths), stomach (736 000 deaths), liver (695 000 deaths), colorectal (608 000 deaths), breast (458 000 deaths) and cervical cancer (275 000 deaths) are identified as the most common types of cancers worldwide. In the region of south-east Asia, the most common cancers are lung (14.7%) and breast (22.4%) cancers among men and women respectively (World Health Organization, 2008a).



### 2.3 Burden of cancer in Malaysia and treatment options available

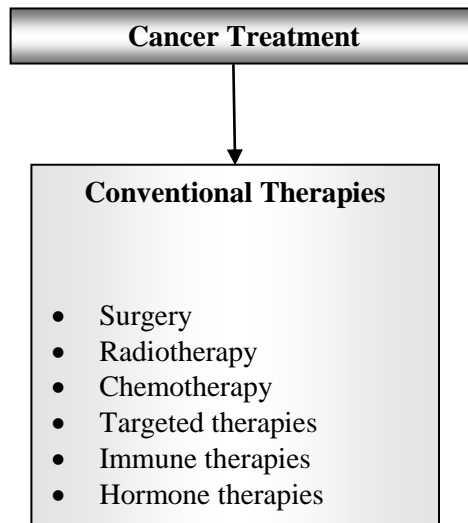
In Malaysia, during the recent years, diseases such as hypertension, ischemic heart disease, diabetes mellitus and cancer have largely replaced the diseases such as malaria, tuberculosis and infant gastrointestinal diseases (World Health Organization, 2013). Changes in lifestyle habits such as excessive smoking, alcohol consumption, and sexually transmitted diseases have also increased the incidence of cancers. In 2006, a total of 21,773 cancer cases were diagnosed among Malaysians in Peninsular Malaysia and were registered in the National Cancer Registry (NCR). This included 9,974 males and 11,799 females. Regardless of sex, the Age Standardized incidence Rate (ASR) for all cancers during the year 2006 was 131.3 per 100,000 (Malaysian Cancer Statistics, 2006). The five most common cancers identified were breast, colorectal, lung, cervix and nasopharynx. Estimated incidence and mortality due to the five most common cancers among Malaysians (both sexes) are summarized in Table 2.1.

**Table 2.1: Estimated incidence and mortality due to five most common cancers among Malaysians (both sexes)**

<b>Cancer</b>	<b>Incidence N (%)</b>	<b>Mortality N (%)</b>
Breast	4485(14.0)	1716(8.5)
Colorectum	3651(11.4)	2356(11.7)
Lung	3628(11.3)	3309(16.5)
Cervix-uteri	2126(6.6)	631(3.1)
Nasopharynx	2000(6.3)	297(1.5)

*Source: Malaysian Cancer Statistics, 2006*

The ASR among males and females were 128.6 per 100,000 and 135.7 per 100,000 respectively. While looking at the ethnic variations, cancer seems to be more predominant among the Chinese as compared to those of Malay and Indian descent. The ASR for Chinese males and females was 148.0 per 100,000 and 151.5 per 100,000 respectively, while for Malay males and females it was 94.5 per 100,000 and 96.4 per 100,000 respectively (Malaysian Cancer Statistics, 2006). This variation could be due to genetic differences as well as awareness towards reporting cancer symptoms to oncology professionals. Lack of awareness of the early signs of cancer and a fear of conventional treatments are among the reasons Malay cancer patients are reported to seek treatment from local traditional practitioners before seeking advice from oncology professionals (Lim, 2002). Furthermore, modern health care services in Malaysia rely largely on many traditional systems of treatment that reflect different groups and cultures. During the past few decades considerable attention has been given to traditional modes of healing, recognizing their role in the national health care system. Some of the common treatment methods available for Malaysian oncology patients are summarized in Figure 2.1.



**Figure 2.1: Types of cancer treatments available in Malaysia**  
*Source: Malaysian Oncology Society, 2011*

### ***Conventional therapies***

Cancer treatment is multidisciplinary and requires the skills of a team of experts. Conventional treatments are those that are widely used in the modern health care system. They are usually considered as Evidence Based Medicines (EBM) i.e. the safety and efficacy of these therapies have been well established through clinical trials. Professionals trained in this stream of treatment include oncologists, oncology nurses, radiation therapists, and oncology pharmacists. The conventional treatment offered by hospitals in Malaysia usually includes surgery, chemotherapy, radiotherapy, hormonal therapy and palliative care. The oncology services in government hospitals face a lack of experts and equipments. However; networking between government and private hospitals has helped in coping with the ever growing burden of cancer on the Malaysian health care system (Lim, 2006). Surgical procedures and chemotherapy is usually provided in most of the government, district and private hospitals throughout the country. Simultaneously, radiotherapy services are provided by private radiology centres. In 2002, there were 14

radiology centres all over the country including two in government hospitals, three in universities and nine in the private sector (Lim, 2002). Currently a number of private oncology centres are emerging in the major cities where the facilities are comparable to developed countries. For example, in Penang state itself there are six private hospitals fully equipped with major cancer treatment services offering treatments to many patients from neighbouring countries, making Penang a hub for health tourism.

The location of hospitals and the services provided has a major impact on patients' behaviour in seeking cancer treatments. Considering the case of the northern region of Malaysia, the Penang General Hospital provides major oncology services for most types of cancers, while the hospital in Alor Star has expertise in gynaecological cancer and caters for most of such cases. With such collaborative care and mutual understanding, cancer patients from the northern region are receiving the best of cancer care.

#### **2.4 Use of Complementary and Alternative Medicines (CAM) among cancer patients**

The use of CAM for health and for healing purposes has long existed in human society. In the modern era, therapies which are now used to complement or as an alternative to conventional medicines, were the only way of cure in ancient times. However, a boost in modern drug delivery options excluded CAM. The basis of many of the modern treatments for cancer originated in pre-modern society and were used for treatment and prevention. For example, Vincristine (Oncovin®) was used as folk remedy for centuries until scientists revealed that this medicinal plant has a number of alkaloids, some of which are responsible for myelo-suppression (decreased activity of the bone marrow) (Costa-Lotufo et al., 2005).

In the modern era of the 21<sup>st</sup> century, many of the underdeveloped countries such as African and some of the south East Asian countries rely solely on CAM as a source of treatment (World Health Organization, 2008b). Lack of health care facilities, poverty and the disease burden on the health care system forced many patients to choose CAM as their first option for treatment. At the same time cultural influences and a lack of knowledge regarding modern therapies turns many cancer patients towards CAM. In this context defining CAM is a difficult task, as what is considered as CAM in one region of the world could be part of conventional treatment in other regions.

## **2.5 CAM definition**

Defining CAM and ordering them into different categories is not an easy task. CAM is a broad field and CAM modalities are constantly increasing. ‘Complementary’ and ‘alternative’ medicines are two distinct terms which have a great difference in meaning. ‘Complementary’ can mean therapies which are used to complement conventional medicines. On the other hand ‘alternative’ treatments are something alternative to conventional therapies. However, within the literature on CAM there is a certain amount of ambiguity. The word CAM is simply used in most of the literature as therapies alternative to conventional medicines (Micke et al., 2009; Sewitch & Rajput, 2010). However, looking at the meaning of ‘complementary’ it could be therapies which are used to complement the conventional medicines. Eisenberg and colleagues in an attempt to evaluate the use of CAM amongst the US population, defined alternative or unconventional therapies as “medical treatments that are not widely used in US medical schools or generally available at US hospitals” (Eisenberg et al., 1993). Complementary medicine was originally defined by Ernst and colleagues as “ a diagnosis, treatment and/or prevention that complements

mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual frameworks of medicine” (Ernst et al., 1995).

In recent years significant emphasis has been given to defining CAM from a cultural context, since what is considered as CAM in European/Western cultures could be part of daily health care practice in other regions of the world (for e.g. acupuncture in North America vs China). A blended and more flexible definition of CAM has been given by Zollman and Vickers who define CAM as “a broad domain of healing resources that encompasses all health systems, modalities and practices, and their accompanied theories and beliefs other than those intrinsic to the politically dominated health system of a particular society or culture in a given historical period” (Zollman & Vicker, 1999). A similar definition is given by the WHO, where CAM is defined as “a broad set of health care practices that are not part of that country's own tradition and are not integrated into the dominant health care system” (World Health Organization, 2008b). Within this thesis, CAM is defined as “a group of diverse medical and healthcare systems, practices, and products that are not currently part of conventional medicines” (National Centre for Complementary and Alternative Medicines, 2011). Table 2.2 provides different types of CAM therapies classified by the US National Centre for Complementary and Alternative Medicines (NCCAM).

**Table 2.2: US National Centre for Complementary and Alternative Medicine (NCCAM) classification of the major types of CAM**

CAM CATEGORIES	EXAMPLES
<b>Biologically Based Therapies</b> which use substances found in nature to promote health.	Nutritional supplements (vitamins, mineral, enzymes)
	Special diet(herbs, animal products, juices)
<b>Mind Body Complementary Therapies</b> which uses a variety of techniques to enhance the mind's capacity to affect bodily function and symptoms.	Prayers for health reasons/spirituality
	Others (meditation, T'ai chi, music, yoga, Qigong, hypnotherapy, Reiki)
<b>Whole Medical System</b> which are complete systems of theory and practice outside the conventional allopathic model	Traditional Chinese medicines
	Homeopathy
	Ayurveda
<b>Energy Medicines</b> which involves the use of energy fields, either the unconventional use of electromagnetic fields, or the manipulation of energy fields that purportedly surround and penetrate the human body.	Light therapy, Ozone therapy
<b>Manipulative Body Based Therapies</b> which are based on manipulation and/ or movement of parts of the body.	Massage, herbal baths/aromatherapy

*Source: National Centre for Complementary and Alternative Medicines, 2011*

## 2.6 Complementary and Alternative Medicines (CAM) in Malaysia

Malaysian society represents a refined amalgamation of multiple races and cultures which offers a wide range of traditional methods of healing. Understanding the roots of the Malaysia's historical background and the health care system may help to understand CAM use among Malaysian cancer patients. Before independence the local people were reported to have their health beliefs and practices which reflect the medical traditions of the Arab, the Hindus and various other people who were settled in the Malay Peninsula at that time (Chee & Barraclough, 2007). A large migration of Chinese and Indian labourers brought with them their healers and healing medicines. Simultaneously, Malaysia's rich tropical

biodiversity is a reliable source of natural products. In general, diverse culture with different ethnic races and the unique flora and fauna makes Malaysia as a platform for several kinds of traditional medicines.

The current health care system in Malaysia is based on western medicine which is dominant politically and culturally. A growing interest in traditional modes of healing globally has encouraged many countries to recognize the importance of traditional medicines in their primary health care systems (World Health Organization, 2008b). The WHO, through its traditional medicines program has encouraged countries to recognize the preventive and curative aspects of traditional medicines in the nation's health care system (World Health Organization, 2008b).

The main objectives of WHO traditional medicines program are:

- i. To facilitate the integration of traditional medicine into national health care systems
- ii. To promote the rational use of traditional medicine through the development of technical guidelines and standards.
- iii. To disseminate information on various forms of traditional medicines
- iv. To ensure patient safety by upgrading the skills and knowledge of traditional medicine providers.

Based on the above objectives, Malaysia established policy on CAM in 1999, with the aim to integrate CAM into the Malaysian health care system to achieve a holistic approach towards enhancing health and the quality of life (National policy on traditional/complementary medicine, 2001). The Traditional and Complementary Medicines (T/CM) division was established under the ministry of health Malaysia which



aims to promote proper use of CAM, provision of appropriate education and training to CAM practitioners as well as the establishment of strong research activities in CAM development. Malaysian policy on CAM defines CAM as “Traditional and Complementary Medicine (T/CM) practice together is other than practice of medicine or surgery by registered medical practitioners, as defined in Medical Act 1971, (Malaysia)” (National policy on traditional/complementary medicine, 2001). Table 2.3 provides different types of CAM practices offered by traditional and complementary medicines unit, ministry of health, Malaysia for patients with different chronic diseases such as stroke and cancer (Portal Rasmi Bahagian Perubatan Tradisional & Komplementari, 2011).

**Table 2.3: Common CAM practices in Malaysia**

CAM practices	Examples
<b>Traditional Malay Medicine (TMM)</b>	Malay herbs, Malay massage, Bekam (Cupping)
<b>Traditional Chinese Medicines (TCM)</b>	Acupuncture & Moxibustion, Chinese herbs, Tuina, Qigong
<b>Traditional Indian medicines (TIM)</b>	Ayurveda, Siddha, Unani, Yoga
<b>Homeopathy Medicines</b>	A system for treating disease based on the administration of minute doses of a drug that in massive amounts produces symptoms in healthy individuals similar to those of the disease itself.
<b>Complementary Medicines</b>	<i>Manipulative based therapies</i> (Chiropractor, osteopathy, therapeutic massage, spa therapy, reflexogy, Thai massage, Swedish massage, Balinese/Javanese massage, Shiatsu massage, and aromatherapy).
	<i>Energy medicine</i> (colour vibration therapy, crystal healing, reiki, aura metaphysics, roaha, bach flower, phytophysics)
	<i>Mind body soul therapy</i> (hypnotherapy, psychotherapy)
	<i>Biological based practices</i> (nutritional therapy, naturopathy)
<b>Islamic Medicine Practices</b>	The effort at seeking treatment for physical and spiritual ailments; done by a Muslim who is knowledgeable and skilled in treatment methods using Quranic verses, Hadith, the practices of the pious and righteous scholars, and of the venerated religious teacher; and also skilled with the use of methods or materials are permitted by the Islamic law.

*Source: Portal Rasmi Bahagian Perubatan Tradisional & Komplementari, 2011*

## **2.7 Prevalence of CAM use among cancer patients**

In general CAM use is common among healthy individuals as well as patients with chronic diseases such as arthritis, HIV/AIDS and cardiovascular diseases (Callahan et al., 2009; Dhalla et al., 2006; Yeh, Davis, & Phillips, 2006). On average 40% of cancer patients from western societies including Australia, Canada, Europe, New Zealand and the USA use CAM (Horneber et al., 2012). In the US, a population based survey reported that 40% of cancer survivors had used CAM during the previous year (Mao et al., 2007). In a systemic review of 52 studies including 14 countries from western and eastern regions showed that the prevalence of CAM use ranged from as low as 5% to as high as 60% with an average prevalence of 31.4% in adult cancer patients (Verhoef et al., 2005).

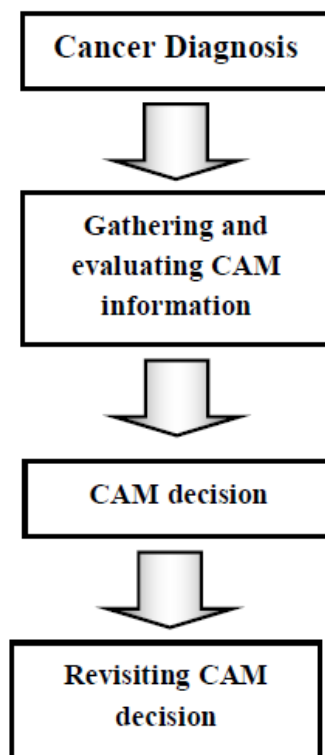
Very few studies reported that the prevalence of CAM use among Asian cancer patients which is relatively higher than that of Western countries (Ben-Arye et al., 2012). For example, among the Asian cancer population the reported CAM prevalence is, China (93.4%), Sri Lanka (67.4%), Malaysia (64%), Thailand (60.9%), Singapore (56%), Pakistan (54.5%), Turkey (42.3%) and in India (34.3%) (Liu et al., 2012; Broom et al, 2010; Shaharudin et al., 2011; Puataweepong, Sutheechet, & Ratanamongkol, 2012; Shih, Chiang, & Chan, 2009; Malik, Khan, & Khan, 2000; Tarhan et al., 2009; Broom et al., 2009). The wide variation in the frequency of CAM use shown within these studies could be due to understandings of CAM, the list of CAM therapies provided during interviews (predefined list of CAM given vs. recall of CAM without being prompted), frequency of CAM use and restrictions to consider only certain CAM therapies as a study's objective.

The understanding of the concept of CAM may vary the pattern of response. Different people consider CAM in different ways, for example, prayers and spiritual therapies are perceived as a daily life practice for some patients and thus not reported as CAM but for others it can be considered as CAM (Elizabeth Johnston, 2005).

It is also noticeable that the duration of CAM use may also affect the percentage reported. Surveys investigating CAM use since cancer diagnosis may have a high CAM prevalence compared to surveys investigating CAM use within a limited duration (for example, the last six months or a year). Similarly one may also argue that face to face interviews may introduce some bias when eliciting responses, especially if the survey is conducted in a conventional oncology setting or the interviewer is a nurse or pharmacist from the same setting thus forcing patients to respond positively in a socially desirable manner. Since fear of termination of therapy is reported among the reasons for CAM non-disclosure this debate could be acceptable to some extent (Robinson & McGrail, 2004).

## **2.8 The CAM use decision making process**

The decision to use CAM is a highly complex process which revolves around many issues. A simplified model of the CAM decision making process is given in Figure 2.2.



**Figure 2.2: Summary of CAM decision making process**

An individual's perspective towards health and disease may affect the treatment decision. Factors affecting CAM use are diverse and are not merely due to a dissatisfaction with conventional medicines but more as an alternative to avoid cancer recurrence, to strengthen the body after or during cancer treatment and for psychological well being (Gerber et al., 2006). Mao and colleagues while investigating CAM users' unmet need, found out that emotional, physical, nutritional, financial, treatment related information and employment factors were the common unmet needs among 50% of cancer patients (Mao et al., 2008). A similar review concluded that the CAM use was associated with a strong belief in CAM, a need for control and considering CAM as a last resort and hope for cure (Verhoef et al., 2005).

The emotional impact of cancer diagnosis, perceptions of the disease, the availability of different treatment options and the cost of therapy may act as pulling or pushing factors in CAM use (Verhoef & White, 2002). Patients with a passive behaviour towards treatment may rely on their physician's advice. However, patients actively participating in the treatment decision may contribute to the CAM decision making process.

The first phase in the CAM decision making process involves gathering information about CAM. Due to the availability of a wide range of CAM, patients usually find themselves with a pool of CAM therapies where choosing one or picking the best one is always a challenging task (Boon et al., 1999). Recommendations from friends and family members and other cancer survivors are some of the sources reported to help patients in CAM selection (Hirai et al., 2008; Hyodo et al., 2005). Patient judgment to the potential risks and benefits of CAM and the possible interactions with conventional medicines may also affect CAM decision (Verhoef & White, 2002).

The cost and availability of CAM may also affect the decision to use CAM (Balneaves et al., 2006; Gupta et al., 2002). Although low cost and easy access are among the reasons given for CAM use this is not true in all cases (Ezeome & Anarado, 2007). Homemade traditional therapies may provide patients with easy and cheap access to these therapies, but most of the commercial products including mega vitamins, herbal drinks and supplements are relatively expensive. Traditional Chinese Medicines (TCM) are easily available in China but may not be so easily available for patients from other parts of the world. Travelling or shipment cost may also affect a patient's decision to use CAM. Diagnosis with cancer may also affect a patient's productivity (job loss) or the cost of

conventional treatment may be a burden (Choi et al., 2007). In such situations the extra cost of CAM therapies may affect patient decisions regarding using CAM. Thus beside affordability, the availability of certain CAM may affect the CAM decision making process (Bodeker & Kronenberg, 2002).

Ascertaining the appropriate phase of cancer to start a CAM in order to avoid interaction with conventional therapies is another aspect which affects the decision of CAM use (Shen et al., 2002). Using one CAM at a time to avoid CAM-CAM interactions as well as to evaluate the effectiveness of a certain CAM could also be an important factor in CAM decisions. Similarly patient decisions to use non-invasive CAM therapies while undergoing conventional treatment may also affect the choice of CAM modalities. Therapies like massage, relaxation techniques, yoga, Qigong, and music therapies have been commonly used by cancer patients to meet those psychological needs which are not fully supported by conventional therapies (Deng & Cassileth, 2005). Patients were also reported to revisit their decision to use CAM after the end of conventional treatment in order to regain strength and energy after going through chemotherapy or radiotherapy (Balneaves, Weeks, & Seely, 2008). At the same time, fear of cancer recurrence or metastasis may also force patients to revisit their CAM decision and to try therapies which they rejected during the initial phase (Henderson & Donatelle, 2004).

In summary the CAM decision making process is highly individualized, complicated and revolves around multiple factors. Patients' values, beliefs, knowledge and specific health care needs may affect this highly complex process.

## **2.9 Theoretical explanations for CAM use**

### **2.9.1 The health belief model and its connectivity with CAM use**

Several health behaviour models have been proposed to understand an individual's health-related behaviour. The best known model in public health is the Health Belief Model (HBM) which was introduced to understand human behaviour towards seeking health services such as immunization and screening (Becker, 1974). The model's four key components are conceptualized as; perceived susceptibility, perceived severity, perceived benefits, and perceived barriers. The model assumes that an individual's health behaviour depends upon beliefs regarding the impact of the illness and its consequences, provided that the individual has a distinct course of action by which to proceed.

Although few studies have utilized HBM in understating cancer patients' CAM use, some of its constructs well apply to identifying reasons why people choose to use CAM. Perceived severity of illness may contribute to CAM use. Patients with poor knowledge regarding cancer and its treatment and the perceived severity of untreated cancer may delay the process of seeking proven therapies while searching for CAM. Perceived susceptibility of getting cancer may also contribute to using CAM to prevent cancer occurrence. Similarly, perceived susceptibility to cancer recurrence is also linked to CAM use among cancer survivors (Henderson & Donatelle, 2004). Perceived benefits of both conventional and CAM therapies may affect a decision to use CAM (Boon et al., 2000). On the other hand perceived severity of the side effects caused by conventional therapies is given as reason for CAM use (Verhoef & White, 2002). In certain cases CAM is perceived