HEALTH-SEEKING BEHAVIOUR AND DELAYED PRESENTATION OF ORAL CANCER PATIENTS IN MALAYSIA: A QUALITATIVE STUDY

NURIZYANI BINTI AZHAR

FACULTY OF DENTISTRY
UNIVERSITY OF MALAYA
KUALA LUMPUR

2017

HEALTH-SEEKING BEHAVIOUR AND DELAYED PRESENTATION OF ORAL CANCER PATIENTS IN MALAYSIA: A QUALITATIVE STUDY

NURIZYANI BINTI AZHAR

DESSERTATION SUBMITTED IN FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF DENTAL SCIENCE

FACULTY OF DENTISTRY
UNIVERSITY OF MALAYA
KUALA LUMPUR

2017

UNIVERSITY OF MALAYA

ORIGINAL LITERARY WORK DECLARATION

Name of Candidate: Nurizyani Azhar

Registration/Matric No: DGC140009

Name of Degree: Master of Dental Science

Title of Project Paper/Research Report/Dissertation/Thesis ("this Work"):

Health-seeking Behaviour and Delayed Presentation of Oral Cancer Patients in Malaysia: A Qualitative Study

Field of Study:

I do solemnly and sincerely declare that:

(1) I am the sole author/writer of this Work;
(2) This Work is original;
(3) Any use of any work in which copyright exists was done by way of fair dealing and for permitted purposes and any excerpt or extract from, or reference to or reproduction of any copyright work has been disclosed expressly and sufficiently and the title of the Work and its authorship have been acknowledged in this Work;
(4) I do not have any actual knowledge nor do I ought reasonably to know that the making of this work constitutes an infringement of any copyright work;
(5) I hereby assign all and every rights in the copyright to this Work to the University of Malaya ("UM"), who henceforth shall be owner of the copyright in this Work and that any reproduction or use in any form or by any means whatsoever is prohibited without the written consent of UM having been first had and obtained;
(6) I am fully aware that if in the course of making this Work I have infringed any copyright whether intentionally or otherwise, I may be subject to legal action or any other action as may be determined by UM.

Candidate's Signature Date:

Subscribed and solemnly declared before,

Witness's Signature Date:

Name:

Designation:

ABSTRACT

Objective: The aim of this study was to explore the pattern of health-seeking behaviour among oral cancer patients in Malaysia and identify behaviours that lead to their delayed presentation.

Method: A qualitative exploratory study was carried out using semi-structured in-depth interviews among 35 oral cancer patients having disease stages ranging from TNM stage III to IV, who were treated at six tertiary regional centres managing oral cancer throughout Peninsula Malaysia, Sabah and Sarawak. A focus group discussion was carried out for a methodological triangulation purposes. All interviews were audio-recorded, transcribed verbatim and coded using NVivo (version 10.0) qualitative software. The coding process was based on the priori themes of the Self-Regulatory Model's components which were; participants' symptom interpretations, coping strategy and their appraisal of coping efforts. All transcribed verbatim from both semi-structured in-depth interviews and focus group discussion were analysed using framework analysis.

Results: 35 participants tended to interpret their early disease signs and symptoms as a minor condition and did not consider it as requiring immediate attention. This was found to be one reason for the delay in presentation at the clinic. Those from a low education background failed to interpret their symptoms. Participants were unconcerned about its presence, most likely due to a lack of knowledge and awareness regarding oral cancer. Four main types of coping procedures which accounted for patients' delay in seeking help emerged: 1) self-remedy 2) self-medication using unconventional medicine; 3) seeking traditional healers/medicine and 4) consulting general medical practitioners (private sector) instead of the dentists. Participant-related factors such as socio-demographic characteristics (age, gender and residential area), socio-economic status, cultural beliefs and religious practices influenced delay in seeking help among oral cancer patients in

Malaysia. Smoking, excessive alcohol consumption and betel quid did not influences participants' health-seeking behaviour due to their limited knowledge regarding these high-risk habits that may be a contributing factor of oral cancer. Participants' preference to seek private sector general medical practitioners as their first options of seeking care (due to lack of knowledge) was one other reason for prolonged delay in diagnosis that may lead to professional delay. A health-seeking pathway was constructed based on the data (adapted from the Self-Regulatory Model) to show participants' pattern of seeking care. The emergent themes such as (i) misdiagnosis by healthcare professionals due to 'incorrect history provided by participants', 'doctor's lack of awareness regarding early sign and symptom of oral cancer' and 'poor doctor-patient's communication' led to a professional delay in the present study. Moreover, the (ii) availability and accessibility of cheaper over-the-counter medicines in pharmacies were found associated with participants delay in diagnosis.

Conclusion: Participants low levels of public knowledge and awareness regarding oral cancer as well as their psychological factors were found to influence their health-seeking behaviour in terms of symptom interpretation, coping strategy and appraisal of coping efforts which resulted in their delay in seeking help and being diagnosed early. General medical practitioners' inability to detect early signs of oral cancer led participants to experience a professional delay.

ABSTRAK

Objektif: Tujuan kajian ini adalah untuk meneroka corak tingkah laku kesihatan dalam kalangan pesakit-pesakit kanser mulut di Malaysia dan mengenal pasti tingkah laku yang mengakibatkan kelewatan mereka untuk hadir mendapatkan bantuan.

Kaedah: Satu kajian kualitatif dijalankan menggunakan kaedah temu bual separa berstruktur secara mendalam dalam kalangan 35 orang pesakit kanser mulut yang terdiri daripada peringkat TNM III dan IV, dirawat di enam buah hospital yang menjadi pusat pengurusan pesakit kanser mulut di seluruh Semenanjung Malaysia, Sabah dan Sarawak. Perbincangan secara berkumpulan telah dijalankan untuk tujuan *'methodological triangulation'*. Semua sesi temu bual tersebut dirakamkan, disalin kata demi kata dan dikodkan menggunakan perisian kualitatif NVivo (versi 10.0). Proses *'coding'* dilakukan berdasarkan tema terdahulu iaitu komponen *'Self-Regulatory Model'* terdiri daripada; tafsiran peserta terhadap gejala, strategi menghadapi gejala dan penilaian mereka terhadap usaha yang dijalankan. Kedua kaedah iaitu temubual separa berstruktur yang mendalam dan perbincangan secara berkumpulan telah disalin kata demi kata dan dianalisis menggunakan kaedah *'framework analysis'*.

Keputusan: 35 orang peserta mentafsirkan tanda-tanda dan gejala awal penyakit mereka sebagai perkara kecil dan tidak memerlukan perhatian segera. Perkara ini didapati telah menjadi salah antara punca kelewatan mereka hadir ke klinik. Mereka yang terdiri dari latar belakang pendidikan yang rendah, gagal mentafsir gejala mereka. Peserta kurang prihatin mengenai gejala, disebabkan oleh kurangnya pengetahuan dan kesedaran mengenai kanser mulut. Empat jenis kaedah yang menyumbang kepada kelewatan pesakit mendapatkan bantuan ialah: 1) rawatan sendiri; 2) rawatan sendiri menggunakan ubat konvensional; 3) mendapatkan bantuan dari pengamal perubatan tradisional dan 4) mendapatkan bantuan pengamal perubatan umum (sektor swasta) dan bukannya doktor gigi. Faktor-faktor yang berkaitan dengan peserta seperti ciri-ciri sosio-demografi (umur,

jantina dan kawasan perumahan), status sosio-ekonomi, kepercayaan budaya dan amalan agama mempengaruhi mereka dalam mencari bantuan dalam kalangan pesakit kanser mulut di Malaysia. Merokok, pengambilan alkohol yang berlebihan dan mengunyah sireh tidak mempengaruhi tingkah laku kesihatan peserta-peserta kerana pengetahuan mereka terhad mengenai tabiat berisiko tinggi tersebut, yang menjadi faktor penyumbang kepada kanser mulut. Keutamaan para peserta untuk mendapatkan bantuan dari pengamal perubatan umum di sektor swasta sebagai pilihan pertama mereka bagi mendapatkan rawatan (kerana kekurangan pengetahuan) adalah salah satu sebab lain yang mengakibatkan kelewatan yang lebih lama sebelun didiagnosis seterusnya menyebabkan kelewatan profesional. Langkah-langkah yang diambil oleh para pserta untuk mendapatkan bantuan telah dibina berdasarkan data (disesuaikan dengan *Self-Regulatory Model*) untuk menunjukkan corak tingkah laku peserta mendapatkan rawatan. Tema-tema baru yang muncul seperti: (i) Kesilapan diagnosis oleh pengamal perubatan awam kerana 'maklumat gejala yang kurang tepat daripada peserta,' ‘kurang kesedaran dalam kalangan pengamal perubatan mengenai tanda awal dan gejala kanser mulut 'dan' komunikasi ‘doktor-pesakit' membawa kepada kelewatan profesional dalam kajian ini. Selain itu, (ii) Kemudahan akses terhadap ubatan moden yang lebih murah di farmasi didapati mempengaruhi kelewatan peserta didiagnosis.

Kesimpulan: Tahap pengetahuan yang rendah dan kesedaran mengenai kanser mulut serta faktor-faktor psikologi para peserta didapati mempengaruhi tingkah laku kesihatan dari segi tafsiran terhadap gejala, strategi menangani gejala dan penilaian dalam usaha yang dijalankan, menyebabkan kelewatan mereka untuk mendapatkan bantuan dan didiagnosis awal. Ketidakupayaan para pengamal perubatan awam mengesan tanda awal kanser mulut menyebabkan para peserta mengalami kelewatan profesional.

ACKNOWLEDGEMENTS

Firstly, I would say my gratitude to Allah S.W.T for giving me guidance and strength to complete this dissertation. I must say, a lot of hard work and determination was required in order to complete this research dissertation. Thanks to my parents, Tn. Hj. Azhar bin Md. Sis, Pn. Hjh. Hafizah binti Md. Nor and my siblings (Nurliyana Azhar, Aidil Hakim Azhar, Fatin Adidah Azhar, Muhammad Arif Fikri Azhar), for all the supports, encouragement and unconditional love.

I would like to thank, my beloved supervisor, Associate Professor Dr. Jennifer Geraldine Doss. Thanks for teaching and introducing me to this field study. I found out it enjoyable and interesting. This study has produced very interesting results especially for future studies. I also feel grateful for the resources provided by University of Malaya. I would like to thank Oral Cancer Research & Coordinating Centre (OCRCC) for providing me with advices and technical supports. All staffs that assisted me during data collections and data analysis, thank you. Special acknowledge to Eeswari a/p Perisamy and Noor Atiekah binti Md Nor, for accompanying me throughout the journey. I value all the research skills that I acquired through this research dissertation. Thanks to my best friends who had supported me through all this hardship, Saidah Fasiha binti Nordin, Syazwani Azwa binti Sulaiman, Hartina binti Rosli, ‘Atifah binti Jumaat, Norliza binti Mazlan, and a heartfelt thanks to all of my friends who aided me without complaint, Nor Syafika Isa, Wan Afifah Wan Jusoh, Nur Edlyn Nadia Zuraiju, and Maria Ismail. Finally, special thanks to Mohd Taufiq bin Norizam for the kind endless supports and motivations.

Last but not least, thanks to all participants. I deeply appreciate their trust and courage for willing to take part in this study. They will forever be my inspiration.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF APPENDICES

CHAPTER 1

INTRODUCTION

Cancer is becoming the leading cause of death in the world (Noonan, 2013). It is currently the second leading cause of death in United State (Seigel *et al*., 2015). There were 21,700 cancer deaths in Malaysia in 2012, and on a global scale, cancer has overtaken heart disease as the leading cause of death (Yahaya *et al.,* 2015). Based on the Health Facts 2014 released by Ministry of Health Malaysia, cancer is one of the top ten reasons of hospitalisation and one of the top five causes of death in both government and private hospitals. It is alarming that The National Cancer Registry of Malaysia (NCR) recorded 21,773 Malaysians being diagnosed with cancer but estimates that almost 10,000 cases are unregistered every year (Ministry of Health Malaysia, 2003).

Head and neck cancer ranks fourth in terms of incidence and fifth in terms of mortality worldwide (Adrien *et al.,* 2014) whereas the NCR Malaysia Report in 2007 showed that head and neck cancer (13.2%) as one of the top five leading cancers among the general population in Malaysia. Squamous cell carcinoma is the predominant histology involving almost 95% of all head and neck cases (Wong *et al.*, 2015) and among all types of cancer, oral cancer ranks as the sixth most common cancer worldwide. It consists of a heterogeneous group of tumours which differ in their origin tissue, histopathology and anatomical site (Fernandez *et al.,* 2015). A high rate of oral cancer incidence and mortality in South-central Asia regions such as Bangladesh, India, Pakistan and Sri Lanka (GLOBOCAN, 2012) and oral cancer is the most common form of cancer and constitutes about a third of all cancers in their countries (Kumar *et al*., 2001).

Oral cancer patients' worldwide, are often associated with presenting at advanced stage disease which leads to a high rate of mortality (Scott *et al*., 2007; Gomez *et al*., 2009). The majority of patients with head and neck cancer in Malaysia has been diagnosed at advanced stage (TNM stage III and IV) (Shashinder *et al.,* 2008) and notably in Malaysia, 67.1% of oral cancer cases presenting at late stages (Doss *et al*., 2011). Tongue and mouth cancer are the top ten most frequent cancer for both male and female Indian ethnic in Peninsular Malaysia, 2003-2005 (Lim *et al*., 2008). Ghani *et al*., (2013) reported oral cancer patients in Malaysia having low 5-year of survival rate and those diagnosed with advanced stages usually have a poor prognosis of both cure and survival. This is because the treatment for most forms of oral cancer has permanent effects on organs essential for normal human activities such as breathing, speaking, eating and drinking. Thus, early detection of oral cancer is important because the quality of life (QOL) of oral cancer patients is highly associated with the extent of surgery and other interventions in the head and neck area (Esmailbeigi *et al*., 2014). As treatment prognosis and patient survival are much better at early stages of presentation, hence it would be imperative that barriers preventing Malaysian oral cancer patients from presenting early at the dental clinics are identified and addressed urgently.

Delay in diagnosis has been attributed as the main reason for poor patient survival rates (Johnson *et al*., 2011) and most oral cancer patients have reported delays in seeking help from a healthcare professional after self-discovery of symptoms of oral cancer (Kumar *et al*., 2001). Recent research has indicated that behavioural aspects such as patients' health-seeking behaviour as most likely reasons for their delayed presentation at a healthcare centre (Norsa'dah *et al*., 2012). Dwivedi and colleagues (2012) defined patient delay (primary delay) as the time taken from the onset of symptoms to the first

contact with medical persons. Previous research has reported that patient delay generally constitutes the majority of overall total delay time and is said to be influenced by patients' characteristics and health-seeking behaviour (Scott *et al*., 2007).

Health-seeking behaviour can plainly be defined as any activity undertaken by individuals who perceive themselves as having a health problem in order to understand their ailment and undertaking an appropriate remedy (Ahmed *et al*., 2000). There are growing literature on health-seeking behaviours and the determinants of health services utilization especially in the context of developing countries (Ahmed *et al*., 2005; Shaikh & Hatcher, 2004; Walsh *et al*., 2005). In Malaysia, published data on the health-seeking behaviour of an oral cancer patient is still lacking when compared to the health-related behaviour of patients with other cancers or chronic illness. Several research have focused on health-seeking behaviour for chronic illness in Malaysian population (Amal *et al*., 2011); Malaysian cancer patients' perceptions of cancer screening (Farooqui *et al*., 2013); understanding barriers among Malaysian women with breast cancer seeking help (Norsa'adah *et al*., 2012); and oral health-seeking behaviour among Malaysians with type II diabetes (Sahril *et al*., 2014). Based on the existing gaps in knowledge of Malaysian oral cancer patients' health-seeking behaviour and reasons for delayed presentation, more research in this area is certainly justified.

One model that can be utilised to understand patients' appraisal and subsequent health-seeking behaviour is the Self-Regulatory Model (SRM) developed by Leventhal and colleagues from the early 1980s (Hale *et al*., 2007). The term 'self-regulation' is used because human beings have an extensive ability to control their inner states, processes

and responses. The Self-Regulatory Model of illness provides a framework for understanding how individuals' symptoms and emotions experienced during a health threat influences their perception of illness and guides their subsequent coping behaviour (Browning *et al*., 2009). This model proposes a hierarchically organised model of an adaptive system featuring three main constructs of symptom interpretation, coping strategy and appraisal (Llewellyn *et al*., 2007).

Clearly, a health-seeking behaviour is a result of several different inter-related factors affecting a person's self-regulation of illness from biological characteristics to behavioural and social conditions. Thus, exploring factors that influence health-seeking behaviour among oral cancer patients in delaying seeking help for treatment would be essential. Three major themes outlined from previous studies include patients' socio-demographic characteristics, health-related behaviours and psychosocial factors (Noonan, 2013). A delay in seeking care could also partly be explained by tumour related factors such as the site of the tumour and the type of symptom experienced by the patients (Kerdpon & Sriplung., 2001; Onizawa *et al*., 2003; Tromp *et al*., 2004). These themes will be embraced by the present study.

The social profile among developing countries is said to be responsible for the high rate of oral cancer incidence and mortality due to socio-demographic characteristics, socio-economic status and negative health-related factors such as smoking and betel quid chewing (Kerdporn & Sriplung, 2001). Malaysia is a country located in Southeast Asia and constitutes Peninsula Malaysia (West Malaysia) and another two states (Sabah and Sarawak) separated on the Borneo Island (East Malaysia). It comprises a multicultural

society consisting of approximately 60% Malays, 30% Chinese, 10% Indian and others (Muhamad *et al*., 2012) who are rich in their respective religious and cultural beliefs. By exploring Malaysian oral cancer patients' health- seeking behaviours that lead to their late presentation, a greater and more in-depth understanding about important cultural and religious-related barriers can be gained. Such insights can be used as a basis for planning future health education programs to educate Malaysians and improve oral cancer awareness among the public.

In addition, understanding these patients' health-seeking behaviour that results in their delayed presentation would certainly fill existing gaps in knowledge which is intended to reduce the proportion of oral cancer cases presenting and being diagnosed at advanced stages. It is envisioned that by this improvement in knowledge and understanding, oral cancer patients' survival and treatment prognosis could be subsequently improved by early detection, thus reducing the overall disease burden and enhancing Quality of Life (QOL) for this group (Lim, 2002; Scharloo *et al*., 2005). Moreover, expenditure or costs incurred by the government in administering more cutting-edge treatment for advanced stage patients can be minimised if patients are seen and diagnosed earlier. This would also simultaneously reduce treatment costs incurred by patients.

This present study would greatly emphasise the development of new knowledge in the field of dental public health, social science and health psychology in Malaysia. This is because health and disease are best described as the effects of a blending of biological, psychological and social factors (The British Psychological Society, 2011). Thus,

exploring the health-seeking behaviour and delayed presentation of oral cancer patients among Malaysians is significant in order to motivate Malaysians to seek treatment and develop more effective healthy lifestyle guidelines.

1.1 Aim

The aim of this study is:

To explore the pattern of health-seeking behaviour among Malaysian oral cancer patients and identify behaviour that lead to their delayed presentation.

1.1.1 Specific objectives

To explore patients' responses to symptoms that result in a delay in seeking help in terms of their

a) Symptom interpretation

b) Coping strategy

c) Appraisal of coping efforts

2. To explore patient-related factors that result in their delay in seeking care in terms of their

a) Socio-demographic factors

b) Psychological factors

c) High risk habits practised (smoking, excessive alcohol consumption, betel quid chewing)

d) Oral cancer symptoms' characteristics

3. To describe patients health-seeking pathway and options of seeking care.

CHAPTER 2:

LITERATURE REVIEW

Cancers were commonly diagnosed with advanced stage disease in Malaysia, as in other developing countries. It was estimated that around 5 out of every 10 patients with oral cancer were diagnosed with advanced stage disease (Scott *et al*., 2007). Advanced stages of cancer are classified as stage III and IV, whereas stage I and II as an early-stage according to the TNM classifications (Morelatto *et al*., 2007). Stages III and IV includes the tumour that has grown into nearby tissues and spread to nearby lymph nodes in the neck. Thus, delayed in oral cancer diagnosis requires more radical treatments and associated with poorer prognosis (Falcao *et al*., 2015).

An early diagnosis of oral cancer provides a better prognosis as well as a reduction in treatment cost (Abdo *et al*., 2007). The treatment received by oral cancer patients with advanced tumour such as an extensive surgical resection for flap reconstruction, neck dissection and postoperative radiation contributes to poor prognosis (Rathod *et al*., 2015). Recent research has shown that the treatment outcomes for head and neck cancer patients in Malaysia remain fall behind those of developed countries (Wong *et al*., 2015). Treatments affected patients' communication, nutrition's uptake, physical appearance and the overall impacts of this disease on their quality of life (Eadie *et al*., 2014; Wissinger *et al.,* 2014).

2.1 Types of delay

A high percentage (67%) of oral cancer patients in this country present at advanced TNM stage of their disease (Doss *et al*., 2011; Ghani *et al*., 2013; Saleh *et al*., 2014). An early quantitative study by Khoo and colleagues (1996) in Malaysia showed that 50% of patients were reported a delay in seeking help from healthcare professionals for more than three months after they noticed their sign and symptom of oral cancer. Patients were considered delayed seeking help if they took more than three weeks after discovering their symptom (Llewellyn *et al.*, 2004). The study of total delay time was explored widely in most chronic diseases (Walter *et al*., 2012). Various studies were carried out to identify numerous measurements of delay in terms of total duration. However, previous studies reported inconsistency in terms of the measurement of total delay duration. Each of these terminologies has been either addressed by different names or time intervals.

For instance, Anderson's Model of Total Patient Delay proposed that the total delay time comprises of; appraisal delay, illness delay, behavioural delay, scheduling delay and treatment delay (refer Table 2.1). Over the years, an evidence-based refinement of the Anderson model which comprises of; appraisal delay, help-seeking delay, diagnostic delay and pre-treatment delay were made by Walter *et al*., (2012). On the contrary, Dwivedi and colleagues (2012) defined total delay into three components of total time duration; primary delay (patient delay), secondary delay (professional delay) and tertiary delay (system delay). The primary delay is defined as the time taken from the onset of symptoms to the first contact with a medical person. Whereas secondary delay is the time taken from the first medical contact to a confirmed diagnosis and tertiary delay is the time taken from a confirmed diagnosis to an initiation of treatment. Although, diagnostic delay accumulated from a range of patient delay, professional delay and health system delay,

there was a particular interest on how patients' perceived their sign and symptom that contributed to their decision to seek help (Roetzheim *et al*, 1999; Mcleod *et al*, 2009; Singh *et al*, 2010; Quaife *et al*., 2014). In the previous studies of total delay duration, patient delay generally constitutes the majority of overall total delay time (Onizawa *et al*., 2003; Smith *et al*., 2005).

In other word, a patient delay is the time interval between the day patients first became aware of their unexplained sign and symptom inside their mouth until they decided to seek help from a healthcare professional (De Nooijer *et al*., 2001; Groome *et al*., 2011). Patient delay suggested that the time interval were solely associated with patients' characteristics (Scott *et al*., 2006; Dwivedi *et al.*, 2012). This concurs with Lee and colleagues (2011), which reported that patient delay was the main factor of delay in diagnosis and initiation of treatment among head and neck cancer patients in a study conducted at one of a public hospital in Malaysia.

Table 2.1: Models of total delay time

Authors	Models	Stages of delay
Andersen & Cacioppo, (1995)	The General Model of Total Patient Delay.	**Appraisal delay** – the time a person takes to evaluate a symptom as a sign of illness. **Illness delay** – the time a person takes from the first sign of illness until deciding to seek professional medical care. **Behavioural delay** – the time between a person deciding an illness requires medical care and deciding to act on the decision to seek help. **Treatment delay** – the time between the first appointment with a healthcare professionals and the onset of treatment.
Walter et al., (2012)	Model of Pathway to Treatment.	**Appraisal delay** – the time interval from the patient first recognise their symptoms and begins to interpret them until they perceive they should consult a healthcare professionals. **Help-seeking delay** – the time interval from the patients first believe they should seek help and ends at their first consultation with a healthcare professionals. **Diagnostic delay** – the time interval the patient present to a healthcare professional until diagnosis is made. **Pre-treatment delay** – time interval from the diagnosis to the start of treated.
Dwivedi et al., (2012)	Framework of Primary, Secondary and Tertiary Delays in Cancer Patients.	**Primary delay** – the time from the onset of symptoms to first contact with medical persons. **Secondary delay** – the time from contacting the first medical person to a confirm diagnosis. **Tertiary delay** – the time form a confirmed diagnosis to the start of treatment.

2.2 Health-seeking behaviour

Health behaviour is defined as any activity undertaken by individuals who see themselves as healthy for the purpose of preventing disease or detecting it at an asymptomatic stage (Kasl & Cobb, 1966). For instance, regular exercises, healthy food intake and utilisation of healthcare services. Whereas illness behaviour is defined as any activity undertaken by individuals who perceive themselves as having a health problem for the purposes of defining their stage of health, discovering and undertaking an appropriate remedy (Mechanic, 1986). For example, consumed a Paracetamol during fever. Although health and illness behaviour were defined distinctively, both coexist in a relationship. These behaviours were not qualitatively different but they existed on a continuum. Rather than being either healthy or ill, individuals progress along this continuum from healthiness to illness and back again (Ogden, 2012).

Early studies of illness behaviour seek the understanding of individuals' process of seeking care with the presence of their sign and symptom. A prior study by Mechanic (1968) emphasised on the impact of a symptom that could be very important to influence individuals' decision to consult a healthcare professional. Besides, ten variables of patients' response to their sign and symptom were determined. These includes; (i) the visibility, recognisability and perceptual salience of the symptoms, (ii) the perceived seriousness of the symptoms, (iii) the extent to which symptom disrupt work, family and other social activities, (iv) the frequency of the appearance of symptoms and their persistence or frequency of recurrence, (v) the tolerance thresholds of others who are exposed to the symptoms, (vi) the knowledge, cultural assumptions and understanding of the person and relevant others, (vii) other needs or practical matters competing with the illness response, (viii) competing possible interpretations which can be assigned to

symptom once recognised, (ix) emotional barriers in the form of fear and anxiety, (x) the availability, physical proximity and the financial or emotional costs of taking various courses of action.

The studies of health and illness behaviour can also be explained and termed as individualistic and collectivist approaches (Locker, 1989; Coreil, 2008). The individualistic approach means that individuals' behaviour were due to their own characteristics. However, the studies of behaviour through individualistic approaches tended to ignore the impact of social life on individuals decision process. Therefore, collectivist approach explained that predicting the behaviour of individuals can be made by referring to the context of their social life (Friedson, 1986). This approach suggests that health and illness behaviour were often influenced by the 'lay referral system'. Individuals' social network such as family and friends were often consulted before their decision making. Zola (1973) introduced the term 'triggers' to explain the influences of several factors (e.g: cultural beliefs and social groups) in individuals' decision to seek help. This 'triggers' would affect patients' decision to seek help even if they interpret their sign and symptom as an indication of an illness.

Health psychologists turned to the study of health belief as a potential predictor of behaviour by using the concept of people behave in line with the way they think (Mann *et al.,* 2013). Health belief is the perception of risk or belief about the severity of an illness. Studies regarding health belief have contributed to the understanding of health and illness behaviour. Researchers in the field of health psychology determined various theories in explaining health belief. For instances; the 'Attribution Theory' (Heider, 1944;

1958) that stated individuals are motivated to understand the causes of events enabling them to predict and control. Besides, the theory of 'Health Locus of Control' (Wallston & Wallston, 1982), described individuals differ in their tendency to regards events as controllable or uncontrollable by them. On the other hand, 'Unrealistic Optimism' (Weinstein, 1983, 1984) explained regarding the inaccurate perception of risk and susceptibility of an illness by patients.

In recent years, health and illness theories were further integrated into stages of health behaviour model. Advances in the study of health psychology helped researchers to improve the development of health and illness behaviour models to predict possible behavioural patterns. A number of structured models were developed based on these collective health and illness beliefs (MacKian, 2003). This psychological approach to health and illness behaviour were used to give a better understanding of the nature of the relationship between health and behaviour (Leventhal *et al.*, 2008).

The studies that look beyond an individual for the influenced of social determinants were referred as the concept of social cognition. The term `social cognition model' was used to refer health and illness model that specifies into individuals psychological states (e.g. beliefs, susceptibility) as the main determinants of behaviours. Although other factors such as social background and cultural practices influenced patients' health and illness behaviour, the effect was completely mediated by their individuals' psychological states. Some of the most widely applied health model in the field of health and medicine research were (refer Table 2.2): the 'Health Belief Model' (Rosenstock, 1966), the 'Protection Motivation Theory' (Rogers, 1975) and the 'Theory of Planned Behaviour'

(Azjen & Fishbein, 1980). On the other hand, the Trans-theoretical Model or Stages Model used similar concepts but were organised in a different way (refer Table 2.2). According to this model, behavioural change involves movement through a sequence of discrete, qualitatively distinct and stages. Thus, these behavioural theories and models focus on individuals, social and environmental factors that determine their behaviour (individualistic or collectivistic).

On the other hand, Bandura, (1977) was the first researcher to emphasise the interactions of individuals and their social background through 'social cognition theory'. This theory explains that human behaviour is the information processing capacities and their learning (behaviour) are influenced by their previous experience and observation. Based on the concept of social cognition theory, Leventhal *et al.,* (1980) examined the relationship between individuals' cognitive representation (based on their perceived signs and symptoms) and their subsequent coping behaviour. This model attempts to explicate the dynamic psychological mechanisms that lead to success and failure in behaving relative to particular circumstances whereas most health and illness behaviour models focus primarily on behavioural prediction (Mann *et al*., 2013).

Table 2.2: Types of existing Models of Health Behaviour

Authors	Models	Aims	Stages of model
Prochaska, DiClemente & Norcross, 1982	The Trans-Theoretical Model of Behaviour	To describe the process involved in behavioural change.	pre-contemplation contemplation preparation action maintenance
Rosestock, (1966), Further by Becker & colleagues, (1977)	The Health Belief Model	To predict preventive health behaviours and behavioural response to treatment in acutely and chronically ill patients. Behaviour is a product of a set of cure beliefs that have been re-defined over the years.	susceptibility severity cost benefits cues to action
Rogers (1975-1985)	The Protection Motivation Theory	To explain why people engage in unhealthy practices and offer suggestions for changing those behaviours. People protect themselves based on threat appraisal and coping appraisal.	severity susceptibility response effectiveness self-efficacy fear
Ajzen & colleagues, (1986)	The Theory of Planned Behaviour	To study the relations among beliefs, attitudes, behavioural intentions & behaviours. Behaviours intentions should be conceptualised as 'plan of action in pursuit of behavioural goals', and these are the results of following composite beliefs.	attitude towards a behaviour subjective norm perceived behavioural control
Leventhal & colleagues (1980s)	The Self-Regulatory Model	A system of conscious personal management that involves the process of guiding one's own thoughts, behaviours and feelings to reach goals.	symptom interpretations coping strategy appraisal

In general, health-seeking behaviour can be described as a sequence of remedial actions that individuals undertake to rectify their perceived illness (Ahmed *et al.,* 2000). This behaviour was initiated by a symptom that individuals perceived as a sign of their illness (Tromp *et al.,* 2005). In the broadest sense, health-seeking behaviour includes all behaviours associated with establishing, maintaining and controlling a healthy physical and mental state as well as reducing the impact and progression of an illness. Health-seeking behaviour was based on a mixture of health and illness behaviour concepts.

On the other hand, the underlying cause of patient delay was highly depended on individuals' health-seeking behaviour. The studies of health-seeking behaviour, cannot be explained from a pathological perspective. Illness was viewed as the result of a combination of biological, psychological and social factors. According to sociology literature, a health-seeking behaviour is influenced by individuals themselves, type of diseases, the availability and accessibility of health care services (Cummings *et al*., 1980). Moreover, this behaviour was an important factor in predicting longevity and mortality of individuals (Mann *et al*., 2013).

Almost all deadly and chronic illness can be prevented when individuals change their health-seeking behaviour. By acknowledging the role of behaviour, individuals were fully responsible for their own health and illness (McKeown, 1979). The concept of health-seeking behaviour was commonly studied by many healthcare researchers to understand potential factors that could influence individuals to behave differently in relation to their delay in seeking help.

There were two main approaches in the studies of health-seeking behaviour; (i) the determinants of behaviour (barriers for help-seeking). This includes factors that influence patients' health-seeking behaviour (Bedri, 2001). (ii) The other approach is the development of health-seeking pathways models (the process of help-seeking) (MacKian *et al*., 2003). The development of pathways models described series of steps an individual takes for seeking help. Suchman (1965) was the first researcher to describe health-seeking behaviour in a logical sequence of steps beginning with perceptions and evaluations of symptoms and ending with the use of different types of care.

2.3 The development of Self-Regulatory Model

The Self-Regulatory Model (Leventhal *et al*., 1980) is deemed appropriate to be used as a tool to explore health-seeking behaviour among oral cancer patients in Malaysia. A previous study by Scharloo and colleagues (2005) were carried out on Health-Related Quality of Life (HRQOL) outcomes among head and neck cancer patients by using Illness Perception Questionnaire-Revised (based on the Self-Regulatory Model). A negative symptom interpretation was found associated with poor HRQOL among head and neck cancer patients. This model was also applied to multiple illnesses and health-related behaviour including coronary heart disease (Petrie *et al*., 1996), human immunodeficiency syndrome (HIV) medication adherence (Reynolds, 2003), and diabetes self-management (Paddison *et al.,* 2010). Components of the Self-Regulatory Model were examined among oncology patients (Johnson *et al.,* 1989; Ward *et al*., 2000; Donovan & Ward, 2005; Donovan *et al*., 2008), explaining pre-hospital delay in patients with acute myocardial infarction (Walsh *et al.,* 2004) and among lung cancer patients who smoke at the time of diagnosis (Browning *et al*., 2009). This model is relevant to the present study as a previous research indicated that Self-Regulatory Model is a useful

framework for understanding head and neck cancer patients' health and illness belief (Llewellyn *et al*., 2007).

The Self-Regulatory Model was originally derived from the previous study of the 'Fear-Drive Model' by Dollard and Miller, (1950). This model assumes that fear is a motivational state and actions/procedures that reduce fear were reinforced/learned. Moreover, 'low' and 'high' fear messages about a specific health threat were discovered. The model predicted that when strategies were paired with a 'high' fear message, individuals would develop more favourable attitudes about coping strategy for avoiding the threat presented or otherwise. However, the effects of fear on attitudes were proved short-lived in which it last from 24 to 48 hours (Leventhal & Niles, 1965).

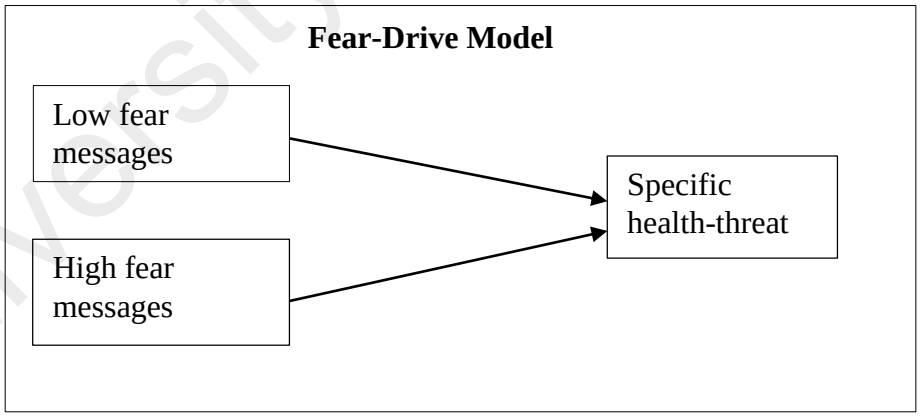


Figure 2.1: The Fear-Drive Model (Dollard & Miller, 1950)

Taken together, the absences of the interaction between 'fear level' and 'action plans' to facilitate fear reduction and learning proved to be impractical to the Fear-Drive Model. This led to the development of the 'Parallel Process Model' by Leventhal in the early 1970s. The Parallel Process Model posited that health threats generated both

cognitive representations as well as the emotional responses to a health threat and a corresponding needs for managing these threats.

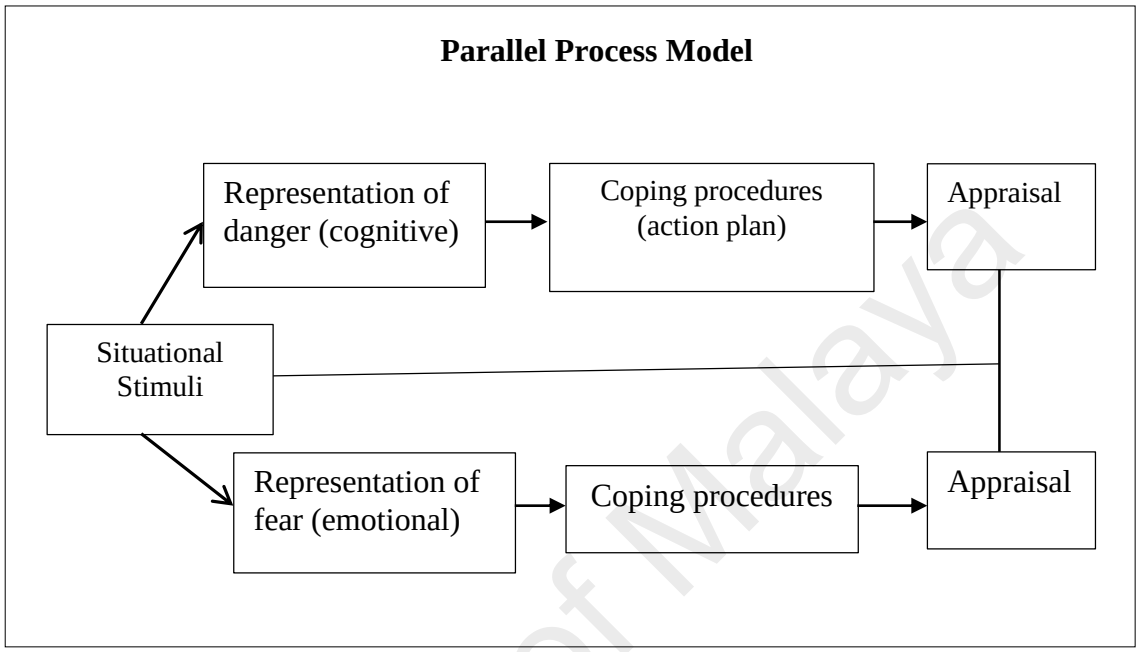


Figure 2.2: The Parallel Process Model (Leventhal, 1970)

2.4 The Self-Regulatory Model (SRM)

The development of this model started when Leventhal and colleagues, (1980) incorporated health and illness beliefs into Self-Regulatory Model to examine the relationship between individuals' cognitive beliefs and their subsequent coping behaviour. The concept of self-regulation was defined as controlling oneself through self-monitoring, goal setting, feedback, self-reward, self-instruction and enlistment of social support (McAlister *et al*., 2008). Self-regulation was used to explore health-seeking behaviours as a human being have an extensive ability to control their inner states, process and responses (Baumeister, 2005; Robinson *et al*., 2015).

The Self-Regulatory Model described problem solving in three stages: (i) symptom interpretation; (ii) coping strategy and (iii) appraisal (Diefenbach & Leventhal, 1996). An individual interpreted a symptom only when they were confronted with a health threat. A health threat was usually discovered through a symptom interpretation (individual perceived symptom) or social messages (input from a range of source such as family, friends and media regarding the nature of symptoms). In general, symptom interpretation is the patient's belief and expectations about his/her illness. These symptom interpretations were governed by two parallel processes; the cognitive and emotional processing.

The development of a cognitive symptom interpretation was constructed according to its' five components; (i) identity (the name or label of a threat), (ii) timeline (threats trajectory), (iii) consequences (belief consequence of a threat), (iv) cause (threat's causal mechanism) and (v) control/cure (something to be done to control the treat). For example, an individual identify mouth ulcer as the beginning of his/her illness (label). It is an acute condition/short term (timeline) and minor consequences. It can be caused by several factors (e.g. tongue inflammation). The outcome (of mouth ulcer) is controllable. This five components of cognitive symptom interpretations helped individuals created a profile about their illness. Symptom interpretation enabled individuals to identify a health threat thereby planning a suitable coping strategy.

As followed the model, symptom interpretation is also governed by patients' emotional process. Patients' emotional reactions during their cognitive symptom interpretations can be seen through the changes in their emotional states. These emotions

were often subtle and ranging from ‘annoyance about the potential impact on work’ to ‘worrying that the symptom as a precursor to something more serious’. Both cognitive symptom interpretations and emotional process guided patients to a subsequent coping behaviour.

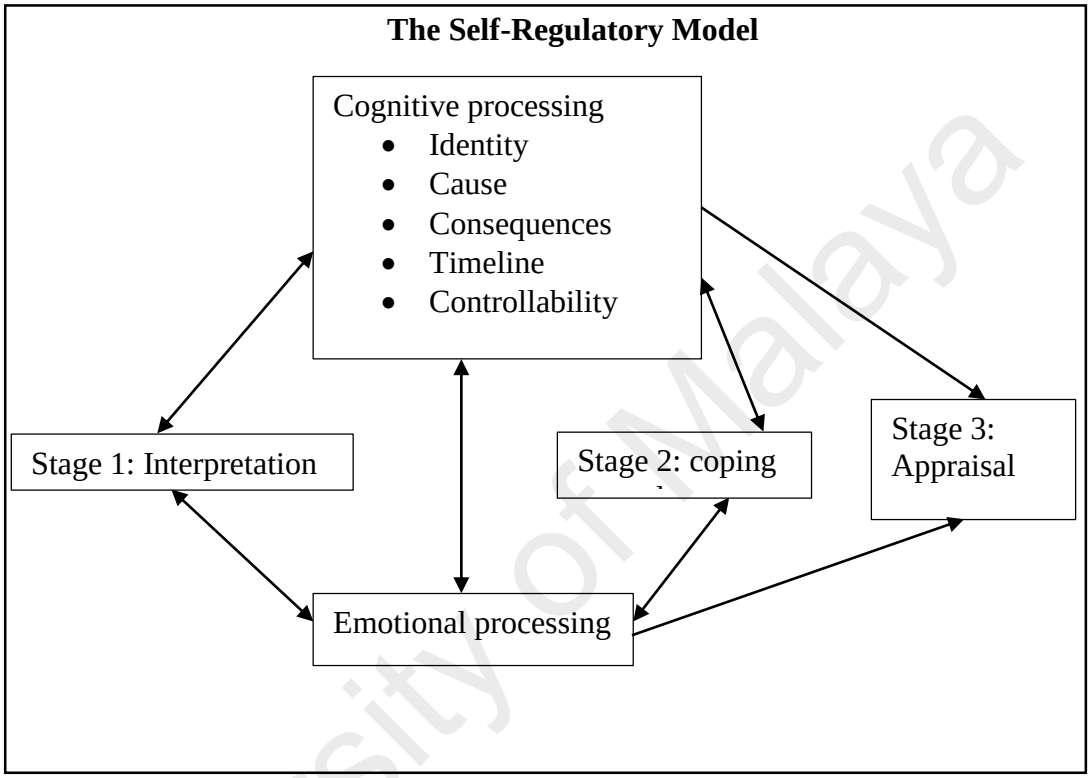


Figure 2.3: The Self-Regulatory Model (based on Leventhal, 1980)

The next stage of the model is the development and identification of a suitable coping strategy. Individuals developed their coping strategy in attempted to return to a state of health normality (illness is not the normal state). Taylor and colleagues, (1984) defined coping strategy as consisted of three processes; (i) the search for meaning (reasons for illness), (ii) the search for mastery (preventive measurements) and (iii) the process of self-enhancement (emotional bias. e.g. I am still healthy than a lot of people). Coping strategy may consist of numerous type of coping, depending on individuals’ symptom interpretations. Coping strategy was commonly classified as; (i) the approach

coping (taking pills, going to the doctor, resting) and (ii) avoidance coping (denial, positive thinking). Additionally, some researchers may categorise these coping strategies into; (i) problem-focused coping strategy and (ii) emotion-focused strategy (Yahaya *et al*., 2015).

Finally, the appraisal is the last stage of the Self-Regulatory Model. This process involves individuals to evaluate the effectiveness of their coping strategy. Hence, they would appraise and determine whether to continue with their coping strategy or to opt for an alternative coping strategy (Hale *et al*., 2007). Furthermore, Leventhal and colleagues, (2003) clearly illustrated that the nature of the model (the process of symptom interpretations, coping strategy and appraisal) was not in a linear pathway, but dynamic and ongoing in order to maintain individuals health normality.

2.5 Factors associated with patients' health-seeking behaviour

Health-seeking behaviour was shaped by various aspects of socio-demographic, socio-economic status, cultural and psychological factors (Mechanic, 1986; Shaikh & Hatcher, 2004). Despite the differences in research designs regarding the studies of health-seeking behaviour, researchers outlined few major reasons that could influence patients' delay their seeking help from healthcare professionals (Panzarella *et al*., 2014). Reasons for the delay were categorised as follows; (i) patient socio-demographic characteristics; (ii) negative health-related behaviours and (iii) psychological factors (Noonan, 2013). Additionally, symptom characteristics were also included as one of the reasons that lead to a delay in seeking help in many studies (Guggenheimer *et al*., 1989; Scott *et al*., 2005).

2.5.1 Socio-demographic characteristics (socio-economic status, educational level, cultural beliefs and religious practices) that influence health-seeking behaviour

Socio-demographic factors such as residential area, lack of awareness, economic problem, family-related problem and types of cancer were associated with reasons for delayed presentation (Dwivedi *et al*., 2012). Socio-demographic characteristics were specific to an individual, thereby influenced and guided his/her symptom interpretation and coping strategy (Browning *et al*., 2009). Although some studies showed that socio-demographic factors as consistently not associated with patient delay (Kerdpon & Sriplung, 2001; Kumar *et al*., 2001; Pitiphat *et al*., 2002; Onizawa *et al*., 2003; Brouha *et al*., 2005; Morelatto *et al*., 2007; Rogers *et al*., 2007) other studies showed otherwise (Llewellyn *et al*., 2004; Ahmed *et al*., 2005; Agarwal *et al*., 2011; Noonan, 2013; Dodd *et al*., 2015). Therefore, social profile among countries was seen to be responsible for the inconsistency of patients' health-seeking behaviour (Kerdporn & Sriplung, 2001; Warnakulasuriya, 2010). Variations in behaviours were determined by the characteristics of individuals' social background (Freidson, 1970). Social factors were seen to interact with the biological and personal determinants at a collective level to shape patients characteristics such as high-risk behaviours, environmental exposures and access to health care services (Patrick *et al*., 2005). Although some studies predicted that certain demographic groups might be unaware of their sign and symptom of oral cancer as one of the reasons for delay in seeking help (Groome *et al.,* 2011) other study showed otherwise.

Educational level and awareness among oral cancer patients were often highlighted as the main reasons for patients delay in seeking help from healthcare professionals (Sankeshwari *et al*., 2015; Al-Maweri *et al*., 2014; 2015; Hassona *et al*., 2015). The relationships between knowledge and awareness with patient delay were reported in many studies of oral cancer (Brouha *et al*., 2005; Llewellyn *et al*., 2005; Scott *et al*., 2008; Rogers *et al*., 2010; Zohoori *et al*., 2012; Esmaelbeigi *et al*., 2014). Previous research has shown that patients from a low educational background tended to experience more patient delay (Llewellyn *et al*., 2004; Formosa *et al.*, 2015). For instance, in Bangladesh, those who had a higher level of education were less likely to choose self-treatment or consult traditional healers such as allopathic practitioner (Ahmed *et al*., 2005). The consequences of having low educational level and awareness were reflected through a poor public perception of oral cancer, symptom interpretation, fear of diagnosis and their options of seeking care (Sharma & Nagpal, 2015; Razavi *et al*., 2015). A recent research by Monteiro and colleagues, (2015) reported that breast cancer is the most mentioned being as heard of (69.8%), while oral cancer is one of the least heard of (23.7%) in a general population of Oporto city, Portugal. Thus, the knowledge about early signs and symptoms of oral cancer aids more accurate patients' symptom interpretation and their decision to seek help.

Furthermore, low socio-economic status was likely to be one of the reasons for delay in seeking help from healthcare professionals (Ahmed *et al*., 2005). Financial consideration was said to be associated with reasons for the delayed presentation at a healthcare centre (Amal *et al*., 2006; Dwivedi *et al*., 2012). However, the relationship between socio-economic status and health-seeking behaviour warrants further investigation (Scott *et al*., 2008). In some developed countries, socioeconomic status did

not affect patients delay in seeking help as well as the stage of disease at diagnosis (Rogers *et al*., 2007; Johnson *et al*., 2010; Adrien *et al*., 2014). On the contrary, costs were certainly a barrier in seeking appropriate health care in most South Asian countries, thus limiting patients' options of seeking help (Shaikh & Hatcher, 2004).

Cultural beliefs and religious practices often lead to self-remedy and consultation with traditional healers among rural communities in most South Asian countries including Malaysia (Shaikh & Hatcher, 2004; Wong *et al*., 2013). In accordance with the socio-economic status, self-remedy or the less expensive care provided by traditional healers emerged as the main alternatives for some low-income countries (Ahmed *et al*., 2005). Thus, majority of the population in most countries in Southeast Asian region were reported to consult traditional healers to a greater extent, unlike western countries. These healing practices were influenced by existing belief systems that were predominant in some countries (Abubakar *et al*., 2013).

Therefore, cultural beliefs and religious practices were also identified as an important factor for the delay in seeking help in some countries. The concept of culture refers to shared patterns of thought and behaviour that characterise a social group which are learned through social processes and endure through time (Coreil, 2008). Another study by Kerdporn & Sriplung, (2001), reported that seeking traditional medication before medical practitioners in Thailand was one of the factors related with advanced stage other than the location of tumour at the floor of mouth and having ulcer. Cultural beliefs and religious practices influenced individuals' social attitudes toward cancer and also their participation in screening early detection programmes (Ahmed *et al*., 2005, Maree &

Wright., 2010, Iskandarsyah *et al*., 2014). On the other hand, Kulkarni and colleagues, (2015) suggested that oral cancer knowledge and awareness should be implemented among traditional healers.

Moreover, the gaps between utilisation of health care services widen oral health disparities among patients with different social and ethnic populations (Patrick *et al*., 2005). In some Asian countries, women were usually not allowed to visit a health facility or health care provider alone or to make the decision to spend money on health care. For instance in Pakistan, gender disparities, nutrition, health care seeking, education and general care make a woman highly vulnerable and disadvantaged (Shaikh & Hatcher, 2004).

2.5.2 The practice of high-risk habits (smoking, excessive alcohol consumption, betel quid chewing) that influence health-seeking behaviour

The high-risk habits such as smoking, excessive alcohol consumption and betel quid chewing were associated with patient delay in seeking treatment in most studies for the last number of years (Chen *et al*., 1999; Kerdporn & Sriplung., 2001; Pitiphat *et al*., 2002; Onizawa *et al*., 2003; Brouha *et al*., 2005). Furthermore, recent research indicated that the determinants of disease burden and outcomes were interrelated with public knowledge of early detection and lifestyle risk factors associated with oral cancer (Luryi *et al*., 2014).

It was reported that the practices of oral risk habits such as smoking, betel quid chewing and alcohol consumption were the main risk habits of oral cancer among Malaysian population (National Cancer Registry Report Malaysia, 2007). A lack of knowledge and awareness were reported among the public in this country regarding the risk habits, early signs and symptoms and the benefits of detecting this disease at an early stage (Al-Dubai *et al*., 2012; Ghani *et al*., 2013).

Oral cancer patients especially those who smokes and drinks excessive alcohol before diagnosis were reported having a lower level of health value and perceived health competence than a general population sample (Lowry *et al*., 1999; Vora *et al*., 2000; Tromp *et al*., 2005; Al-Shammari *et al*., 2006). Smokers were proven less aware of the oral health effects of smoking than non-smokers (Al-Shammari *et al.,* 2006). Other study reported that smokers demonstrated positives mood effects from smoking and that smoking can help them to cope with difficult circumstances (Graham, 1987). From a prior study by Browning and colleagues (2009), majority patients continued to smoke, which contributed to an increase in their sign and symptom. None or light smokers were found to perceive their own risk to be low, thus led them to mislabel their signs and symptoms as minor condition and delay in seeking help from a healthcare professional (Pitiphat *et al*., 2002; Llewellyn *et al*., 2004; Bornstein *et al*., 2012). Those who smokes lower amounts of tobacco prior to diagnosis have a longer patient delay (Humphris *et al*., 2004). Additionally, former smokers were found having 4.3 times greater risk of delay in diagnosis compared with current smokers (Pitiphat *et al.,* 2002).

Patients with shorter duration of symptom tended to be smokers or drinkers, with lower gum and floor of mouth tumours and more at advanced disease (Rogers *et al*., 2007). However, patients' level of education influenced their smoking prevalence, as those with higher education were least likely to smoke and success in quitting their habit (Pierce *et al*., 1989). In contrast, patients from poverty background have a higher prevalence of smoking. A large proportion of people living in low and middle-income countries possess adequate knowledge about smoking tobacco but have inadequate awareness (Gupta & Kumar, 2014). Most recently, Tiwari and colleagues (2014), reported that preventing the initiation of a habit was far easier than stopping it, thus suggested a school-based smoking prevention programs for community awareness among children and the public.

Another study showed that high alcohol consumption has been identified as one of the factors in patient delay (Tromp *et al*., 2004; Rogers *et al*., 2007). Excessive drinkers showed more apparent psychological distress before receiving treatment (Tromp *et al.*, 2004). The personalities of individuals who consumed excessive amounts of alcohol were characterised by a tendency to deny or repress unpleasant events, indifference, depression and a tendency to act passively. This resulted in a failure to consult a healthcare professional as soon as suspicious lesions occur until it is at advanced stage (Tromp *et al.*, 2004). However, individuals might use alcohol as a self-therapy and a short-term coping strategy (Friedman & Kimball, 1986).

Epidemiologic data suggested that the high incidence of oral cancer in some Southeast Asian countries were closely related to their high prevalence of betel quid chewing. This high-risk habit is a traditional custom seen in some cultures including Malaysia (Chen *et al*., 1999). In a study by Zain and Ghazali (2001), suggested that oral cancer in this country was closely related to patient's cultural habits such as betel quid chewing. Although the awareness regarding the effects of betel quid was satisfactory among the public, the population usually were not willing to quit the habit (Khan *et al*., 2013).

2.5.3 Psychological factors that influence health-seeking behaviour

Psychological factors such as dental fear and anxiety lead patients to delay their seeking help (Armfield *et al*., 2007). Fear and denial were often assumed to be a common response to the detection of cancer symptoms and responsible for the undue patient delay in seeking help (Clark, 1999; Tromp *et al*., 2004; Llewellyn *et al*., 2004; Scott *et al*., 2007). Dental fear can result from previously traumatic or negative dental experience (Locker *et al*., 1996). A significant vicious cycle of dental fear whereby the delaying of dental visits is related to increased dental problems (Armfield *et al*., 2007). This concurs with Esmaelbeigi *et al*., (2014), stated that the risk of diagnostic delayed among oral cancer patients was associated with the number of visits to a dental clinic before diagnosis and treatment.

2.5.4 Oral cancer symptoms' characteristics

Delay in seeking help could be partly explained by the tumour-related factors such as the site of the tumour and the types of symptoms experienced by the patients (Kerdpon & Sriplung., 2001; Onizawa *et al*., 2003; Tromp *et al*., 2004; Forman *et al*., 2015). On the basis of oral squamous cell carcinoma clinical characteristics, the primary signs and symptoms includes pain, foreign body sensation, swelling, ulcer, mass leukoplakia and other lesion site such as tongue, gingiva, buccal mucosa (cheeks), palate, floor of mouth, lips, minimal and maximal diameter of the lesion (Gao & Guo, 2009).

However, Guggenheimer *et al*., (1989) concluded that the early carcinomas were probably asymptomatic. Patients' subsequent health-seeking behaviour were commonly misinterpreted as innocuous oral or dental problems (Rogers *et al*., 2007). This can be seen as not being able to recognise the importance or seriousness of the symptom contributes to delay in seeking help (Corner *et al.*, 2006). Even if individuals were aware of their sign and symptom, it would not automatically imply that they would be aware of cancer or seek help from healthcare professionals (de Nooijer *et al*. 2002). Similarly, Amir *et al.*, (1999), found that there was no significant association between the nature of the first symptoms and the urgency with which patients interpreted their symptoms.

2.6 Gaps based on the existing research

It was estimated 300,400 new cases and 145,400 deaths from oral cancer occurred worldwide based on the global cancer statistics in 2012 (Torre *et al*., 2015). The highest rates of incidence and deaths from this disease were found in developing countries than developed countries. As a developing nation, Malaysia comprises a multicultural society

with approximately 60% Malays, 30% Chinese, 10% Indian and others (Department of Statistics Malaysia, 2017) and Malaysian subsequently reports delayed in oral cancer diagnosis (Khoo *et al*., 1996; Doss *et al*., 2011).

Malaysian National Cancer Registry (NCR) was first started in 2002. Although there were deficiencies, the data were probably the most accurate cancer data available in this country. The registry covers only Peninsular Malaysia, and not East Malaysia. Malaysian National Cancer Registry Report 2007-2011 has shown that head and neck cancer (13.2%) as one of the top five leading cancers among the general population. The prevalence of tongue and mouth cancer incidence was in the top 10 most frequent cancers for both male and female among Indian ethnic groups (Azizah *et al.*, 2016).

Over the years, there were various studies regarding oral cancer in this country including; the prevalence and incidence of oral cancer by states and ethnicities, epidemiological studies, high-risk habits (smoking prevalence, excessive alcohol consumption, betel quid chewing,) and promoting awareness of oral cancer (Hirayama, 1966; Ramanathan *et al*., 1976; Ng *et al*., 1985; Zain & Ghazali, 2001; Razak *et al*., 2009; Saleh *et al*., 2012; Ghani *et al*., 2013). To date, little-known facts regarding oral cancer patients' experiences, perceptions and beliefs about the disease itself in Malaysia. Therefore, a qualitative study is an appropriate method for obtaining insight into oral cancer patients' beliefs and local knowledge related to the diseases in Malaysia. This method is also used for exploring the reasons for certain health-seeking behaviour.

The concept of health-seeking behaviour were widely used in many studies of specific disease in Malaysia (Amal *et al*., 2011; Tee *et al*., 2011; Norsa'adah *et al*., 2012; Farooqui *et al*., 2013; Khakbazan *et al*., 2014; Abidin *et al*., 2014; Sahril *et al*., 2014; Yew, 2015; Yu *et al*., 2015). However, there was no common approach applied and the methodologies varied widely. Thus, the knowledge on health-seeking behaviour among oral cancer patients in Malaysia is not yet known. Moreover, the concept of studying health-seeking behaviour from a self-regulatory perspective is still lacking in published data in this country. The information from health-seeking behaviour through the process of self-regulation is important to combat delayed presentations and poor prognosis among oral cancer patients.

CHAPTER 3:

METHODOLOGY

This is a qualitative exploratory study. The qualitative method was deemed appropriate to explore in depth people's responses and subsequent behaviour pattern when noticing any abnormal symptom/lesion in their oral cavity.

3.1 Study Design

Therefore, a phenomenological study was applied as the methodological orientation for this study. Phenomological approaches in the study were based on the experience from the perspective of an individual (oral cancer patients). In addition to individual face-to-face semi-structured in-depth interviews, a focus group discussion (FGD) was used for methodological triangulation purposes to achieve the study aims. Triangulation means gathering and analysing data from more than one source to gain full perspective of the same situation (Lacey & Luff, 2001). Both methods (semi-structured in-depth interviews and focus group discussion) were commonly used in the healthcare research to gain understanding and insight into the thoughts of a certain group of patients on a particular phenomenon (Gill *et al.*, 2008).

Table 3.1: Sampling points for the qualitative study

Region	Participating Hospitals
West coast, Peninsula Malaysia	Hospital Tengku Ampuan Rahimah, Klang (HTAR)Hospital Kuala Lumpur (HKL) Faculty of Dentistry, University Malaya (UM)
East coast, Peninsula Malaysia	School of Medical Sciences, University Sains Malaysia (USM)
Sabah	Hospital Queen Elizabeth (HQE), Kota Kinabalu
Sarawak	Hospital Umum Sarawak (HUS), Kuching

3.2 Participants

The inclusion criteria of the sample participants were diagnosed adult oral cancer patients who were 18 years old and above. 'Late-stage' was defined as T3/T4 tumours, and 'early-stage' was defined as T1/T2 tumours, according to the TNM classification (Morelatto *et al*., 2007). In order to study reasons for delay, patients diagnosed with disease staging from TNM stage III to IV were recruited. In this study, 'delay in seeking-help' is defined as the length of time for patients with advance TNM stage III and IV to have recognised their first symptoms of illness until the first contact with a medical practitioner. However, exclusion criteria were mentally incoherent patients based on their medical records.

Map of Malaysia

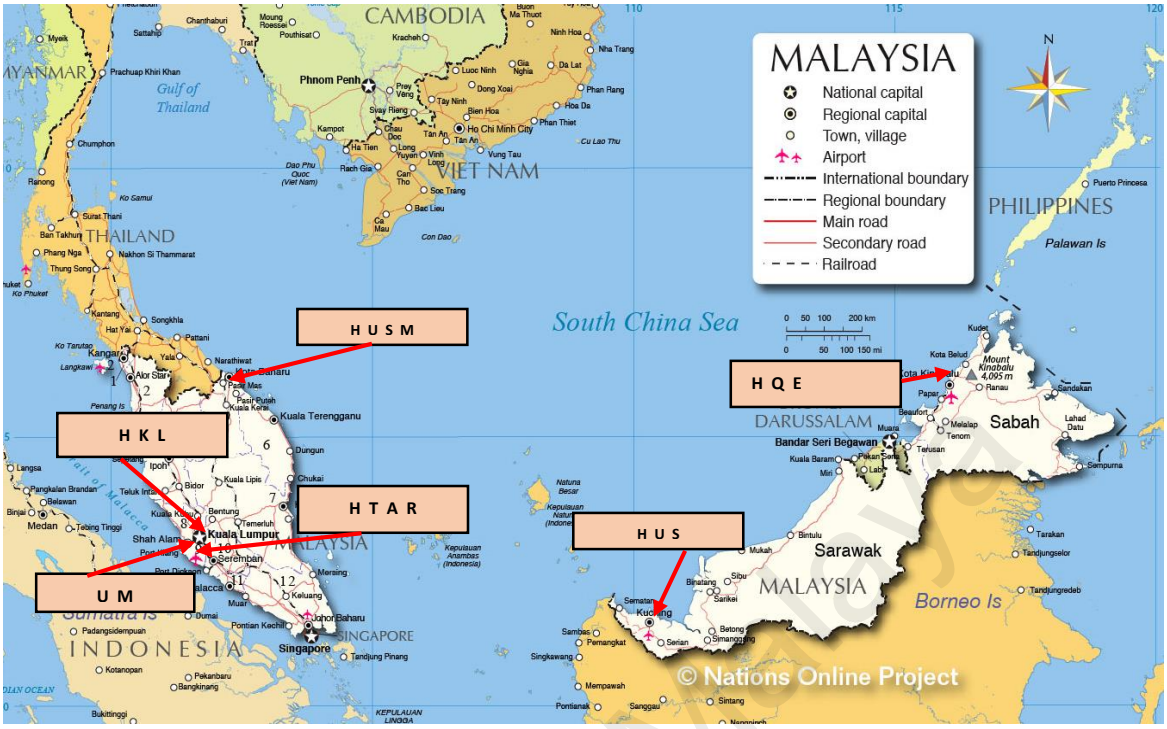


Figure 3.1: Location of sampling points for the qualitative study

3.3 Sampling points

Six hospital-based oral surgery specialist clinics which serve as regional referral centres managing oral cancer patients were chosen as the sampling points for this study. (APPENDIX D). These comprised four government hospitals (HTAR, HKL, HUS and HQE) and two university teaching hospitals Faculty of Dentistry, UM and School of Medicine, USM). Of these , two were situated in the Peninsula West-Coast (Hospital Tengku Ampuan Rahimah, Hospital Kuala Lumpur, Faculty of Dentistry, University of Malaya), one in the Peninsular East-Coast (School of Medical Sciences, University Sains Malaysia) and two in East Malaysia (Hospital Queen Elizabeth, Hospital Umum Sarawak). These hospitals were chosen based on the premise that most oral cancer patients in the aforementioned regions were referred and managed in these centres. Table 3.1 and Figure 3.1 show the sampling points used in this study and its location in Malaysia.

Table 3.2: Number of participants at each centre for the in-depth interviews

No.	Participating Hospitals	No. of participants		Ethnicity					Total (N)
		Male	Female	M	C	I	Sb	Swk	
1.	Hospital Tengku Ampuan Rahimah, Klang (HTAR)	2	3		2	3			5
2.	Hospital Kuala Lumpur (HKL)	2	2		2	2			4
3.	Faculty of Dentistry, University Malaya (UM)	3	2		3	2			5
4.	School of Medical Sciences, University Science Malaysia (USM)	4	3	7					7
5.	Hospital Queen Elizabeth (HQE), Kota Kinabalu	4	3				7		7
6.	Hospital Umum Sarawak (HUS), Kuching	3	4					7	7
	Total	18	17	7	7	7	7	7	**35**

Table 3.3: Details of participants for the focus group discussion

Participant	Gender	Ethnicity	Regional area
P01	Male	Chinese	Kuala Lumpur
P02	Female	Malay	Kedah
P03	Female	Malay	Perak
P04	Female	Indigenous Sabahan	Kota Kinabalu
P05	Female	Indian	Kuala Lumpur
P06	Female	Chinese	Selangor

3.4 Sampling technique

Purposive sampling was used whereby participants of various ethnicities (Malay, Chinese, Indian, Indigenous of Sabah and Sarawak) throughout Malaysia were sampled from Malaysia's multicultural society. Various ethnicities used from this study were meant to include importance differences in cultural and health-behaviours. The differences are considered important for social phenomena studied by qualitative research (Allmark, 2004). Despite the fact that a qualitative study cannot be generalised to

represent a multicultural society in Malaysia, any ethnicities excluded may be insufficient to explained the results as such factor were important to examine cultural differences among oral cancer patients in Malaysia.

3.5 Baseline sample size

An estimate of 45 oral cancer patients was planned to be recruited based on a purposive heterogeneous sampling of different ethnicities (Malay, Chinese, Indian, Indigenous Sabahan and Indigenous Sarawakian) and geographical areas throughout Peninsula Malaysia, Sabah and Sarawak. Table 3.2 shows the number of patients for the qualitative study. However, the final sample size was determined based on saturation point. The number of participants from each ethnicity were not specified but an increase in numbers were allowed to represent the diversity. A total number of 35 participants were recruited at saturation point. As for the focus group discussion, a total number of six oral cancer survivors were recruited from various parts of Peninsular Malaysia, Sabah and Sarawak (Table 3.3).

3.6 Instruments

A set of semi structured core and probing questions (based on Leventhal's Self-Regulatory Model) was drafted and used by the researcher in the in-depth face-to-face interviews with participants. (APPENDIX F)

3.7 Ethics

Ethical approval number (DF CO1401/0015(L)) was obtained from the Medical Research Ethics Committee, Faculty of Dentistry. (APPENDIX A). Patient Information Sheet and Patient Consent Forms were given to every participants. (APPENDIX B & APPENDIX C).

3.8 Procedure

Patients who were willing to participate were asked to read the Patient Information Sheet and sign the Patient Consent Form. Interviews were conducted in an isolated room to ensure privacy for participants. The interviews were carried out using either the national language Bahasa Melayu or English. If the participants were not fluent in both Bahasa Melayu and English, a carer (family member) who could speak dual languages was used as an interpreter. The presence of research clerks at every centre also facilitated the interactions during the in-depth interviews' sessions as they understand and familiar with the participants. At the end of each interview, every participant was given a token RM30 for their participation. Each interview was audio-recorded and subsequently transcribed verbatim by both the researcher and a professional transcriber (Investigator triangulation).

Besides this, a focus group discussion to explore group experiences was used in this study to triangulate the data methodologically. The focus group discussion was conducted by the researcher during the National Mouth Cancer Awareness 2014, held in Kuching, Sarawak. Six participants (oral cancer survivors) were recruited using purposive sampling from various parts of Peninsular Malaysia, Sabah and Sarawak for the focus group discussion. The number of participants were chosen based on logistic reasons. The

researcher facilitated this focus group discussion using a set of probing questions to explore participants' experiences of symptom interpretation and coping strategies. Figure 3.2 shows the flow chart for data collection process.

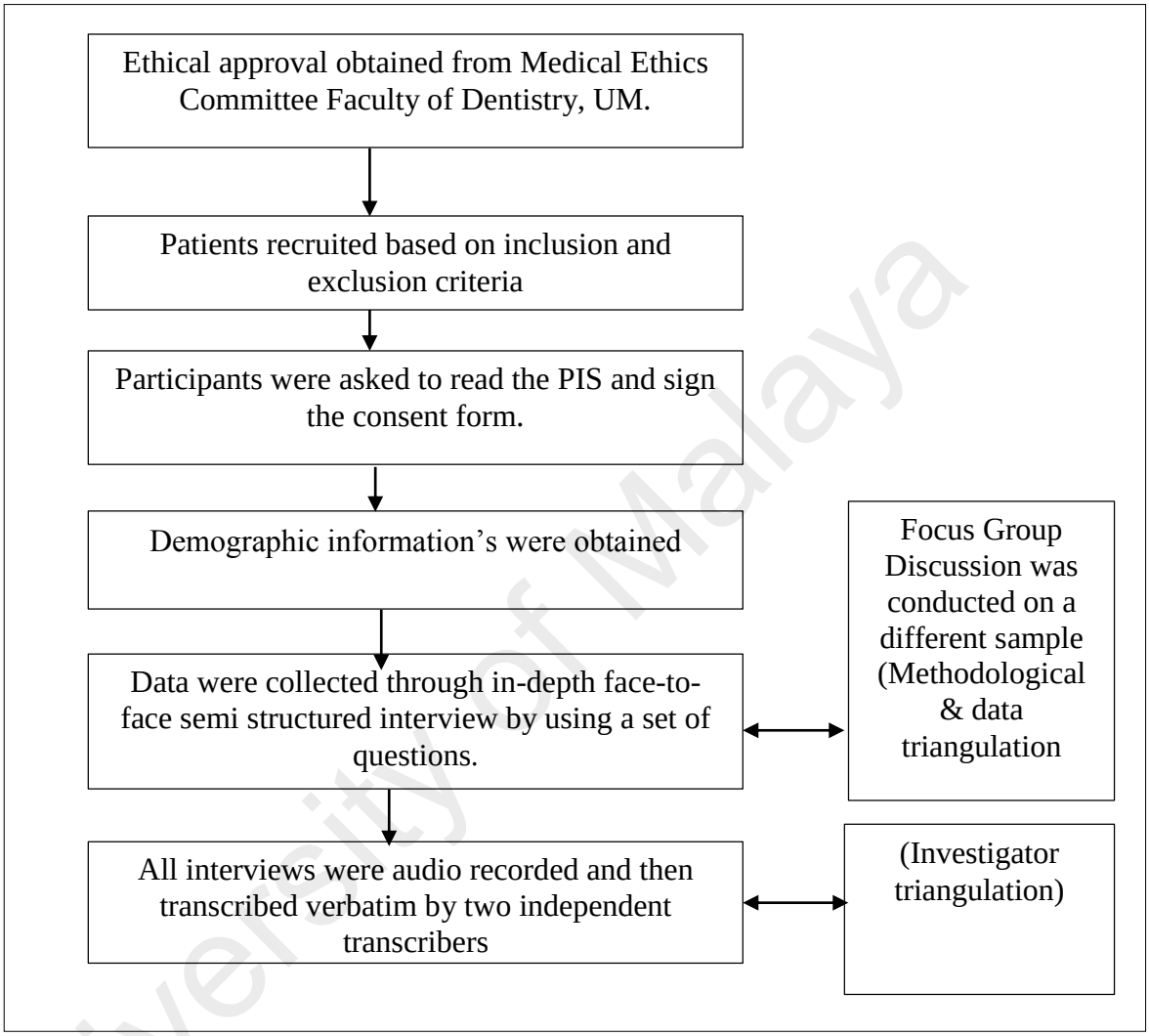


Figure 3.2: The flow chart of data collection

3.9 Data collection and analysis

Data was collected through face-to-face semi-structured in-depth interviews by using a set of probing questions prepared by the researcher based on the Leventhal's Self-Regulatory Model. Interviews were conducted by the researcher herself to remove interviewer bias. Two interview sessions were conducted as a pre-test for the researcher to familiarise herself with the procedural conduct of the face-to-face semi-structured in-depth interview. Firstly, information on participants' demographic details were obtained,

namely age, gender, marital status, level of education, socio-economic status, and information on negative health related behaviours namely smoking, betel quid chewing, and excessive alcohol consumption. During the semi-structured in depth interviews and focus group discussion, participants were asked about: i) their response to the presence of their early oral cancer symptom. These questions were based on the Self-Regulatory Model of Illness which comprises components such as symptom interpretation, coping strategy and appraisal of coping effort; ii) any potential barriers to seek help; and iii) factors influencing their health-seeking behaviour.

The qualitative data obtained from the interviews and focus group discussion were analysed using framework analysis, a systematic matrix-based approach which provides clear steps and produces highly structured outputs of summarised data (Scott *et al*., 2007). The first step was 'familiarization' which includes transcribing and reading the data. The audio recorded interviews and focus group discussion were transcribed verbatim by three transcribers and all versions were compared by a panel consisting of an independent transcriber and researcher herself, to ensure quality of transcripts and consistency in analysis of transcripts (Investigator triangulation). This is because consistency in label selection, alignment and quality of the resultant transcripts have important implication to the data (Bryman, 2001). Where the researcher had doubts on a particular verbatim, clarification was sought by cross-checking with the field notes and through discussion with the other transcribers. The second step was 'identifying priori themes' that described or explained aspects of the data based on the Self-Regulatory Model (symptom interpretation, coping strategy and appraisal of coping strategy) as well as emerging themes. Then, 'coding' was done to give a conceptual label that corresponded to themes (Lacey & Luff, 2001). This study used 'case charting' where summarized data was put

into a matrix form (columns and rows). Table 3.3 showed an example of a case charting constructed (refer APPENDIX J).

Table 3.4: The process of case charting

No.	Case	Participant's symptom interpretation	Coping strategy
1.	**UM01001**	Normal mouth ulcer	He consulted General practitioner (private clinic)
2.	**HQE02009**	He had high fever, headache and probably did not realise any abnormalities inside his mouth. He finally realised he had a few ulcers.	He was assuming it was a high fever and headache. However, it got worsen and he finally went to the hospital.
3.	**HUSM05014**	Normal mouth ulcer	She pricked the ulcer using needles (self-remedy)

Finally, 'mapping and interpretation' was done to search for patterns and concepts (Gale *et al.*, 2013). This means the results from the semi-structured in-depth interviews, focus group discussion and field notes were visually displayed (diagrams) in order to develop interpretations. These interpretations was then used to construct the health-seeking pathway of oral cancer patients in Malaysia from the onset of first symptom until the point of diagnosis, based on Leventhal's SRM, 1980. (refer Figure 4.1).

Data analysis were facilitated using an advance qualitative software Nvivo 10.0. Audio recorded interviews and focus group discussion were imported into the software (Figure 3.3). All audio recorded were then transcribed verbatim (Figure 3.4). A priori codes were developed before examining the data and stored within nodes. Nodes (theme nodes) created were rooted according to the Self-Regulatory Model components (Figure 3.5). The process of coding were carry out as shown in Figure 3.6. The usage qualitative software enhanced data quality in terms of data consistency, reliability and validity (Figure 3.7).

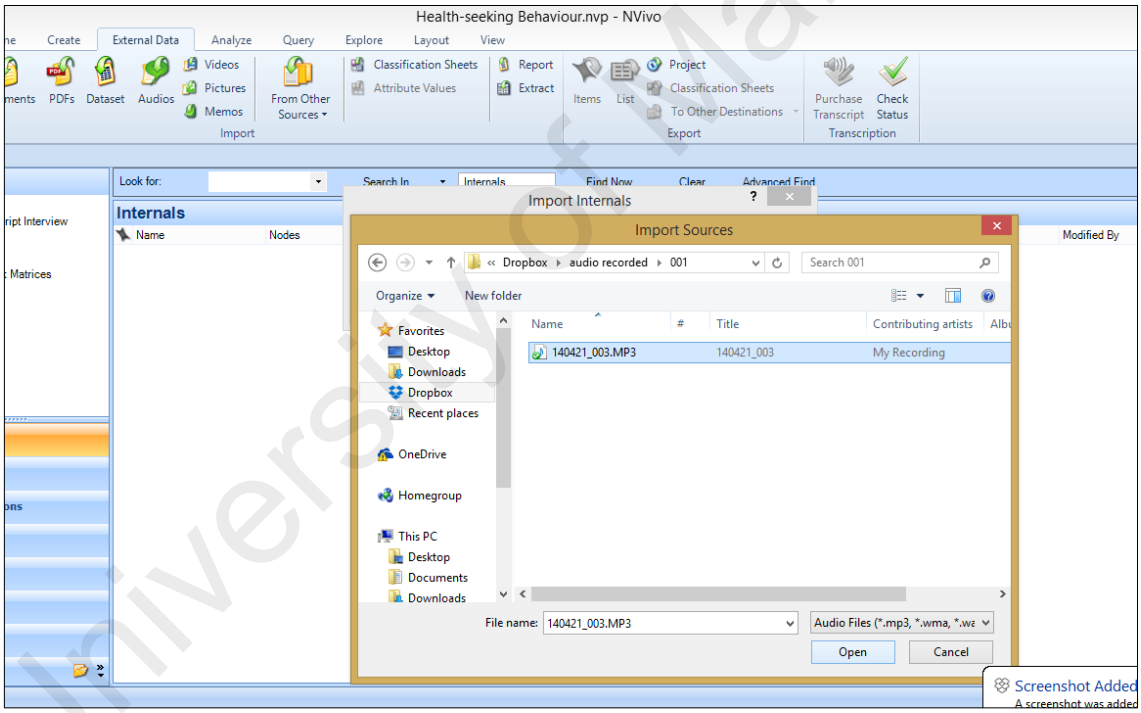


Figure 3.3: Importing audio recorded interviews into Nvivo software

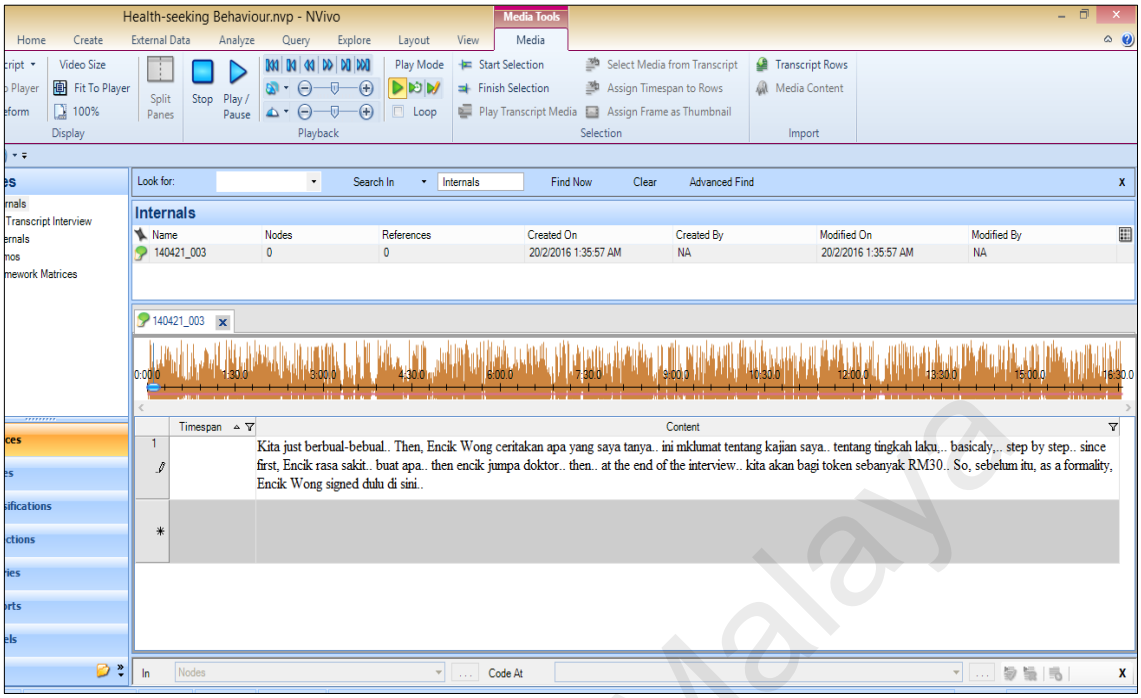


Figure 3.4: The process of transcription

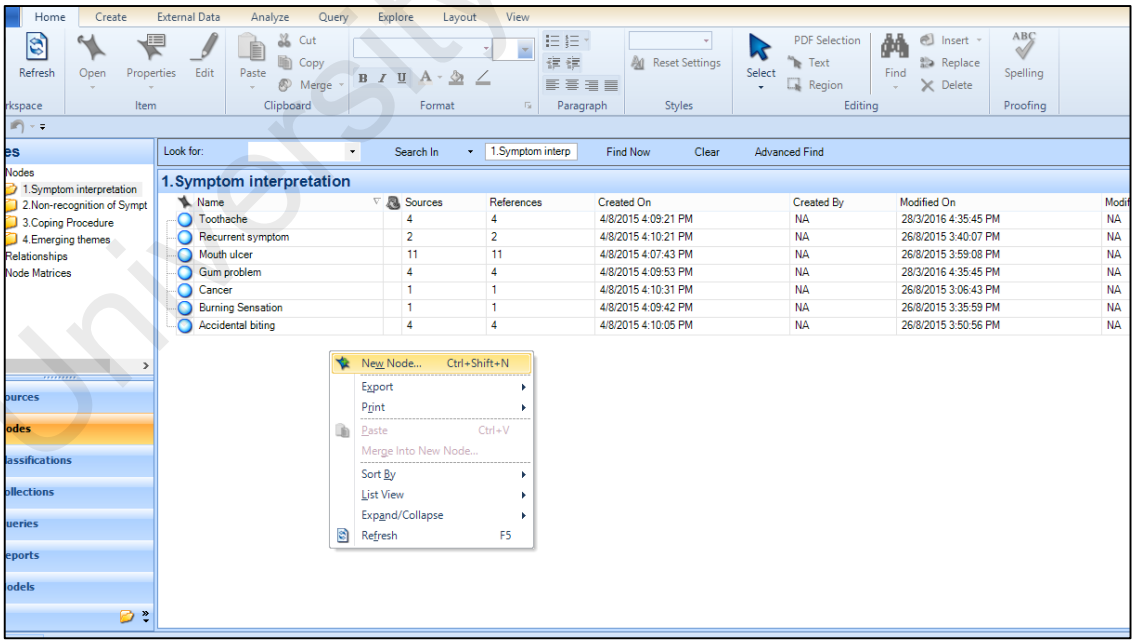


Figure 3.5: Nodes created in accordance to priori and emergent themes

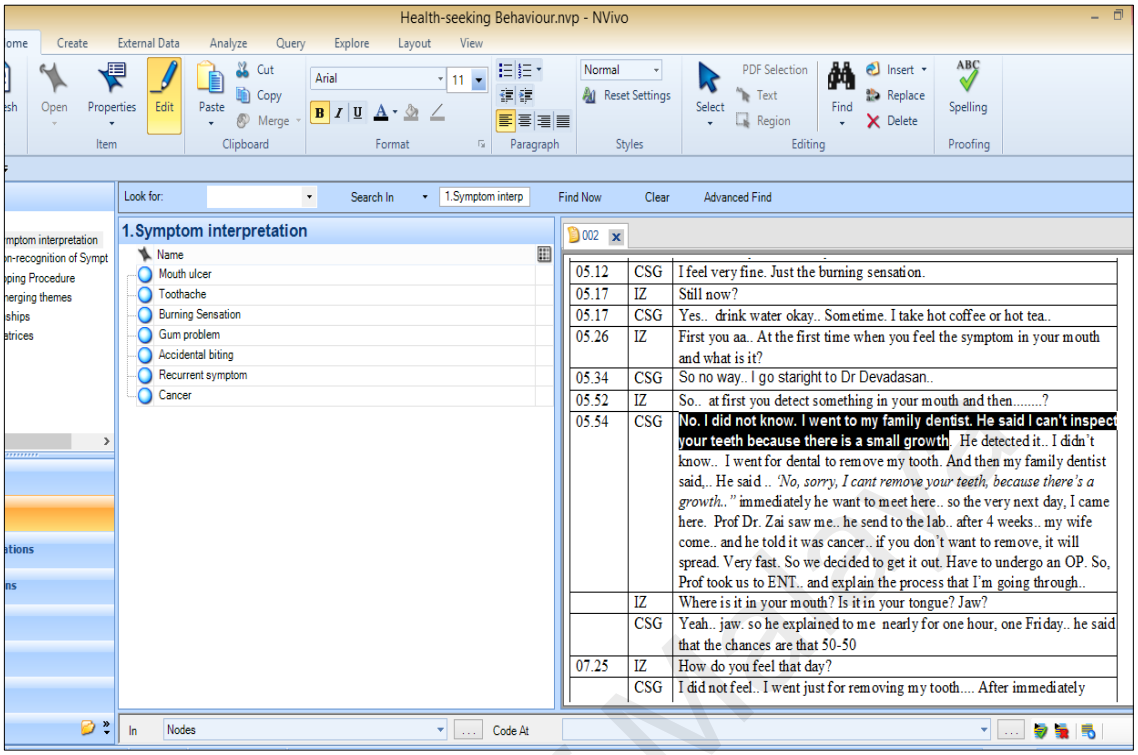


Figure 3.6: The coding process

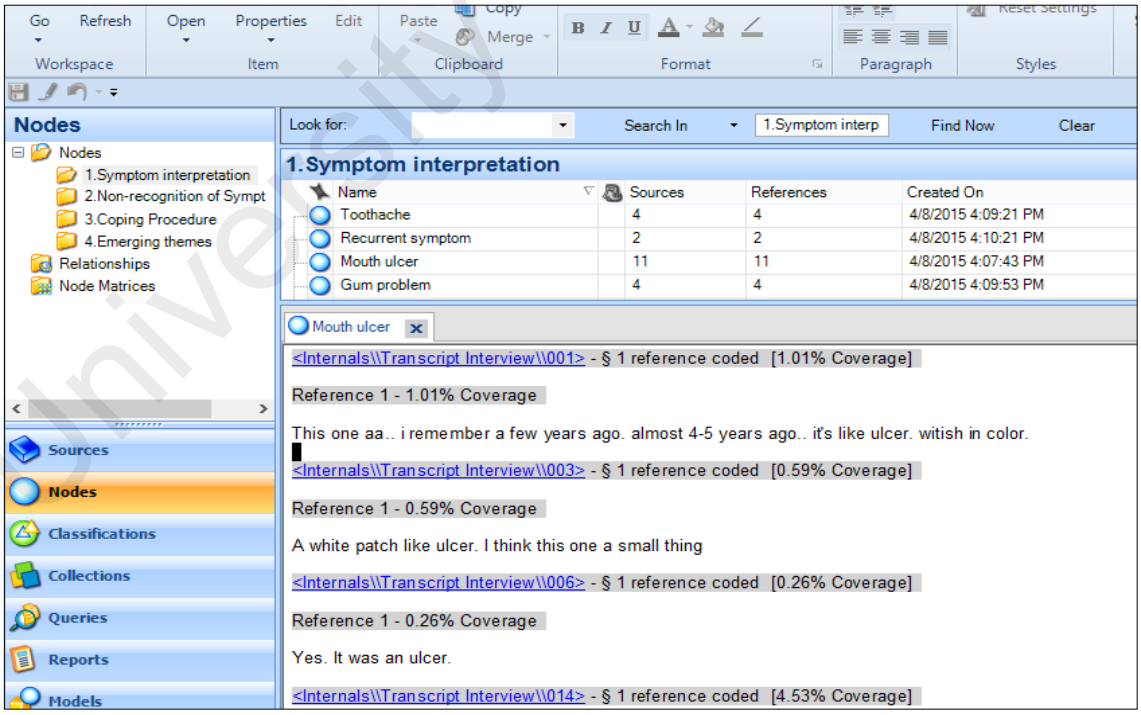


Figure 3.7: Data analysis using Nvivo version 10.0

3.10 Reliability

All interviews were coded, by two persons; a researcher trained in qualitative methods and a dental public health specialist. These two codings were compared by the aforementioned persons and any ambiguities were resolved in discussion. Categories were reduced to major themes through ongoing discussion and the re-reading of transcripts by the coders. Cross-checking, refinement of themes and using the Self-Regulatory Model as a broad framework supported the rigor and trustworthiness of the data.

The process of generating themes from the data was clearly documented using framework analysis and facilitated by a qualitative software Nvivo version 10.0 (QSR International Ptd. Ltd). Reliability in this research was delineated by clearly describing and documenting the process of generating themes from the data.

3.11 Validity

Validity was obtained by presenting adequate quotations from transcribed verbatim, data consistency and triangulation. This qualitative study has ensured 'triangulation' by gathering and analysing data from more than one source to gain sufficient knowledge about the circumstances of the study.

- Methodological triangulation in this study involved the use of multiple qualitative methods which was the semi-structured in-depth interviews and focus group discussion. Validity was established as the results reported similar findings.

- Data triangulation involved comparing different data sources from the audio recordings and transcripts from ‘in-depth interviews’, ‘focus group discussion’ and ‘field notes (notes taken by the researcher while in the field/clinics)’.
- Investigator triangulation involved by using different transcribers during the transcription process. The transcripts from each transcribers were compared to establish validity in the present study. The consistency of the study findings was enhanced through member checking. According to Bryman (2001), if different researchers using the same research technique arrive at the same results, this helps to confirm data reliability. Furthermore, by using researchers from different background and class groups can be used to check for observer and interviewer bias.

CHAPTER 4

RESULTS

4.1 Characteristics of sample

Table 4.1 shows the demographic characteristics of study participants. Forty-five oral cancer patients who met the inclusion criteria were expected to be recruited for this study. However, a total number of 35 participants were finally interviewed at saturation point. A point in the data collection process where no new data emerged. The sample ranged from 30 to 81 years old with almost two-thirds in the 51-70 year old age range. Eighteen participants had low educational levels (n=11; received primary education, n=7; had no formal schooling and n=3; were illiterate). The majority of the male participants (n=10) were past smokers whereas only one female participant had a past history of smoking. On the other hand, betel quid chewing was practised only by female participants (n=10).

In this study, triangulation was assured by one session of focus group discussion in addition to semi-structured in-depth interviews, as a way of gaining different insights into the same situation. Despite that, participants (oral cancer survivors) for the focus group discussion were recruited from various parts of Malaysia. A total number of six oral cancer survivors (1 male, 5 female) were recruited for the focus group discussion (Table 4.2). The age of participants ranged from 40-67 years old. All of the results presented in the following sections were from 'semi-structured in-depth interviews', 'focus group discussion' and 'field notes' (notes taken by the researcher while in the field via observations).

4.2 Delay in diagnosis

In this present study, delay in diagnosis was reported as being contributed by patients, healthcare professionals or both. All participants (n=35) were diagnosed with advanced stage cancer (stages TNM III and IV). Twenty-eight participants reported a delay in seeking help from a dentist. They first consulted general medical practitioners (GPs) and traditional healers for treatment. Sixteen participants (n=16) experienced multiple consultations whereas twelve (n=12) of them were referred to a dental clinic by their general medical practitioners after their first consultation. The rest of participants (n=6) discovered their symptoms accidentally during their regular dental appointments (wear a denture, routine visit) and also while attending regular health programmes organised by local public hospitals. Only one participant suspected himself having cancer symptoms due to his family history.

Table 4.1: Demographic and negative health-related habits of study participants from the in-depth interviews

Variable	n (%)
Sex	
Male	17 (48.6)
Female	18 (36.0)
Age	
30-40	2 (5.7)
41-50	6 (17.1)
51-60	12 (34.3)
61-70	10 (28.6)
71-80	2 (5.7)
81-90	1 (2.9)
Marital status	
Married	32 (91.4)
Single	2 (5.7)
Divorced/separated/widowed	1 (2.9)
Ethnicity	
Malay	7 (20.0)
Chinese	6 (17.1)
Indian	9 (25.7)
Indigenous Sabah	6 (17.1)
Indigenous Sarawak	7 (20.0)
Level of education	
No formal schooling	6 (17.1)
Primary education	11 (31.4)
Secondary education	15 (42.9)
Tertiary education	3 (8.6)
Smoking history	
Never	24 (68.6)
Past	11 (31.4)
Current	0 (0)
Alcohol consumption	
Never	33 (94.3)
Past	0 (0)
Current	2 (5.7)
Betel quid chewing	
Never	24 (68.6)
Past	0 (0)
Current	10 (28.6)

Table 4.2: Details of participants' characteristics from the focus group discussion

Participant	Age	Gender	Ethnicity	Marital Status	Occupation	Tumour location	Treatment received
P01	40	Male	Chinese	M	Self-employed	Tongue	Surgery & Radiotherapy
P02	40	Female	Malay	M	Teacher	Tongue	Surgery & Radiotherapy
P03	45	Female	Chinese	M	Teacher	Base of tongue	Surgery
P04	35	Female	Indigenous Sabahan	M	Government Servant	Tongue	Surgery
P05	68	Female	Indian	M	Lecturer	Buccal Mucosa	Surgery, Radiotherapy & Chemotherapy
P06	50	Female	Malay	M	Teacher	Tongue	Surgery & Radiotherapy

4.3 Participants' responses to symptom

4.3.1 Participants' symptom interpretations

Table 4.3, shows participants' cognitive interpretation about their early symptoms based on their illness beliefs. The reasons for making the interpretations are also detailed in Table 4.3. Cognitive interpretation in this present study referred to participants' individual brain-based skills which involve perceptions, motor skills, memory and visual processing about a symptom (Bandura, 1994). The types of symptoms interpretations by participants in this present study include mouth ulcer (n=13), toothache (n=4), burning sensation (n=2), gum problem (n=4) and accidental biting (n=4). Apparently, only one participant interpreted their symptom as cancer due to a family history.

Table 4.3: Participants cognitive symptom interpretations of oral symptoms

Participants' symptom interpretations	Participants' interpretation beliefs	Reasons for their beliefs	Verbatim
Ulcer	Participants recognised soreness inside their mouth that were round, white or grey in colour, with a red edge or border. They perceived their symptom as a mouth ulcer.	The reasons for their beliefs were because of mouth ulcer would usually harmless and clear up on its own. Additionally, fever with the appearance of the mouth ulcer is severe.	*"For this one (symptom). I remember a few years ago, about 4 to 5 years ago. It started with an ulcer something whitish inside my mouth"* (P.1; male, 43 y/o)
Toothache	A toothache was considered as a normal condition. Participants believed their illness were due to tooth pain that might be sharp, throbbing, or constant. For some participants, pain occurs only when the pressure was applied to their tooth.	The reasons for their belief were because a toothache was not serious and will be healed after extracting the particular tooth. Pain might be caused by their tooth decay or damaged fillings.	*"No. Nothing is inside my mouth. It just felt like a toothache"* (P.18; male, 66 y/o)
Burning sensation	Participants belief that a painful sensation of the tongue, lips, or palate or areas all over mouth as a sign of an illness. They described a feeling of numbness at their tongue. Participants believed it was caused by eating hot spicy food.	It was a norm to correlate food in making sense of the symptom experienced. Participants assumed that hot-spicy foods were things that irritate their mouth and burning sensation as the consequences.	*"Something like a burning sensation…spicy. The pain radiates below my jaw… "* (P.4; female, 58 y/o)
Gum problem	Participants believed that their gum is soft, thus, it was normal to bleed. Swollen and bleeding gums can be symptoms of gum disease.	Although, symptom could be a serious condition; but participant believed it would resolve. Participants assumed bleeding gums were caused by using the wrong techniques with toothbrushes and floss.	*"Hot. I always felt pain on my gum. My gums used to bleed."* (P.15; male, 49 y/o)
Accidental biting	Participants believed that a cut inside their mouth was due to an accidental biting. It was a normal situation and regarded as a minor problem and common for people to accidentally bite their tongue or cheeks.	It will heal from the previous experience. A small wound on the tongue or cheek heals by itself with time provided.	*"I thought, it was nothing. Something like accidentally bitten the tongue"* (P.19; male, 35 y/o)

Cancer	Participant interpreted his symptom as a serious condition. Thus, it is important to take immediate action.	Family history	"*Well, when I had pain. I suspected already since my father died because of tongue cancer*" (P.34; male, 71 y/o)

The excerpt below is one of the incidents extracted from the researchers' field notes regarding participant' cognitive interpretation. Field notes were documented to enhance credibility of the findings.

Patient 5, *an Indigenous Sarawakian (Iban) male, aged 57 years, who was educated to secondary school (form 3). Patient interpreted his illness as a minor condition. There was a slight cut on his tongue which he believed was due to accidentally biting his tongue. He also spotted a white patch on his tongue. Hence he interpreted his symptom as a normal ulcer at the left lateral border of the tongue. He contended that it was not painful but he had difficulty eating and drinking.* (Field note: May, 2014)

4.3.2 Emotional responses to symptom

Participants demonstrated emotional responses simultaneously with cognitive interpretations upon discovering their symptoms. These emotional reactions varied from 'positive expectancies' to 'fear that something serious might happen'. The present study has shown that participants' emotional state will change in accordance to their symptom interpretations. The change in emotional state govern their decision to plan a coping strategy.

For example, *"I never thought it was a cancer. I don't think it was cancer. I thought it was an ulcer.* **(**positive expectancies) *But the ulcer grew bigger, I felt worried and decided to visit a polyclinic* (fear that something serious might happen)*"* (P.19; male, 35 y/o). Another example, "*I have this problem. A non-healing ulcer... a white patch on my tongue. I was wondering why it did not heal (worried). I went back and forth to the clinics*

(private general medical practitioners) for months. My bonjela also has been used up" (P.35; male, 60 y/o)

4.3.3 Non-recognition of symptom

The majority of participants were unable to recognise early oral cancer symptoms. Patients who were unable to interpret their symptom and the reasons for non-recognition are shown in Table 4.4. Some of them had insufficient general knowledge and awareness to perform cognitive interpretations. Ten participants in the present study stated that they did not interpret their symptom at all. Moreover, six of them only discovered the existence of their early symptom existence after been told by their general medical practitioners or dentists.

Table 4.4: Participants who were unable to interpret symptoms

Participants' symptom interpretations	Participants' illness beliefs	Reasons	Verbatim
No idea and cognitively failed to interpret	Participants believed that it was nothing serious, the symptom was not painful, disturbed daily activities and gave emotional impact thus they decided to ignore it as a sign of an illness.	Very low educational level and health awareness. Hence, failed to interpret symptoms. Some participants just left to general practitioner to explain about their symptom.	*"It was not painful. At first, I saw a small thing (a growth) inside my mouth. ....I thought there is no reason for it"* (P.12; male, 65 y/o) *"I had no idea about 'it'. I did not know about the symptom"* (P. 13; male, 61 y/o)
Co incidental finding (do not interpret)	Participants' only realised their symptom after accidentally discovered by healthcare professionals.	Participants had very low level of awareness about the presence of the symptom.	*"He (Doctor) detected it (symptom). I did not know. I went for dental clinic to remove my tooth. And then my family dentist said. He (Doctor) said. 'No, sorry, I can't remove your teeth, because there is a growth." immediately he (Doctor) wants to meet me here, so the very next day, I came here. Doctor saw me. He sends the sample to the lab after 4 weeks, my wife came along and doctor told it was cancer. He said, 'if you don't want to remove, it will spread.*

Very fast'. So we decided to get it out. Have to undergo an operation. So, doctor took us to Ear, Neck, and Tongue Department (ENT) and explained the process that I will be going through" (P.2; male, 59 y/o)

The excerpt below is one of the incidents extracted from the researchers' field notes regarding patients who did not interpret their symptom.

Patient 10*, an Indigenous Sabahan (Bajau) female, aged 59 years, who did not have formal education. Patient did not notice her symptom at all. She coincidentally went to a free mouth screening programme organised by the local clinic in Kota Belud, where the lesion was detected. She was fast referred to Hospital Kota Belud and then Hospital Queen Elizabeth (HQE). She was only later diagnosed with oral cancer in Hospital Queen Elizabeth.* (Field note: May, 2014)

4.4 Participant's coping strategy

Participants' coping strategy in response to symptoms are tabulated in Table 4.5. Self-Remedy and Self-Medication were commonly used as a coping strategies among the study participants. The most common coping strategies were self-remedy and self-medication. The other coping strategies such as visiting Malay traditional healers and using traditional Chinese medicine are still in use and prevalent in Southeast Asia countries like Malaysia. In addition, some participants simultaneously consulted both traditional healers and general medical practitioners.

For example, *"It is a white patch like an ulcer. I think 'this one' (ulcer) is a small thing. I bought medicine out of clinics (pharmacy) but still did not heal. Then I came to see the doctor and also used traditional medicine"* (P.3; male, 60 y/o).

Another example, "*I can't recall when we consulted traditional healer. I think after we visited the clinic. My elder sister suggested to consult traditional healer. We suspected that maybe someone had done a bad thing to mom (superstitious beliefs). But there was no improvement. So we just stopped"* (proxy (daughter) of P.21; female, 68 y/o). However, majority of the participants chose to seek help from general medical practitioners either in private or public healthcare service. None of the participants sought help from a dentist in response to their early oral cancer symptom.

Table 4.5: Participants' coping strategy in response to symptom

Type of coping strategy	Participants' coping strategy in response to symptom	Reasons	Verbatim
Self-Remedy	Prick with needle	Participants wanted to remove the fluid (puss) by using a needle. it will usually heal small, fluid-filled mouth blisters may appear on the lips.	"*I used a needle to prick it*" (P.14; female, 46 y/o)
	Self-extract the tooth	A moving tooth caused participant to self-extract his tooth.	"*When my tooth got loose. I pulled it myself*" (P.15; male, 49 y/o)
	Eat sweets	The presence of symptom bring oneself discomfort, therefore, she distracted the pain by eating sweets thing.	*"I eat sweets and keep it there to distract myself from the discomfort"* (P.6; female, 46 y/o)
	Rub with salt	It was a common practised where the participant would usually rinse their mouth using salt to reduce discomfort from a toothache.	*"I used salt. I just rub it (there) to reduce pain"* (P.33; male, 66 y/o)
Self-Medication	Bonjela	The easiest way to get medicine without consulting a general medical practitioner. Despite that, it was cheaper and time consuming.	*"Yes. I bought it from pharmacy. I used Bonjela"* (P.17; male, 51 y/o)
	Panadol		*"No. Nothing. It is like toothache. It went off when I took Panadol. After 1-2 weeks it will come again but when I took Panadol, it went off again"* (P.18; male, 66 y/o)
	Herbal tea		"*My friend came to me with this herbal tea from Kelantan. I took that one but also it did not cure my ulcer. It tasted just like tea. Every day I drank this tea and rinsed my mouth after eating*" (P.3; male, 60 y/o)

Consult Traditional Healers	*Air Tawar* (Prayer water)	The belief that it is a superstitious phenomenon. Thus, needed some prayers from the shaman.	*"I went to the Shaman. He said someone with bad intentions had done something to me (superstitious beliefs/ witchcraft). It is clear that when in the evening. I felt hot (fever)"* (P.18; male, 66 y/o)
	Duri landak (porcupine spine) & *Pil Azimat (*charm pil*)*	Traditional medicine practised by their ancestors.	*"Yes. I have previously tried traditional medicine. Once I tried to find 'Senseh' (Chinese physician) and also went to a Malay kampung (Village). I ate porcupine spine. One gram of it cost RM 700. At that time I was still working and had income. Every time I consumed it cost RM 700. I ate the original spine. I ate it because it was recommended by my boss's relatives. During this time, my lifestyle was not good… Lack of sleep and I continued eating mutton. The Senseh gave me 'pil azimat' (charm pill) but it had no effect*" (P.15; male, 49 y/o)
Consult GPs	Antibiotic, bon jela, cream, injection, mouth rinse, pain killer, Panadol, no medicine	Participants consumed prescribed medicines by their general medical practitioners to reduce pain (due to patients' complaint about their current condition/symptom).	*"One day when I saw something whitish inside my mouth. I went to the clinic straight away. He (GP) checked several times but my ulcer did not heal. So he referred me to the hospital*" (P.1; male, 43 y/o)
			"It grew quite fast. I went to the clinic several times. I paid for a check-up. They said nothing. 'It' kept on growing. Then, I went to the hospital. They sent me to the dental clinic for treatment. Only then they took a sample (of the tissue) and sent it to the lab" (P.19; male, 35 y/o)

4.5 Participants' appraisal of coping efforts

Many participants appraised their coping efforts when their symptoms persisted, become severe or their initial coping strategy failed. Moreover, participants would also re-interpret their symptom when symptom persisted despite the use of self-remedy, self-medication or other coping efforts.

For example, "*I was not satisfied with my condition after visiting clinics. I wanted to get well. So, I went to the hospital*" (P.25; female, 63 y/o).

Other participants started to appraise their coping efforts as the tumour grew bigger and impacted them especially in terms of pain.

For example, "*This growth is there… so she kept applying this for 2-3 months.... but it was not really effective but last month it grew bigger and then she finally felt painful....*" (Proxy (daughter) of P.24; female, 87 y/o).

Participants' appraisal of symptom interpretation and coping strategy were also triggered by the acquisition of new information from the mass media or advice from their relatives (lay referral system).

For example, "*When I got backed to work, my boss was so shocked. But he told me it was not cancer. In December, 2008, I checked from the internet for more information*" (P.15; male, 49 y/o).

Another example,

I: *Before you met the doctor, what did you think about your symptom?*
P: *I thought it's nothing... This one... (Ulcer) my daughter also said nothing...*
I: *Previously, Did it happened to you frequently?*
P*: Before this, No. It happened so suddenly. I like to eat hot food. I never take cold food... sometimes my wife scolded me. I think it is because of the hot food...*
I: *So you think this is because of your habit to eat hot food?*
P: *Yaa.. My wife also said...* (P.3; male, 59 y/o)

Objective 2: Participant-related factors that result in their delay in seeking care

4.6 Participants-related factors

Besides self-regulation, patient-related factors are often associated with individual's behaviour. Patient-related factors that influence individual's health-seeking behaviour were outlined as the socio-demographic factors (socio-economic status, educational level and cultural beliefs and religious practices), negative health-related habits (smoking, betel quid chewing, excessive alcohol consumption), psychological factors and symptom characteristics.

4.6.1 Socio-demographic factors

Socio-economic status

Based on the present study, socio-economic status did not emerge as a major factor that influences participants' decision to seek help from a healthcare practitioner.

For example, *"No. I never think about financial aspects before coming here"* (P.3; male, 60 y/o).

Other examples,

I: *Okay... Have you ever considered financial constraint before consulting doctor?*
P: *No...no lah...* (P.26; female, 60 y/o)

I: *Did you consider financial aspects before consulting doctor?*
P: *No la…* (P.34; male, 71 y/o)

However, socio-economic status appeared as most likely reason for the delay in seeking treatment after being diagnosed with oral cancer.

For example, *"At that time I did not realise anything. After I was diagnosed with cancer. I became worried about the treatment cost. I am poor and I can't afford to have cancer because it will affect my livelihood. So I thought it is okay as long as it does not spread. I just kept on working for almost a year"* (P.15; male, 49 y/o).

Other examples,

"*It's a lie if I said I did not think about money at all. But the doctor informed me that the cost would be subsidised by the government. He told me the whole cost would be not more than RM 500*" (P.9, male; 38 y/o).

"*Yes. I did think about the money constraints for the cancer treatment. But, the payment has been discussed earlier with the doctor before admitted to ward. It was still affordable. If not, I'll be having trouble for the medicinal fees*" (P.21, female, 68 y/o).

<u>Cultural beliefs and religious practices</u>

Cultural beliefs and religious practices often lead to self-remedy, self-medication and consultation with traditional healers. This present study has shown that participants believed that the traditional healer which is also known as shaman (*bomoh*), has the ability to pray for healthiness to God.

For example, *"Consulting traditional healers is like asking for prayers"* (P.11; male, 56 y/o).

Participants had strong beliefs that the symptom occurred due to an evil/ghost spirit. For example, *"I went to a traditional healer before coming here (hospital). The shaman told me, it could be probably someone with bad intentions sending the evil spirit to me. That is why my body felt hot every evening. But after that, I felt fine"* (P.18; male, 66 y/o).

Some participants expressed strong beliefs in traditional medicine.

For example, "*So, this is our home medicine. We believe in it. We just apply the watermelon powder for the ulcer.*" (P.24; female, 87 y/o).

Educational level and lack of awareness

Educational level and awareness about oral cancer were influential factors on participants' response to symptom and coping strategy. Table 4.6 shows majority of the participants who were interviewed from the semi-structured in-depth interview had low educational level. They were at risk of delay in seeking help and diagnosis as seen in some of their verbatim responses.

For example one participant said,

"I went to primary school until standard 3 (9 years old)" (P.30; female, 59 y/o).

Other example, *"I did not go to school. But I can read"* (P.26; female, 60 y/o).

Some participants were illiterate and lacked awareness, thus not having knowledge about oral cancer symptoms.

For examples,

"I did not go to school. I do not know how to read. I can only read 'Jawi' (Malay's traditional writing system) and the holy book Al-Quran" (P.16; female, 63 y/o).

"No. I do not know how to read and write. I know nothing" (P.18; male, 66 y/o).

Table 4.6: Participants level of education for the in-depth interviews

Age group (years)	Male (N=17)				Female (N=18)				Total N
	Illiterate	Primar-y educati-on	Second-ary educati-on	Tertiary educati-on	Illiterate	Non formal school	Prima-ry educat-ion	Second-ary educati-on	
30 – 40	-	-	2	-	-	-	-	-	2
41 – 50	-	-	2	-	-	-	2	2	6
51 – 60	-	1	5	2	-	1	3	1	13
61 – 70	1	1	1	1	1	1	4	-	10
71 – 80	-	-	1	-	1	1	-	-	3
81 – 90	-	-	-	-	-	1	-	-	1
Total	**1**	**2**	**12**	**3**	**2**	**4**	**9**	**3**	**35**

Knowledge about early oral cancer symptoms and awareness are shown to be wholly inadequate in the present study. Unlike participants from the in-depth interview, participants from the focus group discussion were from a higher educational background (teachers/lecturers) but they still misinterpreted their early oral cancer symptoms and consulted general medical practitioners as their options of seeking care.

For example, one participant stated,

"*I thought it was an ulcer. I went to consult a GP. The GP asked me, he said 'Do you feel any pain?' I said, 'Yes. Every time I eat'. Then the GP said, 'If you feel pain, it's okay. It does not matter'. So I ignored it for a month but still the ulcer did not heal. So, I finally went to seek a dentist"* [01:15:45].

4.6.2 High-risk habits (smoking, excessive alcohol, consumption betel quid chewing)

The practices of oral habits such as smoking, betel quid chewing and excessive alcohol consumption were the main risk habits for oral cancer and could be related to patient delay. The present study reported some participants practising these negative health behaviours. Nevertheless, relatedly to low educational level and lacked awareness, participants only stopped their risk habits before or after a confirmed diagnosis and did not think these habits influenced their intention to seek help from a healthcare professional (Table 4.7). Based on the present study, excessive alcohol consumption was not identified as one of the high-risk habit practised by the sample participants. Furthermore, only a few participants drink alcohol but only occasionally on social functions.

Table 4.7: Participants' related factors in terms of their high-risk habits

High-risk habits	Reasons for stopping habits	Verbatim
Smoking	Participants decided to stop smoking after been advised by their doctors. Usually, Malaysian smokers stop this habit after receiving a little bit of knowledge due to their oral cancer diagnosis. However, some of them continue to smoke and only stop when symptom becomes more serious.	*"I only stop smoking after I had been diagnosed with oral cancer"* (P.20; male 51 y/o) *"I had been diagnosed with cancer. But I told myself, it was nothing serious as long as it does not spread. So, I kept working for almost a year and I still smoked"* (P. 15; male, 49 y/o)
Betel quid chewing	Participants decided to stop chewing betel quid after they were advised by their doctors. Usually, elderly people stopped due to the persistence of symptom that causes pain and some stop because they already do not have teeth to keep chewing the betel quid.	*"I quit chewing betel quid recently since February. That was after doctor advised me to do so"* (P. 4; female, 58 y/o) *"I do not have teeth anymore. It is difficult for me to keep chew betel quid"* (P.8; female, 78 y/o)

4.6.3 Psychological factors

Table 4.8, shows psychological factors that influence delay in seeking help in this present study. Psychological factors such as 'fear' and 'denial' led to an avoidance coping strategy by participants in response to their symptom. Avoidance coping strategy can be described as a strategy whereby participants use their inner thought to reduce emotional distress and cope with their symptom emotionally.

Table 4.8: Participants' related factors in terms of psychological factors

Psychological factors	Reasons	Verbatim
Fear	Participant's trauma due to his/her previous experience.	"I just *withstood the pain. I am afraid of hospitals. I have fear of needles and injections That is why I went so late"* (P.11; male, 56 y/o) *"I am not afraid of doctors. I am just afraid of needles and injections"* (P.22; female, 49 y/o)
Denial	Participant's strong sense of unrealistic optimism due to his/her healthy lifestyle led them denying their symptom could be something as serious as cancer.	"*I had never got sick. I rarely had fever*" (P.12; male, 65 y/o) *"I am very self-aware about my own health. I am afraid of dying. That is true, I always make sure to go exercise and eat a lot of fruits"* (P.1; male, 43 y/o)

The excerpt below is one of the patient's experiences extracted from the researchers' field notes regarding participant's psychological influence in seeking help for their symptoms.

Patient 1, *a Chinese male, aged 43 years, who was educated to secondary education (SPM). Patient did not smoke or drink alcohol. He practiced a healthy lifestyle (plenty of exercise and practiced Kung Fu; a Chinese martial art) and good eating habits (preferred self-cooked meal). He experienced a white patch inside his mouth. He did not think that it was an oral cancer symptom and he could not have cancer due to his healthy lifestyle.* (Field note: April, 2014)

4.6.4 Oral cancer symptom's characteristics

A delay in seeking care was partly explained by tumour-related factors such as the site of the tumour and the severity of symptoms. The most common impact of symptoms that influenced participants' decision to seek help from a general medical practitioners was 'pain'. Majority of participants described their early symptom as non-painful.

For example, "*The early symptom was not painful. It was just a growth*" (P.25; female, 63 y/o).

This situation led to a longer delay in seeking help. Based on the present study, other common types of symptom could also influenced decision to seek help and their options of seeking care.

For example, "*The doctor gave me paracetamol. I have a fever. But I am okay, I am not that sick. I went to private general practitioners clinics"* (P.22, female; 49 y/o)

Perceptions about the seriousness of their illness were influenced by the nature of the initial symptom such as a normal ulcer.

For example, *"It was not painful. Even when I brushed my teeth. It was just the whitish ulcer did not went off"* (P.9, male; 38 y/o).

Objective 3: Participants options of seeking care

4. 7 Participants' options of seeking care

As shown in Figure 4.1, most of the participants preferred self-medication and consulting general medical practitioners from private clinics rather than dentist from public healthcare or dental clinics. Public healthcare services in Malaysia is practically cheap but it involves long waiting hours. It is obvious that majority of participants chose private healthcare as their first option of seeking care due to shorter waiting time.

For example, *"I wanted to make it quick so I went to private. It is my fault. If I went straight away to the hospital, it would not be like this. They do not have expertise there"* (P.12; male, 65 y/o).

"I rarely go to the hospital. I do not like waiting" (P.19; male, 35 y/o).

The reason for consulting general medical practitioners instead of dentists is that patients felt medical doctors could heal them of everything. Trust and confidence in their doctor's medical expertise precluded the need for patients to seek further information themselves. For example, *"The doctor (general medical practitioner) said it was something like a 'wart'. So, I thought it was a 'wart'. I am just a villager. I do not know. If the doctor says so, then I will just trust him"* (P.6; female, 46 y/o).

4.7.1 Health-seeking pathway of oral cancer patients in Malaysia

Figure 4.1 shown the health-seeking pathway of the study participants constructed based on the results. The pathway was meant to describe participants' response to their symptom (cognitively and emotionally) and their coping strategies until a confirmed diagnosis was made. This pathway highlighted the importance of 'fear intensity' and 'awareness and knowledge' to facilitate health-seeking behaviour of the study participants. Moreover, participants' symptom interpretations as well as their options of coping strategy influenced their delayed in presentations at a dental specialist clinic.

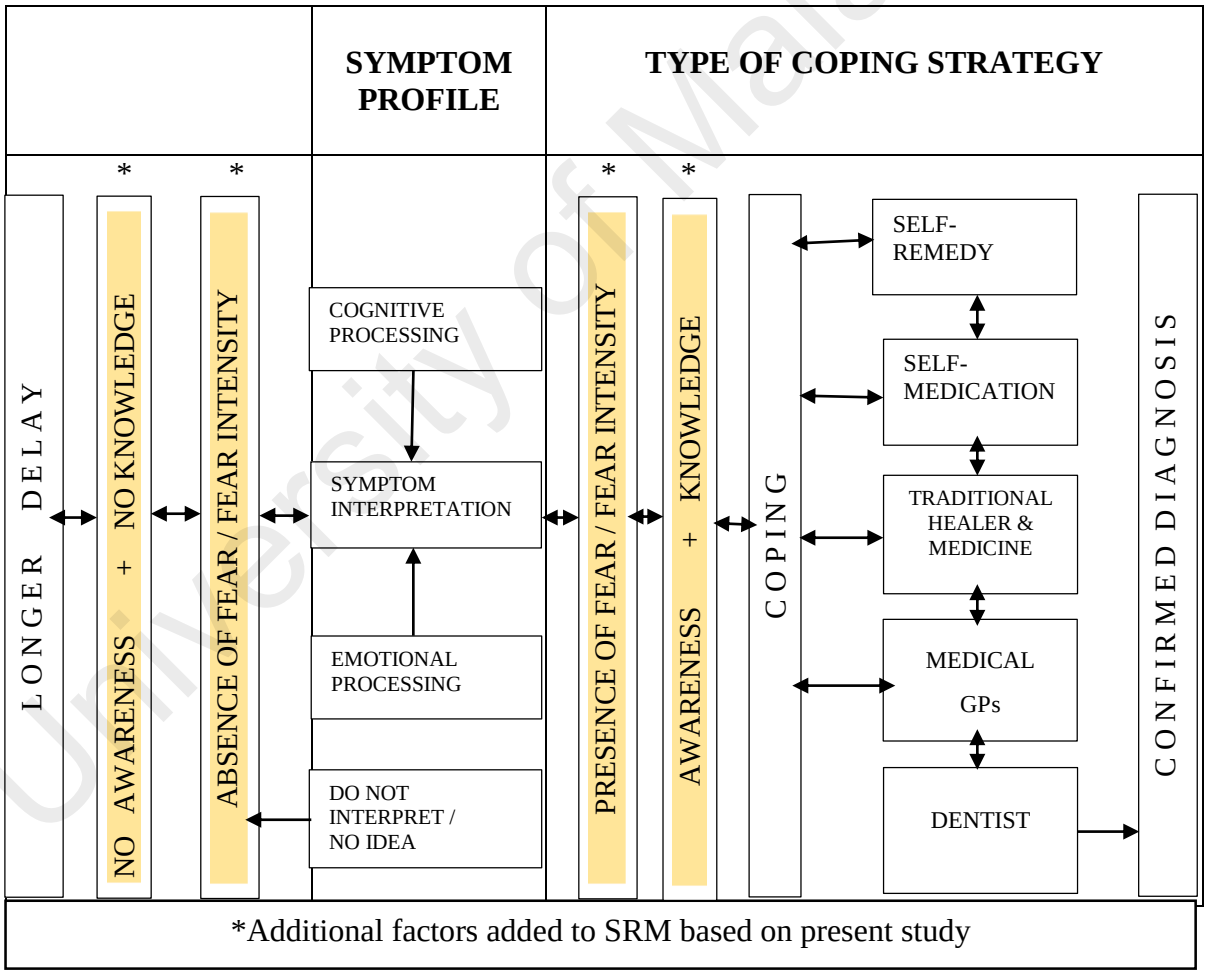


Figure 4.1: Health-seeking pathway of oral cancer patients in Malaysia from the onset of first symptom until the point of diagnosis (adapted based on Leventhal's SRM, 1980)

4.8 Emerging themes

Although the aim of this study was to focus on patient delay and related reasons, several other themes of the study related to patient delay emerged during the process of coding. These themes included the associated roles of the general medical practitioner and pharmacists in contributing to oral cancer patients' delay in Malaysia. Figure 4.2 shows the emergent themes associated with misdiagnosis of early oral cancer symptom by healthcare professionals that led to a professional delay. The professional delay from the present study can be defined as the time interval between participant's first medical contacts to a confirmed diagnosis.

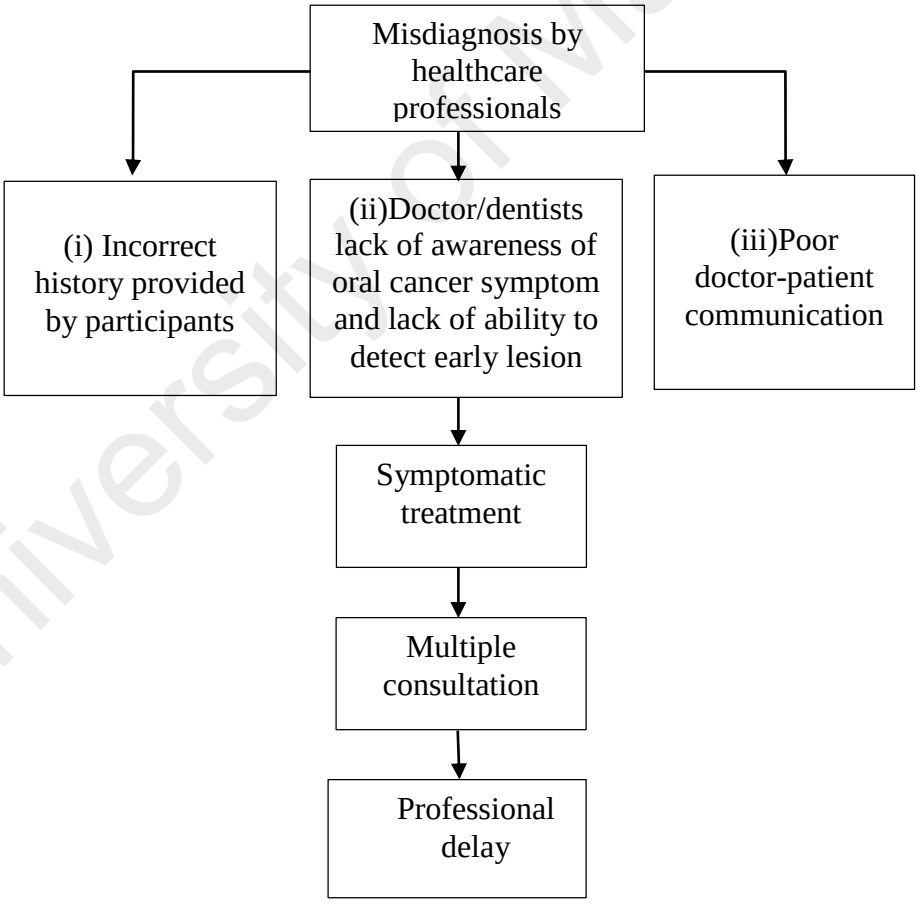


Figure 4.2: Emergent themes associated with delayed diagnosis among the study participants

4.8.1 Misdiagnosis by healthcare professionals

The study findings showed that misdiagnosis by healthcare professionals was influenced by several factors. These factors were outlined in the section below.

i) Incorrect history provided by participants

Participants in the present study tended to give insufficient information about their symptoms during the consultation. Although they may have noticed their mouth ulcer, they never mentioned it to their doctor because they attributed the ulcer to the 'heatiness' of their body as a result of their fever. Thus their focus was only on their fever. Participants' complaints about their illness were based on their own symptom interpretation which may have been inaccurate due to a lack of awareness about early sign and symptom of oral cancer. As such, the general medical practitioners were misguided by participants' complaints resulting in a misdiagnosis whereby symptomatic medications was then prescribed.

For example, *"Firstly, they took and checked my blood but everything was fine. I had high fever and headache. So, the doctor (GP) said maybe my fever was due to because of the current weather which was sunny and rainy. The doctor (GP) said it could be dengue. They took my sample blood several times but did not find anything. I was finally referred to the dental clinic due to my non-healing ulcer, and following this, they referred me here (HQE). They still did not found anything until they took a biopsy of my ulcer. A week later, they told me it was oral cancer stage four"* (P.9; male, 38 y/o).

ii) Doctors' lack of awareness of oral cancer symptom and lack of ability to detect early sign and symptom of oral cancer

Most of the participants in this study did not intentionally delay in seeking treatment for their disease. They lacked knowledge and awareness about oral cancer and the dentists' role in diagnosis the disease. Hence, consulted general medical practitioners for their early oral cancer symptoms. They did not attempt to seek information about their symptoms.

For example,

P: *Almost 5-6 months ago... I went to Clinic Lawas (general medical practitioner) to ask for medicine. He gave me a mouthwash to use.*
I: *Did you immediately consult the doctor?*
P: *Yes. He told me it was nothing serious. He gave me a mouthwash.*
I: *He did not check properly?*
P: *Yes... He checked my mouth. But he told me it was nothing serious and did not take any action. And I thought the same way too. I thoughts it's normal.*

(P.5; male, 57 y/o)

In this study, a lack of awareness regarding oral cancer was found among healthcare practitioners in Malaysia (based on participants' verbatim). Thus, led to doctor misinterpretation of the symptom, normalising the symptom and oversight.

For example,

"Last year in July, I noticed something different on my tongue. I felt a bit of pain. I had nose cancer previously and received treatment in the Radiotherapy Unit (RTU). I asked the doctor there but she told me it was nothing. Just a normal ulcer and she gave me bonjela. In September, 'it' (the symptom) became bigger. So, I went to the Ear, Neck and Tongue (ENT) department. They referred me to the dental clinic. Only then, a biopsy was done on my tongue" (P.20; male, 51 y/o).

In relation with the above verbatim, the excerpt below is extracted from the researcher's field notes.

> Patient 20, *a Chinese male, aged 51 years, who had secondary education (SPM) was a smoker. He was diagnosed with nose cancer earlier and underwent treatment at the Radiotherapy Unit (RTU). He discovered a non-healing ulcer and reported it to the doctor in RTU. Patient claims that the doctor said it was something normal and prescribed him with bonjela. The ulcer grew bigger, he finally went to the Ear, Neck, and Tongue (ENT) Unit by himself in the same hospital. He was then referred to a dental clinic and diagnosed with metastatic tongue cancer.* (Field note: May, 2014)

In addition, participants also reported that general medical practitioners tended to normalise their symptoms as something not unusual or serious. Thus, participants were convinced that there was nothing to worry about and so, allowed their symptoms time to subside.

For example,

"I went to Hospital Keningau back and forth for my ulcer. Finally, there is a growth inside my mouth. The doctor told me it was a wart/benign growth (ketuat). So, I just let it be. 'It' grew bigger within 1 year. I went to the hospital again to meet a specialist. They referred me to dental clinic in Hospital Keningau and after that Hospital Queen Elizabeth (HQE)" (P.6; female, 46 y/o).

"I went to private clinics several times but the doctor said it was nothing. The ulcer kept getting bigger so I finally went to the hospital. I was finally referred to the dental clinic in Hospital Umum Sarawak (HUS). They took a sample for biopsy" (P.19; male, 35 y/o).

iii) Poor doctor-patient communication

In the present study, participants characteristics such as lack of knowledge and general medical practitioners/dentists attitude would influence the amount of quality of information exchanged. This situation could be seen as some participants were elderly. For examples,

"I thought it was nothing. I went to a private clinic in Kota Belud. Doctor (GP) asked me to tell my son to take me to the dental clinic in Hospital Kota Belud. From there, they asked me to go to Hospital Queen Elizabeth in Kota Kinabalu. They did not give me any medicine. He just asked me to go here (HQE)" (P.8; female, 78 y/o).

"The symptom started in March. So, she went to dental clinic in early April. So, the dentist asked my mother to come again within one month to see whether the swollen gum had reduced. The dentist asked her to come again in May, but my mother is very old. She often forgot the date" (Proxy (daughter) of P.21; female, 68 y/o).

4.8.1.1 Symptomatic treatment prescribed by doctors

Misdiagnosis by healthcare professionals causes them to prescribed symptomatic treatment for participants' early sign and symptom of oral cancer. This present study has shown that general medical practitioners or dentists tended to prescribe symptomatic treatment for participants who presented with an obvious symptom. The effect of this symptomatic treatment inevitably contributes to a longer delay before a confirmed diagnosis is made. Participants reported that medications prescribed by their general medical practitioners actually helped them to relieve their pain.

For examples,

"I had always experienced bleeding inside my mouth. I always went to private clinic to request for medicine. I could not bear the pain. Every time I felt pain, I will go to Hospital Kota Belud to ask for medicine. It would heal me" (P.8; female, 78 y/o).

"There is a panel clinic in my office building. I went to that clinic and consulted a GP. He just gave me bonjela. Everything was fine and healed my ulcer. I felt okay, but there was one ulcer that remained" (P.17; male, 51 y/o).

However, symptomatic treatment would only temporarily relieved participants pain from the effect of their early oral cancer symptom. This circumstance led to multiple consultations by the participants in the present study. The present study showed that majority of participants' experienced professional delay. Sixteen (n=16) out of twenty-eight (n=28) participants reported that they had multiple consultations with general medical practitioners.

For example,

"I went to the clinic several times. I paid to get a medical check-up. They said it is nothing. But it (the growth) kept on growing. Then, I went to the hospital. They sent me to the dental clinic for treatment. Only then they took a sample (of the tissue) and sent it to the lab" (P.19; male; 35 y/o).

Participants' multiple consultations due to healthcare professionals' lack of awareness led to a delayed in their diagnosis of oral cancer.

For example,

I: *How long did you take to consult a doctor?*
P: Around *3 months.*
I: *Means you waited for 3 months before you consult a doctor?*
P: *No. I went back and forth to the clinic several times. Then they referred me to Hospital Queen Elizabeth (HQE).*
I: *Oh... What did the doctor at the clinics give you?*
P: *Something like Panadol...* (P.7; female, 75 y/o)

Other examples,

"I consulted a general medical practitioner, not dentist. I went there twice and the doctor just checked my ulcer" (P.12; male, 65 y/o).

"I have a non-healing ulcer. A white patch on my tongue. So, I went to the clinic for several time and they gave me bonjela. After a few months, it did not cure my ulcer. Only then the GP felt strange and referred me to a dental clinic for a biopsy" (P.35; male, 60 y/o).

4.8.2 Availability and accessibility of cheaper over-the-counter medicines in pharmacies

Self-medication plays an important role associated with delay in seeking help in this present study. This study has shown that most participants did not intentionally delay their seeking help. According to the participants, although the cost of public healthcare services was cheaper, participants had to face congestion resulting in a long waiting time. Private healthcare services were less congested but the consultation fees were more expensive.

Purchasing unconventional medicine from the pharmacy was deemed the cheapest and most convenient for participants. Local pharmacy has been identified as potential reasons for patient diagnostic delay among oral cancer patients in this study.

For example,

"I just bought medicine for my ulcer. I rarely go to the clinic. I hate waiting too long" (P.19, male; 35 y/o).

Moreover, pharmacy is easily accessible throughout the country. Most of the participants can afford to buy medicine from pharmacy and view that pharmacy provides quick services. Self-medication by using unconventional medicine such as bonjela and Paracetamol temporarily relieves their pain.

For example,

"No. Nothing. It just felt like a toothache. I took Panadol whenever I felt pain and the pain went off. After a few weeks, it felt painful again. I did not notice anything because I was wearing dentures. But when I took off the denture, then I saw something. I saw a hole, so I went to the clinic" (P.18, male; 66 y/o).

CHAPTER 5

DISCUSSION

5.1 Introduction

This is the first qualitative study to explore patient's health-seeking behaviour within the context of Self-Regulatory Model in Malaysia. This study is the first qualitative study explore the health-seeking pathways among oral cancer patients in Malaysia and the determinants of their behaviours with the context of the Self-Regulatory Model (participants-related factors that resulted in delayed diagnosis). Delay in seeking help in the present study was considered as the time from the onset of symptoms to participants' first contact with healthcare professionals (medical practitioner/dentist). This is in tandem with the definition of patient delay by Dwivedi and colleagues, (2012). Other studies measured the time taken from when an individual noticed a symptom as a sign of an illness until deciding to seek healthcare professionals as an 'illness delay' (Andersen & Cacioppo, 1995).

In this study, the Self-Regulatory Model was applied and conceptualised as the behavioural change for the maintenance of health and illness management among the study participants (oral cancer patients). It was suggested that individuals search to understand their illness by developing symptom interpretations (Diefenbach & Leventhal., 1996). Individuals act as active problem solvers by attempting to understand their symptom interpretations through seeking information and testing hypotheses (Hale *et al.*, 2007). Participants' response to symptoms is based on individuals' beliefs or acquired knowledge (previous experience). Hence, a cognitive 'profile' comprising; the

identity of the symptom (label), cause (possible causes), consequences (minor or major health threat), timeline (expectations of duration it might last) and controllability/curability (ability to control the threat) was constructed. On the other hand, emotional responses such as fear, anxiety or depression were also an essential process to symptom interpretations and are expressed simultaneously during cognitive responses. Both cognitive and emotional responses to the detection of potential malignant symptoms are crucial to prompt an individuals' health-seeking behaviour (Woolley *et al.*, 2006).

5.1.1 Cognitive symptom interpretations

Following the presence of a symptom, individuals in the present study sought to understand the meaning of their illness. Their common cognitive responses to oral cancer symptoms were interpreted as mouth ulcers (n=13), toothache (n=4), burning sensation (n=2), gum problem (n=4), accidental biting (n=4) and cancer (n=1). These findings concur with other studies worldwide (Scott *et al*., 2006). Studies have listed out some of the most common symptom interpretations which are mouth ulcer, physical trauma, a side effect of medication, thrush, food allergy, burnt mouth, gum disease and cancer (Scott *et al*., 2007). This study participants' interpretations of their signs and symptoms were influenced by their beliefs regarding the cause, consequences, timeline and perceived control over an illness.

In the present study, most of the participants interpreted their early oral cancer symptom as a normal mouth ulcer. Recurrent aphthous stomatitis or commonly known as mouth ulcer is one of the most common oral mucosal disorders. Exact causes, precise

etiological and pathogenesis of the ulcer remain unclear (Swain *et al*., 2012). The pain from a mouth ulcer generally lessens in a few days and usually heals without treatment. Thus, the specific criteria of a mouth ulcer mimicking normal conditions as an early sign of oral cancer often confused participants. This delayed them in planning a coping strategy (Tromp *et al.,* 2005). Therefore, a mouth ulcer was always mistakenly perceived as a minor condition rather than as an early sign of oral cancer by most participants.

Furthermore, if the symptom did not involve growths participants tended to relate their current condition with their previous experiences. For example, toothache and gum disease were the cause of their tooth mobility and gum soreness. Participants also related their symptom interpretations with physical trauma such as a burning sensation because of eating hot-spicy foods or accidental biting that could cause intraoral wounds. Only one participant suspected his symptoms as an early sign of oral cancer due to a family history with the same type of cancer.

As alluded to by previous studies using the Self-Regulatory Model, individuals construct symptom interpretations using schematic structures of illness based on their prior experiences or those derived from their general knowledge (Wyke *et al.,* 2013). As can be seen in the present study, most of the cognitive symptom interpretations did not appear to be threatening to them. This finding is in accordance with previous research on the prevalence of chronic illness and health-seeking behaviour in Malaysia, whereby mild illness was reported as the main reason for not seeking treatment (Amal *et al*., 2011). However, participants might change their interpretations due to the severity of the

symptoms. The components of cognitive symptom interpretations such as identity, cause, consequences, timeline and control/curability were found to change over time. The participants in the present study showed a lack of knowledge regarding early signs and symptoms of oral cancer and the consequences driven by their symptoms. Public education through effective oral cancer awareness campaigns should be strategized based on the possible types of symptoms that lead to oral cancer.

5.1.2 Emotional symptom interpretations

In tandem with the model, participants in this study demonstrated emotional responses, parallel with their cognitive responses to construct symptom interpretations. As their symptoms appeared to be non-threatening to most of the study participants, their emotional responses ranged from 'annoyance about potential impacts' of the symptom to 'worrying that the symptom is an indication of something more serious'. This concurs with a previous study by Diefenbach & Leventhal (1996). However, there were a few participants who have no response at all. These findings are also consistent with other studies which showed that lack of worry (emotional responses) about the nature of symptoms caused the delay in seeking help among breast cancer patients in Malaysia (Khakbazan *et al*., 2014).

This implies that oral cancer patients in Malaysia who lacked fearfulness about their condition were most likely to delay in seeking help. Thus, future health/oral health campaigns should convey messages that instil a sense of fear to trigger and promote a help-seeking behaviour.

5.1.3 Non-recognition of symptoms

The oral cavity (mouth) includes lips, inside lining of the lips and cheeks (*buccal mucosa*), teeth, gums, front two-thirds of the tongue, floor of the mouth and hard palate. Therefore, it would be hard to overlook any appearance of any signs and symptoms inside the mouth. Despite that, an astonishing number of the study participants (n=10) had no idea about their symptom and did not notice it early. They were unable to construct an interpretation.

The interval time that an individual takes to evaluate a symptom as a sign of illness is commonly known as 'appraisal delay' (Anderson & Cacioppo, 1995). A weak self-consciousness and lack of general knowledge about the disease can result in a non-recognition of the symptom. Participants noticed something abnormal but did not perceive it as an indication of any detrimental disease. They tended to ignore any abnormalities in their mouth until it was 'painful', 'affected oral functions', 'had an emotional impact' and 'affected their quality of life'. This led to appraisal delay. A previous qualitative study by Gill *et al*., (2012) concurs with these findings whereby patients define symptoms at a point when they 'can't do usual activities', undergo 'psychological suffering' and experience the impact of living with the 'symptom severity'.

Sensory factors related to the nature of the symptom such as pain or bleeding led to a decrease in appraisal delay (Safer *et al*., 1979). In relation to this, pain was identified by the study participants as the reason for their decision to seek help rather than their

symptom interpretations. A previous study suggested that pain was the initial symptom that leads to the diagnosis of cancer (Siqueira *et al.,* 2004; Gill *et al.,* 2012). As can be seen, pain was consequentially associated with advanced TNM staging as well as the location of the tumour inside patients mouth (Cuffari *et al.,* 2006).

Thus, there were no logical reasons found between the nature of the first symptoms and the urgency of symptom interpretations or seeking help (Amir *et al.,* 1999). Consequently, in the absence of any notable impacts on oral functions, participants with low self-consciousness were unable to interpret any symptom. As long as the symptom had not taken effect, participants would not consider seeking help as an option (Brander *et al*., 2014).

In contrast, some participants in the present study realised the existence of their early lesions only after being informed by their general medical practitioners or before being referred to dental specialist clinics. Some of these lesions were detected coincidentally by the dentist during patients' regular dental visits for other treatment such as tooth extraction (n=2) and denture construction (n=3). A mouth screening programme organised by local public dental clinics also lead to the detection of oral cancer lesions in one participant.

Overall, the participant sample in this study exhibited low self-consciousness and lacked general knowledge about the disease. This clearly indicates that the Malaysian

public should be educated regarding early signs and symptoms of oral cancer, its risk habits and also be trained with personal skills to do Mouth Self-Examination (MSE). Besides this, there is an essential need to motivate the public to practice regular preventive dental visits. Behavioural interventions based on health beliefs and social cognition theory (e.g. health and illness models) should be implemented among the public in order to promote the practice of health behaviour.

5.2 Participants' coping strategy

Upon discovering a symptom the aligned cognitive and emotional responses eventually triggered participants in the present study to engage in behaviours with the aim of seeking a remedy for their condition. Nevertheless, the time taken from the point an individual decides their illness requires medical care until they seek help is known as 'behavioural delay' (Andersen & Cacioppo, 1995). Walter *et al.*, (2012) on the other hand termed it as 'help-seeking delay' which was defined as the time interval when patients first believe they should seek help until their first consultation with a healthcare professional.

Following the Self-Regulatory Model, participants planned their coping strategies only when they defined a symptom as a sign of an illness. Hence, two types of coping strategies were reported; 'approach coping' (problem focus solving) and 'avoidance coping' (emotion focus coping) (Walsh *et al.*, 2004; Yahaya *et al.*, 2015). The present study findings reveal four participant coping strategies. The most common coping strategies reported among the study participants were; self-remedy, self-medication, consulting traditional healers and consulting general medical practitioners.

5.2.1 Self-remedy

The most common coping strategy found in the present study is self-remedy, which is one of the elements of self-care. Self-care is defined as what people do for themselves to establish and maintain health, prevent and deal with illness (WHO, 2000). Therefore, from the present study, self-remedy was defined as individuals managing their illness without consulting either doctors (general medical practitioners/dentists) or pharmacist. Self-remedy is based mostly on participants' common sense and this is considered a weak coping strategy in terms of problem focus coping strategy and reflected their low oral health care awareness. None of the patients mentioned that the self-remedy they practiced was learn from their family or others. It can be a risky form of health care than using well known pharmaceutical products (self-medication). For instance, participants pricked their ulcer using a needle, self-extracted their loosening tooth, ate sweets to distract pain from the mouth ulcer and applied salt for a toothache. This can be explained by the fact that participants exhibited a low health care awareness which caused them to minimise the seriousness of their symptom. They resisted to seek help from any healthcare professionals (general medical practitioners, dentists or pharmacists) or even traditional healers as they regarded their symptom something trivial. In other words, self-remedy is normally practised by participants in order to reduce the inconvenient presence of their symptom.

5.2.2 Self-medication

The other common coping strategy found in the present study is self-medication. This coping strategy refers to the practice of using 'unconventional medicine' without discussing symptoms with any medical doctor. 'Unconventional medicine' refers to any

treatment that is not normally used by doctors to treat cancer (Campion, 1993). In other words, participants treated their illness with 'unconventional medicines' to cure their self-recognised symptoms without any prescription from a general medical practitioner or dentist.

As can be seen, the pharmaceutical care industry is growing rapidly for the prevention and treatment of diseases in both developed and developing countries including Malaysia. This concurs with another study reporting about the practice of self-medication as a notable behaviour among Malaysians with acute diarrheal disease (Tee *et al*., 2011). 'Unconventional medicines' such as pills (e.g. Paracetamol), mouth ointments (e.g. Bonjela) and mouthwashes from pharmacies are more accessible and much cheaper than seeing a general medical practitioner in a private clinic. This helps participants to cure their symptoms without incurring the financial costs and time of seeing a medical doctor or dentist. This also concurs with Jaafar *et al*., (1992) who also reported that the main causes of delay among Malaysians in visiting a dentist were attributed to work commitments and the lack of perceived need for urgent care. Similarly, oral cancer patients in this study preferred self-medication as in readily available medicinal products rather than enduring the experience of long waiting time at most public healthcare centres.

5.2.3 Consulting traditional healers

The other common coping strategy is the consumption of traditional medicine by consulting traditional healers. Some participants preferred consulting only traditional

healers and used traditional medicine as an alternative while others simultaneously consulted their general medical practitioners or dentist. These study findings concur with other research in Malaysia, reporting that some Indigenous communities in Peninsular Malaysia have adapted themselves to the mainstream healthcare system and concurrently believe strongly in traditional medicine (Yew *et al*., 2015).

Malaysia, a multi-ethnic nation has diverse cultural beliefs and religious practices. Both Malay traditional healers (shaman/*bomoh*) and Chinese traditional medicine (*senseh*) are very popular in this country as in other Southeast Asian countries. Some of the study participants believed that their illness was caused by a ghost/evil spirit. Thus, they sought traditional healers to pray for them. An example of this is the '*Air Tawar*' (holy water) which is preyed upon by reciting holy words from the Quran. This study concurs with Yew and colleagues (2015) who reported that religion often offers hope to those suffering from an illness and produced a positive feeling for participants after they consulted a traditional healer. Previous research has shown that cultural compatibility and widespread presence of traditional healers in Malaysia results in a late presentation, advanced stage diagnosis of cancer and a higher mortality rate than in Western countries (Merriam & Muhamad., 2013).

5.2.4 Consulting a general medical practitioner

Most participants consulted general medical practitioners as one of their coping strategies. Participants stereotypically decided to consult general medical practitioners due to the eventual severity of their symptom and affected oral functions. At this point, participants

tended to entrust their general medical practitioners to treat their ailments instead of dentists. It is interesting to note that they seem to view general medical practitioners as gatekeepers of their oral health as well. Although there were some participants who immediately consulted a general medical practitioner after discovering their symptoms, most of them went through all the aforementioned coping strategies before finally doing so (refer Figure 4.1).

5.3 Participants' appraisal of coping effort

Appraisal of coping effort is the last stage noted of the model (Wyke *et al.,* 2013). The finding for the 'appraisal' phase in this reflects that participants were the decision makers who actively thought of solutions to cope with their illness until their emotional equilibrium was restored. For instance, participants tried various types of coping strategies until they stopped worrying about the severity of their illness. Based on the model, the present study participants' behaviour were monitored as an on-going process to appraise the outcomes of their coping strategy. In other words, the self-regulatory process enabled participants to develop an adaptive symptom interpretation and coping strategies over their illness continuum.

In this study, appraisal included re-interpretation of symptoms and changing coping strategy accordingly. Participants tended to continuously change their symptom interpretations and their coping strategy when their earlier coping efforts failed. For instance, participants consulted a general medical practitioner after their self-medication did not heal their early lesion. Thus, Scott and colleagues, (2006) listed out three main

factors causing re-appraisal of symptom interpretations which are; the persistence of symptoms, receiving new information and symptom developments.

5.4 Participants-related factors that results in diagnostic delay

Other than an individualistic approach, the study of health-seeking behaviour can also be approached by exploring the social circumstances surrounding participants. The Self-Regulatory Model used in this study focuses on participants' self-regulation states and their social determinants of decision making along with the process of symptom interpretations, coping strategy and appraisal. Previous studies have shown that delay in seeking help may be influenced by an individual's social and environmental factors such as socio-demographic factors, socio-economic status, negative health-related behaviours, psychological factors and disease symptom characteristics (Noonan, 2013). The inconsistency in oral cancer patients' survival and mortality rates between developed and developing countries could be due to their differing social background (Kerdporn & Sriplung, 2001; Shaikh & Hatcher, 2004). As such, factors that influence participants' health-seeking behaviour are further discussed in the following sections.

5.4.1 Socio-demographic factors and socio-economic status

Theoretically, demographic characteristics refer to age, sex, religion, educational level, marital status and the place of residence. Whereas sociological characteristics focus more on objective traits, such as the household status and social groups. Socio-demographic factors show a notable difference between developing countries and developed countries (Ford & Farah, 2013). In developed countries, socio-demographic factors have shown to

be not associated with patient delay (Rogers *et al.,* 2007), whereas developing countries in Southeast Asia such as Bangladesh, Pakistan and Thailand (Kerdporn & Sriplung, 2001; Shaikh & Hatcher, 2004; Ahmed *et al.,* 2005) have shown otherwise, whereby socio-demographic factors were major barriers for seeking appropriate healthcare services.

Malaysia, as a developing nation is expected to experience similar reasons for delayed presentations of oral cancer patients as other developing countries. On the contrary, the present study findings showed otherwise. In this case, participants seem to portray a different pattern of health-seeking behaviour. This could be due to diverse socio-demographic backgrounds of the study participants throughout the country. Malaysia consisted of developed cities despite the presence of rural areas throughout both Peninsula Malaysia and the Borneo Island. This concurs with Rogers and colleagues (2011), who reported that socio-demographic factors in terms of accessibility of the health care services were not identified as the reasons for a delay in seeking help. In Malaysia, this could be because public health clinics, staffed by health assistants and private general medical practitioners clinics as well as pharmacies are easily accessible throughout all parts of Malaysia, be it in small rural towns or big cities in all its thirteen states.

However, delay in diagnosis may have occurred in these instances due to the referral process of patients from smaller clinics/hospitals until a confirmed diagnosis was made at a regional specialist clinic where diagnostic facilities were available. For example, if participants visited a private clinic in Keningau, they were referred to Hospital Keningau.

Following this, they were eventually referred to Hospital Queen Elizabeth for biopsy, a confirmed diagnosis and initiation of treatment. This led to 'treatment delay'. Treatment delay is defined as the time between the first appointment with a healthcare professional and the onset of treatment (Anderson & Cacioppo, 1995). Walter and colleagues (2012) defined this particular time interval as 'diagnostic delay'.

Participants' old age and low educational level are two associated demographic factors that may have influenced their self-regulatory process via their low self-care awareness which led to a delay in diagnosis. Other than that, participants' appraisal of their symptom interpretations and coping strategies could have been triggered by the acquisition of new information from the mass media or advice from the relatives (lay referral system). According to Friedson (1986), individuals' social network such as family and friends are usually consulted and decisions are made mutually. This concurs with another study on health-seeking behaviour among diabetes patients in Kuala Selangor, which revealed that strong family support is determinants of appropriate health-seeking behaviour (Abidin *et al*., 2014).

Socio-economic status, on the other hand, was not an identified reason for the present study participants delayed help seeking. This study has shown that majority of participants did not consider their financial status a barrier for seeking help from healthcare professionals (general medical practitioners/dentists/pharmacists). This could be because both public and private healthcare services were still affordable for most of them. Currently, the cost of public healthcare services is heavily subsidised by the

government in Malaysia. Johnson and colleagues (2010) found no evidence showing that patients with a lower socioeconomic status with head and neck cancer presented at a different stage than patients with higher socioeconomic status. These findings also concur with Adrien *et al*., (2014) who reported that no significant association between socio-economic factors and stage at presentation was due to their country health care system (French social security system) and its wide coverage on the population. A good example of this is the '1(one) Malaysia Clinics which were implemented by the government in many rural and urban areas throughout the country to ensure greater accessibility of health care for its population at just the cost of one Malaysian Ringgit. Jaafar *et al*., (1992) reported that more than 5O % of Malaysians who thought they needed treatment delayed their visit to dental clinics for more than a month whereby factors related to financial problems were ranked very low.

However, socio-economic status has distinctively shown influences on the present study participants' coping strategy options. This is because, the public healthcare clinics, although much more affordable, have a long patient waiting time. In contrast, private healthcare clinics, have quick services but at much higher costs. Therefore, most participants preferred purchasing medicine from the pharmacy nearby as it provided the best of both options (self-medication). In the present study, participants from various socio-demographic and socio-economics background in Malaysia practised self-medication frequently. These findings concur with a previous study by Chang & Trivedi, (2003) reported that self-medication is prevalent in most economies.

Despite that, only a few participants did consider their financial status after they had been diagnosed with oral cancer and may have delayed their treatment uptake. Participants from low-income groups were more worried about the cost of treatment. Fortunately, the treatment cost is currently highly subsidised by the government. Therefore, socio-economic status is perceived not as the main factor contributing to delay in seeking help but having some influence on delay in diagnosis and initiation of the treatment.

5.4.2 Cultural beliefs and religious practices

In relation to socio-demographic factors, cultural beliefs and religious practices have been seen as one of the barriers that contributes to delay in seeking help in most Southeast Asian countries. More often than not, cultural beliefs and religious practices were seen to influence some participants' symptom interpretation and options of seeking care. This is because, participants' symptom interpretations and coping strategies were derived culturally within which an individual has been raised regarding their knowledge of health and illness (Locker, 1989). Consulting traditional healers despite the advances of modern medicine is seen as a common practice among Asian countries. This concurs with reports by Muhammad and colleagues (2012) that such practices are still common in Malaysia. Moreover, about 80% of Malaysians still consulted traditional healers or '*bomoh*' (shaman) at some time in their life for health-related issues (Al-Naggar *et al.,* 2012; Muhamad *et al.,* 2012) and some might even simultaneously consult healthcare professionals. Additionally, these cultural beliefs and religious practices are deeply rooted in the lives of most ethnic groups in Malaysia and are difficult to abort since it has been practised over the years by their ancestors (Merriam *et al.,* 2013). Kerdpon and Sriplug

(2001) reported that using traditional herbal medicine before professional healthcare consultation significantly increases the risk of advanced stage oral cancer.

These factors continue to exert an impact on patients' symptom interpretation and options of seeking care among cancer patients in Malaysia (Chin & Noor, 2014). As such, public education and awareness are needed to break patients' norms of cultural views on their illness perceptions; from consulting traditional healers to considering healthcare professionals as their first options of seeking help. Other studies suggested that herbalist shop owners should also be educated with the appropriate knowledge regarding oral health (Varela-Centelles, *et al*. 2012). Perhaps educating traditional healers in Malaysia through oral health promotion campaign may seem timely too.

5.4.3 Educational level and lack of awareness

Low educational levels and lack of awareness did not universally contribute to delay in seeking help, but these factors were associated with patient delay (Llewellyn *et al.,* 2004; Awojobi *et al.*, 2012; Al-Maweri *et al*., 2014; Panzarella *et al.,* 2014; Shepperd *et al.*, 2014; Al-Maweri *et al*., 2015; Hassona *et al*., 2015). Based on the present study, the majority of participants received only primary education (n=11), with some of the elderly and female participants not having any formal schooling (n=7). This factor could have influenced participants' health-seeking behaviour such as symptom interpretations and their options of seeking care. A previous study showed that patients with primary education had a 70% lower risk of delay compared to illiterate patients, whereas the lowest risk of delay was among those who received secondary and tertiary education

(Esmailbeigi *et al.*, 2014). In relation with this, the public awareness, knowledge about signs and symptoms of oral cancer and the risk factors may decrease the disease burden of head and neck cancer (Luryi *et al*., 2014). Thus, strategies to improve the effectiveness of educational and awareness campaign regarding oral cancer are required across the lower social strata in our population; among the urban poor and also among isolated rural communities (e.g. Indigenous population).

In terms of the self-regulatory process, the present study participants' symptom interpretations and coping strategies were governed by their acquired knowledge (experiences) and awareness about oral cancer (concern). Previous research argued that the concern (awareness) about oral cancer partially mediated the effect of help seeking, whereas level of education did not (Logan *et al*., 2013). In Malaysia, lack of knowledge and awareness of oral cancer were identified as one of the main reasons for patient delay in seeking help (Ghani *et al.*, 2013). The delivery of information through simple poster and leaflet campaign is likely to have limited impact (Milan *et al.*, 2011). As such, more effective methods of information delivery should be considered to reach all social strata and geographical regions in Malaysia.

5.4.4 High-risk habits-related factors (smoking, betel quid chewing, excessive alcohol consumption)

Previous studies have reported that high-risk habits such as smoking, betel quid chewing and excessive alcohol consumption were associated with greater risk for delay in seeking help (Ostroff *et al.*, 1999; Brouha *at al.*, 2005; Scott *et al.*, 2007). Pitiphat *et al*., (2002)

reported that former smokers have '4.3 times' greater risk of delayed diagnosis than current smokers whereas, individuals using excessive amounts of alcohol have a tendency to deny and act passively, which may result in a failure to consult a healthcare professional (Tromp *et al.*, 2004). In Malaysia, it was reported that the practice of oral habits such as smoking, betel quid chewing and excessive alcohol consumptions were the main risk factors for oral cancer (Tan *et al.*, 2000; Zain, 2001).

This study showed that high-risk habits such as smoking (n=11) and betel quid chewing (n=10) did not influence participants' health-seeking behaviour. These habits neither affected participants' decision to seek help nor their self-regulatory process. Participants reported that they stopped practising their high-risk habits only after being diagnosed and advised by their doctors. This is in agreement with previous research that majority of smokers, betel quid chewers and alcohol consumers were not aware that their lifestyles were placing their long-term health at serious risk (Amarasinghe *et al*., 2010). There was a lack of knowledge and understanding of the risk of oral cancer among participants with high-risk habits. This finding concurs with a previous study by Lowry & Craven, (1999) who reported that individuals with high-risk habits such as smoking profess ignorance regarding their sign and symptoms of oral cancer. As such, the lack of knowledge and understanding about oral cancer and its risk habits among the Malaysian population needs to be addressed urgently by oral health planners and health authorities in the country in order to reduce oral cancer patients' delay in seeking care.

5.5 Psychological factors

Psychological factors are identified reasons that could contribute to diagnostic delay among most cancer patients worldwide (Tromp *et al.*, 2004; Scott *et al.*, 2007). Most studies have suggested that psychological factors were the main predictors of delay in help seeking rather than associated factors such as socio-demographic factors, socio-economic status and other high-risk habits (such as smoking, betel quid chewing and excessive alcohol consumption).

In the present study, psychological factors led participants to practice emotion-focused coping strategy (avoidance coping strategy). Participants used their psychological state (emotion focused coping) to cope with their illness and maintain their health, thereby delaying their problem focus coping strategy such as self-remedy or seeking help from a healthcare professional. There were two types of psychological determinants that could be noted from the study participants. These include fear intensity and denial.

5.5.1 Fear

Findings from the present study showed that participants' fear resulted in two types of action. On one hand, fear of the symptom (health threat) appeared to trigger positive actions that eventually lead participants to seek help from a healthcare professional (problem-focused coping strategy). Whereas fear of the doctor (trauma) triggered negative actions which contributed to a longer delay in the presentation at the clinic (avoidance coping procedure). This concurs with previous research that showed people

with higher dental fear (trauma) visited the dentist less often and indicated a longer expected time before visiting a dentist in the future (Armfield *et al.*, 2007).

Some participants had very good health locus of control. Health locus of control refers to where the cause of health is perceived by participants to be located either internally (due to oneself) or externally (due to others) (Wallston & Wallston, 1982). Individuals differ in their perception in regarding illness as being within their control or not. Therefore, only participants who deemed themselves as responsible for their illness were most likely to comply with their coping strategies.

In summary, most participants in the present study did not feel threatened (fear) by their symptom. Their fear could have initially been reduced by them minimising the seriousness of their symptoms. This may have happened when participants normalised their symptom by reducing their emotional stress, thus rendering 'seeking treatment' and 'help from a healthcare professional' less urgent, resulting in longer delay (Dubayuva *et al.*, 2010). Eventually, only participants who felt threatened by their prolonged symptoms would have sought help than those with a strong sense of denial.

5.5.2 Denial

The aforementioned section showed that participants' 'fear' led to 'denial' of their symptoms. It resulted from participants' unrealistic optimism that with their healthy lifestyle, they could not get cancer. Unrealistic optimism is the belief that the problem is

preventable by individual actions (Weinstein, 1987). The belief that the problem had not yet appeared and would not appear in the future caused many participants' to think that they were less likely to experience oral cancer because they practised a healthy lifestyle. Under many circumstances, unrealistic optimism appears to buffer the immune system from the effects of psychological stressors such as fear and anxiety (Segerstorm, 2005). As a result, there is a physiological cost to be paid as unrealistic optimism tends to encourage oral cancer patients to delay seeking help. In the present study, a strong sense of denial leads to undesirable optimism. Practising a flexible optimism may be therefore most adventurous. Although it is good to be optimistic about their health, participants need to be realistic and open to the fact that cancer can happen to anyone regardless of age, gender, race or religion (Forgead *et al*., 2012).

5.6 Oral cancer symptom's characteristics

From the present study, some participants immediately sought help after self-discovering their symptom but yet were diagnosed at a late stage of the disease. As noted, several studies have suggested that symptom characteristics could have influenced delay in presentation at a healthcare centre (Onizawa *et al.*, 2003; Scott *et al.,* 2005). This concurs with previous research which indicated that although the stage of a disease depends on time since disease onset, some tumours do not present themselves until they are at a late stage (Scott *et al*., 2005; Groome *et al*., 2011). However, a previous study reported that some patients were asymptomatic during their presentation at a healthcare centre (Dwivedi *et al*., 2012). Therefore, participants' symptom characteristics could be one of the reasons explaining their diagnostic delay.

5.7 Participants health-seeking pathway and options of seeking care

One of the dominant approaches to health-seeking behaviour studies involves the process of healthcare seeking and the development of pathways models (MacKian, 2003). Based on the overall findings of the present study, a theoretical model was constructed (adapted from the Self-Regulatory Model) to describe the health-seeking pathway of the sample participants in Malaysia. This pathway was meant to describe the process by which participants try to make sense of their symptoms to the point of diagnosis (refer Figure 4.1).

Participants with oral cancer symptoms (e.g. mouth ulcer) interpreted their symptom based on their existing knowledge (previous experiences). Then, they attempted to cope with its' effects by planning a coping strategy. Anderson and colleagues (1995) suggested that the time interval involved during this stage can be described as 'appraisal delay' (time taken to evaluate a symptom as a sign of illness) and 'illness delay' (time taken from the first symptoms until deciding to seek healthcare professionals).

Participants' symptom interpretations were expected to be linked to their selections of coping strategy. However, new symptom interpretations were formed when participants obtained new information or their coping strategy failed. This condition may have involved changes in their coping strategy (action plan). Participants' views and their coping strategies often constrained them from seeking more information and their efforts to obtain it (Leydon *et al*. 2000). This could be due to their perspectives on health and illness beliefs based on health psychologist's theory that people behave in line with the

way they think. On the other hand, non-recognition of symptoms led to an avoidance coping strategy causing longer delay in seeking help.

The process of symptom interpretations, coping strategy and appraisal were reported as dynamic and on-going as suggested by the model. In other words, individuals self-regulate by continuously appraising their coping strategies including re-interpretation of symptoms until a state of emotional equilibrium has been attained. Therefore, numerous measurements of delay can be made in total duration time until the initiation of treatment.

Based on the current study findings that participants chose self-remedy, self-medication, visited traditional healers or consulted general medical practitioners, strategies should be emphasised to encourage people to seek help from a dentist regarding their oral health problems. In terms of preference for seeking help, participants preferred to seek help from a general medical practitioner rather than a dentist (refer Figure 4.1). Most participants live with the belief that medical practitioners can treat all ailments, for instance even a mouth ulcer. The present study showed that none of the participants consulted a dentist in the first place for their early oral cancer symptoms, although a previous study in Malaysia indicated that knowledge about early symptom and high-risk habits associated with oral cancer were high and majority of public dentists in Malaysia were reported to conduct opportunistic screening and advised their patients on risk habit cessation (Saleh *et al.*, 2014). Consulting a general medical practitioner instead of a dentist for early oral cancer symptoms among the study participants could have increased

their risk of diagnostic delay. This concurs with other studies that most of the oral cancer patients were diagnosed at an earlier stage if they presented at dental clinics (Horowitz *et al.*, 1996; Johnson *et al*., 2010; Stroller *et al*., 2011). Therefore, impactful education is needed to correct this public misconception and direct Malaysians to consult dentists regarding oral health issues.

5.8 Limitation of the Self-Regulatory Model for use among the study participants

The Self-Regulatory Model has revealed psychological concepts such as illness belief (symptom interpretation), motivation (coping strategy) and self-regulation (appraisal). Besides the role of environmental and social interactions, the Self-Regulatory Model employs a focuses on individuals' psychological states. Based on the present study, participants have to be psychologically ready to perform an effective self-regulation process. This concurs with Patrick and colleagues (2006) that individuals have to be psychologically ready to be aware of their symptom as a sign of an illness.

A key construct that emerged through various applications and elaborations of this model is the notion of self-efficacy. Self-efficacy can simply be defined as the belief about one's ability to perform a behaviour that brings the desired outcome (Bandura, 1994). The Self-Regulatory Model requires participants to feel competent to perform a health practice (Coreil, 2008). There were some aspects of the study participants' behaviour which did not work in tandem with the self-regulation process. These are discussed in the section 5.8.1, 5.8.2 and 5.8.3.

5.8.1 Participants' non-recognition of symptoms

The first aspect is the non-recognition of the symptoms of oral cancer. Without a clear vision of the symptoms and reasons to solve problems, it would be inadequate to perform effective self-regulation. The Self-Regulatory Model does not include a pathway for non-recognition of the symptom. As such, the fit of this model in explaining the health-seeking behaviour of such oral cancer patients in Malaysia from the study participants is limited from this aspect. Based on the present study, participants who did not recognise their symptom did not feel the need to seek treatment and help from a healthcare professional. Thus, the cognition (identity, timeline, consequences, cause, and control/cure) and emotional responses were insufficient to build a symptom interpretation. Non-recognition of the symptoms eventually prolongs the process of symptom interpretation and causes a delay in planning an appropriate coping strategy.

5.8.2 Individual's illness perceptions/beliefs

The other aspect is the individual's perceptions regarding their symptoms. The way individuals interpret and label their symptom was shown to influence their self-regulation process. As can be seen, planning a coping strategy depends on individuals' illness perceptions. In the present study, participants perceived their symptom as non-serious. For example, participants categorised burning sensation inside their mouth as a minor condition that would heal by itself. Anderson *et al* (2010) reported that body signs and sensations were hardly interpreted by participants as potential symptoms of cancer. Clark (1999) concurred by reporting that if the symptom did not appear to be a health threat (due to a lack of awareness) patients will have difficulty recognising abnormalities and often neglected it.

5.8.3 Motivations

The third aspect is an individual's motivation. The aspects of the Self-Regulatory Model when applied among oral cancer patients in Malaysia revealed that each participant's self-regulation process varied according to their motivations. Motivation can be briefly defined as the activation to action. Most human motivation is cognitively generated (based on cognitive symptom interpretation). In the present study, most of the participants did not take immediate action after discovering the symptoms until it was painful. In this case, a symptom interpretation was insufficient to motivate individuals to take action by seeking help from a healthcare professional. In addition, some participants who had mouth soreness and loose teeth decided to self–pull their own teeth without consulting a dentist despite the severity of their oral condition.

Self-efficacy plays a key role in motivations. This clearly shows that the strength of participants' self-regulation depends on their self-efficacy to maintain their current or future health status. Self-efficacy refers to people's beliefs about their abilities to produce designated levels of performance that affect their lives (Bandura, 1994).

5.9 Additional elements required for use among Malaysian oral cancer patients for the health-seeking pathway

Although the concepts of the Self-Regulatory Model is comprehensive and dynamic ranging from symptom interpretation to coping strategy, some modifications might be needed in order to fit it for use among oral cancer patients in Malaysia. The process of self-regulation needs a trigger rather than a natural process. As such, findings of this study

suggest a modification to the Self-Regulatory Model (as shown in Figure 4.1) for the use among oral cancer patients in Malaysia.

5.9.1 The inclusion of 'fear intensity' element into the Self-Regulatory Model for use among Malaysians

Indeed, the fear intensity is a vital aspect in stimulating the self-regulation process of individuals. As noted in the present study, low fear intensity acted as a barrier for an individual's self-regulation process. This concurs with de Nooijer and colleagues (2001) who showed that fear was found to be either stimulating or a barrier for health-seeking behaviour.

Fear intensity was strongly associated with participants' health-seeking behaviour. Anxiety and worrying about the persistence and seriousness of symptoms brought on a stronger type of fear which triggered participants to seek help to cure their current condition (which they perceived as a threat to their health). Whereas a low intensity of fear usually resulted in participants presenting late at clinics (general medical practitioners/dentists). This was because participants did not felt threatened by their symptoms. Individuals' failure to manage fear intensity could lead them to engage in avoidance coping instead of problem-focused coping (refer Figure 4.1). For example, participants avoided coping by minimising their fear intensity.

5.9.2 The inclusion of 'knowledge and awareness' element of the health-seeking pathway

Another stimulant needed for the study participants to perform effective self-regulation process is their general knowledge and awareness about the disease. The Self-Regulatory Model currently assumes that patients have sufficient knowledge to execute a task upon discovering a symptom (Mann *et al*., 2013). Without proper knowledge and awareness, effective self-regulation would certainly not happen.

In the present study, there were two situations that caused diagnostic delay. Firstly, participants' lack of knowledge and awareness about early signs and symptoms of oral cancer resulting in symptom misinterpretations. For example, participants interpreted high fever as the cause of mouth ulcers rather than a non-healing ulcer as the reason for their high fever. Thus, participants tended to consult general medical practitioners to cure their high fever. The general medical practitioners then prescribed participants with unconventional medicines such as Paracetamol.

Secondly, a lack of knowledge and awareness tended to misguide participants in their coping strategies. For example, participants interpreted their symptoms as a toothache and consumed Panadol (self-medication) which then temporarily relieved their symptoms resulting in them being physically and emotionally satisfied with their coping strategy. However, these situations inevitably lead to a delay in diagnosis (refer Figure 4.1).

5.10 Emergent themes

In the present study, two main emergent themes were found associated with participants' diagnostic delay. 'Misdiagnosis by healthcare professionals' and 'accessibility of cheap over-the-counter medication at pharmacies' are discussed in the following sections below.

5.10.1 Misdiagnosis by healthcare professionals

Participants (n=28) in the present study have reported a delay in diagnosis due to misdiagnosis by healthcare professionals which led to a professional delay. The Professional delay is defined as the time taken from the first contact with a healthcare professional to a confirmed diagnosis (Dwivedi *et al*., 2012). This complies with a quantitative research by Khoo *et al*., (1996) that delayed diagnosis of oral cancer in Malaysia was due to patient, healthcare professionals or both. Healthcare professionals (general medical practitioners and dentists) played an important role in prevention and detection of oral cancer. The aspects of urgent referral, confirmed diagnosis, initiation of treatment and short waiting time for all investigations, including the very first ones prescribed by the general medical practitioners were reported as the most important part of the diagnostic pathway by most cancer patients (Booji *et al*, 2013).

A lack of knowledge and awareness among general medical practitioners and dentists regarding early signs and symptoms of oral cancer were reported from the verbatim in the present study. Both general medical practitioners and dentists play a major role in recognition of oral mucosal changes that leads to malignancy among the study

participants. The first contact with healthcare professionals (general medical practitioner/dentist) was important (Abdo *et al*., 2007) considering the time intervals could change the process of subsequent diagnostic delay until a confirmed diagnosis is made (Mitchel *et al*., 2015). Thus, healthcare professionals' knowledge in oral cancer itself and the risk factors associated with the disease needs to be sufficient (Awan *et al*., 2014). Most patients who were diagnosed at advanced stage reported an inadequate oral mucosa examination by healthcare professionals (general medical practitioners) during their consultation (Panzarella *et al*., 2014). Other studies showed that more than 50% of general medical practitioners or dentist could not identify the cancerous lesions and gave false guidance to the patients (Chintala *et al*., 2014). However, majority of general medical practitioners and dentists wanted further training regarding oral cancer examination for oral cancer and confidence level (Canto *et al*., 2012; Awan *et al*., 2014; Kujan *et al*., 2014; Saleh *et al*., 2014). A lack of knowledge and awareness among healthcare professionals and dentists also led to a symptom misinterpretation. This can be explained by the present study, where a participant attributed his illness as a high fever with the presence of an ulcer and thereby consulted a general medical practitioner. This symptom misattribution led to initial misdiagnosis and insufficient examination by the general medical practitioner. Nevertheless, in other cases, accurate diagnosis was difficult because of non-specific symptoms reported by the participants at presentation.

Besides, the attitudes of the general medical practitioners and dentists towards the early symptoms of oral cancer was an important issue. This study noted that participants reported that their general medical practitioner and dentists stereotypically normalised their symptom without further investigation about their symptom. Vedsted and colleagues

(2015) reported that waiting until the symptom becomes more serious could affect a stage progression in some cancers. Thus, both general medical practitioners and dentists needed to explore the probability and marginalise the danger for any signs and symptoms of oral cancer. For instance, newly diagnosed patients with oral and oropharyngeal cancers needed to be carefully examined because a small portion could have another cancer in a nearby area such as in the lung, mouth and throat or other nearby areas (Forman *et al*., 2015).

Other than that, misdiagnosis by healthcare professionals could have been influenced by incorrect information (regarding signs and symptoms) provided by participants. Symptom characteristics usually influences healthcare professionals' interpretations, decision about management and further investigations (Vedtsed *et al*., 2015). Despite relevant screening activities, 85-90% of all cancers were diagnosed on the basis of symptomatic presentation (Hensen *et al*., 2011; Dwivedi *et al.,* 2012; Emery *et al*., 2014). On the other hand, doctor-patient communication also influenced misdiagnosis by healthcare professionals. In the present study, participants felt that their general medical practitioners did not listen to them. Some of them were very old and did not understand their doctor's explanation. Participants from a low educational background tend to feel shy and passive during consultation. Therefore, doctor's communication skills are important in order to obtain critical information that could improve diagnostic accuracy (Choi *et al*., 2008). Besides this, doctor's response to their patients' ideas, expectations and concerns were the crucial aspects of their delivery of care (Abu-Serriah *et al*., 2014). A previous study by Awojobi *et al*., (2015) identified several barriers for a discussion with patients including system factors (for example, time constraints and a

lack of financial incentive), patient factors (for example, fear of invoking undue anxiety) and dentist factors (for example, a lack of sufficient knowledge, training and self-confidence).

In this study, healthcare professionals often attributed participants' symptom to a non-cancer cause and treated them according to their complaints. Subsequently, healthcare professionals (general medical practitioners and dentists) tended to prescribe symptomatic treatment (due to their misdiagnosis) for an early oral cancer symptom. Thus, symptomatic treatment resulted in temporarily relieved pain among the study participants, though it did not heal the cause of their illness. Further diagnostic delay occurred until the symptomatic treatment failed.

In the present study, participants reported experiencing multiple consultations with general medical practitioners before a confirmed diagnosis was made at the dental specialist clinic (due to a misdiagnosis by the healthcare professionals). A previous study showed 20% of cancer patients who visited a general medical practitioner with a potential sign and symptom of malignancy went through multiple consultations before referral (Lyratzopoulos *et al*., 2014). Training primary healthcare providers such as general medical practitioners about the oral cancer screening examination helped in detecting oral cancer at an early stage (Aggnur *et al*., 2014; Wee *et al*., 2015).

Although majority of oral cancer patients from the study participants reported presenting late at a dental specialist clinic, most of them did not intentionally delay their seeking help. Some of the participants immediately consulted a general medical practitioner as their first option of seeking care. This concurs with studies that patients with oral lesions often present to their general medical practitioners regarding early oral cancer symptom such as mouth ulcer instead of a dentist (Canto *et al*., 2002; Loignon *et al*., 2010). They were not aware of consulting a dentist for mouth symptoms regarding mouth due to limited knowledge. A previous quantitative study in Malaysia reported that majority of oral cancer patients in this country consulted a general medical practitioner as their first options of seeking help (Khoo *et al*., 1998). Ghani and colleagues (2013) reported a lack of general knowledge and awareness among Malaysians regarding risk habits, early signs and symptoms and the benefits of detecting oral cancer at an early stage. As a consequence, participants did not seek for more information about their symptom and their prescribed medicines after their first consultations with their general medical practitioners.

In the present study, pain influenced participants to re-consult their general medical practitioners when medications (e.g. Paracetamol, Bonjela, mouthwash) failed to cure their ailments. Therefore, strategies to improve public knowledge about oral cancer and attitudes towards early diagnosis and treatment are urgently needed (Al-Maweri *et al*., 2015; Formosa *et al*., 2015; Hassona *et al*., 2015). A development of a national guideline for follow-up of oral lesions, training and increasing awareness of general medical practitioners and dentists in detecting early signs and symptoms of oral cancer could reduce diagnostic delay and improve patients' prognosis (Esmailbeigi *et al*., 2014).

5.10.2 Availability and accessibility of cheaper over-the-counter medicines in pharmacies

In the present study, participants were managing their ailments without consulting either general medical practitioners or dentists due to the accessibility of cheap over-the-counter medicines in the pharmacies nationwide. Considering the growth of the pharmaceutical industry, patients worldwide increasingly practise self-medication (Grant *et al*., 2010; Rogers *et al*., 2010). In conjunction with the studies, practising self-medication could be one possible reason for delay in oral cancer diagnosis among participants. The World Health Organization (WHO) suggested that self-medication involves the use of medicinal products by the consumer to treat self-recognised disorders or symptoms or the intermittent or continued use of a medication prescribed by a physician for chronic or recurring diseases or symptoms.

The lack of knowledge and awareness regarding early signs and symptoms of oral cancer among participants in the present study led most of them to practice self-medication instead of consulting a healthcare professional (general medical practitioners and dentists). Participants perceived their sign and symptom of oral cancer as non-serious. Therefore, they consumed medicine which they bought from the pharmacy nearby. Educational strategies are urgently needed to improve pharmacists' ability to discern patients with potential sign and symptom of malignancy (such as a non-healing ulcer) and advise them to consult a dentist (Rogers *et al*., 2010; Varela-Centelles *et al*., 2012).

In this study, the improvement in the supply and availability of pharmaceuticals care and the ease of access to medicines resulted in participants to delay their seeking help from healthcare professionals. Thus, participants with early oral cancer symptoms preferred to buy medicine from the pharmacy as it is accessible throughout any geographical area, ranging from deprived to affluent neighbourhoods in Malaysia. Moreover, self-medication was considered most compatible and economic for all groups from low- to a high income groups in the present study.

The public hospital or clinic services provides cheaper medical fees than private clinics, but the waiting list was very long. Private healthcare services on the other hand, have no waiting lists but were more expensive. Pharmacies, in turn, has no waiting time, quick services and provides affordable and reasonable price for their pharmaceuticals products. Furthermore, self-medication did not acquire any consultation fees. However, self-medication exposed participants to the risks of; incorrect self-diagnosis, absence of specialising knowledge, incorrect dosage and duration of use and the danger of side-effects. This concurs with another study by Chang & Trivedi (2004). The habits of self-medicating which provide symptomatic relief more often than not is a notable cause of patient delay in seeking help from healthcare professionals.

In summary, pharmacy forms an important component of the health care system. The pharmacist is often assisted by non-pharmacist staff and must ensure that the services rendered by these auxiliaries correspond to established standards of practice. A formal referral pathway through pharmacists can be used to improve the early detection of cancer

(Badenhorst *et al*., 2015). Besides, an adequate knowledge regarding oral health among pharmacists and herbalists should be made mandatory as it is directly related to general health of a population (Aggnur *et al*., 2014; Gouraha *et al*., 2014).

CHAPTER 6

CONCLUSION

Limitations

It is acknowledged that the current study has several limitations. The majority of participants were from a low socio-economic status with corresponding low educational levels. However, considering that the profile of Malaysian oral cancer patients mostly is from this stratum, the findings are meant to be reflective of the overall oral cancer patient group in the country. Although patients were recruited from only public hospitals throughout Malaysia, this sample is still deemed to be reflective of the majority of oral cancer patients in Malaysia who are mostly managed by these six hospitals which are main regional referral centres throughout Peninsula Malaysia, Sabah and Sarawak.

Potential recall bias among participants may have occurred might happen throughout the in-depth interviews and focus group discussion. However, some measures were taken to reduce such situation. One method was to use validated questions (based on the Self-Regulatory Model) during data collections (semi-structured interviews and focus group discussion). Besides that, the language barrier was another possible limitation of this study. Nevertheless, a research clerk at each centre who was conversant with the local dialect and the presence of the caregiver helped to minimise this bias. Finally, interviewer bias was kept to a minimum due to the researcher being the only interviewer.

Conclusion and recommendations

In conclusion, the health-seeking behaviour of oral cancer patients in the study can be partly explained by the Self-Regulatory Model with some limitations. These study findings revealed that most participants interpreted their symptoms either as mouth ulcers, toothache, burning sensation, gum problem and accidental biting whereas only one interpreted it as cancer. These participants' coping strategies included self-remedy, self-medication, traditional medicines and consulting general medical practitioners. They continuously evaluated their coping procedures as either being effective or ineffective which then determined whether they continued with it or changed their coping strategy.

The present research indicated that factors such as socio-demographic characteristics, socio-economic status and negative health-related factors (smoking, excessive alcohol consumption and betel quid chewing) had minimal impact on the patients' self-regulation process and thus were not main reasons for a diagnostic delay. Cultural beliefs and religious practices influenced patients' health-seeking behaviour in terms of consulting traditional healer and consuming traditional medicines as options of seeking care.

The present study findings indicate that, there are an existing awareness and knowledge about the importance of modern medicine among Malaysians unlike their awareness about oral cancer which is severely lacking. Psychological factors (fear and denial) prominently influenced participants' symptom interpretation which determined their subsequent health-seeking behaviour. In addition, the findings of this study showed

that some participants' knowledge and awareness about oral cancer increased their cognitive skills and enabled them to make better choices among the available health related options available for them. Knowledge and awareness are key points to reducing psychological barriers (fear intensity and denial) that lead to a delay in seeking help. In summary, this study highlights that health-seeking behaviour of Malaysian oral cancer patients' in this study can be explained through the self-regulation process which is influenced mainly by their psychological factors and knowledge/awareness about the disease.

Some recommendations are made based on this study findings;

1) **Education and awareness for the public**

- Firstly, the importance of creating and improving oral cancer awareness among the Malaysian public cannot be over emphasised. They should be made aware of the impacts of the disease such as poor prognosis and compromised quality of life. Therefore, all current awareness campaigns or programmes organised by both government and Non-Government Organisations (NGOs) should utilise health threatening messages to instil fear among the public.
- The public should be educated on recognising any potential signs and symptoms of oral cancer. Disseminating relevant educational messages and developing personal skills regarding Mouth Self Examination (MSE) could be made more effective by utilising mass media and also the involvement of Non-Government Organisations (NGOs) in the country. Malaysian should be encouraged to practise desirable health-seeking behaviour such as the importance of seeking help when faced with early sign and symptom of oral cancer.

- The importance of seeking help from dentists regarding oral health diseases has to be also emphasised. It is intriguing that patients consult a general medical practitioner for the presence of a mouth ulcer. The role of the Ministry of Health Malaysia and NGO's would be crucial to achieve this through oral health promotion and awareness campaigns.

2) Interventions

- The approaches to health/oral health promotion need to rely on social psychological models of behaviour change.
- Behavioural interventions – The focus at this level is the individual's psychology make up. Personality traits, self-efficacy and motivations should be considered to build more self-health conscious individuals in the country who then are more likely to practice preventive dental visits and other practice behaviour.
- Self-regulatory interventions – Interactive talks and training workshop should be provided as part of health care promotions, workshops or programmes organised by both public and private sectors to enable the public to enhance self-efficacy optimally.

3) Education and awareness for healthcare professionals

- Training and equipping general medical practitioners and dentists with the necessary skills to recognise and detect early lesions of oral cancer and subsequent referral to the nearest dental clinics are certainly warranted.
- Doctors' attitudes to patients require further investigations on their delivery of health care. Doctor-patient communication plays an important role to reduce misdiagnosis of oral cancer.

- Oral cancer knowledge and MSE should be made compulsory in the university curricular for both medical and dental students.
- Other allied health care workers such as pharmacists and their staff should be trained and educated on oral cancer knowledge. Pharmacists should be able to provide information on signs and symptoms of oral cancer, protocols for mouth ulceration and advice patients with suspicious oral lesion of more than two weeks duration to seek a dentist, instead of just prescribing symptomatic medication

4) Improving healthcare system

- Policy makers, academicians and healthcare professionals should incorporate the knowledge from studies regarding oral cancer patients' health-seeking behaviour for improving their health services and health care delivery strategies. Improvements are required to render the health care system more sensitive to the local (culture, ethnicities, age and religious practices) dynamics of the community.
- Currently, national research on system delay (availability, cost, effectiveness, responsiveness) for oral cancer patients in Malaysia is still lacking and warrant further research. The development of a health-seeking model to better understand how the Malaysians oral cancer population engages with the health system should be developed.

5) Future research

- For further research, the quantitative part of the study could be carried out among oral cancer patients in Malaysia by using the Illness Perception Questionnaire (IPQ) by Weinman and colleagues (1996). The quantitative part of this study could generate important information and generalise the results back to the population as a whole.
- Further research is required to explore reasons for 'professional delay' among healthcare professionals in Malaysia. An in-depth qualitative study is urgently needed to explore this phenomenon.

REFERENCES

Abdo, E. N., Garrocho, A. A., Negri, S. L. C., Barbosa, B. B., & Pordeus, I. A. (2007). Time elapsed between the first symptoms, diagnosis and treatment of oral cancer patients in Belo Horizonte, Brazil. *Medicina Oral Patologia Oral Y Cirugia Bucal, 12*(7): 469-473.

Abidin, S. I. Z., Sutan, R., & Shamsuddin, K. (2014). Prevalence and determinants of appropriate health seeking behaviour among known diabetics: results from a community-based survey. *Advances in Epidemiology*.

Abubakar, A., Baar, A. V., Fischer, R., Bomu, G., Gona, J. K., & Newton, C. R. (2013). Socio-cultural determinants of health-seeking behaviour on the Kenyan coast: a qualitative study. *PLOS One, 8*(11). doi:10.1371/journal.pone.0071998.t001.

Abu-Serriah, M., Bharmal, R. V., Gallagher, J., & Ameerally, P. J. (2014). Patients' Expectations and online presence of oral and maxillofacial surgery in the United Kingdom. *British Journal of Oral & Maxillofacial Surgery, 52*(2): 158-162. doi: 10.1016/j.bjoms.2013.10.010.

Adrien, J., Bertolus, C., Gambotti, L., Mallet, A., & Baujat, B. (2014). Why are head and neck squamous cell carcinoma diagnosed so late? Influence of health care disparities and socio-economic factors. *Oral Oncology, 50*(2): 90-97.

Agarwal, A. K., Sethi, A., Sareen, D., & Dhingra, S. (2011). Treatment delay in oral and oropharyngeal cancer in our population: The role of socio-economic factors and health-seeking behaviour. *Indian Journal Otolaryngology Head Neck Surgery, 63*(2): 145-150.

Aggnur, M., Garg, S., Veeresha, K. L., & Gambhir, R. S. (2014). Oral health status, Treatment needs and knowledge, attitude and practice of health care workers of Ambala, India - A cross-sectional study. *Annals of Medical and Health Sciences Research, 4*(5).

Agrawal, M., Pandey, S., Jain, S., & Maitin, S. (2012). Oral cancer awareness of the general public in Gorakhpur City, India. *Asian Pacific Journal of Cancer Prevention, 13*(10): 5195-5199. doi: 10.7314/Apjcp.2012.13.10.5195.

Ahmed, S. M., Adams, A. M., Chowdhury, M., & Bhuiya, A. (2000). Gender, socioeconomic development and health-seeking behaviour in Bangladesh. *Social Science & Medicine, 51*(3): 361-371.

Ahmed, S. M. (2005). Exploring health-seeking behaviour of disadvantaged populations in rural Bangladesh: Karolinska University Press.

Ahmed, S. M., Tomson, G., Petzold, M., & Kabir, Z. N. (2005). Socioeconomic status overrides age and gender in determining health-seeking behaviour in rural Bangladesh. *Bulletin of the World Health Organization, 83*: 109-117.

Akin, S., & Durna, Z. (2013). A comparative descriptive study examining the perceptions of cancer patients, family caregivers, and nurses on patient symptom severity in Turkey. *European Journal of Oncology Nursing, 17*(1): 30-37. doi: 10.1016/j.ejon.2012.02.002.

Alami, A. Y., El Sabbagh, R. F., & Hamdan, A. (2014). Knowledge of oral cancer among recently graduated medical and dental professionals in Amman, Jordan. *Journal of Dental Education, 77*(10): 1356-1364.

Alice E Simon1, Jo Waller1, Kathryn Robb1, & Wardle1, a. J. (2010). Patient delay in presentation of possible cancer symptoms: the contribution of knowledge and attitudes in a UK population sample. *Cancer Epidemiology, Biomarkers and Prevention, 19*(9): 2272-2277.

Allmark, P. (2004). Should research samples reflect the diversity of the population? *Journal of Medical Ethics, 30*(2): 185-189.

Al-Dubai, S. A., Ganasegeran, K., Alabsi, A. M., Alshagga, M. A., & Ali, R. S. (2012). Awareness and knowledge of oral cancer among university students in Malaysia. *Asian Pacific Journal of Cancer Prevention, 13*(1): 165-168.

Al-Maweri, S. A., Addas, A., Tarakji, B., Abbas, A., Al-Shamiri, H. M., Alaizari, N. A., & Shugaa-Addin, B. (2014). Public awareness and knowledge of oral cancer in Yemen. *Asian Pacific Journal of Cancer Prevention, 15*(24), 10861-10865. doi: 10.7314/Apjcp.2014.15.24.10861.

Al-Maweri, S. A., Tarakji, B., Alsalhani, A. B., Al-Shamiri, H. M., Alaizari, N. A., Altamimi, M. A., & Darwish, S. (2015). Oral cancer awareness of the general public in Saudi Arabia. *Asian Pacific Journal of Cancer Prevention, 16*(8): 3377-3381.

Al-Naggar, R. A., Bobryshev, Y. V., Abdulghani, M. A. M., Rammohan, S., & Al-Jashamy, K. (2012). Knowledge and perceptions of cancer and cancer prevention among Malaysian traditional healers: A qualitative study. *Asian Pacific Journal Cancer Prevention, 13*: 3841-3850.

Al-Shammari, K. F., Moussa, M. A., Al-Ansari, J. M., Al-Duwairy, Y. S., & Honkala, E. J. (2006). Dental patient awareness of smoking effects on oral health: Comparison of smokers and non-smokers. *Journal of Dentistry, 34*(3): 173-178. doi: 10.1016/j.jdent.2005.05.006.

Altizer, K., Quandt, S. A., Grzywacz, J. G., Bell, R. A., Sandberg, J., & Arcury, T. A. (2013). Traditional and commercial herb use in health self-management among rural multi-ethnic older adults. *Journal of Applied Gerontology, 32*(4): 387-407. doi: 10.1177/0733464811424152.

Amal, N. M., Paramesarvathy, R., Tee, G. H., Gurpreet, K., & Karuthan, C. (2011). Prevalence of chronic illness and health seeking behaviour in Malaysian population: Results from the third national health morbidity survey (NHMS III) 2006. *Medical Journal Malaysia, 66*(1): 36-41.

Amarasinghe, H. K., Usgodaarachchi, U. S., Johnson, N. W., Lalloo, R., & Warnakulasuriya, S. (2010). Public awareness of oral cancer, of oral potentially malignant disorders and of their risk factors in some rural populations in Sri Lanka. *Community Dentistry and Oral Epidemiology, 38*(6): 540-548. doi: 10.1111/j.1600-0528.2010.00566.x..

Amir, Z., Kwan, S. Y. L., Landes, D., Feber, T., & William, S. A. (1999). Diagnostic delays in head and neck cancers. *European Journal of Cancer Care, 8:* 198-203.

Andersen, B. L., Cacioppo, J. T., & Roberts, D. C. (1995). Delay in seeking a cancer diagnosis: delay stages and psychophysiological comparison processes. *British Journal of Social Psychology, 34*(1):33-52.

Andersen, R. S., Paarup, B., Vedsted, P., Bro, F., & Soendergaard, J. (2010). 'Containment' as an analytical framework for understanding patient delay: A qualitative study of cancer patients' symptom interpretation processes. *Social Science & Medicine, 71*(2): 378-385.

Armfield, M. J., Stewart, J. F & Spencer, A. J. (2007). The vicious cycle of dental fear: Exploring the interplay between oral health, service utilization and dental fear. *Biomed Central Oral Health, 7*: 1.

Awan, K. H., Khang, T. W., Yee, T. K., & Zain, R. B. (2014). Assessing oral cancer knowledge and awareness among Malaysian dental and medical students. *Journal of Cancer Research and Therapeutics, 10*(4): 903-907. doi: 10.4103/0973-1482.138011.

Awojobi, O., Scott, S. E., & Newton, T. (2012). Patients' perceptions of oral cancer screening in dental practice : A cross sectional study. *BMC Oral Health, 12*(55): 55.

Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social change*. New Jessey: Prentice-Hill.

Azizah, A. M., Norsaleha, I. T., Noor Hashimah, A., Asmah, Z. A., & Mastulu, W. (2016). Malaysian National Cancer Registry Report 2007–2011. National Cancer Institute.

Badenhorst, J., Todd, A., Lindsey, L., Ling, J., & Husband, A. (2015). Widening the scope for early cancer detection: identification of alarm symptoms by community pharmacies. *International Journal of Clinical Pharmacy, 37*(3): 465-470.

Ballard, K., Lowton, K., & Wright, J. (2006). What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertility and Sterility, 86*(5): 1-6.

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioural change. *Psychological Review, 84*(2): 191.

Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), *Encyclopedia of human behaviour* (vol. 4, pp.71-81). New York: Academic Press.

Baumeister, R. F. (2005). The cultural animal: Human nature, meaning, and social life. Oxford University Press, NY.

Baumeister, R. F., & Vohs, K. D. (2007). Self-Regulation, ego depletion, and motivation. *Social and Personality Psychology Compass, 1*(1): 115-128.

Bedri, N. (2001). Health-seeking behaviour for vaginal discharge: pathways, factors and process influencing early modern care use for abnormal vaginal discharge in the Sudan. Ph.D. thesis. Manchaster: University of Manchester, U.K.

Booij, J. C., Zegers, M., Evers, P. M., Hendriks, M., Delnoij, D. M & Rademakers, J.

J. (2013). Improving cancer patient care: development of a generic cancer consumer quality index questionnaire for cancer patients. *BMC Cancer, 13*: 203.

Bornstein, M. M., Frei, M., Sendi, P., Ramseier, C. A., & Reichart, P. A. (2012). Patients' awareness of the potential benefit of smoking cessation. A study evaluating self-reported and clinical data from patients referred to an oral medicine unit. *Clinical Oral Investigations, 16*(1): 55-62. doi: 10.1007/s00784-010-0488-5.

Borreani, E., Wright, D., Scambler, S., & Gallagher, J. E. (2008). Minimising barriers to dental care in older people. *BMC Oral Health 8*(1): 7. doi: 10.1186/1472-6831-8-7.

Brandner, S., Müller-Nordhorn, J., Stritter, W., Fotopoulou, C., Sehouli, J., & Holmberg, C. (2014). Symptomization and triggering processes: Ovarian cancer patients' narratives on pre-diagnostic sensation experiences and the initiation of healthcare seeking. *Social Science & Medicine, 119*: 123-130.

Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research, 60*(6): 631-637.

Brouha, X. D., Tromp, D. M., Hordijk, G. J., Winnubst, J. A., & de Leeuw, J. R. (2005). Oral and pharyngeal cancer: Analysis of patient delay at different tumor stages. *Head Neck,* 27(11): 939-945. doi: 10.1002/hed.20270.

Browning, K. K., Wewers, M. E., Ferketich, A. K., Otterson, G. A., & Reynolds, N. R. (2009). The self-regulation model of illness applied to smoking behavior in lung cancer. *Cancer Nursing, 32*(4): 15-25. doi: 10.1097/NCC.0b013e3181a0238f.

Bryman, A. (2001). Social Research Methods. Oxford, UK: Oxford University Press.

Cameron, L. D., & Leventhal, H. (2003). *The self-regulation of health and illness behaviour*. London: Psychology Press.

Campion, E. W. (1993). Why unconventional medicine? *The New England Journal of Medicine*, *328*(4): 282.

Canto, M. T., Horowitz, A. M., & Child, W. L. (2002). Views of oral cancer prevention and early detection: Maryland physicians. *Oral Oncology, 38*(4): 373-377. Doi:10.1016/S1368-8375(01)00074-4.

Carter, L. M., & Ogden, G. R. (2007). Oral cancer awareness of undergraduate medical and dental students. *BMC Med Education, 7*: 44. doi: 10.1186/1472-6920-7-44.

Carver, C. S., Scheier, M. F., & Segerstrom, S. C. (2010). Optimism. *Clinical Psychology Review, 30*(7): 879-889.

Castillo, A. D., Godoy-Iquierdo, D., Vazquez, M. L., Leventhal, E. A., & Leventhal, H. (2013). Illness beliefs about hypertension among non-patients and healthy relatives of patients. *Health, 5*(4A): 47-58.

Centelles, P. V., Seoane-Romero, J. M., Gómez, I., Diz-Dios, P., de Melo, N. S & Seoane, J. (2012). Timing of oral cancer diagnosis implications for prognosis and survival. *Oral Cancer*, 173-188.

Chang, F. R., & K Trivedi, P. (2003). Economics of self-medication: theory and evidence. *Health Economics, 12*(9): 721-739.

Chen, Y. K., Huang, H. L., Lin, L. M., & Lim, C. C. (1999). Primary Oral Squamous carcinoma: An analysis of 703 in southern Taiwan. *Oral Oncology, 35*: 173-179.

Chintala, A., Muttagi, S., & Agarwal, C. (2014). Reasons for diagnostic delay and its association with socioeconomic factors in advanced oral cancer patients. *Journal of Advance Med Dental Science Research, 2*(4).

Chin, V. Y. W & Noor, N. A. M. (2014). Sociocultural determinants of health and illness: A theoretical inquiry. *Malaysian Journal of Society and Space, 10*(1): 49-59.

Choi, Y., Dodd, V., Watson, J., Tomar, S. L., Logan, H. L., & Edwards, H. (2008). Perspectives of African Americans and dentists concerning dentist-patient communication on oral cancer screening. *Patient Education and Counselling, 71*(1): 41-51. doi: 10.1016/j.pec.2007.11.011.

Clark, D. M. (1999). Anxiety Disorders: Why they persist and how to treat them? *Behaviour Research and Therapy, 37*: 5-27.

Cohn, S. (2014). From health behaviours to health practices: an introduction. *Social Health and Illness, 36*(2): 157-162. doi: 10.1111/1467-9566.12140.

Colella, G., Gaeta, G. M., Moscariello, A., & Angelillo, I. F. (2008). Oral cancer and dentists: Knowledge, attitudes, and practices in Italy. *Oral Oncology, 44***:** 393-399. doi: 10.1016/j.oraloncology.2007.05.005.

Coreil, J. (2008). Behavioral and Social Science Theory. In K. H. S. Quah (Ed.), *International Encyclopaedia of Public Health* (vol. 6, pp. 101-114). Oxford, UK: Oxford University Press.

Cuffari, L., de Siqueira, J. T. T., Nemr, K., & Rapaport, A. (2006). Pain complaint as the first symptom of oral cancer: a descriptive study. *Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology, and Endodontology*, *102*(1): 56-61.

Cummings, K. M., Becker, M. H., & Maile, M. C. (1980). Bringing the models together: An empirical approach to combining variables used to explain health actions. *Journal of Behavioural Medicine, 3*(2): 123-145.

De Camargo Cancela, M., Voti, L., Guerra-Yi, M., Chapuis, F., Mazuir, M., Curado, M. P. (2010). Oral cavity cancer in developed and in developing countries: Population-based incidence. *Head and Neck*, *32*(3): 357–67.

De Nooijer, J., Lechner, L., & de Vries, H. (2001). A qualitative study on detecting cancer symptoms and seeking medical help; An application of Andersen's model of total patient delay. *Patient Education and Counselling, 42*(2): 145-157.

Department of Statistic Malaysia. www.dosm.gov.my. Archived from the original on 7th May 2015. Retrieved 21st Aug 2017.

Diefenbach, M.A., & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *The Journal of Social Distress and the Homeless, 5*: 11-38.

Dios, P. D., Gonzalez, N. P., Leston, J. S., Carmona, I. T., Posse, J. L., & Varela-

Centelles, P. (2005). "Scheduling delay" in oral cancer diagnosis: A new protagonist. *Oral Oncology, 41*(2): 142-146. doi: 10.1016/ j.oraloncology.2004 .07.008.

Dodd, V. J., Schenck, D. P., Chaney, E. H., & Padhya, T. (2015). Assessing oral cancer awareness among rural Latino migrant workers. *Journal of Immigrant and Minority Health, 18*(3): 552-560. doi: 10.1007/s10903-015-0228-7.

Dollard, J., & Miller, N. E. (1950). *Personality and psychotherapy: An analysis in terms of learning, thinking, and culture*. New York, McGraw-Hill.

Donovan, H. S., & Ward, S. (2005, January). Representations of fatigue in women receiving chemotherapy for gynaecologic cancers. In *Oncology Nursing Forum* (col. 32, no. 1).

Doss, J. G., Thomson, W. M., Drummond, B. K & Raja Latifah, R. J. (2011). Validity of The FACT-H&N (v 4.0) among Malaysian oral cancer patients. *Journal of Oral Oncology, 47*: 648-52.

Dubayova, T., van Dijk, J. P., Nagyova, I., Rosenberger, J., Havlikova, E., Gdovinova, Z., Groothoff, J. W. (2010). The impact of the intensity of fear on patient's delay regarding health care seeking behaviour: A systematic review. *International Journals of Public Health, 55*: 459-468.

Dwivedi, A. K., Dwivedi, S. N., Deo, S., Shukla, S., Pandey, A., & Dwivedi, D. K. (2012). An epidemiological study on delay in treatment initiation of cancer patients. *Health, 4*(2): 66-79. doi: 10.4236/health.2012.42012.

Eadie, T. L., Lamvik, K., Baylor, C. R., Yorkston, K. M., Kim, J., & Amtmann, D. (2014). Communicative participation and quality of life in head and neck cancer. *Annals of Otology, Rhinology & Laryngology, 123*(4): 257-264.

Emery, J. D., Gray, V., Walter, F. M., Cheetham, S., Croager, E. J., Slevin, T., & Geelhoed, E. (2014). The Improving Rural Cancer Outcomes (IRCO) Trial: a factorial cluster-randomised controlled trial of a complex intervention to reduce time to diagnosis in rural patients with cancer in Western Australia: a study protocol. *BMJ Open, 4*(9): e006156.

Esmaelbeigi, F., Hadji, M., Harirchi, I., Omranipour, R., Vand, R. M., & Zendehdel, K. (2014). Factors affecting professional delay in diagnosis and treatment of oral cancer in Iran. *Archives of Iranian Medicine, 17*(4): 253.

Falcao, B., Januzzi, E., & Santos, F. (2015). Oral rehabilitation following head and neck cancer treatment review of literature. *Journal of Palliative Care & Medicine, 2015*.

Farooqui, M., Hassali, M. A., Knight, A., Shafie, A. A., Farooqui, M. A., Saleem, F., Aljadhey, H. (2013). A qualitative exploration of Malaysian cancer patients' perceptions of cancer screening. *BMC Public Health, 13*(48).

Feng, R., Wang, D.-B., Chai, J., Cheng, J., & Li, H.-P. (2014). Total delay for treatment among cancer patients: A theory-guided survey in China. *Asian Pacific Journal of Cancer Prevention, 15*(10): 4339-4347. doi: 10.7314/apjcp.2014.15.10.4339.

Ferlay, J., Soerjomataram, I., Dikshit, R., Eser, S., Mathers, C., Rebelo, M., Bray, F.

(2015). Cancer incidence and mortality worldwide: Sources, methods and major patterns in GLOBOCAN 2012. *International Journal of Cancer, 136*: 359-386.

Fernandez, A., Cordova, P., Badenier, O & Esguep, A. (2015). Epidemiological characterization of oral cancer: Literature review. *Journal of Oral Research*. *4*(2): 137-145.

Ford, P. J., & Farah, C. S. (2013). Early detection and diagnosis of oral cancer: Strategies for improvement. *Journal of Cancer Policy, 1*(1-2): 2-7. doi: 10.1016 /j.jcpo. 201 3.04.002.

Forgeard, M., & Seligman, M. (2012). Seeing the glass half full: A review of the causes and consequences of optimism. *Pratiques Psychologiques, 18*(2): 107-120.

Forman, M. S., Chuang, S. K., & August, M. (2015). The accuracy of clinical diagnosis of oral lesions and patient-specific risk factors that affect diagnosis. *Journal of Oral Maxillofacial Surgery*, 1-6.

Formosa, J., Jenner, R., Nguyen-Thi, M. D., Stephens, C., Wilson, C., & Ariyawardana, A. (2015). Awareness and knowledge of oral cancer and potentially malignant oral disorders among dental patients in Far North Queensland, Australia. *Asian Pacific Journal of Cancer Prevention*, *16*(10): 4429-4434.

Franceschi, S., Barra, S., La Vecchia, C., Bidoli, E., Negri, E & Talamini, R. (1992). Risk factors for cancer of the tongue and the mouth: A case-control study from northern Italy. *Cancer, 70*(9): 2227-2233.

Friedman, L. A & Kimball, A. (1986). Coronary heart disease mortality and alcohol consumption in Framingham. *American Journal of Epidemiology, 124*(3): 481-489.

Freidson, E. (1986). The medical profession in transition. In L. Aiken and D. Mechanic (Eds) Applications of Social Science to Clinical Medicine and Health Policy, New Brunswick: Rutgers University Press.

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology, 13*: 117-124.

Gao, W., & Guo, C. B. (2009). Factors related to delay in diagnosis of oral squamous cell carcinoma. *Journal of Oral Maxillofaciology Surgery,* 67: 1015-1020. doi: 10.1016/j.joms.2008.12.022.

Ghani, W. M. N., Doss, J. G., Jamaluddin, M., Kamaruzaman, D., & Zain, R. (2013). Oral cancer awareness and its determinants among a selected Malaysian population. *Asian Pacific Journal of Cancer Prevention, 14*(3): 1957-1963.

Gill, A., Chakraborty, A., & Selby, D. (2012). What is symptom burden: A qualitative exploration of patient definitions. *Journal of Palliative Care, 28*(2): 83.

Gomez, I., Seoane, J., Varela-Centelles, P., Diz, P & Takkouche, B. (2009). Is diagnostic delay related to advanced-stage oral cancer? A meta-analysis. *European Journal Oral Science, 117*: 541–546.

Gouraha, A., Torwane, N. A., Yadav, S., & Maheshwari, A. (2014). Approach of

pharmacists and herbalists while offering guidance on potentially malignant oral lesions: A cross-sectional survey. *Journal of Cancer Research and Therapeutics, 10*(3): 618-622. doi: 10.4103/0973-1482.137947.

Graham, H. (1987). Women's smoking and family health. *Social Science & Medicine, 25*(1): 47-56.

Grant, E., Silver, K., Bauld, L., Day, R., & Warnakulasuriya, S. (2010). The experiences of young oral cancer patients in Scotland: Symptom recognition and delays in seeking professional help. *Br Dent J, 208*(10): 465-471. doi: 10.1038/sj.bdj. 2010.450.

Groome, P. A., Rohland, S. L., Hall, S. F., Irish, J., Mackillop, W. J., & O'Sullivan, B. (2011). A population-based study of factors associated with early versus late stage oral cavity cancer diagnoses. *Oral Oncology, 47*: 642-647. doi: 10.1016/ j.oraloncology.2011.04.018.

Grundy, J., & Annear, P. (2010). Health-seeking behaviour studies: A literature review of study design and methods with a focus on Cambodia. Health Series and Health Finance Knowledge Hub. Nossal Institute for Global Health at the University of Melbourne. Australia.

Guggenheimer, J., Verbin, R. S., Johnson, J. T., Horkowitz, C. A., & Myers, E. N. (1989). Factors delaying the diagnosis of oral and oropharyngeal carcinomas. *Cancer, 64*(4): 932-935.

Gupta, B., & Kumar, N. (2014). A cross-country comparison of knowledge, attitudes and practices about tobacco use: findings from the global adult tobacco survey. *Asian Pacific Journal of Cancer Prevention, 15*(12): 5035-5042. doi: 10.7314 /Apjcp.2014.15.12.5035.

Hale, E. D., Treharne, G. J & Kitas, G. D. (2007). The common-sense model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs?. *Rheumatology*, 46: 904–906.

Hassona, Y., Scully, C., Abu Ghosh, M., Khoury, Z., Jarrar, S., & Sawair, F. (2015). Mouth cancer awareness and beliefs among dental patients. *International Dental Journal, 65*(1): 15-21. doi: 10.1111/idj.12140.

Heider, F & Simmel, M. (1944). An experimental study of apparent behavior. *The American Journal of Psychology, 57*(2): 243-259.

Heider, F. (1958). The psychology of interpersonal relations. New York: Wiley.

Hensen, R. P., Olesen, F., Sorensen, H. T., Sokolowski, I. S., & Sondergaard, J. (2008). Socioeconomic patient characteristics predict delay in cancer diagnosis: A Danish cohort study. *BMC Health Services Research, 8*(49): 1-10.

Hirayama, T. (1966). An epidemiological study of oral and pharyngeal cancer in Central and South-East Asia. *Bulletin of the World Health Organization, 34*(1): 41.

Howell, J. L., Shepperd, J. A., & Logan, H. (2013). Barriers to oral cancer screening: A focus group study of rural Black American adults. *Psycho-Oncology, 22*: 1306-1311.

Horowitz, A. M., Goodman, H. S., Yellowitz, J. A., & Nourjah, P. A. (1996). The need for health promotion in oral cancer prevention and early detection. *Journal of Public Health Dentistry, 56*(6): 319-330.

Humphris, G. M., Freeman, R., & Clarke, H. M. (2004). Risk perception of oral cancer in smokers attending primary care: a randomised controlled trial. *Oral Oncology, 40*(9): 916-924. doi: 10.1016/j.oraloncology.2004.04.008.

Hussain, S. A., & Sullivan, R. (2013). Cancer control in Bangladesh. *Japanese Journal of Clinical Oncology, 43*(12): 1159-1169. doi: 10.1093/jjco/hyt140.

Iskandarsyah, A., de Klerk, C., Suardi, D. R., Soemitro, M. P., Sadarjoen, S. S., & Passchier, J. (2014). Psychosocial and cultural reasons for delay in seeking help and nonadherence to treatment in Indonesian women with breast cancer: A qualitative study. *Health Psychology, 33*(3): 214-221.

Jaafar, N., Jalalluddin, R. L., Razak, I. A., & Esa, R. (1992). Investigation of delay in utihzation of government dental services in Malaysia. *Community Dentistry and Oral Epidemiology, 20*: 144-147.

Jessop, D. C., Craig, L., & Ayers, S. (2014). Applying Leventhal's self-regulatory model to pregnancy: Evidence that pregnancy-related beliefs and emotional responses are associated with maternal health outcomes. *Journal of Health Psychology, 19*(9): 1091-1102.

Johnson, S., Corsten, M. J., McDonaldc, J. T & Chund, J. (2010). Socio-economic factors and stage at presentation of head and neck cancer patients in Ottawa, Canada: A logistic regression analysis. *Oral Oncology*, 46: 366-368. doi: 10.1016 /j.oraloncology.2010.02.010.

Johnson, N. W., Warnakulasuriya, S., Gupta, P. C., Dimba, E., Chindia, M., Otoh, E. C & Kowalski, L. (2011). Global oral health inequalities in incidence and outcomes for oral cancer causes and solutions. *Advance in Dental Research*, *23*(2): 237-246.

Kasl, S. V., & Cobb, S. (1966). Health behavior, illness behavior and sick role behavior: Health and illness behavior. *Archives of Environmental Health: An International Journal, 12*(2): 246-266.

Kerdporn, D. S., H. (2001). Factors related to advanced stage oral squamous cell carcinoma in Southern Thailand. *Oral Oncology, 37*: 216-221.

Khakbazan, Z., Taghipour, A., Roudsari, R. L., & Mohammadi, E. (2014). Help seeking behavior of women with self-discovered breast cancer symptoms: A meta-ethnographic synthesis of patient delay. *Plos One, 9*(12): 110262.

Khan, M. S., Bawany, F. I., Shah, S. R., Hussain, M., Arshad, M. H., & Nisar, N. (2013). Comparison of knowledge, attitude and practices of betelnut users in two socio-economic areas of Karachi. *Journal of the Pakistan Medical Association, 63*(10): 1319-1325.

Khoo, S. P., Shanmuhasuntharam, P., Mahadzir, W. M., Tay, K. K., Latif, A., & Nair, S. (1996). Delay in diagnosis of oral cancer in Malaysia: A study of five centres. *Annals of Dentistry. University of Malaya, 3*.

Khoo, S. P., Shanmuhasuntharam, P., Mahadzir, W. M., Tay, K. K., Latif, A., & Nair, S.

(1998). Factors involved in the diagnosis of oral squamous cell carcinoma in Malaysia. *Asia-Pacific Journal of Public Health, 10*(1): 49-51.

Kroeger, A. (1983). Anthropological and socio-medical health care research in developing countries. *Social Science & Medicine*, *17*(3): 147–161.

Kujan, O., Abuderman, A., Azzegahiby, S., Alenzi, F. Q., & Idrees, M. (2013). Assessing oral cancer knowledge among Saudi medical undergraduates. *Journal of Cancer Education, 28*(4): 717-721. doi: 10.1007/s13187-013-0527-4.

Kujan, O., Alzoghaibi, I., Azzeghaiby, S., Altamimi, M. A., Tarakji, B., Hanouneh, S., Taifour, S. (2014). Knowledge and attitudes of Saudi dental undergraduates on oral cancer. *Journal of Cancer Education, 29*(4): 735-738. doi: 10.1007/s13187-014-0647-5.

Kulkarni, R. S., Arun, P. D., Rai, R., Kanth, V. S., Sargaiyan, V., & Kandasamy, S. (2015). Awareness and practice concerning oral cancer among Ayurveda and homeopathy practitioners in Davangere District: A speciality-wise analysis. *Journal of Natural Science and Biologiy Medicine, 6*(1): 116-119. doi: 10.4103/0976-9668.149104.

Kumar, S., Heller, R. F., Pandey, U., Tewari, V., Bala, N., & Oanh, K. T. H. (2001). Delay in presentation of oral cancer: A multifactor analytical study. *The National Medical Journal of India, 14*(1): 13-17.

Lacey, A., & Luff, D. (2001). Qualitative data analysis. Sheffield: Trent Focus. 320-357.

Lee, S. C., Tang, I. P., Avatar, S. P., Ahmah, N., Selva, K. S., Tay, K. K., & Vikineswaran, T. (2011). Head and neck cancer: Possible causes for delay in diagnosis and treatment. *Medical Journal Malaysia, 66*(2): 101-104.

Leventhal, H., & Niles, P. (1965). Persistence of influence for varying durations of exposure to threat stimuli. *Psychological Reports, 16*(1): 223-233.

Leventhal, H. (1970). Findings and theory in the study of fear communications. *Advances in Experimental Social Psychology, 5*: 119-186.

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. *Contributions to Medical Psychology, 2*: 7-30.

Leventhal, H., Diefenbach, M. A., Leventhal, E. A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research, 16*: 143-163.

Leventhal, H., Leventhal, E. A., & Contrada, R. (1998). Self-regulation, health and behaviour: A perceptual-cognitive approach. *Psychology & Health,* 13: 717-733.

Leventhal, H., Weinman, J., Leventhal, E. A., & Philips, L. A. (2008). Health psychology: The search for pathways between behavior and health. *Annual Review of Psychology, 9*: 477-505.

Leydon, G. M., Boulton, M., Moynihan, C., Jones, A., Jean Mossman, Boudioni, M., & McPherson., K. (2000). Cancer patients' information needs and information seeking behaviour: In depth interview study. *BMJ*.

Lim, G. C. C. (2002). Overview of cancer in Malaysia. *Japan Journal of Clinical*

Oncology, 32(1): 37-42.

Lim, R (Ed). Cancer incidence in Peninsular Malaysia, 2003-2005. National Registry, Kuala Lumpur.

Lim, R. (2008). Improving cancer pain management in Malaysia. *Oncology, 74*: 24-34. doi: 10.1159/000143215.

Llewellyn, C. D., Johnson, N. W & Warnakulasuriya, S. (2004). Factors associated with delay in presentation among younger patients with oral cancer. *Journal of Oral Surgery Oral Medicine Oral Pathology Oral Radiology Endo, 97*: 707-13.

Llewellyn, C. D., McGurk, M., & Weinman, J. (2007). Illness and treatment beliefs in head and neck cancer: Is Leventhal's common sense model a useful framework for determining changes in outcomes over time?. *Journal of Psychosomatic Research, 63*(1): 17-26.

Locker, D. 1989. An introduction to behavioural science & dentistry. Tavistock/ Routledge. London, UK.

Locker, D. (1996). Applications of self-reported assessments of oral health outcomes. *Journal of Dental Education, 60*(6): 494-500.

Logan, H. L., Fillingim, R. B., Bartoshuk, L. M., Sandow, P., Tomar, S. L., Werning, J. W., & Mendenhall, W. M. (2010). Smoking status and pain level among head and neck cancer patients. *Journal of Pain, 11*(6): 528-534. doi: 10.1016/j.jpain.2009.09.006.

Logan, H. L., Shepperd, J. A., Pomery, E., Guo, Y., Muller, K. E., Dodd, V. J., & Riley, J. L. (2013). Increasing screening intentions for oral and pharyngeal cancer. *Annals of Behavioral Medicine, 46*(1): 96-106. doi: 10.1007/s12160-013-9480-z.

Loignon, C., Allison, P., Landry, A., Richard, L., Brodeur, J.-M., & Bedos, C. (2010). Providing humanistic care dentists' experiences in deprived areas. *Journal of Dental Research, 89*(9): 991-995.

Lowry, R. J., & Craven, M. A. (1999). Smokers and drinkers awareness of oral cancer: A qualitative study using focus groups. *Br Dent J, 187*(12): 668-670.

Luryi, A. L., Yarbrough, W. G., Niccolai, L. M., Roser, S., Reed, S. G., Nathan, C. A. O., Judson, B. L. (2014). Public awareness of head and neck cancers a cross-sectional survey. *JAMA Otolaryngology-Head & Neck Surgery, 140*(7): 639-646. doi: 10.1001/jamaoto.2014.867.

Lyhne, N. M., Christensen, A., Alanin, M. C., Bruun, M. T., Jung, T. H., Bruhn, M. A., Grau, C. (2013). Waiting times for diagnosis and treatment of head and neck cancer in Denmark in 2010 compared to 1992 and 2002. *European Journal of Cancer, 49*(**7**): 1627-1633. doi: 10.1016/j.ejca.2012.11.034.

Lyratzopoulos, G., Wardle, J., & Rubin, G. (2014). Rethinking diagnostic delay in cancer: How difficult is the diagnosis? *BMJ, 349*: 7400.

MacKian, S. (2003). A review of health seeking behaviour: Problems and prospects. *Health Systems Development Programme*.

Mackian, S., Bedri, N., & Lovel, H. (2003). Up the garden path and over the edge: Where

might health-seeking behaviour take us?: Review article. *Health Policy and Planning, 19*(3): 137-146.

Macleod, U., Mitchell, E., Burgess, C., Macdonald, S., & Ramirez, A. (2009). Risk factors for delayed presentation and referral of symptomatic cancer: Evidence for common cancers. *British Journal of Cancer, 101*: 92-101.

McAlister, A. L., Perry, C. L., & Parcel, G. S. (2008). How individuals, environments, and health behaviors interact. *HEALTH BEHAVIOR, 169*.

McKeown, T. (1979). The role of medicine.

Mann, T., de Ridder, D., & Fujita, K. (2013). Self-regulation of health behavior: Social psychological approaches to goal setting and goal striving. *Health Psychology, 32*(5): 487-498.

Maree, J. E., & Wright, S. E. (2010). How would early detection be possible? An enquiry into cancer related knowledge, understanding and health seeking behaviour of urban black women in Tshwane, South Africa. *European Journal of Oncology Nursing, 14*: 190-196. doi: 10.1016/j.ejon.2009.10.009.

Mechanic, D. (1961). The concept of illness behaviour. *Journal of Chronic Disease, 15*: 189-194.

Mechanic, D. (1968). General practice in England and Wales: results from a survey of a national sample of general practitioners. *Medical Care, 6*(3): 245-260.

Mechanic, D. (1986). The concept of illness behaviour: culture, situation and personal predisposition. *Psychological Medicine, 16*(1): 1-7. doi:10.1017/s003329170000 2476.

Merriam, S., & Muhamad, M. (2013). The multiple roles of traditional healers in cancer treatment in Malaysia. *Asian Pacific Journal of Cancer Prevention, 14*(6): 3593-3601.

Milan, R. (2011). Summary of patient awareness of oral cancer health advice in a dental access centre: A mixed methods study. *British Dental Journal, 210*(6): 262-263. doi: 10.1038/sj.bdj.2011.220.

Minghella, E., Lakhani, M., Hughes, C., & Thomas, B. (2010). Delayed diagnosis of cancer: Thematic review. United Kingdom.

Ministry of Health Malaysia. (2014). Health Facts 2014. Planning Division Health Informatics Centre.

Mitchel, E. D., Rubin, G., Merriman, L., & Macleod, U. (2015). The role of primary care in cancer diagnosis via emergency presentation: qualitative synthesis of significant event reports. *British Journal of Cancer, 112*: 50-56.

Molassiotis, A., Wilson, B., Brunton, L., & Chandler, C. (2010). Mapping patients' experiences from initial change in health to cancer diagnosis: a qualitative exploration of patient and system factors mediating this process. *European Journal of Cancer Care, 19*: 98-109.

Monteiro, L. S., Warnakulasuriya, S., Cadilhe, S., Sousa, D., Trancoso, P. F., Antunes, L., Pacheco, J. J. (2015). Oral cancer awareness and knowledge among

residents in the Oporto city, Portugal. *Journal of Investigative and Clinical Dentistry*. doi: 10.1111/jicd.12158.

Morelatto, R. A., Herrera, M. C., Ferna´ ndez, E. N., G, C. A., & Lo´ pez de Blanc, S. A. (2007). Diagnostic delay of oral squamous cell carcinoma in two diagnosis centers in Co´rdoba Argentina. *Journal of Oral Pathology Medicine 36*: 405-408. doi: 10.1111/j.1600-0714.2007.00547.

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health, 17*(1): 1-16.

Muhamad, M., Merriam, S., & Suhami, N. (2012). Why breast cancer patients seek traditional healers? *International Journal of Breast Cancer*. *2012*: 1-9. doi:10.1155/2012/689168.

National Cancer Registry, Ministry of Health Malaysia (2007). Malaysian Cancer Statistics-data and figure Malaysia 2007.

Nerenz, D. R & Leventhal, H. (1983). Self-regulation theory in chronic illness. In: Burish TG, Bradley LA, eds. Coping with chronic disease research and applications. New York: Academic Press, 13–37.

Ng, K. H., Siar, C. H., Ramanathan, K., Murugasu, P & Chelvanayagam, P. I. (1985). Squamous cell carcinoma of the oral mucosa in Malaysia — any change? *Southeast Asian Journal of Tropical Medicine and Public Health, 19*: 602–606.

Noonan, B. (2013). Understanding the reasons why patients delay seeking treatment for oral cancer symptoms from a primary health care professional: an integrative literature review. *European Journal of Oncology Nursing,* 1-7. doi: 10.1016/j.ejon.2013.07.00.

Norsa'adah, B., Rahmah, M. A., Rampal, K. G., & Knight, A. (2012). Understanding barriers to Malaysian women with breast cancer seeking help. *Asian Pacific Journal of Cancer Prevention, 13*(8): 3723-3730. doi: 10.7314 /apjcp. 2012. .8.3 723.

Nosarti C, Crayford T, Roberts JV, Elias E, McKenzie K, David AS. (2000) Delay in presentation of symptomatic referrals to a breast clinic: Patient and system factors. *British Journal of Cancer*, *82*: 742–748.

O'Connor, S. M., Jardine, A. G., & Millar, K. (2008). The prediction of self-care behaviors in end-stage renal disease patients using Leventhal's self-regulatory model. *Journal of Psychosomatic Research, 65*(2): 191-200.

Ogden, J. (2012). *Health Psychology*. McGraw-Hill Education (UK).

Omar, Z. A., & Tamin, N. S. I. (2011). National Cancer Registry Report 2007: Malaysia Cancer Staistics-data and figure. Putrajaya, Malaysia.

Onizawa, K., Nishihara, K., Yamagata, K., Yusa, H., Yanagawa, T., & Yoshida, H. (2003). Factors associated with diagnostic delay of oral squamous cell carcinoma. *Oral Oncology, 39*: 781-788. doi: 10.1016/S1368-8375(03)00075-7.

Ostroff, J. S., Hay, J. L., Primavera, L. H., Bivona, P., Cruz, G. D., & LeGeros, R. (1999).

Motivating smoking cessation among dental patients: smokers' interest in biomarker testing for susceptibility to tobacco-related cancers. *Nicotine and Tobacco Research, 1*(4): 347-355.

Paddison, C. A. M., Alpass, F. M., & Stephens, C. V. (2010). Using the common sense model of illness self-regulation to understand diabetes-related distress: The importance of being able to 'make sense' of diabetes. *New Zealand Journal of Psychology, 39*(1).

Panzarella, V., Pizzo, G., Calvino, F., Compilato, D., Colella, G., & Campisi, G. (2014). Diagnostic delay in oral squamous cell carcinoma: The role of cognitive and psychological variables. *International Journal of Oral Science, 6*: 39-45.

Parkin, D. M., Fredy, B., Ferlay, J., Pisani, P. (2002). Global cancer statistics 2002. *CA Cancer Journal of Clinical, 55*: 74 – 108.

Pati, S., Hussain, M. A., Chauhan, A. S., Mallick, D., & Nayak, S. (2013). Patient navigation pathway and barriers to treatment seeking in cancer in India: A qualitative inquiry. *Cancer Epidemiology, 37*(6): 973-978. doi: 10.1016 /j.canep. 2013.09.018.

Patrick, D. L., Lee, R. S. Y., Nucci, M., Grembowski, D., Jolles, C. Z & Milgrom, P. (2006). Reducing oral health disparities: A focus on social and cultural determinants. *BMC Oral Health, 6*(1): 1-17.

Petersen, P. E. (2009). Oral cancer prevention and control – The approach of the World Health Organization. *Oral Oncology, 45*: 454-460. doi: 10.1016 /j.oraloncology. 2008.05.023.

Petrie, K. J., Weinman, J., Sharpe, N., & Buckley, J. (1996). Role of patients' view of their illness in predicting return to work and functioning after myocardial infarction: longitudinal study. *BMJ, 312*(7040): 1191-1194.

Petti, S. (2009). Lifestyle risk factors for oral cancer. *Oral Oncology, 45*(4-5): 340-350. doi: 10.1016/j.oraloncology.2008.05.018.

Pitiphat, W., Diehl, S. R., Laskaris, G., Cartsos, V., Douglass, C. W., & Zavras, A. I. (2002). Factors associated with delay in the diagnosis of oral cancer. *Journal of Dental Research, 81*(3): 192-197. doi: 10.1177/154405910208100310.

Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research & Practice, 19*(3): 276.

Quaife, S., Forbes, L., Ramirez, A., Brain, K., Donnelly, C., Simon, A., & Wardle, J. (2014). Recognition of cancer warning signs and anticipated delay in help-seeking in a population sample of adults in the UK. *British Journal of Cancer, 110*(1): 12-18.

Rakhshan, M., Hassani, P., Ashktorab, T., & Majd, H. A. (2013). The nature and course of illness perception following cardiac pacemaker implantation: A self-regulatory approach. *International Journal of Nursing Practice, 19*(**3**): 318-325.

Ramanathan K, Lakshimi S. (1976). Oral carcinoma in Peninsular Malaysia: Racial

variations in the Indians, Malays, Chinese, and Caucasians. *Monograph on Cancer Research, 18*: 27-36.

Rana, M., Gellrich, N. C., Czens, F., Kanatas, A., & Rana, M. (2014). Coping with oral cancer: The impact of health and disease-related personality traits. *Supportive Care in Cancer, 22*(11): 2981-2986. doi: DOI 10.1007/s00520-014-2300-6.

Rathod, S., Livergant, J., Klein, J., Witterick, I., & Ringash, J. (2015). A systematic review of quality of life in head and neck cancer treated with surgery with or without adjuvant treatment. *Oral Oncology, 51*(10): 888-900.

Razak, A. A., Saddki, N., Naing, N. N., & Abdullah, N. (2009). Oral cancer presentation among Malay patients in Hospital Universiti Sains Malaysia, Kelantan. *Asian Pacific Journal of Cancer Prevention, 10*: 1131-1136.

Razavi, S. M., Tahani, B., Nouri, S., & Khazaei, A. (2015). Oral cancer knowledge and practice among dental patients and their attitude towards tobacco cessation in Iran. *Asian Pacific Journal of Cancer Prevention, 16*(13): 5439-5444.

Reynolds, K., Lewis, B., Nolen, J. D. L., Kinney, G. L., Sathya, B., & He, J. (2003). Alcohol consumption and risk of stroke: A meta-analysis. *JAMA, 289*(5): 579-588.

Robinson, S. A., Rickenbach, E. H., & Lachman, M. E. (2015). Self-regulatory strategies in daily life: Selection, optimization, and compensation and everyday memory problems. *International Journal of Behavioural Development*, 1-11.

Rogers, R. W. (1975). A protection motivation theory of fear appeals and attitude change. *The Journal of Psychology*, *91*(1): 93-114.

Rogers, S. N., Pabla, R., McSorley, A., Lowe, D., Brown, J. S., & Vaughan, E. D. (2007). An assessment of deprivation as a factor in the delays in presentation, diagnosis and treatment in patients with oral and oropharyngeal squamous cell carcinoma. *Oral Oncology, 43*(7): 648-655. doi: 10.1016/j.oraloncology.2006.08.001 .

Rogers, S. N., Lowe, D., Catleugh, M., & Edwards, D. (2010). An oral cancer awareness intervention in community pharmacy. *British Journal of Oral & Maxillofacial Surgery, 48*(7): 498-502. doi: 10.1016/j.bjoms.2009.09.015.

Rogers, S. N., Vedpathak, S. V., & Lowe, D. (2011). Reasons for delayed presentation in oral and oropharyngeal cancer: The patients perspective. *British Journal of Oral Maxillofacial Surgery, 49*(5): 349-353. doi: 10.1016/j.bjoms.2010.06.018/.

Roetzheim R, Pal N, Tennant C, Voti L, Ayanian J, Schwabe A, Krischer J. 1999. Effects of health insurance and race on early detection of cancer. *Journal of the National Cancer Institute*, *91*: 1409–15.

Rosenstock, I. M. (1966). Why people use health services? *The Milbank Memorial Fund Quarterly, 44*(3): 94-127.

Rosma, M. D., Sameem, A. K., Basir, A., Mazlipah, I. S., & Norzaidi, M. D. (2010). The use of artificial intelligence to identify people at risk of oral cancer: Empirical evidence in Malaysian university. *International Journal of Scientific Research in Education, 3*(1): 10-20.

Razali, S. M & Yassin, A. M (2008). Complementary treatment of psychotic and epileptic patients in Malaysia. *Transcultural Psychiatry*, *45*(3): 455–469.

Safer, M. A., Tharps, Q. J, Jackson, B. A., Leventhal, H. (1979). Determinants of three stages of delay in seeking care at a medical of an alternative questionnaire. *Medical Care*, *17*: 11–29.

Sahril, N., Aris, T., Mohd Asari, A. S., Yaw, S. L., Saleh, N. C., Omar, M. A., Abu Talib, N. (2014). Oral health seeking behaviour among Malaysians with type II diabetes. *Journal of Public Health Aspects, 1*(1): 1. doi: 10.7243/2055-7205-1-1.

Saleh, A., Kong, Y. H., Vengu, N., Badrudeen, H., Zain, R., & Cheong, S. C. (2014). Dentists' perception of the role they play in early detection of oral cancer. *Asian Pacific Journal Cancer Prevention, 15***(**1): 229-237.

Sankeshwari, R., Ankola, A., Hebbal, M., Muttagi, S., & Rawal, N. (2015). Awareness regarding oral cancer and oral precancerous lesions among rural population of Belgaum district, India. *Global Health Promotion*, 1-9.

Scharloo, M., Baatenburg de Jong, R. J., Langeveld, T. P., van Velzen-Verkaik, E., Doorn-opden Akker, M. M., & Kaptein, A. A. (2005). Quality of life and illness perceptions in patients with recently diagnosed head and neck cancer. *Head Neck, 27*(10): 857-863. doi: 10.1002/hed.20251.

Scott, S. E., Grunfeld, E. A., & McGurk, M. (2005). The idiosyncratic relationship between diagnostic delay and stage of oral squamous cell carcinoma. *Oral Oncology, 41*: 396-403. doi: 10.1016/j.oraloncology.2004.10.010.

Scott, S. E., Grunfeld, E. A., & McGurk, M. (2006). Patient's delay in oral cancer: A systematic review. *Community Dentistry and Oral Epidemiology, 34*(5): 337-343.

Scott, S. E., McGurk, M., & Grunfeld, E. A. (2007). The process of symptom appraisal: Cognitive and emotional responses to detecting potentially malignant oral symptoms. *Journal of Psychosomatic Research, 62*: 621-630. doi: 10.1016 /j.jpsychores.2006.12.020.

Segerstrom, S. C. (2005). Optimism and immunity: do positive thoughts always lead to positive effects? *Brain, Behavior, and Immunity, 19*(3): 195-200.

Shaikh, B. T., & Hatcher, J. (2004). Health seeking behaviour and health service utilization in Pakistan: Challenging the policy makers. *Journal of Public Health, 27*(1): 49-54. doi: 10.1093/pubmed/fdh207.

Sharma, G., & Nagpal, A. (2015). Can the diagnostic delay of oral cancer by healthcare practitioners be prevented? Who should bear the blame of delay? *Journal of Family and Community Medicine, 22*(2): 124-125. doi: 10.4103/2230-8229. 155398.

Shashinder, S., Choo, P. K., Gopala, K. G. (2008). Outcome of patients with head and neck cancers: 10- year experience of a otorhinolaryngology-head and neck unit in a tertiary hospital of a developing country. *European Journal of Cancer Care*. 17: 93-97.

Shepperd, J. A., Howell, J. L., & Logan, H. (2014). A survey of barriers to screening for

oral cancer among rural Black Americans. *Psycho-Oncology, 23*(3): 276-282. doi: Doi 10.1002/Pon.3414.

Siegel, R. L., Miller, K. D & Jemal, A. (2015). Cancer Statistics 2015. *CA Cancer Journal Clinical*, *65*: 5-29.

Singh, H., Hirani, K., Kadiyala, H., Rudomiotov, O., Davis, T., Khan, M. M., & Wahls, T. L. (2010). Characteristics and predictors of missed opportunities in lung cancer diagnosis: an electronic health record–based study. *Journal of Clinical Oncology, 28*(20): 3307-3.

Siqueira, J. F., & Barnett, F. (2004). Inter appointment pain: mechanisms, diagnosis, and treatment. *Endodontic Topics, 7*(1): 93-109.

Sloan, F. A & Gelband, H. 2007. Cancer control opportunities in low and middle income countries. National Academic Press, Washington, USA.

Smith, L. K., Pope, C., & Botha, J. L. (2005). Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. *Lancet, 366*: 825-831.

Stefanuto, P., Doucet, J. C., & Robertson, C. (2014). Delays in treatment of oral cancer: A review of the current literature. *Oral Surgery, Oral Medicine,Oral Pathology and Oral Radiology, 117*(4): 424-429. doi: 10.1016/j.oooo.2013.12.407.

Stoller, E. P., Grzywacz, J. G., Quandt, S. A., Bell, R. A., Chapman, C., Altizer, K. P., & Arcury, T. A. (2011). Calling the doctor: A qualitative study of patient-initiated physician consultation among rural older adults. *Journal of Aging and Health, 23*(5): 782-805.

Suchman, E. A. (1965). Stages of illness and medical care. *Journal of Health and Human Behavior*, 114-128.

Swain, N., Pathak, J., Poonja, L. S., & Penkar, Y. (2012). Etiological factors of recurrent Aphthous stomatitis: A common perplexity. *Journal of Contemporary Dentistry, 2*(3): 96-100.

The British Psychological Society. (2011).What is Health Psychology? A guide for the public.

Tan, B. S., Rosman, A., Ng, K. H., & Ahmed, N. (2000). Profile of the betel/tobacco quid chewers in six Malaysian Estates. *Annals of Dentistry University Malaya, 7*: 1-5.

Taylor, S. E., Lichtman, R. R., & Wood, J. V. (1984). Attributions, beliefs about control, and adjustment to breast cancer. *Journal of Personality and Social Psychology, 46*(3): 489.

Tee, G. H., Kaur, G., Ramanathan, P., Amal, N. M., & Chinna, K. (2015). Health seeking behavior among Malaysians with acute diarrheal disease. *The Southeast Asian Journal of Tropical Medicine and Public Health, 42*(2).

Tiwari, R. V., Megalamanegowdru, J., Gupta, A., Agrawal, A., Parakh, A., Pagaria, S., & Sahu, A. (2014). Knowledge, attitude and practice of tobacco use and its impact on oral health status of 12 and 15 year-old school children of Chhattisgarh, India. *Asian Pacific Journal of Cancer Prevention, 15*(23): 10129-10135. doi: 10.7314/Apjcp.2014.15.23.10129.

Torre, L. A., Bray, F., Siegel, R. L., Ferlay, J., Lotet-Tieulent, J., & Jemal, A. (2015). Global Cancer Statistics, 2012. *CA: A Cancer Journal for Clinician, 65*: 87-108.

Tromp, D., Brouha, X., De Leeuw, J., Hordijk, G., & Winnubst, J. (2004). Psychological factors and patient delay in patients with head and neck cancer. *European Journal of Cancer, 40*(10): 1509-1516.

Tromp, D. M., Brouha, X. D., Hordijk, G. J., Winnubst, J. A., Gebhardt, W. A., van der Doef, M. P., & De Leeuw, J. R. (2005). Medical care-seeking and health-risk behavior in patients with head and neck cancer: The role of health value, control beliefs and psychological distress. *Health Education Research, 20*(6): 665-675. doi: 10.1093/her/cyh031.

Tromp, D. M., Brouha, X. D., Hordijk, G.-J., Winnubst, J. A., & de Leeuw, R. J. (2005). Patient and tumour factors associated with advanced carcinomas of the head and neck. *Oral Oncology, 41*(3): 313-319.

Varela-Centelles, P., Pedrosa, R., lopez-Nino, J., Sanchez, M., Gonzalez-Mosquera, A., Mendez, A & Seoane, J. (2012). Oral cancer awareness at chemist's and herbalist's shops: New targets for educational interventions to prevent diagnostic delay. *Oral Oncology*, 48: 1272-1275.

Vedsted, P., & Olesen, F. (2015). A differentiated approach to referrals from general practice to support early cancer diagnosis – the Danish three-legged strategy. *British Journal of Cancer, 112*: 65-69. doi:10.1038/bjc.2015.44.

Vora, A. R., Yeoman, C. M., & Hayter, J. P. (2000). Alcohol, tobacco and paan use and understanding of oral cancer risk among Asian males in Leicester. *British Dental Journal, 188*(8): 444-451. doi: DOI 10.1038/sj.bdj.4800506a.

Wallston, K. A., & Wallston, B. S. (1982). Who is responsible for your health? *The construct of health locus of control in social psychology of health and illness* (pp. 65-95): Lawrence Erlbaum Hillsdale, NJ.

Walsh, J. C., Lynch, M., Murphy, A. W., & Daly, K. (2004). Factors influencing the decision to seek treatment for symptoms of acute myocardial infarction. *Journal of Psychosomatic Research, 56*(1): 67-73. doi: 10.1016/s0022-3999(03)00082-5.

Walter, F., Webster, A., Scott, S., & Emery, J. (2012). The andersen model of total patient delay: A systematic review of its application in cancer diagnosis. *Journal of Health Services Research and Policy, 17*(2): 110-118. doi: 10.1258/jhsrp.2011.010113.

Warnakulasuriya, S. 2009. Global epidemiology of oral and oropharyngeal cancer. *Oral Oncology*, *45*(4-5): 309-16.

Warnakulasuriya, S. (2010). Living with oral cancer: epidemiology with particular reference to prevalence and life-style changes that influence survival. *Oral Oncology, 46*(6), 407-410.

Wee, A. G., Zimmerman, L. M., Pullen, C. H., Sitorius, M. A., & Paskett, E. D. (2015). Need for primary care providers to carry out annual oral cancer examinations. *Journal of Dental Health, Oral Disorders & Therapy, 2*(2): 1-6.

Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health, 11*(3): 431-445.

Weinstein, N. D. (1988). The precaution adoption process. *Health Psychology, 7*(4): 355.

Wissinger, E., Griebsch, I., Lungershausen, J., Byrnes, M., Travers, K., & Pashos, C. L. (2014). The humanistic burden of head and neck cancer: A systematic literature review. *PharmacoEconomics, 32*(12): 1213-1229.

Wong, Y. F., Yusof, M. M., Ishak, W. Z. W., Alip, A., & Phua, V. C. E. (2015). Treatment outcome for head and neck squamous cell carcinoma in a developing country: University Malaya Medical Centre, Malaysia from 2003-2010. *Asian Pacific Journal of Cancer Prevention, 16*(7); 2903-2908.

Woolley, E., Magennis, P., Shokar, P., Edward, D & Rogers, S. N. 2006. The correlation between indices of deprivation and health-related quality of life in patients with oral and oropharyngeal squamous cell carcinoma. *British Journal of Oral and Maxillofacial Surgery, 44*: 177–186.

World Health Organization. (2000). The world health report 2000: health systems: improving performance. World Health Organization.

World Health Organization, WHO guidelines for the regulatory assessment of medical products for use in self-medication. *WHO Drug Inform* 2001; *14*: 18-26.

Wyke, S., Adamson, J., Dixon, D & Hunt, K. (2013). Consultation and illness behaviour in esponse to symptoms: A comparison of models from different disciplinary frameworks and suggestions for future research directions. *Social Science & Medicine*, *86*: 79-87.

Yahaya, N. A., Subramaniam, P., Bustam, A. Z & Taib, N. A. (2014). Symptom experiences and coping strategies among multi-ethnic solid tumor patients undergoing chemotherapy in Malaysia. *Asia Pacific Journal of Cancer Prevention, 15*; 1-8.

Yew, V. W. C., Sia, M., Lam, K. C., Sarmila, M. S & Selvadurai, S. (2015). Education and awareness of modern health care amongst aboriginal people: The case of the Jakuns of Peninsular Malaysia. *Malaysian Journal of Society and Space, 11*(3): 79-85.

Yew, V. W. C. (2015). Collecting qualitative research data on health-seeking behaviour of Peninsular Malaysia's aboriginal people. *Malaysian Journal of Society and Space, 11*(11): 45-52.

Zain, R. B. (2001). Cultural and dietary risk factors of oral cancer: A brief overview. *Oral Oncology, 37*: 205-210.

Zain, R. B., & Ghazali, N. (2001). A review of epidemiological studies of oral cancer and precancer in Malaysia. *Annal Dent Univ Malaya, 8*: 50-56.

Ziyani, I., Ehlers, V., & King, L. (2004). Using triangulation of research methods to investigate family planning practice in Swaziland.

Zohoori, F. V., Shah, K., Mason, J., & Shucksmith, J. (2012). Identifying factors to

improve oral cancer screening uptake: A qualitative study. *PLoS ONE, 7*(10): 47410-47416. doi: 10.1371/journal.pone.0047410.t001.

Zola, I. K. (1973). Pathways to the doctor—from person to patient. *Social Science & Medicine, 7*(9): 677-689.

LIST OF PUBLICATIONS AND PAPERS PRESENTED

A paper on *'Health-seeking behaviour and delayed presentation of oral cancer patients in a developing country: A qualitative study'* was presented on August 14th, 2015 at the '29th Annual Scientific Dental Research Southeast Asian Division (IADRSEA) in Bali, Indonesia.

APPENDIX A

ETHICS APPROVAL

UNIVERSITY OF MALAYA
The Leader in Research & Innovation

MEDICAL ETHICS COMMITTEE
FACULTY OF DENTISTRY
ADDRESS: 50603, KUALA LUMPUR, MALAYSIA
TELEPHONE: 03-79676461 FAXIMILE: 03-79676456

NAME OF ETHICS COMMITTEE/IRB: Medical Ethics Committee, Faculty of Dentistry **ADDRESS:** Faculty of Dentistry, University of Malaya, 50603, Kuala Lumpur	**ETHICS COMMITTEE/IRB REFERENCE NUMBER:**
PROTOCOL NO: **TITLE:** Health Seeking/Illness Behaviours and Delayed Presentation of Malaysian Oral Cancer Patients	DF CO1401/0015(L)
PRINCIPAL INVESTIGATOR: Prof. Madya Dr. Jennifer G. Doss **TELEPHONE:** 012-9715921	

The following item [√] have been received and reviewed in connection with the above study to be conducted by the above investigator.

[√] Investigator's Checklist — Ver date: 17 February 2014
[ ] Approval Form for Presentation at Department — Ver date: 7 March 2014
[√] Application Form
[√] Study Protocol
[√] Brief CV of Main Investigator
Patient Information Sheet (PIS):
[√] BM version
[√] English version
[ ] Others: _____
Consent Form:
[√] BM version
[√] English version
[ ] Others: _____

and have been

[√] Approved
[ ] Conditionally approved (identify item and specify modification below or in accompanying letter)
[ ] Rejected (identify item and specify reasons below or in accompanying letter)

Investigator are required to:

1) follow instructions, guidelines and requirements of the Medical Ethics Committee.
2) report any protocol deviations/violations to Medical Ethics Committee.
3) comply with International Conference on Harmonization – Guidelines for Good Clinical Practice (ICH-GCP) and Declaration of Helsinki
4) note that Medical Ethics Committee may audit the approved study.
5) ethics approval by the Medical Ethics Committee, Faculty of Dentistry is only valid for 2 years from the date of approval. Please update your project status (on-going/ completed) by submitting study report/ study closure report form (UM-DMEC-SR01).

Date of approval: 7 March 2014

c.c Dean
Faculty of Dentistry

Head
Department of Community Oral Health & Clinical Prevention

Secretary
Medical Ethics Committee
Faculty of Dentistry

PROF. DR. NOOR HAYATY ABU KASIM
Chairperson
Medical Ethics Committee

APPENDIX B

PATIENT INFORMATION SHEET

PATIENT INFORMATION SHEET

Please read the following information carefully. Do not hesitate to discuss any questions you may have with your doctor.

Study Title

Health seeking/illness behaviour and delayed presentation of Malaysian oral cancer patients.

Introduction

Oral Cancer is the sixth most common cancer worldwide. The vast majority of cancers of the head and neck are squamous cell carcinomas. In some Southeast Asian countries such as Bangladesh, India, Pakistan, and Sri Lanka, oral cancers are the most common forms of cancer and constitute about a third of all cancers. Around 5 out of every 10 patients with oral cancer presents with advanced stage disease. The reasons for delayed diagnosis and the effect of that delay is a complex and much debated issue in cancer. Patients delay is defined as the time from the onset of symptoms to first contact with medical persons. A patient's cognitive and emotional responses to the detection of potential malignant symptoms are crucial in their decision to seek help. Health seeking/illness behaviour can be described as a sequence of remedial actions that individuals undertake to rectify perceived ill health. This study is a qualitative exploratory that require an in-depth face-to-face semi-structured interviews.

What is the purpose of this study?

The purpose of this study is to explore the pattern in health seeking/illness behaviour of Malaysian oral cancer patients and identify health seeking/illness behaviour that lead to their delayed presentation.

What are the procedures to be followed?

The following step will be carried out :

1) **You will be given a form to record your demographic details. You will be asked to explain your symptoms and your emotional reactions to the presence of your symptom.**

2) **We would also require your permission to tape recorded the interview session.**

Who should not enter the study?

All patients are encouraged to participate in this study. Patients who are mentally incoherent (based on confirmed medical case) should not participate in this study.

What will be the benefits of the study:

(a) To you as a subject?

This study allows you to share your initial beliefs concerning the identity, timeline, cause, consequences and control of your symptom.

(b) To the investigator?
Findings of the study will provide us on better understanding of your disease, besides helping Malaysian oral cancer patients for early detecting.

What are the possible drawbacks?

None.

Can I refuse to take part in the study?

Yes. This study is totally voluntary and will not affect the treatment or examination of your teeth/mouth.

Who shall I contact if I have additional questions during the course of the study?

Main and other investigators:

(1) Research Assistant : Nurizyani Binti Azhar
Tel. No.: 017-896 4893
Address: Jabatan Pergigian Masyarakat, Universiti Malaya.
Email address: izyani2orange@yahoo.com

(2) Lecturers/supervisor: Prof Madya Dr. Jennifer G. Doss
Tel. No.: 012-9414589
Address: Jabatan Pergigian Masyarakat, Universiti Malaya
Email address: jendoss@um.edu

APPENDIX C

PATIENTS CONSENT FORM

CONSENT BY PATIENT FOR OBSERVATIONAL RESEARCH ***FACULTY OF DENTISTRY, UM, K.L.***

I, ……Identity Card No. ……
(Name of patient)

of……
(Address)

hereby agree to take part in the clinical research (observational study) specified below :

Title of Study :

……the nature and purpose of which has been explained to me by …… *(Name & designation of doctor)* and interpreted by……*(Name & designation of interpreter)*to the best of his/her ability in…… language/dialect.

I have been told about the nature of the observational research in terms of methodology, possible adverse effects and complications (as per the patient information sheet). After knowing and understanding all the possible advantages and disadvantages of this observational research, I voluntarily consent of my own free will to participate in the observational research specified above.

I understand that I can withdraw from this observational research at any time without assigning my reason whatsoever and in such a situation shall not be denied the benefits of usual treatment by the attending doctors.

Date …… Signature or thumbprint……
(Patient)

IN THE PRESENCE OF

Name ……,

I/C No. ……., Signature ……
(Witness for signature of patient)

Designation …….. Date .....

I confirm that I have explained to the patient the nature and purpose of the above mentioned observational research.

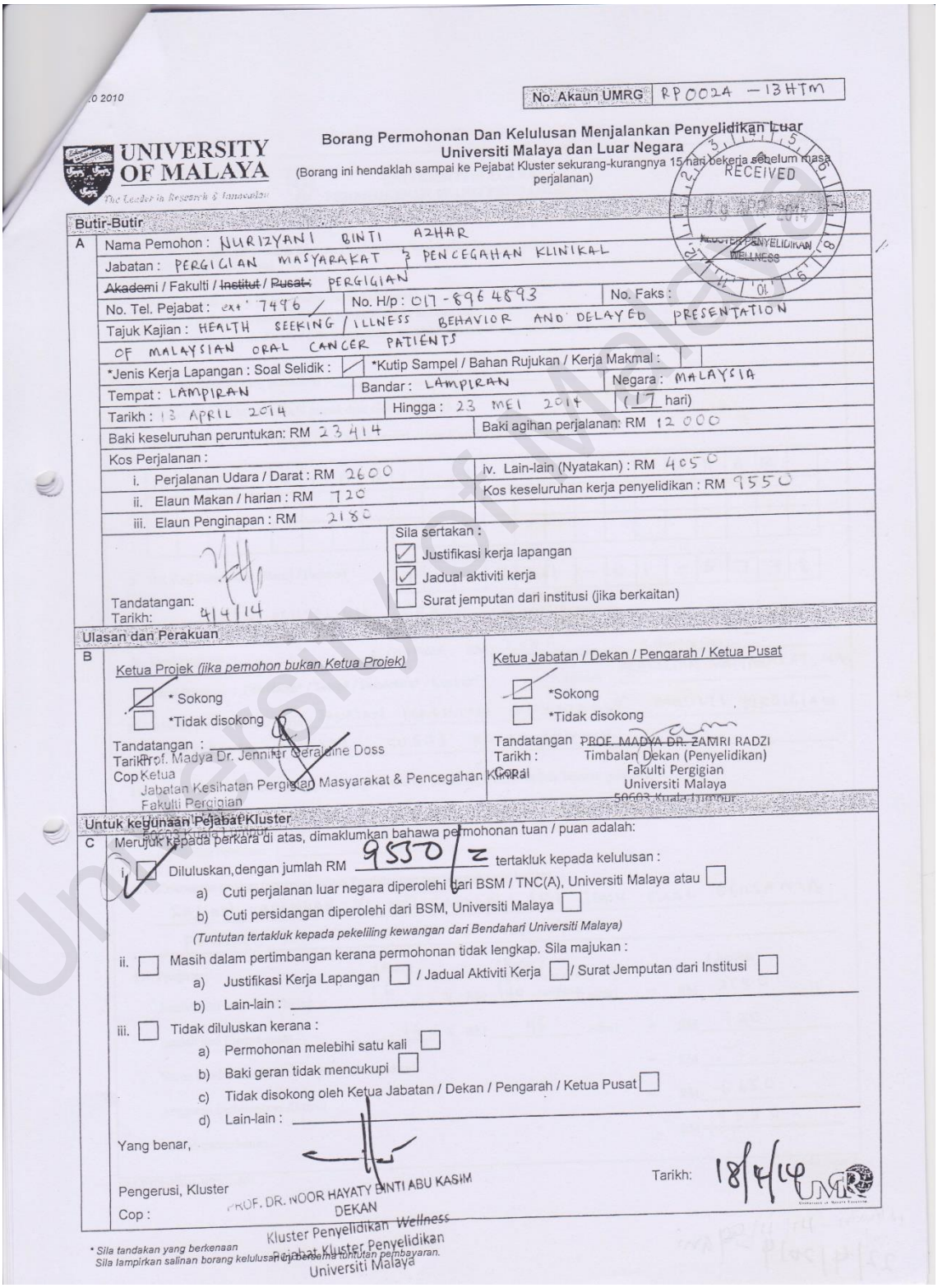
Date …….... Signature ……..
(Attending doctor)

CONSENT BY PATIENT FOR CLINICAL RESEARCH

R.N. :
Name:
Sex :
Age :
Unit :

APPENDIX D

APPLICATION AND APPROVAL FORM FOR RESEARCH OUTSIDE UNIVERSITY OF MALAYA



.0 2010

No. Akaun UMRG: RP0024 – 13HTM

UNIVERSITY OF MALAYA
The Leader in Research & Innovation

Borang Permohonan Dan Kelulusan Menjalankan Penyelidikan Luar Universiti Malaya dan Luar Negara
(Borang ini hendaklah sampai ke Pejabat Kluster sekurang-kurangnya 15 hari bekerja sebelum masa perjalanan)

RECEIVED
3 JUN 2014
KLUSTER PENYELIDIKAN WELLNESS

Butir-Butir

A

Nama Pemohon : NURIZYANI BINTI AZHAR
Jabatan : PERGIGIAN MASYARAKAT & PENCEGAHAN KLINIKAL
~~Akademi~~ / Fakulti / ~~Institut~~ / ~~Pusat~~: PERGIGIAN
No. Tel. Pejabat : ext' 7496 | No. H/p : 017-8964893 | No. Faks :
Tajuk Kajian : HEALTH SEEKING / ILLNESS BEHAVIOR AND DELAYED PRESENTATION OF MALAYSIAN ORAL CANCER PATIENTS
*Jenis Kerja Lapangan : Soal Selidik : ✓ | *Kutip Sampel / Bahan Rujukan / Kerja Makmal :
Tempat : LAMPIRAN | Bandar : LAMPIRAN | Negara : MALAYSIA
Tarikh : 13 APRIL 2014 | Hingga : 23 MEI 2014 | (17 hari)
Baki keseluruhan peruntukan: RM 23414 | Baki agihan perjalanan: RM 12000
Kos Perjalanan :
i. Perjalanan Udara / Darat : RM 2600
ii. Elaun Makan / harian : RM 720
iii. Elaun Penginapan : RM 2180
iv. Lain-lain (Nyatakan) : RM 4050
Kos keseluruhan kerja penyelidikan : RM 9550

Tandatangan:
Tarikh: 4/4/14

Sila sertakan :
☑ Justifikasi kerja lapangan
☑ Jadual aktiviti kerja
☐ Surat jemputan dari institusi (jika berkaitan)

Ulasan dan Perakuan

B

Ketua Projek *(jika pemohon bukan Ketua Projek)*
☑ * Sokong
☐ *Tidak disokong
Tandatangan :
Tarikh:
Cop Ketua
Prof. Madya Dr. Jennifer Geraldine Doss
Jabatan Kesihatan Pergigian Masyarakat & Pencegahan Klinikal
Fakulti Pergigian
Universiti Malaya
50603 Kuala Lumpur

Ketua Jabatan / Dekan / Pengarah / Ketua Pusat
☑ *Sokong
☐ *Tidak disokong
Tandatangan
Tarikh :
Cop
PROF. MADYA DR. ZAMRI RADZI
Timbalan Dekan (Penyelidikan)
Fakulti Pergigian
Universiti Malaya
50603 Kuala Lumpur

Untuk kegunaan Pejabat Kluster

C

Merujuk kepada perkara di atas, dimaklumkan bahawa permohonan tuan / puan adalah:

i. ☑ Diluluskan, dengan jumlah RM 9550/= tertakluk kepada kelulusan :
a) Cuti perjalanan luar negara diperolehi dari BSM / TNC(A), Universiti Malaya atau ☐
b) Cuti persidangan diperolehi dari BSM, Universiti Malaya ☐
(Tuntutan tertakluk kepada pekeliling kewangan dari Bendahari Universiti Malaya)

ii. ☐ Masih dalam pertimbangan kerana permohonan tidak lengkap. Sila majukan :
a) Justifikasi Kerja Lapangan ☐ / Jadual Aktiviti Kerja ☐ / Surat Jemputan dari Institusi ☐
b) Lain-lain :

iii. ☐ Tidak diluluskan kerana :
a) Permohonan melebihi satu kali ☐
b) Baki geran tidak mencukupi ☐
c) Tidak disokong oleh Ketua Jabatan / Dekan / Pengarah / Ketua Pusat ☐
d) Lain-lain :

Yang benar,

Pengerusi, Kluster
Cop :
PROF. DR. NOOR HAYATY BINTI ABU KASIM
DEKAN
Kluster Penyelidikan Wellness
Pejabat Kluster Penyelidikan
Universiti Malaya

Tarikh: 18/4/14

* Sila tandakan yang berkenaan
Sila lampirkan salinan borang kelulusan ini bersama tuntutan pembayaran.

APPENDIX E

PARTICIPANTS DEMOGRAPHIC DETAILS FORM

Patient's demographic details

Name: _____

Reg. No: _____

Site of the tumour: _____

1. Gender
- Male
- Female

2. Age (in 2014)
- _____

3. Race
- Malay
- Chinese
- Indian
- Kadazan
- Iban
- Others _____

4. Highest level of education you completed?
- No formal school
- Primary education
- Secondary education
- Tertiary education (undergraduate/postgraduate)

5. Residence
- Rural
- Urban

1

6. Current Occupation

- Employer
- Employee
- Unemployed
- Self employed
- Pensioners
- Housewife
- Others _____

7. What is your current household income in RM per month?

- <RM 3000
- RM 3000 – 5000
- RM 5000 – 10 000
- > RM 10 000

8. Marital status

- Unmarried
- Married
- Divorced
- Separated
- Widowed
- Living together

9. Current High Risk Behaviour

- Smoking
  - Never _____
  - Current smoker _____
  - Past smoker (Last smoked 2 years ago) _____
  - New smoker _____

- Alcohol Drinker
  - Never _____
  - Current _____
  - Past (Last consumptions 2 years ago) _____

- New smoker _____

- Betel quid chewers
  - Never _____
  - Current chewer _____
  - Past chewer (Last consumptions 2 years ago) _____
  - New chewer _____

- Dietary intake:
  - Vegetables & fresh fruits
    - Never
    - 1-3 times per month
    - 3-4 times per week
    - 1-3 times per day
  - Spicy food
    - Never
    - 1-3 times per month
    - 3-4 times per week
    - 1-3 times per day
  - Others
    - Salted and marinated food _____
    - Preserved food _____
    - Meat intake _____

APPENDIX F

PROBING QUESTIONS (BASED ON SELF-REGULATORY MODEL)

NAME:

No.	Objectives	English	B.M
	Stage 1 : Symptom interpretation		
1.	Representations of illness (a) Identity	C : What is the first symptom you encountered? P : Was it an ulcer (a red/white patch, a lump, swelling, numbness, difficulty in moving jaw, tongue)? C : What did you think of it? P : How did you interpret it when you noticed it the first time (Based on your opinion and observation)	
	(b) Cause	C : Did you ever felt the symptom before? P : e.g : _____ How often did you experience your symptom? C : Why did you think it happened? (reasons that caused illness/symptom) P: Could it be because of...? (smoking, alcoholic, chew betel quid, have a family history) (in refer to socio-demographic form)	
	(c) Timeline	C : When you encountered the symptom, In your opinion, were you aware how long the symptom might last?	
	(d) Consequences	C : How much did the symptom affect your life? P : Did it give an impact on you physically? (e.g : can't talk, less appetite) P : Did it impact you socially? (e.g : stop social activities and isolating yourself from people)	
	(e) Curability/controllability	C : Did you think you could keep the symptom under control? P : How much control did you feel you have over your symptom? (very confident it's just a normal thing and will recovered itself)	

1

	Influential factors (a) Socio-demographic factors - Income - Education (b) Psychological factors - Dental fear (c) -ve health related behaviour - Smoking - Drinking alcohol - Chew betel quid - Unhealthy diet (d) Symptom characteristics	*Try to relate all influential factors with any possible answers of the cognitive component	
2.	Emotional responses	C : How did you feel at the moment when you discovered the symptom in your mouth? P : Do you think it was a threat to your life and body? P : Did it cause you fear? P : Did it affect your mood at all? C : How much does your illness affect you emotionally? P : Does it makes you angry? (scared, upset, depressed)	
	Influential factors (a) Socio-demographic factors - Income - Education (b) Psychological factors - Dental fear (c) -ve health related behaviour - Smoking - Drinking alcohol - Chew betel quid - Unhealthy diet (d) Symptom characteristics	*Try to relate all influential factors with any possible answers of the emotional responses.	

	Stage 2 : coping		
	Approach coping strategy	C : What did you do in order to cope with the symptom? P : How did you self-treatment (consume anything) C : Where did you go? P : Did you tell a specific person? P : Did you go to traditional healer? (medical doctor, religious practitioner) P : How did the traditional healer treat you? P : What is the purpose of _____? What kind of protection does it afford?	
	Influential factors (a) Socio-demographic factors - Income - Education	C : What influenced your coping strategy? P : What made you decided to seek helps? P : Who helped you decide, to seek help? (family, friends) P : Did you prefer seeking help from a religious practitioner? P : Before seeking help, did you consider financial aspects? P : Previously, did you have any information regarding symptoms of oral cancer? P : From where did you get the information?	
	(b) Psychological factors - Dental fear	C : Previously, did you regularly go for dental check-up? P : Why? (if no) P : Do you think it is okay not to have a regular dental checking?	

	(c) Negative health related behaviour - Smoking - Drinking alcohol - Chew betel quid - Unhealthy diet	C : Do you smoke? P : How many years have you been smoking? P : Did you stop smoking after realizing your symptom? P : What made you stop? Who influenced you? P : Do you think your smoking habit is somewhat related to symptom?	
	(d) Symptom characteristics	C : Were your symptom noticeable? P : Was it obvious?	
2.	Avoidance coping (did not predict any serious consequences)	C : If you did not predict any serious consequences, did you ignore the symptom? P : Why? P : How long did you wait until eventually it affect your daily routine?	
	Stage 3 : Appraisal of symptom		
1.	Effective	C : Was your coping strategy effective? P : For how long did your coping strategy effectives?	
2.	Ineffective	C : What did you do when your coping strategy is ineffective, and the symptom seems persistent? P : Does re-interpretation occurred? P : Gives reasons why your initial belief change? P : What was your another options of seeking care? C : How long did it takes you to see the doctor from the first noticeable symptom? P : More than 3 month? (6 months, a year)	

APPENDIX G

INDEPENDENT TRANSCRIBER - 1

Bursar
University of Malaya

Dear Sir:
Payment of Honorarium via Project No: RP002A-13HTM, SAGA Project no: 6005094 Account Balance: RM 21,795.20

I wish to confirm that NURUL SURAYA MOHD ZAIN has assisted me in carrying out various works in the project mentioned above between 01/07/2014 and 31/08/2014

He/She has carried out Cik NURUL SURAYA MOHD ZAIN has carried out transcribing work for an audio recorded tape for a qualitative research on oral cancer patients. Total length of recording: 10 hour 24 minutes 7 seconds Recording rate: RM100/1 hour Total = (10x RM100) + (24X RM1.70) = RM (1000 + 40.80) = RM1040.80 Please pay to Cik NURUL SURAYA MOHD ZAIN (800813-14-5596) and send cheque to JABATAN PERGIGIAN MASYARAKAT, FAKULTI PERGIGIAN, UNIVERSITI MALAYA. .

Please pay RM 1,040.80 to NURUL SURAYA MOHD ZAIN (800813145596) and send the cheque to: JABATAN PERGIGIAN MASYARAKAT DAN PENCEGAHAN KLINIKAL, 50603, FAKULTI PERGIGIAN, UNIVERSITI MALAYA

Yours truly,

Approved By:

_____
Name: JENNIFER GERALDINE DOSS
Date: 21/07/2014

_____
Head / Dean
Date & Cop

APPENDIX H

INDEPENDENT TRANSCRIBER – 2

Bursar
University of Malaya

Dear Sir:
Payment of Honorarium via Project No: RP002A-13HTM, SAGA Project no: 6005094 Account Balance: RM 21,345.20

I wish to confirm that SITI HAJAR BINTI MOHD ROFFEEI has assisted me in carrying out various works in the project mentioned above between 01/09/2014 and 30/09/2014

He/She has carried out Transcribing work for audio recorded focus group discussion among oral cancer patients in Kuching, Sarawak. .

Please pay RM 450.00 to SITI HAJAR BINTI MOHD ROFFEEI (830214105688) and send the cheque to: FACULTY OF COMPUTER SCIENCE AND INFORMATION TECHNOLOGY, 50603, UNIVERSITY MALAYA

Yours truly,

Approved By:

_____
Name: JENNIFER GERALDINE DOSS
Date: 8/10/2014

_____
Head / Dean
Date & Cop

APPENDIX I

TRANSCRIPT VALIDATION

UNIVERSITI MALAYA
KUALA LUMPUR

يونيورسيتي مالايا

The Leader in Research and Innovation

11 Mac 2015

Dr. Thaddius Herman Maling
DrDPH Candidate 2013-2016
Jabatan Pergigian Masyarakat & Pencegahan Klinikal,
Faculti Pergigian,
Universiti Malaya,
50603 Kuala Lumpur,
Malaysia.

Tuan,

Perlantikan Sebagai Penterjemah

Ddengan segala hormatnya perkara di atas.

2. Sukacita dimaklumkan bahawa **Dr. Thaddius Herman Maling** telah dilantik sebagai penterjemah bagi projek UMRG (RP002A-13HTM). Kajian kualitatif tersebut bertajuk "*Health-seeking behaviour and delayed presentations of Malaysian oral cancer patients: A qualitative study*".

3. Untuk makluman, tuan dikehendaki memastikan setiap transkrip dalam Bahasa Melayu yang diterjemah dalam Bahasa Inggeris adalah tepat dan membawa maksud yang sama. Ini adalah untuk memastikan kesahihan dan ketepatan data-data kualitatif yang akan digunakan dalam penyelidikan ini. Semoga tuan dapat menjalankan tugas dan tangungjawab dengan baik. Sekalung penghargaan dan terima kasih diucapkan atas kerjasama tuan.

Sekian terima kasih,

Prof. Madya Dr. Jennifer G. Doss
Ketua Penyelidik.

Pusat Penyelidikan & Penyelarasan Kanser Mulut
Tingkat 7, Banggunan Pascaijazah & Penyelidikan,
Fakulti Pergigian, Universiti Malaya, 50603, Kuala Lumpur, Malaysia.
Oral Cancer Research & Coordinating Center (OCRCC)
7th floor, Postgraduate & Research Tower, Faculty of Dentistry,
University Malaya, 50603, Kuala Lumpur, Malaysia.
Tel: (603) 7967 4896 Fax: (603) 7954 7301 Email: oralcancer2003@um.edu.my

APPENDIX J

CASE CHARTING

No.	Case	Participant's symptom interpretation	Coping strategy
1	UM01001	Mouth ulcer	Chinese herbs General practitioner (private clinic)
2.	UM02002	Accidental finding	He went to dental clinic to extract tooth.
3.	HKL01003	Mouth ulcer	Herbal tea (Traditional medicine) General practitioner (private clinic) Consult a dentist
4.	HQE05004	Mouth ulcer	She complained to her son about having an ulcer and consult a General practitioner.
5.	HQE01005	Mouth ulcer & toothache	General practitioner (private clinic)
6.	HQE06006	Mouth ulcer (minor condition)	Participant did not take any action except eating sweets to deviate the feelings of 'pain'. Finally consulted a general practitioner
7.	HQE07007	No idea. But she thought it was an ulcer.	General practitioner (public hospital) – she was finally referred to dental clinic.
8.	HQE03008	No idea.	General practitioner (private clinic) in Kota Belud, Sabah. She was referred to Hospital Kota Belud before final referred to Hospital Queen Elizabeth, KK.
9.	HQE02009	No idea.	He went to seek help from a general practitioner (private clinics)
10.	HQE04010	Accidental finding	Referred to dental clinic.

11.	HUSM01011	No idea	Self-medicated (Panadol) '*Air tawar*' (prayer water), General practitioner (private clinic), hospital (dental clinic)
12.	HUSM02012	No idea. He guessed it as normal mouth ulcer.	General practitioner (private clinic), hospital KB, hospital USM.
13.	HUSM03013	Accidental finding.	He went to dental clinic to extract loosening tooth.
14.	HUSM05014	Mouth ulcer	She pricked the ulcer using needles (self-remedy) She finally went to dental clinic to extract tooth. Eventually was referred to hospital.
15.	HUSM06015	Gum disease	He pulled his own tooth (self-remedy). Porcupine needle (Chinese traditional medicine). '*Air tawar*' (Malay traditional medicine). He finally went to private hospital in Selayang.
16.	HUSM04016	No idea.	General practitioner (private clinic), hospital USM.
17.	HUS01017	Mouth ulcer.	Applied bonjela (self-medicate) General practitioner (private clinic). Finally was referred to Hospital
18.	HUS02018	Mouth ulcer	Consumed Panadol (self-medicate). 'Air Tawar' (Traditional medicine) General practitioner (private clinic) Hospital
19.	HUS03019	Mouth ulcer	Self-medicated. General practitioner (private clinic) Hospital.
20.	HUS04020	Something serious like a growth (benign tumour).	Immediately consulted the doctor (General practitioner) in radiotherapy unit since he is a nose cancer patient. He was given bonjela. He finally

			went to dental clinic after the symptoms worsened.
21.	HUS05021	Toothache.	She went to see dentist (private clinic) to extract tooth.
22.	HUS06022	No idea.	General practitioner (private clinic)
23.	HKL02023	No idea	General practitioner (public hospital)
24.	HKL03024	Mouth ulcer	'watermelon powder' (Chinese Traditional medicine)
25.	HTAR02025	No idea.	She consulted a general practitioner in a private clinic.
26.	HTAR03026	No idea.	She consulted a general practitioner.
27.	HTAR01027	She had no idea	She consulted a general practitioner.
28.	HTAR04028	No idea. But she saw a cut inside her mouth.	She consulted a general practitioner.
29.	HTAR05029	Toothache. Accidentally founding.	She went to dental clinic to extract tooth.
30.	UM03030	No idea.	She consulted general practitioner.
31.	UM04031	Mouth ulcer	She went to Hospital Assuntha (Private hospital)
32.	UM05032	Mouth ulcer	General practitioner (Private clinic)
33.	HKL04033	Toothache	Dentist (private). He thought there was a growth after tooth extraction. .

34.	UM06034	Cancer	Hospital (public hospital). He had a family history. His father was diagnosed with tongue cancer.
35.	UM07035	Recurrent symptom. Normal mouth ulcer.	General practitioner (private clinic).

APPENDIX K

FOCUS GROUP DISCUSSION'S – VERBATIM

PARTICIPANTS' SYMPTOM INTERPRETATION
• *The doctor (GP) said it was a normal ulcer…. I also went for dentist. Same thing. They said an ulcer. One month applied the medicine (ulcer). But unfortunately, the ulcer did not go away. After a few month, my husband said, "tak boleh jadi... we have to go to the hospital." I went to hospital and then got biopsy and was diagnosed with cancer. It was tongue cancer.* [07:10] • *At first, I had a sore throat. I went to see doctor (GP). It does not heal. After a few weeks, it still does not heal. At the third time, I noticed a white patch like ulcer on my tongue. It size was like a 5 cent shilling. Flat but was not painful like ulcer. I felt uncomfortable. So I went to private GP's clinic .* [13:25] • *Hospital Selayang told me that it was ulcer. They said its nothing. But it was impossible because it was there almost 2-3 months. Sometime it was painful but sometime it does not feel pain. So, they told me to check once again. But I was so afraid. They gave me a refer letter to go General Hospital (HKL)* [23:44] • *I myself thought it was an ulcer. It was very small. I went and see the doctor (GP) after one month. Then the doctor asked me, "Do you feel pain or not?" I said "Pain". Then the doctor said "If you feel pain, its ok. It doesn't matter" So, I ignore it. After one month, still cannot heal...* [01:15:47]

- *It appear, there's a piece look like mushroom on the tip of my tongue. And I... I was actually vaccine at UCSI in Cheras.. and at that time the university send me to Hospital Pantai Bangsar* [01:44]

PARTICIPANTS' NON-RECOGNITION OF SYMPTOM

- *My symptom start with an ulcer. At first, I did not realised the ulcer. I went to dental clinic to extract my tooth. I want to extract my tooth so that it won't hurt my ulcer. But the dentist said it was not a normal ulcer. I was then referred to dental specialist clinic.* [29:11]

PARTICIPANTS' COPING STRATEGIES

- *I went for a few doctor (GP)… The doctor said it was a normal ulcer. I also went for dentist but same thing. They said an ulcer.* [07:10]
- *I went to seek private doctor (GP)...* [13:25]
- *I go and see the doctor (GP) after one month.* [01:15:45]

APPENDIX L

SEMI-STRUCTURED IN-DEPTH INTERVIEWS' - VERBATIM

PARTICIPANTS' SYMPTOM INTERPRETATIONS	VERBATIM
ULCER	• *For this one (symptom). I remember a few years ago, about 4 to 5 years ago. It started with an ulcer something whitish inside my mouth (P.1)* • *A white patch like an ulcer. I think this one (ulcer) is a small thing (P.3)* • *Yes. It was an ulcer (P.6)* • *Tak rasa sakit.. dia macam menaik.. dari kecik semakin besar semakin besar.. isi lembik-lembik.. macam ulser.. (P.14)* • *Ha… symptom pertama.. saya jenis demam yang tak pernah ada ulser mulut.. kan orang kampung kata kalau demam panas ada ulser.. Pada tahun 2012, ada 2-3 (ulser) di lidah dan di bibir.. tapi tak lama.. ada saya beli di farmasi.. saya guna.. bon jela.. saya pergi.. pejabat kita ada.. (P.17)* • *Saya tak terfikir.. saya tak terfikir ini kanser.. saya cuma ingat sakit ulser biasa ja.. Cuma saya tengok semakin membesar.. membesar.. saya pun ke poliknlinik la..(P.19)* • *Aaa...tongue.....got one 'dot' like an ulcer....(P.24)* • *Aaa.... macam biji bulat... Dua tahun lebih tapi tak gatal tak sakit.. (P.27)* • *Macam ulser.....dekat sini..(P.30)* • *It was an ulcer. I thought that was an ulcer (P.32)* • *I have this problem. An ulcer... ulser yang tak baik-baik (P.35)*

TOOTHACHE	• *No. Nothing is inside my mouth. It just felt like a toothache (P.18)* • *It was like a toothache. (P.7)* • *Aaa....ialah....mula-mula sakit gigi (P.21)* • *Sakit gigi lah....mahu dalam sebulan lebih ya mak kan....sebulan juga kan sakit gigi....demam...sakit gigi tu.. (P.29)*
BURNING SENSATION	• *Something like a burning sensation…. The pain radiates below my jaw… (P.4)*
GUM PROBLEM	• *Hot. I always felt pain on my gum. My gums used to bleed. (P.15)* • *I usually have gums bleeding for many years ago. But only recently there was a growth (P.8)* • *Aaa....ialah....mula-mula sakit gigi.... lepas tu kembang gusi dia. . . .pastu doktor beri balik.. (P.21)* • *Gusi bengkak....tapi saya...apa apa tak ada sakit (P.23)*
ACCIDENTAL BITING	• *I thought, it was nothing. Something like accidentally bitten the tongue (P.19)* • *At first, I wear denture. My tongue was accidentally bitten. (P.5)* • *Dia tergigit lidah.. biasa la ni.. (P.11)* • *Ermm...bila dia ada tergigit something. (P.26)*

CANCER	• *Well, when I had pain. I suspected already since my father died because of tongue cancer (P.34)*
PARTCIPANTS' NON-RECOGNITION OF SYMPTOM	**VERBATIM**
NO IDEA AND FAILED TO INTERPRET	• *It was not painful. At first, I saw a small thing (a growth) inside my mouth. ....I think there is no reason for it (P.12)* • *I do not know what it is…. (P.9)* • *I have no idea about 'it'. I did not know about the symptom (P. 13; male, 61 y/o)* • *Kita ingat kan....sikit-sikit gitu lah... tiada apa-apa kan...(P.16)* • *I do not know. Just very painful. I believe doctor. That's why I used bonjela. But very painful. (P.20)* • *Tak ada apa....biasa sahaja... (P.22)* • *Tak ada sakit....cuma... Tumbuh lah. (P.25)* • *…lepas tu saya datang tengok check aaa.... mulut.....tengok... saya pun takut....dia isi ada keluar kan....macam penyakit lain lah.. Saya tidak tahu apa.. (P.28)* • *Tidak tahu… Dalam tu macam....ada bulat.. (P.31)* • *Darah-darah pun semua tak ada. Ini macam banyak keras punya. Sudah satu .tumbuh lagi ada banyak. Keluar lagi banyak. Tak ada sakit. (P.33)*
ACCIDENTAL FINDING (DO NOT INTERPRET)	• *He (Doctor) detected it (symptom). I did not know. I went for dental clinic to remove my tooth. And then my family dentist said. He (Doctor) said. 'No, sorry, I can't remove your teeth, because there is a growth." immediately he (Doctor) wants to meet me here, so the*

	very next day, I came here. Doctor saw me. He sends the sample to the lab after 4 weeks, my wife came along and doctor told it was cancer. He said, 'if you don't want to remove, it will spread. Very fast'. So we decided to get it out. Have to undergo an operation. So, doctor took us to Ear, Neck, and Tongue Department (ENT) and explained the process that I will be going through (P.2) • *Tak.... bawa pergi.....sebab dia orang ada program (P.10)* • *Pasal tunjuk.....bila buka...tengok ada tu...dia rujuk kat pakar.....pakar ambik tisu sikit.....buat test aaa...dia kata kanser..... Kalau tak buat gigi tu...tak tahu lagi. (P.13)*

PARTICIPANTS' TYPE OF COPING STRATEGIES	**COPING PROCEDURE**	**VERBATIM**
SELF-REMEDY	Prick with needle	• *I used a needle to prick it* (P.14)
	Self-extract the tooth	• *When my tooth got loose. I pulled it myself* (P.15)
	Eat sweets	• *I eat sweets and keep it there to distract myself from the discomfort* (P.6)
	Rub with salt	• *I used salt. I just rub it (there) to reduce pain* (P.33)
SELF-MEDICATION	Bonjela	• *Yes. I bought it from pharmacy. I used Bonjela* (P.17)
	Panadol	• *No. Nothing. It is like toothache. It will go off when I took Panadol. After 1-2 weeks it will come again but when I took Panadol, it went off again* (P.18)
	Herbal tea	• *My friend came to me with this herbal tea from Kelantan. I took that one but also did not cure my ulcer. It tasted just like tea. Every day I drank this tea and rinsed my mouth after eating* (P.3)

TRADITIONAL HEALER	*Air Tawar* (Prayer water)	• *I went to the shaman. He said someone with bad intention had done something to me (superstitious beliefs/ witchcraft). It is clear that when in the evening. I felt hot (fever)* (P.18) • *Ada juga.. dua kali la.. dia bagi air tawar ja..*(P.11) • *Aaa...dia cuma mandi...macam ubat kumur ini aja lah....bagi yang macam nak makan makan ni sek ada lah* (P.21)
	Duri landak (porcupine spine) & *Pil Azimat (*charm pil*)*	• *Yes. I have previously tried traditional medicine. Once I tried to find 'senseh' (Chinese physician) and also went to Malay kampung (Village). I ate porcupine spine. 1 gram of it cost RM 700. At that time I was still working and had income. Every time I consumed it cost RM 700. I ate the original spine. I ate it because it was recommended by my boss's relatives. During this time, my lifestyle was not good… Lack of sleep and continue eating mutton. Senseh gave me 'pil azimat' (charm pill) but had no effect* (P.15) • *Yes. I did try Chinese Herbs..* (P.1) • *so she apply those Chinese one called...this called...one watermelon powder.....Chinese shop sell one* (P.24)
CONSULTED A GENERAL MEDICAL PRACTITIONER	Antibiotic, bon jela, cream, injection, mouth rinse, pain killer, Panadol, no medicine	• *One day when I saw something whitish inside my mouth. I went to the clinic straight away. He (GP) checked several times but my ulcer did not heal. So he referred me to the hospital* (P.1) • *I thought it was nothing serious. I went to Klinik Kota Belud (General Practitioner). They referred me to Dental Division in Hospital Kota Belud. They asked me to tell my son and bring me to Hospital in Kota Kinabalu.* (P.4) • *I went to private clinics then to Hospital Lawas. They send my report to Hospital Queen Elizabeth (HQE). They extract my tooth at Luyang. Doctor told me to extract my tooth again in Lawas. In Lawas, they want wanted to send me to Hospital Miri but I do not have passport. So, I was*

refered here (HQE) for an appointment until now. (P.5)

- *I visited Hospital Keningau (General Practitioner) several times. Lastly, there was a growth. They said it was something like a wart.* (P.6)
- *I went back and forth to clinic for several times. Then they referred me to Hospital Queen Elizabeth (HQE).* (P.7)
- *I routinely went to clinic for medicine because I couldn't stand the pain.* (P.8)
- *I immediately went to Hospital Kota Marudu. They took my blood and checked. But everything was fine. It just i had a headache and unusual fever. Now is rainy season. They said maybe because of the seasonal changed. Secondly, maybe because of the Dengue fever. I had been to the hospital several times but still they could not found anything. So they referred me to Hospital Queen Elizabeth. They took a small sample from my tongue. After a week, i have been diagnosed with cancer stage 4.* (P.9)
- *IZ*

  aa.. so, masa ada symptom yang tumbuh

  sikit tu.. cikgu terus jumpa doktor kah?

  AHD

  Ya. Jumpa doktor private.

  IZ

  Ye. Doctor private?

  AHD

  Bukan doktor gigi. .. swasta (GP).. (P.12)

- *Tak da.. biasa.. Cuma nampak semakin besar tengok dalam cermin. jumpa doktor swasta (GP). Dia suruh ke pergigian kerajaan di Machang. Masa tu semakin besar.. ambil surat situ.. suruh pergi Kota*

Bharu. Ambil surat di bedah mulut. Check. (P.14)

- *Ermm....tak boleh hilang....kejap gi klinik.... hospital.... dia beri ubat....ubat tahan* (P.16)

- *MOS*
  Jel.. bon gela.. pejabat kita tu ada klinik ..

  saya ada satu klinik tu.. pun dia bagi jel

  juga..

  IZ

  Masa tu trus jumpa doktor ke? Jumpa

  doktor gigi?

  MOS

  Tak… klinik biasa.. klinik panel.. General

  doctor la..(P.17)

- *It grew quite fast. I went to the clinic several times. I paid for a check-up. They said nothing. 'It' kept on growing. Then, I went to the hospital. They sent me to the dental clinic for treatment. Only then they took a sample (of the tissue) and send it to the lab"* (P.19)
- *Tongue aa.. last year.. July.. July.. saya nampak saya punya tongue ada sedikit sakit.. saya punya marah itu or.. itu RTU punya. Saya sakit o.. saya selalu ada.. ada.. ada tengok patient juga.. 3 malam saya pergi ma… saya… aiya.. itu ulcer ma.. nothing la.. ambik bonjela.. aa.. sampai saya.. September.. dia besar itu.. macam.. saya baru jumpa ENT. ENT then refer saya pergi dental. Baru saya potong..*(P.20)
- *Saya tunggu satu minggu saya baru jumpa doktor...doktor masuk ubat, dia macam panas...saya tak tahan.. saya makan ubat*

		saya agak OK...saya OK.... pergi klinik asal sahaja. klinik swasta. (P.22) • *It's not healing so I went...those...she went and see the GP...then when the GP saw that growth....is not ulcer.*(P.24) • *Aaa....something sudah besar...besar....besar...jadi macam dia biasa ada lubang kan...jadi dia punya lubang...dia report saya...dah besar...dah lubang....sudah rasa sakit kan....baru kita pergi bawa klinik...lepas klinik itu doktor cakap....yang ni boleh baik.....dia bagi dekat...dekat seribu kita spend...klinik sahaja.*(P.26) • *saya rasa macam tu...saya rasa takut lah (takut symptom).... pergi klinik biasa punya....company....suami punya company klinik lah....saya bawa dia.....dia kata dia bagi surat...satu surat terus pergi hospital...jangan pergi mana mana...dia cakap...*(P.28) • *pergi ambik ubat kat klinik pun...tak...tak baik juga...tak cure mana pun. Aaa....klinik biasa.....lepas tu...rujuk ke Hospital Banting.....lepas tu dia minta rujuk ke sini lah...*(P.29) • *Lepas tu dia pergi klinik dia orang bagi surat....suruh hantar hospital...lepas hospital dia orang...aaa...apa..dia orang hantar dentist....dentist...lepas tu dia orang confirm ada...ada kanser*.(P.30) • *Then I went to see the GP.. because I thought it was an ulcer.. but the GP said it doesn't looks like an ulcer. Looks like there's a growth.. so, he recommend me to go to the dental la..*(P.32) • *I see earlier.. I didn't observe my tongue there.. there's an ulcer there.. normally, when you bite your tongue.. it slowly goes off.. but this time no.. it took a long time to heal.. so I came to clinic (GP) and told them.*(P.34) • *Doktor biasa.. general practitioner (GP). Ordinary clinics.. macam kita sakit demam kan.. tapi tengok ulser tu sama saja.. tak baik-baik. Lepas tu makan pun dah mula rasa susah..* (P.35)

APPENDIX M

PREVALENCE OF PARTICIPANTS' HIGH-RISK HABIT

Prevalence of betel quid chewing among participants for in-depth interview

Age group (years)	Male (N-17)		Female (N-18)		Total N
	With habit n (%)	Without habit n (%)	With habit n (%)	Without habit n (%)	
30 – 40	-	2	-	-	2
41 – 50	-	2	2	3	7
51 – 60	-	8	4	-	12
61 – 70	-	4	3	3	10
71 – 80	-	1	1	1	2
81 – 90	-	-	-	1	1
Total	**-**	**17**	**10**	**8**	**35**

Prevalence of alcohol consumption among participants for in-depth interview.

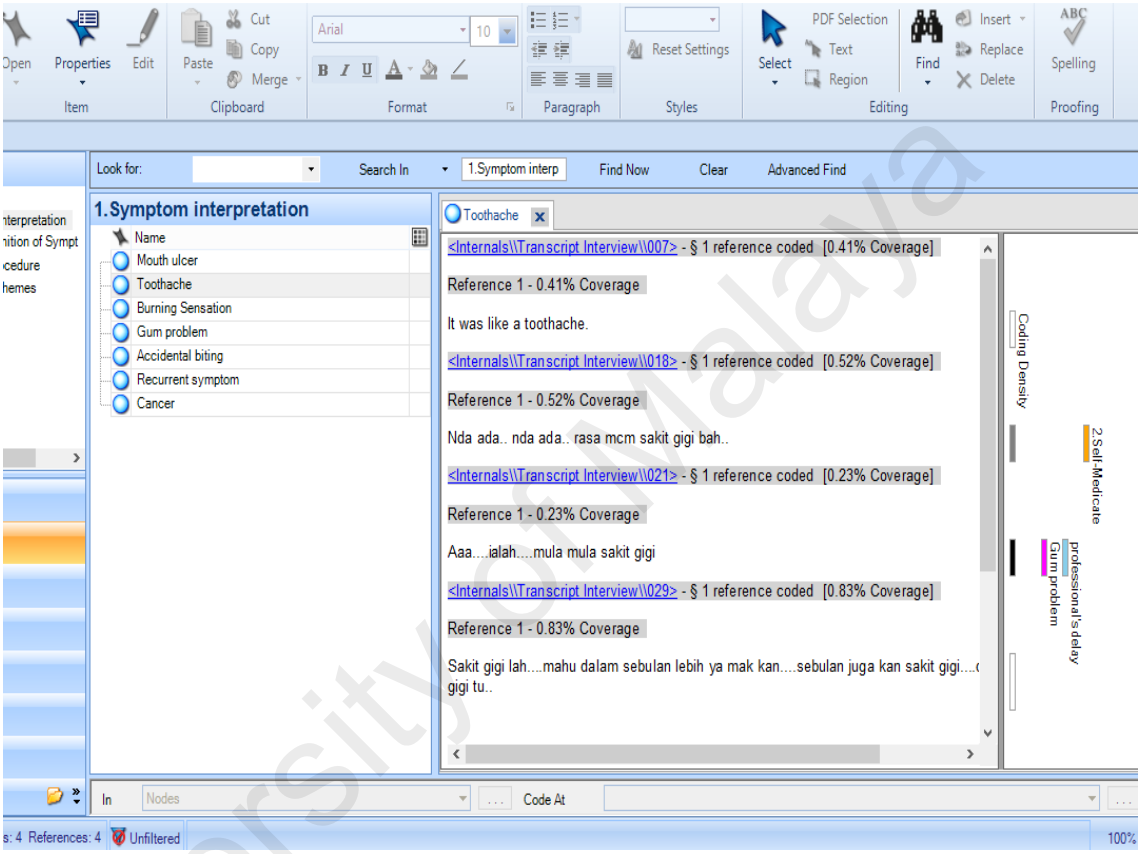
Age group (years)	Male (N-17)		Female (N-18)		Total N
	With habit n (%)	Without habit n (%)	With habit n (%)	Without habit n (%)	
30 – 40	1	1	-	-	2
41 – 50	-	2	-	4	6
51 – 60	1	7	-	5	12
61 – 70	-	4	-	6	10
71 – 80	-	1	-	2	3
81 – 90	-	-	-	1	1
Total	**2**	**15**	**-**	**18**	**35**

Prevalence of smoking behaviour among participants for in-depth interview.

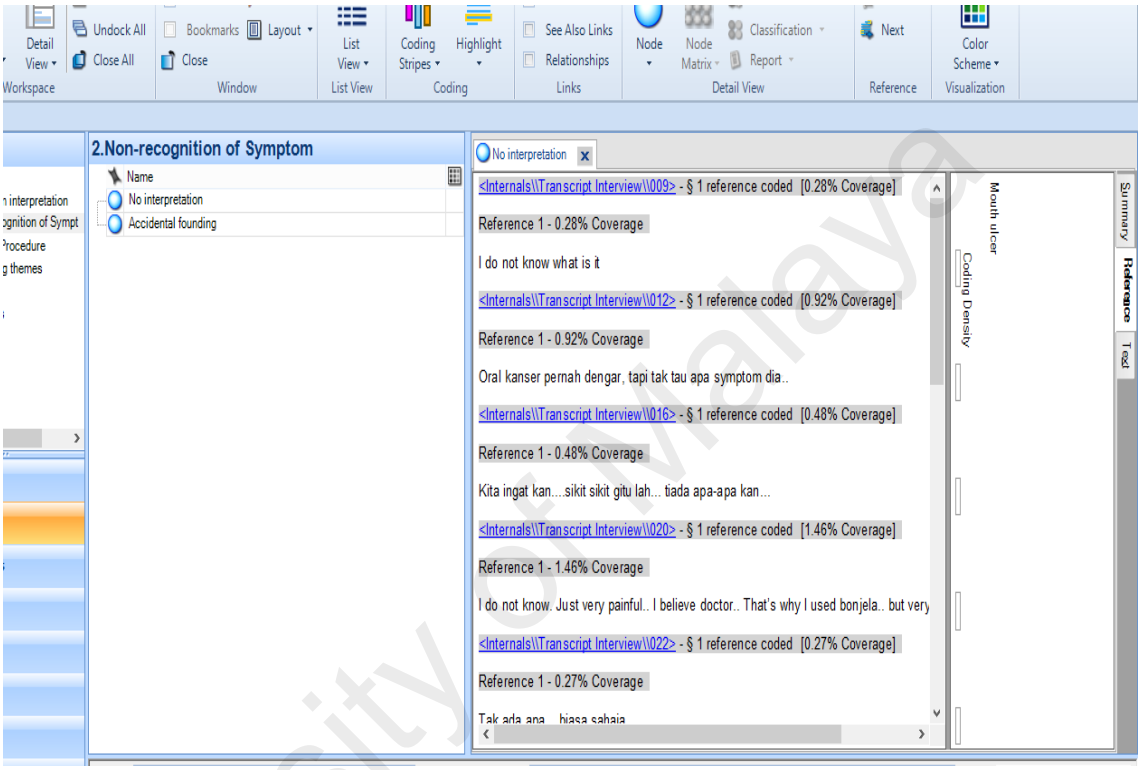
Age group (years)	Male (N-17)		Female (N-18)		Total N
	With habit n (%)	Without habit n (%)	With habit n (%)	Without habit n (%)	
30 – 40	2	-	-	-	2
41 – 50	1	1	1	3	6
51 – 60	4	4	-	5	13
61 – 70	3	1	-	6	10
71 – 80	-	1	-	2	3
81 – 90	-	-	-	1	1
Total	**10**	**7**	**1**	**17**	**35**

APPENDIX N

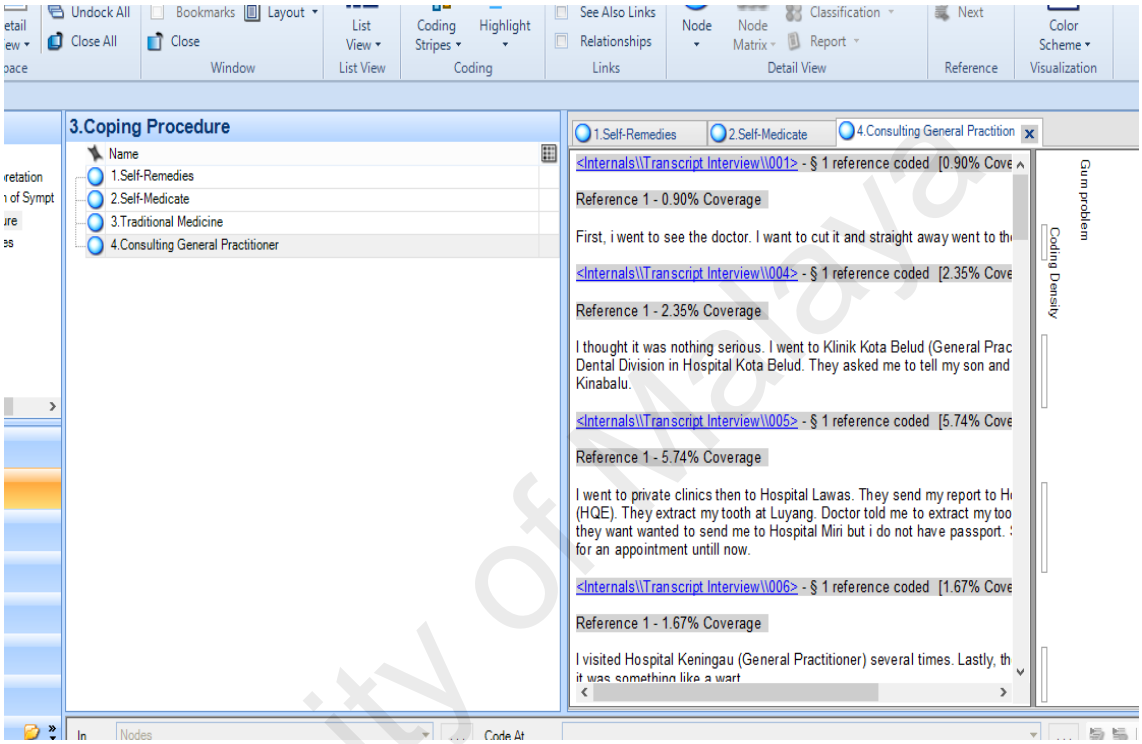
CODING PROCESS OF PARTICIPANTS' SYMPTOM INTERPRETATION



CODING PROCESS OF PARTICIPANTS' NON-RECOGNITION OF SYMPTOM



CODING PROCESS OF PARTICIPANTS' COPING STRATEGY



APPENDIX O

WORDS FREQUENCY FROM VERBATIM