

RESEARCH ARTICLE

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Health-Seeking Behaviour and Delayed Presentation of Oral Cancer Patients in a Developing Country: A Qualitative Study based on the Self-Regulatory Model

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Abstract

Background: The aim of this study was to explore reasons for delayed health-seeking for late stage oral cancer patients. **Methods:** Semi-structured in-depth interviews were conducted with 35 oral cancer patients with TNM stage III to IV disease, who were treated at six tertiary regional centres managing oral cancer throughout Malaysia. Interviews were audio-recorded, transcribed verbatim, coded using NVivo (version 10.0) qualitative software and analysed using *framework analysis*. **Results:** Participants interpreted their early symptoms as a minor condition and did not consider it as requiring immediate attention. Four types of coping strategies causing delayed help-seeking emerged: 1) self-remedy 2) self-medication 3) seeking traditional healers and 4) consulting general medical practitioners (GPs) instead of dentists. Socio-economic factors, cultural beliefs and religious practices have some influence on diagnostic delay. **Conclusion:** Low levels of public knowledge and awareness regarding early signs and symptoms of oral cancer as well as GPs' misdiagnosis of early lesions results in delayed diagnosis.

Keywords: Oral cancer- health-seeking behaviour- awareness- self-regulatory model- patient related-factors

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Introduction

Oral cancer has been reported as the sixth most common cancer worldwide (Noonan, 2014). In some Southeast Asia countries such as Bangladesh, India, Pakistan and Sri Lanka, oral cancer is the most common form of cancer and constitutes about a third of all cancers (Kumar et al., 2001; Ford et al., 2013). The National Cancer Registry (NCR) report in 2007 showed head and neck cancer (13.2%) as one of the top five leading cancers among the general population in Malaysia. Tongue cancer was the 7th most common cancer among ethnic Indian males whereas mouth cancer was the 3rd most frequent among Indian females (Lim et al., 2008). Although the prevalence of oral cancer is low in this country, 60% of oral lesions are found in minority Indian and Indigenous communities in Malaysia due to their high-risk habits practices such as betel quid chewing and tobacco use (Zain and Ghazali, 2001). Recent research in Malaysia has shown that about two-thirds (67.1%) of oral cancer patients present only when the disease is advanced (Omar and Tamin, 2011) and other reports show a similar pattern of delay in other Southeast Asia countries such as India and Thailand (Kerdporn and Sriplung, 2001).

Delay in diagnosis has been attributed as the main reason for poor patient survival rates (Johnson et al.,

2011). Diagnostic delay is an accumulation of a range of patient delay, professional delay, and health system delay (Dwivedi et al., 2012). Previous research has indicated that patient delay constitutes most of the overall total delay time and is influenced by the patients' characteristics especially their health-seeking behaviour (Scott et al., 2006; Quaipe et al., 2014). Patient delay is defined as the time from the onset of symptoms to first contact with medical persons (Groom et al., 2011)

Health-seeking behaviour refers to any activity undertaken by individuals who perceive themselves as having a health problem for the purpose of defining their stage of health until discovering and undertaking an appropriate remedy (Kasl and Cobb, 1966). Malaysia, a developing country, still lacks published data on health-seeking behaviour of oral cancer patients when compared to other cancers or chronic diseases. Considering that patients' health-seeking behaviour could very well account for the high proportion of advanced oral cancer cases presenting late in Malaysia and in view of related gaps in oral cancer knowledge currently apparent, more research in this area is certainly warranted.

The Self-Regulatory Model (SRM) has been used widely to understand patients' health-seeking behaviour in chronic disease such as diabetes mellitus (Paddison et al., 2010), coronary heart disease (Petrie et al.,

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1996) and cancer (Donovan and Ward, 2005). This model was developed by Leventhal (1980, 1998) and describes problem solving in three stages: (i) symptom interpretation; (ii) coping strategy; and (iii) appraisal. The SRM provides a framework for understanding how symptoms and emotions experienced during a health threat, influences an individual's perception of illness, and guides his/her subsequent coping behaviour (Browning et al., 2009). As such, the SRM was deemed appropriate to be used for the present study in order to explore the interpretation of symptom and subsequent health-seeking behaviour of oral cancer patients in Malaysia.

By exploring Malaysian oral cancer patients' health-seeking behaviours that lead to late presentation, a greater and more in-depth understanding can be gained about these potential and important cultural and religious related barriers which would certainly fill existing gaps in knowledge intended to reduce the proportion of oral cancer cases presenting and being diagnosed at advanced stages (TNM stage III and IV). The TNM system describes the tumor, node, and metastases. T means the original (primary) tumor. N means nodes. It denotes whether the cancer has spread to the nearby lymph nodes. M means metastasis.

Thus, this study is aimed at exploring the reasons for advanced stage (TNM III and IV) oral cancer patients' delayed health-seeking behavior and to offer suggestions to improve early cancer diagnosis in a developing country.

Materials and Methods

This is a qualitative exploratory study carried out over a three-month period. The inclusion criteria were diagnosed oral cancer patients, aged 18 years old and above with disease staging from TNM stage III to IV. In this study, 'delay in seeking-help' was defined as the length of time for patients with advance TNM stage III and IV to recognise their first symptoms of illness until the first contact with a medical practitioner. Purposive sampling was used which included participants of various ethnicities throughout Malaysia. However, mentally incoherent patients were excluded based on their medical records. The sample size was determined based on saturation point. Six oral surgery specialist clinics which serve as regional referral centres for oral cancer throughout Malaysia were chosen as sampling points. These included four government hospitals (Hospital Tengku Ampuan Rahimah, Hospital Kuala Lumpur, Hospital Queen Elizabeth and Hospital Umum Sarawak) and two university teaching hospitals (Faculty of Dentistry, University of Malaya, School of Medical Sciences, University Sains Malaysia).

Ethical approval (DF CO1401/0015(L)) was obtained from the Medical Research Ethics Committee, Faculty of Dentistry University of Malaya. This study was also registered with the National Medical Research Registry (NMRR-13-1685-17465), Ministry of Health Malaysia. A research clerk at each centre identified eligible patients who were contacted individually by telephone. Patients were briefed on the study purpose and verbal consent to join the study was obtained. An appointment was made for them at each centre to be interviewed. Participants

were asked to read the patient information sheet and sign the patient consent form. Interviews were then conducted in an isolated room to ensure privacy for participants. The researcher carried out these interviews using either the national language Bahasa Melayu or English. Each interview was audio-recorded and subsequently transcribed verbatim by both the researcher and an independent professional transcriber. Every participant was given a monetary token sum of Malaysian Ringgit 30 for their participation at the end of the interview.

Data Collection and Analysis

Data were collected through face-to-face semi-structured in-depth interviews by using a set of probing questions (Appendix A). A semi structured interview guide was developed after extensive literature review of the SRM (Moss-Morris et al., 2002). The researcher prepared herself for the semi-structure interviews by conducting two prior pre-test interview sessions in order to be familiarised with the procedural conduct of this type of interviews (Daniel and Turner, 2010). Firstly, information on participants' demographic details was obtained. Participants were asked about their response to the presence of symptoms in terms of SRM components which are symptom interpretation, coping strategy and appraisal of coping effort.

The data 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 included transcribing and reading the data. Three different transcribers were tasked to transcribe data from the in-depth interviews separately and all versions were compared by a panel to ensure content validity and consistency of the transcription process. The second step was 'identifying priori themes' that described or explained aspects of the data based on the SRM (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 and Luff, 2001). Subsequently, 'charting' which consist of summarised data in a matrix form (columns and rows) was done. Finally, 'mapping and interpretation' were done to search for patterns and concepts (Gale et al., 2013). All interviews were double coded, by a researcher trained in qualitative methods and by a dental public health specialist whereby ambiguities were resolved in discussion. Categories were reduced to major themes through ongoing discussion and the rereading of transcripts by the coders. Cross-checking, refinement of themes and using the SRM as a broad framework supported the rigor and trustworthiness of the data. Data analysis were facilitated by using Nvivo 10.0. Reliability of data was delineated by clearly describing and documenting the process of theme generation whereas data validity was obtained by presenting adequate patient verbatim responses.

Results

A total number of 35 participants were interviewed at

saturation point. The sample age ranged from 30 to 81 years old. Table 1 shows participants' socio-demographic details at each sampling point. Twenty-one participants had no/low educational levels (11 received primary education, 7 had no formal schooling and 3 were illiterate).

Cognitive and Emotional Symptom Interpretations

Table 2 shows participants' interpretations of their early symptom based on their illness beliefs. Some participants had no idea about their symptom. They did not interpret their symptom and preferred to ignore it. Moreover, some of them only discovered their symptom after been told by the medical General Practitioners (GPs) or dentists.

Participants reported varying emotional responses during the process of symptom interpretation.

"I am lucky because I was worried about the symptom. The symptom did not disturb me. It is not painful, I just felt uncomfortable. If it is a cut, I will feel pain but for this one, I did not feel any" (male, 51 y/o).

Coping Strategy

Participants' coping strategies in response to their symptom interpretation are tabulated in Table 3. The coping strategies used were self-remedy, self-medication, consulting Malay and Chinese traditional healers and seeking help from public or private GPs instead of first visiting the dental clinic.

Appraisal of Coping Efforts

Many participants appraised their coping efforts when their symptoms persisted or became aggravated.

"I was not satisfied with my condition. I wanted to get

well. So, I went to the hospital" (female, 63 y/o).

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

"There was a growth. So she (my mother) kept applying this (watermelon powder/Chinese herbs) for 2-3 months but it was not really effective. Last month it grew bigger and then she (my mother) finally felt painful" (female, 87 y/o).

Factors Associated with Participants' Health-Seeking Behaviour

In the present study, socio-economic status did not emerge as a barrier for participants to seek help from GPs/dentists.

"No. I never thought about financial aspects before coming here (dental clinic)" (male, 60 y/o).

This was most likely because healthcare facilities in this country are highly subsidised by the government.

"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" (male; 38 y/o).

Other factors such as knowledge and awareness influenced participants' health-seeking behaviour. Majority of participants had low educational levels.

"I did not go to school but I can read" (female, 60 y/o).

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

"I did not go to school. I do not know how to read." (female, 63 y/o).

Cultural beliefs and religious practices often lead to self-remedy, self-medication and consultation with

Table 1. Participants Details at Each Sampling Point for the In-Depth Interviews

No.	Participating Hospitals	No. of participants		Ethnicity			Total (N)	
		Male	Female	Malay	Chinese	Indian		Sabahan
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
	Total	18	17	7	7	7	7	35

Table 2. Cognitive Symptom Interpretations

Symptom Interpretations	Verbatim
Ulcer	<i>"For this one (symptom). I remember about 4 to 5 years ago. It started with an ulcer, something whitish inside my mouth"</i> (male, 43 y/o)
Toothache	<i>"No. Nothing was inside my mouth. It just felt like a toothache"</i> (male, 66 y/o)
Burning sensation	<i>"Something like a burning sensation...spicy. The pain radiates below my jaw..."</i> (female, 58 y/o)
Gum problem	<i>"Hot. I always felt pain on my gum. My gums used to bleed."</i> (male, 49 y/o)
Accidental biting	<i>"I thought, it was nothing. I felt like I accidentally bit my tongue"</i> (male, 35 y/o)
Cancer	<i>"Well, when I had pain. I suspected it may be cancer since my father died also because of tongue cancer"</i> (male, 71 y/o)

Table 3. Coping Strategies

Type of coping	Coping procedure	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" (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" (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" (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 rubbed it (there) to reduce pain" (male, 66 y/o)
Self-Medication	Bonjela	The easiest way to get medicine without consulting a medical GP. Despite that, it was cheaper and time consuming.	"Yes. I bought it from pharmacy. I used Bonjela" (male, 51 y/o)
	Panadol		"It is like toothache. The pain will go off when I take Panadol. After 1-2 weeks I had pain again but when I took Panadol, it went off again" (male, 66 y/o)
	Herbal tea		"My friend came to me with this herbal tea from Kelantan. I took that but it did not cure my ulcer. It tasted just like tea. Every day I drank this tea and rinsed my mouth after eating" (male, 60 y/o)
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 this was true when I felt hot (fever) every evening" (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 a 'senseh' (Chinese physician) and also went to the Malay 'kampung' (Village). I ate porcupine spine. One gram of it cost RM 700. At that time I was still working and had some income. Every time I consumed this, 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... I had lack of sleep and continued eating mutton. 'Senseh' gave me a 'pil azimat' (charm pill) but it had no effect" (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" (male, 43 y/o) "It grew quite fast. I went to the clinic several times. I paid for a check-up. They said nothing about it. '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" (male, 35 y/o)

traditional healers.

"Consulting traditional healers is like asking for prayers" (male, 56 y/o).

Moreover, some participants expressed strong beliefs in traditional medicine.

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

Psychological factors such as fear and denial resulted in participants' avoidance coping strategy in response to their symptoms.

"I just withstood the pain. I am afraid of hospitals. I have fear of needles and injections. That is why I went so late" (male, 56 y/o).

"I am very self-aware about my own health. I am afraid of dying. That is true, I always make sure I exercise and eat a lot of fruits" (male, 43 y/o)

Discussion

In the present study, participants interpreted their early oral signs and symptom as an 'ulcer'. Possible reasons for this are that the initial appearance of normal occurring mouth ulcers does not differ much from malignant ones. Thus, most people are unable to differentiate a normal ulcer from a potentially malignant one and often, this results in delayed help-seeking (Tromp et al., 2005). This concurs with Swain et al's (2012) report that mouth ulcers are always mistakenly treated as minor conditions rather than early symptoms of oral cancer. Participants normalised their symptoms of 'burning sensation' because of eating hot-spicy food and self-inflicted physical trauma such as accidental biting. Furthermore, some participants who experienced high fever, misinterpreted it as the cause of their mouth ulcers instead of vice-versa. This lead them to seek help from a GP for their fever rather than their mouth ulcer.

Although some participants noticed their symptom,

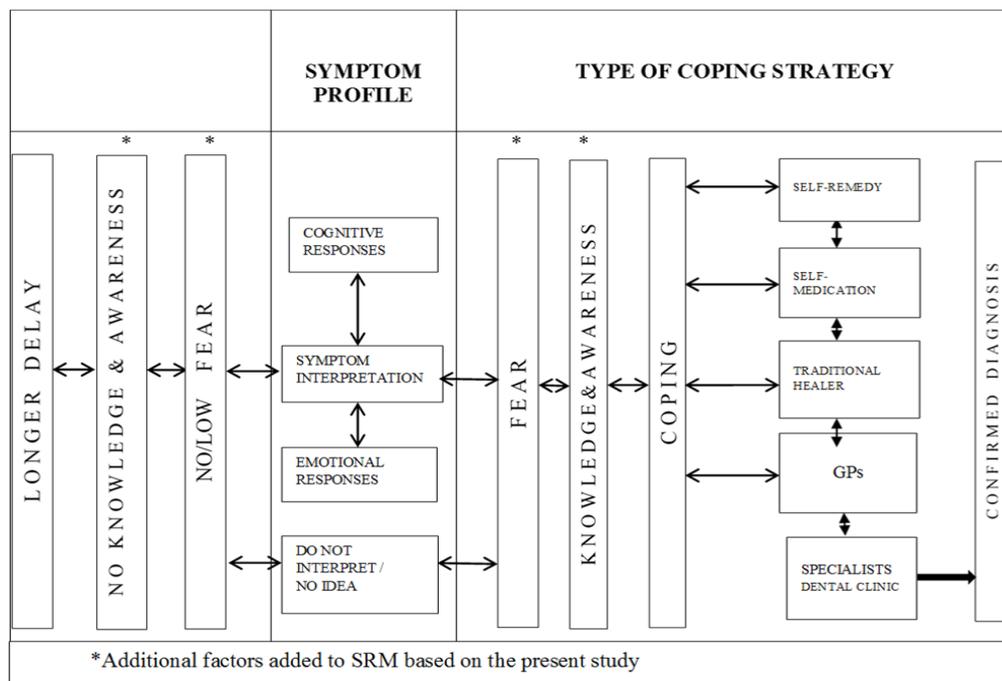


Figure 1. Health- Seeking Pathway of Participants from the Onset of First Symptom Until the Point of Diagnosis (Adapted from the SRM, 1980).

they did not interpret it as an illness due to its' painless nature. This is in accordance with reports by Cuffari et al., (2006) that for mouth cancer, pain is normally associated with lesions of advanced TNM staging and is also said to be the initial symptom that leads to the diagnosis of cancer in previous research (Siqueira et al., 2004). Participants tended to ignore symptoms until it was painful, affected their oral functions, influenced their emotional well-being, and impacted their quality of life. Some participants only realised the existence of their early mouth lesions after it being detected coincidentally by GPs/dentists.

Concurrently, participants also did not show notable emotional responses to symptoms most likely because they normalised their symptoms due to a lack of knowledge about oral cancer. This concurs with Diefenbach and Leventhal's (1996) findings that patients' emotional responses were subtle and ranged from 'annoyance about the potential impacts of the symptom' to 'worrying that the symptom is an indication of something more serious'. However, as their symptoms became severe, their emotional process mirrored that of the SRM which then acted as an essential trigger for them to engage coping strategies.

Based on the present study, a theoretical model was constructed (adapted from SRM) to describe the health-seeking pathway of the participants. This model is meant to describe the process of how participants respond to symptoms until the point of diagnosis (refer Figure 1). Participants resorted to four types of coping strategies, namely self-remedy, self-medication, consulting traditional healers and consulting GPs. The earliest phase of coping strategy was self-remedy. At this phase, participants sought remedies based on their previous experiences or knowledge. Secondly, they practised self-medication by consuming or topically applying

unconventional medicines to treat their self-recognised illness or symptoms. Pills, mouth ointments (eg. Bonjela) and mouthwashes from pharmacies were used by participants as they were easily accessible, cheaper and involved very little time-costs than consulting doctors. Consulting traditional healers was another coping strategy option. In developing countries, for example in Malaysia both Malay traditional healers and Chinese traditional medicine are still relevant and often sought. Merriam and Muhammad (2013) reported that cultural compatibility and widespread presence of traditional healers often result in late presentation, advanced stage diagnosis and a higher mortality rate than in Western countries. Participants eventually consulted GPs from either public or private clinics due to the persistence of the symptom and pain progressively affecting their oral functions. By this time, more often than not the mouth lesion or presence of symptom would have progressed to an advanced TNM stage.

Although there were some participants who immediately consulted GPs after discovering symptoms, majority went through all the aforementioned phases before finally doing so (refer Figure 1). When symptoms persisted or became severe, participants tended to appraise the outcomes of their existing coping strategies. This stage is illustrated as the final phase in the SRM which occurs as an ongoing process undertaken by patients to improve their current situation. 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.

As noted, the self-regulation process is individual-based and influenced by several factors. Socio-economic status

was not shown as a barrier for participants' help-seeking from GPs/ dentists. A reason for this is that medical GP clinics and pharmacies are highly accessible and affordable throughout the country. Additionally, government oral health care facilities in Malaysia is still heavily subsidised, and thus is very affordable for the patients. In this study, findings indicated that educational level and lack of awareness influenced participants' health-seeking behaviour. This may have indirectly affected participants' symptom interpretations and coping strategies. Cultural beliefs and religious practices also influenced health-seeking behaviour and contributed to delay. Consulting traditional healers is still a relevant practice in addition to seeking help from GPs/dentists. Muhamad et al., (2012) and Al-Naggar et al., (2012) reported that such practices are still common among low and middle-income countries. About 80% of Malaysians consult traditional healers at some time in their life for health-related issues whereas some might even simultaneously consult health professionals. Fear intensity is an important factor when facilitating help-seeking behaviour for patients (Dubayova et al., 2010). Two types of behaviour as a result of fear intensity are highlighted in the findings. Fear (of the symptom severity) that triggered positive behaviour eventually lead participants to seek help whereas fear (of injections/doctors) that triggered negative behaviour resulted otherwise. Fear intensity may also be caused by an individual's unrealistic optimism due to his/her healthy lifestyle that eventually leads to 'denial'. Unrealistic optimism is the belief that the problem is preventable by individual actions (Weinstein, 1987) and drives many participants to think that they are less likely to experience oral cancer because they practice a healthy lifestyle. Under many circumstances, unrealistic optimism appears to buffer the immune system from the effects of psychological stressors such as fear. Denial tends to affect health-seeking behaviour resulting in delayed diagnosis.

Overall, the SRM provides a good framework to study health-seeking behaviour and it can be applied to the Malaysian population. However, some aspects may not work in tandem with the self-regulation process. Firstly, participants who did not recognize their symptom were not threatened by it. Non-recognition of symptoms eventually prolongs the process of symptom interpretation and causes delayed diagnosis. Secondly, participants tended to perceive their symptom as non-serious. Thirdly, participants in this study did not take immediate action after discovering their symptom until it was painful. In this case, symptom interpretation was insufficient to motivate individuals to act, clearly indicating that an individual's self-regulation depends on their motivation and sensitivity to maintain their current or future health status.

The process of self-regulation needs a stimulant rather than being a natural process. Fear intensity is a vital trigger for self-regulation (refer Figure 1). Anxiety and worry about the persistence and seriousness of the symptoms instilled a greater fear that triggered participants to seek a cure for their current condition. Low intensity of fear resulted in delayed help-seeking because participants were not threatened by their symptom. Another stimulant

to perform effective self-regulation is knowledge and awareness about the disease (refer Figure 1). In Malaysia, although population awareness of risk habits such as smoking was high via nationwide campaigns by the government and NGOs, the majority remain unaware of early signs and symptoms for oral cancer (Ghani et al., 2013). This lack of knowledge and awareness can inevitably result in symptom misinterpretation.

Limitations of the present study need to be addressed. Firstly, patients were recruited from only public hospitals throughout Malaysia. However, these six hospitals were chosen based on being main regional referral centres which manage most of the oral cancer cases in the country. Secondly, recall bias during the interviews may have been present. Proxies (caregivers) were used during the interview when patients were unable to adequately communicate and provide information. The sample size for this exploratory qualitative study is deemed adequate to answer the research questions. Moreover, the sample were recruited based on a purposive heterogeneous sampling of different ethnicities and geographical areas throughout Peninsula Malaysia, Sabah and Sarawak to allow full representation of Malaysian oral cancer patient diversity.

In conclusion, the health-seeking behaviour of oral cancer patients in Malaysia, (as a developing country) can be explained by the SRM with some modification. The importance of creating and improving oral cancer awareness among the Malaysian public cannot be over emphasised. The role of the Ministry of Health Malaysia with timely involvement from other related agencies would be crucial to achieve this through oral health promotion and awareness campaigns. Besides this, training and equipping GPs with the necessary skills to recognise and detect early oral cancer lesions and subsequently referring patients to the nearest dental clinics is certainly warranted. A standard operating procedure for monitoring pre-cancerous lesions, training and calibration of health-care professionals and pharmacists should be developed to address delay in diagnosis and ultimately improve patients' health outcomes.

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APPENDIX A (Supplement Supporting Data)

List of Probing Questions used by the researcher during the in-depth interviews

SRM Stage 1: Symptom interpretation

Representation of Illness

- Identity-What is the first symptom you encountered?
- Cause-Why did you think it happened?
- Timeline-When you encountered the symptom, in your opinion, were you aware how long the symptom might last?
- Consequences-How much did the symptom affect your life?
- Curability/controllability- Did you think you could keep the symptom under control?

Emotional responses- How did you feel at the moment when you discovered the symptom in your mouth?

SRM Stage 2: Coping strategy

- Approach- What did you do in order to cope with the symptom?
- Avoidance- If you did not predict any serious consequences, did you ignore the symptom?

SRM Stage 3: Appraisal of symptom

Was your coping strategy effective? - What did you do when your coping strategy is ineffective, and the symptom seems persistent? – Did you re-interpret your symptoms?



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