**Public awareness of cancer symptoms and anticipated delay in seeking health care among urban dwellers in Malaysia**

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# ABSTRACT

OBJECTIVES: To evaluate the public awareness of cancer symptoms, perceived barriers to seeking medical help, and their correlates to anticipated delay of help seeking.

METHODS: Using simple random sampling method, we selected 833 households from Community Housing Projects located in metropolitan Kuala Lumpur, Malaysia. The validated Cancer Awareness Measure (CAM) questionnaire was used. Altogether, 2,360 adults fulfilled the age criteria and responded to face-to-face interviews. The analysis of covariance was used to identify the association between demographic, socioeconomic characteristics and knowledge and awareness of cancer symptoms. Binary logistic regression identified the significant determinants of the anticipated delay of help-seeking.

RESULTS: Among 2360 participants, about 70% could not recall any symptom without aided and 25% had anticipated delay for help seeking. Too scared, worried about what doctor will find, and too busy were the highest commonly endorsed barriers to seeking help. The probability of anticipated delay was 29% lower in respondents with higher knowledge of cancer symptoms (Odds Ratio [OR] = 0.71; 95% confidence interval [CI]: 0.68 – 0.74), while it was 49% higher in subjects with any of the emotional barriers (OR = 1.49; CI: 1.32 – 1.68).

CONCLUSIONS: Public awareness of cancer symptoms was low in urban Malaysian and it would subsequently affect health-seeking behaviour. The public education campaigns are needed in order to improve public awareness of cancer symptoms and overcome the emotional barriers. This could further impact on deterring help-seeking for potential cancer symptoms and enhance early diagnosis.

KEYWORDS: cancer; public awareness; Malaysia.

# BACKGROUND

Increasing world’s aging population and adopting unhealthy life style behaviors increase the burden of cancer globally [1]. The global incidence of cancer in 2012 was 14 million and it was forecasted to reach 22 million in next two decades [2]. In 2012, cancer contributed to 8.2 million deaths worldwide, while this figure is expected to reach 13 million in 2032 [2]. Based on GLOBOCAN 2008 report, the majority of new cancer cases (56%) and cancer-related deaths (63%) were occurred in developing economies [3].

In 2008, the most common diagnosed cancers among ASEAN (Association of Southeast Asian Nations) were lung, breast, and liver cancers, whereas the most common causes of cancer mortalities were lung, liver, and colorectal cancers [4]. As an ASEAN country, Malaysia, has a high mortality due to cancer constituting 10.3% of medically certified deaths [5]. The age-standardized incidence rate for all cancers were 137 and 156 per 100,000 in males and females respectively [6]. Similar to other developing nations [7, 8], cancers in Malaysia are presented at late stages [9-11]. For instance, 52.2% of breast cancer patients in Sabah [9], 85% of nasopharyngeal cancer in Sarawak [11], and 77.1% of oral cancer patients in Kelantan sought doctor consultation at their late cancer stages [10]. Cancer presentations at an advanced stage were due to lack of awareness of cancer warning signs, cultural beliefs, and preferences of complimentary and traditional medicine [9].

By early detection and appropriate treatment, about one-third to one-half of deaths due to cancer can be avoided [12]. However, it seems awareness and knowledge of the cancer symptoms of individuals play a significant role in enrollment for cancer screening and prompt help seeking behaviour.

Prior studies conducted in Malaysia assessed the awareness of a particular type of cancer such as cervical [13], breast [14], colorectal [15] and oral cancer [16-19]. However, none of the previous study in Malaysia evaluated the public awareness and knowledge of cancer symptoms in general. The objectives of this study were to explore the awareness of cancer symptoms, identify the barriers to seeking help, and to explore the importance of symptoms awareness and barriers on anticipated delay for help-seeking.

# METHODS

## Design Setting and Data Collection

A cross-sectional survey was carried out in four out of six Community Housing Projects (in Malaysian local language: Projek Perumehan Rakyat [PPR]) located in Lembai Pantai area, Kuala Lumpur.

From four randomly selected PPRs (i.e., including 4728 households), we selected 833 households (i.e., consisting of 3722 individuals) using simple random sampling method. Then, individuals who aged 18 years and above from selected households were recruited for cancer awareness survey. Altogether, 2360 adults fulfilled the age criteria and responded to CAM questionnaire. Written consents were taken from all participants. Ethics application was approved by the University of Malaya Medical Centre; Medical Ethics Committee (Ref. no. 890.161). This survey was conducted from February to November 2012.

## Sample Size

We considered the following assumptions to calculate the sample size. The urban population in Kuala Lumpur to be five million; the true frequencies of the surveyed population to lie between ± 5% of confidence limits; power to be 80%; and, the confidence interval to be 95%. We assumed that at least 50% of our population is aware of one or more cancer symptoms. The calculated sample size was 384. However, to increase the accuracy of our analysis, we included all eligible participants from the household survey. The sample size was determined by OpenEpi online program [20].

## Study Tool

We conducted this study using the cancer awareness measure (CAM) which was designed by Cancer Research UK [21]. This research tool, evaluates the awareness and knowledge of cancer warning signs, idefines the help-seeking barriers, and evaluates the speed of seeking consultation from a doctor. The original CAM questionnaire was translated into local language Bahasa Melayu. Forward and backward translation were performed by independent individuals.

Before conducting the survey, face validity was done with 30 respondents. The intentions were: 1) to assess the comprehensiveness, simplicity, understandability, and clarity of the questionnaire; 2) to diagnose whether there is any inappropriate, redundant or missing items included that may dilute the contents; 3) to evaluate how likely the questionnaire addresses the research objectives; 4) to find the relevancy, flow, arrangement, and proper wording of the inquiries. The internal reliability, assessing by Cronbach’s α, was 0.95 indicating that the questionnaire items measured the same construct. We conducted face to face interviews both pilot testing and survey by using trained interviewers.

*Awareness of warning signs and symptoms*. Awareness (recall) was evaluated using the open question, which emphasizes cancer signs that are remembered. Knowledge (recognition) was assessed using the closed questions, which focuses on guessing and identification of the warning signs of cancer. In closed questions, all questions were illustrating cancer signs. The phrase used for the open question was: ‘There are many warning signs and symptoms of cancer. Please name as many as you can think of.’ The closed question was worded as: ‘The following may or may not be a warning sign for cancer. We are interested in your opinion.’ The items included nine cancer signs including: unexplained lump or swelling, unexplained pain, unexplained bleeding, persistent cough or hoarseness, persistent change in bowel or bladder habits, difficulty swallowing, change in the appearance of a mole, sore that does not heal, and unexplained weight loss. A scoring system for the recall and recognition of cancer symptoms was developed where each correct answer was given a point. The awareness and knowledge of cancer symptoms were then summed and averaged based on different demographic and socioeconomic characteristics.

*Help seeking barriers*. Barriers to help-seeking were divided into three main groups of ‘emotional,’ ‘practical,’ and ‘service’ domains each of which had three components—overall nine items. For instance, ‘I would be too embarrassed,’ ‘too busy,’ and ‘not wanting to waste doctor’s time’ were examples of emotional, practical, and service items. The response options to these questions were ‘No,’ ‘Yes,’ and ‘Yes often,’ which the latter ones were combined as definite desirable answers. The correct responses were analyzed both individually and as a group (i.e. summation).

*Anticipated delay*. The speed of seeking help from a doctor was measured using an open question asking: ‘If you had a symptom that you thought might be a sign of cancer, how soon would you contact a doctor to make an appointment to discuss it?’ We, then, categorized the response to this question to more than 2-weeks (i.e. delayed) and otherwise (i.e. not delayed).

## Demographic and Socioeconomic Variables

The demographic variables included age (in years), gender, marital status (i.e., single, married, divorced, and widow/widower), and ethnic/race (i.e., classified under Malay, Indian, and Chinese/others—we combined the last two groups as the observations were too few). The socioeconomic status (SES) variables were monthly income, highest education obtained, and occupational status. The classifications for income levels were below 1,000 RM; 1,000–1,999RM; 2,000–2,999RM; and, above 3,000 RM. The highest education obtained was categorized as none (no official education); primary (1–6 years); secondary (7–12 years); and, tertiary (above 13 years). Finally, occupational statuses were grouped as paid-employee, self-employed, retired, the house maker, and others [22, 23]. The others included students, traineeship or apprenticeship.

## Statistical Analysis

Descriptive analyzes were conducted for demographic and SES characteristics of respondents as well as for the components of the help-seeking barriers. The average (95% confidence intervals) and analysis of covariance (ANCOVA) were used to assess the demographic and SES difference of cancer awareness and knowledge levels. Finally, binary logistic regression was used to identify the significant determinant of the anticipated help-seeking delay. We analyzed our data using Stata v11.2 (Stata Corp., USA).

# RESULTS

## Sample and characteristics

Respondents’ demographic and socioeconomic characteristics were described in Table 1.

[Table 1 here]

**Awareness and knowledge of cancer warning signs and symptoms**

Among 2360 participants, about 69.7% could not recall any warning sign without aided and 22.1% could not recognize any warning sign of cancer. Figure 1 illustrates the awareness of cancer warning signs among participants. Unexplained lump or swelling was the most recognized (61.9%) and recalled (18.4%) cancer symptom, which was followed by persistent unexplained pain (recognized: 56.3%; recalled: 9.5%) and unexplained bleeding (recognized: 52.2%; recalled: 7.1%).

[Figure 1 here]

Awareness (recall–the open question) among participants was very poor as none of the sub-categories’ averages could reach one (i.e. awareness of at least one cancer symptom). For instance, the lowest awareness was among participants with no education (mean: 0.18; 95% Confidence Interval [CI]: 0.12 – 0.24) and others occupation group (mean: 0.29; CI: 0.24 – 0.33). In addition, analysis of covariance (ANCOVA) showed that the awareness of cancer symptoms differs significantly among education levels as well as occupational statuses. The knowledge of cancer signs (recognition –closed questions), however, was remarkably higher than awareness of them. In assessing the number of warning signs recognized, elder respondents (mean65 and over = 2.47; CI: 2.03 – 2.91) significantly recognized less symptoms comparing to younger people (mean25-34 = 4.81; CI: 4.22 – 4.73), males (3.84; CI: 3.66 – 4.02) did worse than females (4.06; CI: 3.89 – 4.23), Chinese/others had scored lowest (3.58; CI: 2.74 – 4.41) compared to other ethnic/race groups. In addition, respondents with no education (1.94; CI: 1.54 – 2.34), and participants with 1000 to 1999RM monthly salary (3.68; CI: 3.48 – 3.88) had significantly lower knowledge in comparison to other sub-categories of education and income levels respectively. Finally among occupational status classifications, the others category had the minimum knowledge score (3.20; CI: 2.94 – 3.47) comparing to the rest. However, ANCOVA showed that demographic and SES variables were significant independent predictors of the knowledge of cancer signs except the marital status (see Table 2).

[Table 2 here]

## Help Seeking Barriers

Among the respondents, 75% would seek help within two weeks if presented with any warning signs cancer and the mean duration for seeking help after noticing possible cancer symptoms was 1.5 (±2.3) weeks. And the rest, 25% had anticipated delay in help seeking.

Emotional barriers were the highest endorsed barriers to seeking consultation from a Doctor. For instance, about 26.5% of the respondents claimed to be *‘Too Scared’* and 21.7% to be *‘Worried about What Doctors Will Find.’* While, 11.2% claimed to have *‘Difficulty Making an Appointment,’* as a most frequent service barrier and 14.7% endorsed *‘Too Busy’* as the main practical barrier (see Table 3). Existence of one or more emotional barrier was the most serious obstacles to seeking consultation. Among 589 who expressed anticipated delay in help seeking, 34.13% had a least one emotional barrier while 19.52% and 15.28% had at least one practical and service barrier.

[Table 3 here]

## Delay in Seeking Help

Table 4 illustrated the result from the logistic regression identifying the determinant of the delay in seeking help. It revealed that when adjusting for all demographic and socio-economic variables, each unit rise of cancer symptoms knowledge score, the help-seeking delay would reduce by 29% (OR= 0.71; 95% CI: 0.68 – 0.74). In addition, any increment in emotional barriers would increase the likelihood of delay seeking consultation by 49% (OR = 1.49; CI: 1.32 – 1.68).

[Table 4 here]

# DISCUSSION

Our findings showed public awareness and knowledge of cancer symptoms among urban Malaysian are low. This is in line with the studies conducted for specific cancers [15, 16, 24] and the general cancer awareness study conducted among Malaysian undergraduate student [25]. The findings showed that 94.4% of Malaysian undergraduate university students had low awareness and 64.9% had low knowledge of cancer symptoms [25]

However, the score of knowledge (recognition) of cancer warning signs was higher than the score of awareness (recalling). This is consistent with previous studies [26, 27]. According to the nature of study, the participants were asked to answer the warning signs spontaneously. Some people might face difficulty in recalling within limited time so that it resulted in lower scores [26]. For recognition, people could reflect their personal experience and information about cancer and were able to judge whether it is a cancer warning sign or not. In addition, recalling the cancer symptoms would be difficult for people who belong to lower education levels or elderly participants who have cognitive impairment [26]. However, finding of our study showed that there was no age difference in recalling cancer symptoms. Even the younger population had difficulty in recalling the symptoms so as elderly. Nevertheless, the younger respondents in our study had higher score in recognition of symptoms compared to older adults and elderly. Robb et al. [26] found that elderly people had recognized more of the warning signs, whereas we found relatively higher scores in younger respondents which is in line with a previous study which found a decreasing recognition of cancer warning signs and increasing age [27]. The lower levels of awareness and knowledge among senior citizens of Malaysia are worrisome since the chance of getting cancer increases by age.

Education level and occupation status were significantly associated with both awareness and knowledge of cancer symptoms. Similarly, marital status did not play important role for both recall and recognition of symptoms. However, age, gender, and income level had significant association with knowledge of cancer symptoms but not with awareness. Our results generally tallied with previous findings as females [24, 25], higher education levels [24-26], and respondents with regular income (paid-employees) recognized more symptoms of cancer [22].

The ethnicity background of our study participants also played a significant role in recognition of the cancer symptoms where awareness among Indian was higher comparing to Malay ethnic group. This was in line with previous findings in which they emphasized on the ethnic disparities in the awareness of cancer warning signs and suggested ethnicity-based health promotion policies to narrow the gap of awareness among different ethnic groups [28, 29].

The anticipated delay in seeking help was highly associated with recognition of warning signs and emotional barriers. Having good knowledge of cancer symptoms significantly associated with less anticipated delay in help seeking. However, having at least one of the emotional barriers increased the predicted delay [25, 28, 30]. This finding magnifies the importance of recognition (knowledge) of cancer warning signs compared to recall (awareness) or memorizing them. Our results suggest that once a symptom is correctly recognized as a warning sign of cancer, people would not be delaying in seeking professional advices. We did not find any relationship between the anticipated delay and recall of cancer symptoms (awareness), practical, and service barriers that are in line with previous findings [26, 28].

The major obstacles in anticipated delay for help-seeking among our respondents were the emotional barriers. Previous studies in Spain [31] and UK [26] also claimed the psychological fear and worrying about the results of the tests which form emotional barriers stop them from consulting with a doctor. Being *‘too scared’* was the most mentioned emotional barrier in our study, followed by *‘worried what doctor will find’.* These findings were in line with previous studies in which they found the emotional barriers are the toughest barriers to overcome before seeking help from a professional [26, 31]. Robb et al. [26] assumed that the reason behind emotional barriers may be due to the lack of confidence to judge whether their symptom needs medical attention. This assumption was supported by a study conducted in rural Malaysia that there was a significant positive correlation between the knowledge score of warning signs and level confidence in judging whether to seek medical advice or not [15].

# CONCLUSION

Our findings indicated that people from different socioeconomic positions had different levels of knowledge and awareness on cancer warning signs and it would subsequently affect health-seeking behaviour. The public education campaigns are needed in order to improve public awareness of cancer symptoms and overcome the emotional barriers. This could further impact on deterring help-seeking for potential cancer symptoms and improve early presentation.

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Table 1 Demographic characteristics and socioeconomic status of the study (n=2360)

|  |  |
| --- | --- |
|  | Percentage |
| Age (yrs., SD) | 39.8 (± 16.4) |
| Gender |  |
| *Male* | 47.1 |
| *Female* | 52.9 |
| Ethnicity |  |
| *Malay* | 82.4 |
| *Indian* | 15.5 |
| *Chinese / Others* | 2.1 |
| Marital Status |  |
| *Single* | 34.3 |
| *Married* | 56.7 |
| *Divorced* | 5.0 |
| *Widow* | 4.0 |
| Education Level |  |
| *None* | 7.9 |
| *Primary* | 14.8 |
| *Secondary* | 64.9 |
| *Tertiary* | 12.4 |
| Income Level |  |
| *<1000* | 18.2 |
| *1,000-1999* | 38.9 |
| *2000-2999* | 24.5 |
| *≥3000* | 18.7 |
| Occupation Status |  |
| *Paid Employee* | 47.2 |
| *Self-Employed* | 9.8 |
| *Retiree* | 2.8 |
| *Housewife* | 16.9 |
| *Others* | 23.5 |



Figure Awareness of warning signs and symptoms (n = 2360)

**Table 2 Analysis of covariance for recall and recognition of the cancer warning signs**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Awareness (Recall)  score [0 to 9] | | Knowledge (Recognition)  score [0 to 9] | |
| Demographic Groups | **Mean (95% CI)** | ***P*** | **Mean (95% CI)** | ***P*** |
| Age (years) |  |  |  |  |
| *18-24* | 0.37 (0.32 – 0.42) |  | 4.23 (3.95 – 4.50) |  |
| *25-34* | 0.42 (0.36 – 0.49) |  | 4.81 (4.22 – 4.73) |  |
| *35-44* | 0.38 (0.31 – 0.44) |  | 3.97 (3.70 – 4.24) |  |
| *45-54* | 0.44 (0.37 – 0.50) |  | 4.05 (3.77 – 4.32) |  |
| *54-64* | 0.35 (0.27 – 0.43) |  | 3.13 (2.75 – 3.51) |  |
| *65 and over* | 0.33 (0.23 – 0.43) | F(5, 2360) = 0.72 | 2.47 (2.03 – 2.91) | F(5, 2360) = 3.14\*\* |
| Gender |  |  |  |  |
| *Male* | 0.39 (0.35 – 0.44) |  | 3.84 (3.66 – 4.02) |  |
| *Female* | 0.39 (0.35 – 0.43) | F(1, 2360) = 0.37 | 4.06 (3.89 – 4.23) | F(1, 2360) = 3.58\* |
| Ethnicity |  |  |  |  |
| *Malay* | 0.39 (0.36 – 0.42) |  | 3.87 (3.73 – 4.00) |  |
| *Indian* | 0.40 (0.34 – 0.47) |  | 4.50 (4.18 – 4.82) |  |
| *Chinese / Others* | 0.30 (0.13 – 0.46) | F(2, 2360) =0.58 | 3.58 (2.74 – 4.41) | F(2, 2360) = 9.68\*\*\* |
| Marital Status |  |  |  |  |
| *Single* | 0.36 (0.32 – 0.41) |  | 4.02 (3.80 – 4.23) |  |
| *Married* | 0.40 (0.36 – 0.44) |  | 4.01 (3.85 – 4.17) |  |
| *Divorced* | 0.40 (0.28 – 0.52) |  | 3.47 (2.91 – 4.02) |  |
| *Widow* | 0.48 (0.33 – 0.64) | F(3, 2360) = 2.22 | 3.34 (2.75 – 3.92) | F(3, 2360) = 0.73 |
| Education Level |  |  |  |  |
| *None* | 0.18 (0.12 – 0.24) |  | 1.94 (1.54 – 2.34) |  |
| *Primary* | 0.30 (0.24 – 0.36) |  | 3.24 (2.93 – 3.54) |  |
| *Secondary* | 0.43 (0.39 – 0.46) |  | 4.20 (4.04 – 4.35) |  |
| *Tertiary* | 0.45 (0.36 – 0.54) | F(3, 2360) = 8.69\*\*\* | 4.87 (4.53 – 5.22) | F(3, 2360) = 23.01\*\*\* |
| Income Level |  |  |  |  |
| *<1000* | 0.41 (0.35 – 0.48) |  | 3.79 (3.53 – 4.06) |  |
| *1,000-1999* | 0.38 (0.34 – 0.42) |  | 3.68 (3.48 – 3.88) |  |
| *2000-2999* | 0.37 (0.31 – 0.43) |  | 4.36 (4.10 – 4.61) |  |
| *≥3000* | 0.42 (0.35 – 0.49) | F(3, 2360) = 1.10 | 4.17 (3.87 – 4.47) | F(3, 2360) = 3.73\*\* |
| Occupation Status |  |  |  |  |
| *Paid Employee* | 0.44 (0.40 – 0.49) |  | 4.43 (4.25 – 4.60) |  |
| *Self-Employed* | 0.37 (0.29 – 0.46) |  | 3.46 (3.09 – 3.84) |  |
| *Retiree* | 0.63 (0.40 – 0.86) |  | 3.66 (2.93 – 4.38) |  |
| *Housewife* | 0.36 (0.30 – 0.42) |  | 4.04 (3.75 – 4.32) |  |
| *Others* | 0.29 (0.24 – 0.33) | F(4, 2360) = 4.54\*\*\* | 3.20 (2.94 – 3.47) | F(4, 2360) = 6.27\*\*\* |

\* p <0.05; \*\* p <0.01; \*\*\* p <0.001

**Table 3 Help-Seeking Barriers and Delay to Seek Consultation (n=2360)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yes (%) | No (%) | Do not Know (%) |
| Emotional |  |  |  |
| Too Embarrassed | 14.5 | 77.3 | 8.3 |
| Too Scared | 26.5 | 63.4 | 10.1 |
| Worried What Doctor Will Find | 21.7 | 68.0 | 10.3 |
| Service |  |  |  |
| Worried about Wasting Doctor’s Time | 5.0 | 85.0 | 10.0 |
| Difficult to Talk with Doctor | 8.9 | 81.0 | 10.1 |
| Difficult to Make an Appointment | 11.2 | 78.8 | 10.0 |
| Practical |  |  |  |
| Too Busy | 14.7 | 75.2 | 10.1 |
| Many Things to Worry About | 14.6 | 75.3 | 10.1 |
| Difficult to Arrange Transport | 8.1 | 81.9 | 10.0 |

1. At least one of the barrier components exists

**Table 4 Logistic Regression Analysis Results Predicting Delay in Help-Seeking**

|  |  |  |
| --- | --- | --- |
|  | OR1 (CI2) | Prob. |
| Awareness | 0.92 (0.77 – 1.11) | 0.421 |
| Knowledge | 0.71 (0.68 – 0.74) | <0.001 |
| Having an Emotional barrier | 1.49 (1.32 – 1.68) | <0.001 |
| Having a Practical barrier | 0.85 (0.70 – 1.02) | 0.095 |
| Having a Service barrier | 0.95 (0.77 – 1.17) | 0.650 |

1. Odds Ratios were adjusted for all demographic characteristics and socioeconomic status variables; 2. 95% Confidence Interval.