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AN ANALYSIS OF CANCER AWARENESS AND STIGMA AMONG MALAYSIA'S NON-PATIENT POPULATION

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Abstract

Cancer is one of the world's top ten deadliest diseases. The initial shock of being diagnosed with cancer is followed by an understanding of the enormous physical, emotional, and spiritual challenges that lie ahead. Aside from the emotional turmoil that comes with a cancer diagnosis, patients must devise a strategy to deal with and combat the disease. This study is looking into the level of cancer awareness and stigma among Malaysia's non-patient population. Low rates of cancer screening and awareness, delays in seeking medical attention, slow detection and diagnosis times, and insufficient access to high-quality care continue to influence people's willingness to go for cancer screening and treatment, causing the country's cancer survival rates to fall below the global average. As a result, increase public awareness campaigns about cancer screening and health information are needed, particularly in rural areas. These initiatives and activities have the potential to improve public access to resources for cancer screening and treatment in rural areas, particularly for people who are at high risk. In light of the growing number of cancer patients, this study may aid the government and policymakers in examining the elements and causes so that people can become more aware of cancer and improve their level of awareness. Finally, this research will benefit people's well-being and align with the social re-engineering dimension highlighted in Malaysia's 12th Plan.

Keywords: Cancer, cancer awareness, cancer stigma, non- patient population, Malaysia

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1. Background

Cancer is a significant issue affecting the public's health in every region of the world. It is still the leading cause of premature death and illness in Malaysia, which has a significant impact on both the local community and the country's medical care system. According to Globocan (2020), the World Health Organization reported that there were 48,639 new cases of cancer in Malaysia in 2020, and it is anticipated that the cancer incidence in Malaysia will double by the year 2040. Comparing the findings of the Malaysia National Cancer Registry Report for the years 2007–2011 to those of the 2012–2016 report revealed that there was an 11.3% increase in the number of newly diagnosed cases of cancer as well as a nearly 30% increase in the number of deaths caused by cancer (Yusof & Wan Ishak, 2022). In addition, the World Health Organization found that breast cancer is the most prevalent type of cancer in Malaysia, followed by colorectal, lung, nasopharyngeal, and liver cancers. About half of all cancer cases reported to the Malaysia National Cancer Registry are breast, colorectal, and lung cancers (Globocan, 2020). One of the main causes of death for cancer-stricken Malaysian women is breast cancer, followed by cervical cancer. People who have cancer, the communities in which they live, and the national health care system are all being put under a great deal of mental, emotional, and financial strain as the number of cancer cases in the country continues to rise. This will eventually become a major public health concern.

Even though Malaysia is an upper-middle-income nation with a robust healthcare system and effective socioeconomic initiatives, the country's cancer survival rates remain below the global average. This is brought on by a number of obstacles that cancer patients must overcome, such as low rates of cancer screening and awareness, delays in seeking medical attention, slow detection and diagnosis times, and insufficient access to high-quality care (Yusof & Wan Ishak, 2022). Due to the fact that cancer centres are typically only found in major cities, these barriers are particularly common for people who live in rural areas. As for instances, few states in Malaysia such as Perlis, Pahang, and Terengganu do not have any cancer centres, and it can take several hours to a full day, if not longer, to travel to a cancer centre in a major city (Yusof & Wan Ishak, 2022). Some cancer patients may pass away without receiving any cancer treatment because they lack the means to travel to these facilities.

Lack of awareness among the public contributes to cancer cases being reported late to healthcare facilities (Sahu et al., 2020). The importance of cancer awareness has been emphasised as a way to ensure behaviour that supports early detection, while a lack of awareness has been seen as a barrier to this goal (Jayant et al., 1995). As a result, effective prevention, early detection, and increased public awareness must be prioritised in Malaysia's cancer control programme. Additionally, many people in Malaysia are terrified of cancer, but the general public's awareness and knowledge of the warning signs and symptoms of common cancers is still lacking. This is despite the fact that many people in Malaysia are terrified of cancer. In point of fact, despite the fact that cancer can be treated, there are still Malaysians who believe that receiving a cancer diagnosis is equivalent to "receiving the death penalty."

To date, most of cancer awareness studies conducted in Malaysia have generally focused on a single state and/or a specific type of cancer (Keng et al., 2015; Su et al., 2013). As a result, there is a lack of understanding about cancer awareness levels across the country. Poor awareness and knowledge of common cancers is likely to contribute to a delay in seeking help (Waller et al., 2009), diagnosis, and treatment, leading to poor survival outcomes (Niksic et al., 2016). In order to create health promotion

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interventions that will decrease the incidence of cancer and improve early detection and outcomes, it is crucial to assess the awareness levels and knowledge gaps (Koo et al., 2020).

On the other hand, A person's reputation can be damaged by stigma, which transforms them "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 12). Stigma is a trait that carries a negative connotation. This underlines two crucial aspects of stigma, the first of which is the trait that distinguishes one person from another, and the second of which is the devaluation of the individual on the basis of this distinguishing trait (Dovidio et al., 2000). Cancer stigma is perpetuated by a lack of awareness, which fuels many myths and misconceptions about the disease (Pahwa et al., 2005). This stigma affects how people think about cancer, which makes it hard to control, starting with prevention and moves on to treating symptoms.

Despite the importance of studying cancer-related stigma among the general public, relatively few research has done so. Fear of being judged has been found to be a potential barrier to self-examination, screening, and early reporting of cancer symptoms (Azaiza & Cohen, 2008; Kwok & Sullivan, 2006). If cancer stigma could be measured, it would be possible to find out how widespread it is, see how people's views on cancer change in response to public health campaigns or media attention, and find out what makes people more likely to have stigmatised beliefs (Marlow & Wardle, 2014). This research was conducted in order to gain a thorough understanding of public perceptions of cancer and its stigma, particularly among non-patient populations. The results of this study will benefit a wide range of parties, including the ministry of health in determining the current level of public awareness of cancer, the government in planning future budget initiatives or campaigns, academicians in contributing to the existing literature, and the general public, including patients and non-patients, in raising awareness and fostering tolerance and unselfishness. As a result, public awareness on cancer would aid in its future prevention and early detection and safe the life of many people.

2. Methodology

This study uses a questionnaire survey as the primary method of data collection, which is a quantitative research design. Two sets of questionnaires were created using Google Forms and sent to the respondents via email and telegram group. A preliminary set of questionnaires was created to gauge public awareness of cancer. An item pool for the second set of questionnaires was created using data from earlier studies on illness-related stigma in the general population.

2.1. Cancer awareness

The purpose of this questionnaire is to determine the level of cancer awareness. The structured questionnaire consisted of two sections; the first section comprises of the socio-demographic data of respondents; meanwhile section 2 pertains the respondents' awareness towards cancer. For the cancer awareness section, the respondents need to answer 'Yes' or 'No' for the question given. The total of 101 respondents were willing to respond and complete the survey. Descriptive statistics was then carried out on the demographic profiles of the respondents and on the cancer awareness questions to access the percentage, particularly on their awareness towards cancer.

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2.2. Cancer stigma

The purpose of this questionnaire is to determine the cancer stigma in the non-patient population. The online survey was carried out using Google Forms. The link was sent to the respondents via email and telegram group. The questionnaires were divided into two sections. The first section covered on the demographic questions, where the second section covered on the cancer stigma questions, which consist of six variables that contribute to stigmatisation including awkwardness, avoidance, perceived severity, policy opposition, personal responsibility, and financial discrimination. For second section, an item pool was created based on past studies into illness-related stigma in the public. The scales on illness-related stigma were discovered based on a systematic review by Van Brakel (2006), that used the search terms "scales," "measurement," or "evaluation," as well as "stigma" or "discrimination." Items were organised into six topics and then assessed to ensure they contained all pertinent stigmatising characteristics (Jones et al., 1984). Each attitude statement was written so that it could be rated on a 5-point scale: strongly disagree, disagree, neutral, agree, and strongly agree. A total of 101 respondents were willing to respond and complete the survey. Descriptive statistics was carried on the demographic profiles of the respondents and for each variable of cancer stigma questions.

3. Discussion and Findings

These questionnaires been answered by 101 non-patients' respondents in Malaysia through online with two major determinants which are Cancer Awareness and Cancer Stigma.

3.1. Discussion on cancer awareness among non-population patient in Malaysia

3.1.1. Discussion on how to detect cancer

According to a study published in the journal BMC Public Health, certain lifestyle variables like excessive weight, alcohol use, physical inactivity, and smoking have an impact on the cancer burden in Malaysia. If these risk factors are addressed, many cancers may be prevented from developing. The survey shows that in Malaysia, there is a nearly equal distribution of people who know how to detect cancer. More than 50% appear to be aware of how to detect cancer; almost half still do not know anything about it. Due to this, the early detection cancer program campaign in Malaysia was quite unsuccessful. Perhaps there is still a low level of societal acceptance for early cancer detection in Malaysia due to two major determinants, which are knowledge, and consciousness may be the factors that approximately 50% of people are still unaware of the Ministry of Health of Malaysia's aggressively marketed early cancer detection programme. In Belgaum, Sankeshwari et al. (2016) discovered that oral cancer awareness was at its greatest level (93.5%), followed by Agrawal et al. (2012) with 91%, Gopinath Thilak et al. (2015) with 86.9%, and Elango et al. (2009) with 86%. The ease of access to many sources of information on cancer had an impact on the level of cancer awareness. Malaysia offers screening for breast, cervical, colorectal, and prostate cancers, but the proportion of people who do so on a regular basis is far from satisfactory. A lack of understanding about the various cancer screening methods, cultural attitudes, and a lack of encouragement from family members and primary care physicians are some of the primary factors that contribute to the low response rate to cancer screening (Yusof & Wan Ishak, 2022).

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3.1.2. Discussion on early cancer detection program

The National Strategic Plan for Cancer Control Program was established in 2016 with the purpose of placing a greater emphasis on access to cancer care, cancer diagnosis, cancer treatment, and cancer research. Oncologists have begun to visit hospitals in states without oncology facilities to give their knowledge and decrease waiting times for persons with cancer there. The government is also attempting to enhance access to pharmaceuticals by making them more inexpensive for patients (Yusof & Wan Ishak, 2022). On the other hand, previous discussion focused on raising knowledge of early cancer diagnosis, but with that degree of awareness comes the question of how early cancer may be found. This aspect of the research is crucial and will aid in the prevention of cancer in more people. 51% of respondents appear to be aware that cancer can be detected early, which can help them prevent getting cancer. This suggests inferentially that a programme for early cancer detection will not endanger their ability to confront and manage the disease. Given that raising public knowledge of cancer is an essential part of the cancer control programme, careful assessment of the information's source may be helpful. Due to the lack of community discussion and advertising, outdoor patients can be seen as a chance to raise awareness for cancer. Campaigns to raise awareness may be a more effective strategy to inform the public. Cancer education for the general public needs to be prioritised. Utilizing the internet and the media effectively can help spread awareness (Glynn et al., 2011; Saleh et al., 2012).

3.1.3. Discussion on family /relative members suffering of cancer

You might be concerned about how your family and friends will react to cancer diagnosis. The complicated emotions and lifestyle changes brought on by a cancer diagnosis can be stressful for you and the people you care about. It may be possible for you to take action to develop and uphold healthy, symbiotic connections throughout this trying period if you have a clear understanding of the potential changes in how you interact to particular family members and friends. As shown in Table 1, the study found that 36.3 % of the respondents reported having cancer in their family. It is strongly advised that everyone with a family history of cancer get screened as soon as possible. This is because it has been scientifically established that a family history of the disease may have a significant role. According to data from medical facilities, the likelihood that someone would develop cancer in the future is 60% higher when family members have a history of the disease. People with a family history of cancer require more frequent early detection than people without a cancer-stricken relative. It may serve as a helpful reminder to begin living a healthy lifestyle by eating nutritious meals and avoiding those that may cause cancer contributor.

Table 1. Cancer Awareness among Non-Population Patient in Malaysia

Items	Yes	No
Did you know how to detect cancer?	47.53%	52.47%
Did you know about early cancer detection program?	50.59%	49.41%
Did you know how to detect cancer at early stage?	50.00%	50.00%
Is there any of your family/relative been diagnose with cancer?	36.26%	63.74%

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3.2. Discussion on cancer stigma among non-population patient in Malaysia

This study analyses Cancer Stigma Score among non-population patient in Malaysia. The six variables that contribute to stigmatisation include "awkwardness, avoidance, perceived severity, policy opposition, personal responsibility, and financial discrimination". The final cancer stigma score is made up of 23 items and is determined by these criteria. These mechanisms have acceptable to good levels of internal and test-retest reliability and are consistent with the stigma literature.

Table 2. Mean Score for Cancer Stigma among Non-Population Patient in Malaysia

Items	Mean
Awkwardness	
1. I would feel at ease and comfortable around someone with cancer.	3.52
2. I would find it difficult being around someone with cancer	2.16
3. I would find it hard to talk to someone with cancer	2.23
4. I would feel embarrassed discussing cancer with someone who had it	2.35
Mean	**2.56**
Severity	
1. Once you've had cancer you're never 'normal' again	2.35
2. Having cancer usually ruins a person's career	3.03
3. Getting cancer means having to mentally prepare oneself to death	3.16
4. Cancer usually ruins close personal relationships	2.81
5. Cancer devastates the lives of those it touches	2.16
Mean	**2.70**
Avoidance	
1. If a colleague had cancer, I would try to avoid them	1.52
2. I would distance myself physically from someone with cancer	1.55
3. I would feel irritated by someone with cancer	1.35
4. I would feel angered by someone with cancer	1.32
5. I would try to avoid a person with cancer	1.48
Mean	**1.45**
Policy opposition	
1. More government funding should be spent on the care and treatment of those with cancer	4.45
2. Increased spending on cancer services is a waste of money	1.81
3. The needs of people with cancer should be given top priority	4.45
Mean	**3.57**
Personal responsibility	
1. A person with cancer is accountable for their condition	2.65
2. If a person has cancer, it's probably their fault	1.84
3. A person with cancer is to blame for their condition	1.45
Mean	**1.98**
Financial discrimination	
1. It is acceptable for financial institutions to refuse to make loans to people with cancer	1.94
2. Financial institutions should be allowed to refuse mortgage applications for cancer -related reasons	2.42
3. It is acceptable for insurance companies to reconsider a policy if someone has cancer	3.68
Mean	**2.68**
Overall Mean	**2.95**

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3.2.1. Discussion on cancer stigma (awkwardness) among non-population patient in Malaysia

The cancer stigma scale was also used to gauge awkwardness, or whether individuals feel at ease around someone who has the disease. The mean score of 2.56 in table 2 represents the general public's willingness to accept cancer sufferers. It may not be a good attitude to avoid connecting with someone who has cancer when they should help and motivate the sufferers to receive better care. According to a study by Vrinten et al. (2019), between 10% and 17% of people reported feeling uneasy around cancer patients. The awkwardness scale mean scores of female students were found to be greater than those of male students (Çevik et al., 2022).

3.2.2. Discussion on cancer stigma (severity) among non-population patient in Malaysia

The severity factor assesses the belief that learning one has cancer will be terrible. Responses on the severity subscale may be modified given the public's improved understanding of the efficacy of cancer therapies. The feeling of dread is described as "seeing cancer as no mere disease but a demonic enemy makes cancer not just a serious disease, but a shameful one" based on table 2 mean's score group item analyses 2.70 the willingness among public to reject a severity as a factor in stigmatisation. The severity factor assesses the belief that learning one has cancer will be terrible. In reality, the general public is of the opinion that responses on the severity subscale may be adjustable due to increased awareness of the efficacy of cancer treatments. According to Vrinten et al. (2019) Although stigma around cancer is generally low, some parts are more pervasive than others. With regard to cancer screening uptake, stigma is more pervasive in some population categories.

3.2.3. Discussion on cancer stigma (avoidance, policy opposition and financial discrimination) among non-population patient in Malaysia

It would be interesting to consider the differences amongst malignancies. Since the term "cancer" covers a wide range of illnesses, it's possible that different malignancies are seen in varied ways. The previous studies findings revealed that individuals who rated their lifestyle as their top risk factor for developing cancer scored higher on the sub-scale for personal accountability. However, the generalisations we can draw from this are rather constrained because each tumour has a distinct origin. Because of its association with a behavioural aetiology (smoking) and poor prognosis, lung cancer is seen to be more stigmatised than other malignancies, according to studies including patients and medical experts. Studies with patients have indicated that some malignancies with a known behavioural aetiology receive more blame attributions than others, which is consistent with prior findings. As overall judgement, these three determinants should be investigating further especially the policy related to cancer patients on how the policy can ease the process of lifestyle as cancer patients.

Perhaps, cancer patients should be given extra consideration rather than discriminate in terms of financial assistance to ensure the treatment process goes smoothly and the patient will have good motivation with “Zero Cancer Worries Community”. In addition, public should be educated with cancer symptoms in details to make them aware and being helpful rather than being avoidance and skeptical

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about cancer patients. Cancer-related distress and avoidance are linked to a person's health issues (Ohlsson-Nevo, et al., 2020). Patients suffering from cancer may experience a wide variety of symptoms (Reeve et al., 2014), and it is the responsibility of healthcare providers to identify these patients and provide them with effective treatment as well as supportive care in order to improve patients' quality of life and reduce the likelihood of social stigma.

3.2.4. Discussion on cancer stigma (personal responsibility) among non-population patient in Malaysia

Personal Responsibility, also known as "origin" or "controllability," is a key idea in stigma theory that describes the degree to which an individual's actions are seen to have contributed to their sickness. Some theories claim that perceivers attribute personal responsibility to individuals to explain an occurrence (in this case, a cancer diagnosis). Additionally, according to some ideas, perceivers place blame on others to understand why they are ill. As more people are made aware of the lifestyle factors that increase their risk of developing cancer, scores on the Personal Responsibility scale may rise. According to Table 2, the mean score of 1.98 indicates that most respondents can tolerate cancer patients' conditions, even though most of them had never have the bad perception where the patients being suffered because of their lifestyle and conditions. Younger people, those with university educations, and patients who were professionally active made up the majority of the group of patients who reported higher social dysfunction (Ohlsson-Nevo et al., 2020), which may indicate that their social lives are more restricted to work and family as a result of the cancer diagnosis.

3.3. Conclusion on cancer awareness and cancer stigma among non-patient population in Malaysia

According to the findings of our study, individuals should be better informed about cancer, a disease with a high mortality rate, and awareness of the condition should occasionally be heavily encouraged. Additionally, health-related courses must be offered as part of school and university curricula. Increasing cancer awareness and educating the public about cancer would help with future cancer prevention and early cancer diagnosis. As a result, public education should be offered to raise awareness. In conclusion, public education about cancer symptoms and the importance of an early diagnosis for cancer treatment is necessary. Since stigma was first raised in relation to cancer many years ago, there hasn't been much systematic research in this area. If there is actual cause for concern in this area, having a tool that can evaluate cancer stigma will help to determine the implementation of interventions designed in order to reduce stigma.

3.4. Recommendation on cancer awareness and cancer stigma among non-patient population in Malaysia

The risk of developing cancer is also increased by unhealthy levels of stress and distress. The findings of Bilge and Cam (2008) found that 62% of the women thought stress was the main cause of cancer. Future recommendations urge the government to launch initiatives to promote a healthy lifestyle

and stress management to combat cancer. Additionally, a healthy population will lessen the stigma associated with cancer in society. The relationships between cancer stigma and cancer screening uptake, are expected to be much stronger if cancer type-specific measures of stigma were used.

3.5. Limitation cancer awareness and cancer stigma among non-patient population in Malaysia

According to the findings in this study, there are a number of limitations: The awareness that cancer is not contagious, that it can be prevented, and that it can be treated; the awareness that diet and smoking are important risk factors for the formation of cancer; the perception that stress is an important risk factor for the formation of cancer; and the lack of awareness regarding cancer screening.

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