Knowledge and Awareness of Malaysian Cancer Patients and their Family towards Facing and Coping with Cancer

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ABSTRACT: Knowledge and awareness of patients and their families are vital in influencing their manners in handling and taking appropriate action to face a disease, or in this case, cancer. It is often said that the (mis)understanding on a disease lead to the success or failure of the treatment that follows. The objective of this paper is to discuss knowledge and awareness of cancer patients and their family towards cancer, and their ways and strategies in confronting and coping with the disease. This research facilitates survey methods on 295 families with cancer patients from the State of Penang, Kedah, Perlis and Perak of West Malaysia, which was held in 2006-2008. Qualitative interviews were also conducted on 30 patients in order to get a more complete picture on patients’ and families’ attitudes and actions before and after being diagnosed. The findings show that patients’ and families’ knowledge and awareness on cancer were insufficient, which led many of them to acquire wrong decision in coping with cancer. While differences in knowledge and awareness are to certain extent influenced by the socioeconomic background, accessibility to health services and rural-urban environment, this study also revealed the important contribution of socio-cultural and psychological factors that led to late screening and treatment, thus lowering the survival rate of the patients. This study contributes to the understanding on these aspects, which is central in designing appropriate and effective methods in approaching cancer patients and their families.

Keywords: Awareness, cancer patients, coping strategies, knowledge, Malaysia

Introduction

Knowledge and awareness of patients and their families are vital in influencing their manners in handling and taking appropriate action to face a disease, or in this case, cancer. Past research shows that lack of knowledge and awareness in handling and taking appropriate action to face cancer may lead to early death amongst the patients. Lyons (2004) for example argued that lack of awareness on the importance of regular medical check-up has led some patients whom live close to the hospital to not turn up to see the doctor on the appointment date. Factors that brought to this unawareness are related to the socio-economic and socio-cultural reasons, including level of education, accessibility to hospitals, cultural norms and beliefs of the society.

Public’s knowledge and awareness on healthcare, health facilities, and health information are of crucial importance in ensuring public health. Woods et al. (2005) argued that lack of confidence towards modern healthcare and hospitals have led patients and their families to avoid hospitals. Norsa’adah et al. (2011) claimed that trust and favours towards alternative treatment such as traditional healings, and
negative attitude towards modern treatment keep them away from hospitals. Hardisty and Leopold (2005) meanwhile concluded that the inability to read, comprehend, and interpret information on pamphlet, posters, oral explanation from individuals and the media such as television and radio has caused them to delay or avoid screening processes. The information transfer medium also influence the acceptance rate of the community towards healthcare information. For example, dissemination of health information using electronic media and computers are not accessible to all people (Cutchin, 2000). As a result, lack of knowledge and awareness on the benefits of healthcare caused cancer patients and their families to think that it is not beneficial to go to hospitals, especially when the health problem is not that serious (Philips, 1990; Gray, Shaw and Farrington, 2005). The perception of the unimportance of healthcare worsens when a patient is unable to pay for the travelling cost and hospital treatment (Ghazali et al., 2009). This refers to those who live far away from the health centre and those who are on a low income (Kerner et al., 2001). They would only go to the hospital when their condition further deteriorates. Such delay would only make their treatment and healing process harder and they are more prone to the risk of early death after diagnosis (Lim, 2000).

A child patient has higher probability (70-80%) of survival compared to adults if treated early. However, because of poverty and lack of knowledge among parents, the child patients are exposed to high risk of early death after diagnosis. This situation is worse in developing countries (Reyes, 2007). In addition, patients with high income have a higher survival rate compared to those with lower income in both developed and developing countries, as the former are more affordable for medical treatment (Reyes, 2007; Cavalli, 2006).

In addition, social and cultural limitations such as language, cultural norms and beliefs influence one’s awareness in getting early screening and treatment. This usually occurs among traditional society living in rural areas. They feel scared, incompetent, and ashamed to be examined using modern screening method (Smith and Easterlow, 2005; Tripp-Reimer et al., 2001). Meanwhile beliefs and taboos prevented them from getting screened and treatment (National Rural Health Association, 2006). Manderson, Kirk and Hoban’s (2001) studied on women aborigines in Australia found that the women aborigines are uninterested in having a cancer screening even though there are mobile clinics using vans coming to villages, bringing doctors and screening equipments. The doctors complained that the women are too busy with their housework to come for cancer screening. On the contrary, the women perceived that the doctors were only interested in advising them without any intention of examining their health condition. Furthermore, for aborigines, certain body parts such as breasts and cervix are ‘women businesses’ and they feel hesitant if their private body parts are discussed. This situation, in which Manderson, Kirk and Hoban (2001) called ‘cultural safety factors’, has become the limitation for traditional society in rural areas to obtain screening and treatment for cancer. This society upholds the norms that women are not allowed to meet outsiders freely due to personal safety, and in order to conform to cultural norms. In relation to this, Andrews (2006) argued that it was crucial to understand cultural sensitivities especially when related to women’s healthcare.

A study by Wong et al. (2009) revealed that Malaysian women were poorly aware of the indications and benefits of cervical cancer screening and did not see the need for a Pap smear test because they perceived themselves as not at risk of developing cervical cancer. Many thought
that the purpose of a Pap smear test is to detect existing cervical cancer. To conclude, studies discussed above reach to a decision that knowledge and awareness of cancer patients and their family is still little in many societies of the world.

**FIGURE 1** is a model that integrates socio-economic factors, socio-cultural factors and accessibility to healthcare that influence one’s knowledge and awareness to obtain cancer screening and cancer treatment, which will lead to the survival of cancer patients. This model suggests that economic stability, good accessibility to healthcare facilities, and healthy social and cultural context heighten one’s chances to attain cancer screening, prevention efforts, and appropriate treatment, which in turn will increase the potential for the cancer patient to survive (Freeman, 1991). On the contrary, if the patient and the family have poor economic opportunities, coupled with poor accessibility to treatment, and adopt cultural norms and belief that are considered degrading; all of these will prevent ones from getting cancer screening and appropriate treatment, and therefore led to poor survival after being diagnosed.

Most of the societies, especially those who live in the developing nations, have little knowledge on diseases, including cancer. They also have little access to modern treatments. On the contrary, they have better access and knowledge on alternative or traditional treatment/healings (Norsa’adah *et al*., 2011; Samad, 1988; Faziah, 1980; Chen, 1976). This resulted in some of them trying various ways of traditional treatment before having a medical check-up in the hospital. In many cases practical characteristics of the traditional treatment do not fit the condition of the disease, which cause the condition to worsen (Philips, 1990). Moreover, the scarcity in the number of modern medical practitioners which can offer services to the society compared to traditional medical practitioner led them into getting traditional treatment (Chen, 1976). Furthermore, traditional medical treatment is far cheaper compared to modern treatment (Ghazali *et al*., 2009; Samad, 1988). In Malaysia, traditional medical practice or alternative treatment is widely accepted by the society, including among the younger generations, as they might have been exposed to alternative treatment by their parents since they were young (Faziah, 1980).

**FIGURE1**: Interrelation between socio-economic factors, socio-cultural factors and accessibility to healthcare in influencing the opportunities of getting screening and treatment that led to the survival of the cancer patients (Source: Adapted from Freeman (1991). Race, Poverty and Cancer, *Journal of the National Cancer Institute*, 83 (8), April 17, 1991. 526 – 527).
Objective and Methodology

This study aims to discuss knowledge and awareness of cancer patients and their family towards cancer, and their ways and strategies in confronting and coping with the disease. Northern region of Peninsular Malaysia has been purposely chosen as a study site. The respondents Cancer patients and their families were from the states of Pulau Pinang, Kedah, Perlis and North of Perak. Note that, this is in line with the need of the research sponsor, MAKNA (Majlis Kanser Nasional) – a non-governmental body - which intends to explore knowledge and awareness as well as coping strategies of the cancer patients and their family in this area. The patients were registered under MAKNA, and MAKNA is responsible in helping to ease the burden of the patients and the family, by providing material and moral supports, and their well-being is closely monitored by this organisation.

A list of 295 cancer patients in the northern region were provided by MAKNA and all of them were involved in the survey. As MAKNA volunteers, the authors visited the patients and family to update their current situation and needs, and to give advice, guidance moral and psychological supports. Qualitative methods were adopted for this study, in which, during the visit, a survey, in-depth interview and observation were held in order to understand issues around the knowledge and awareness of cancer patients and their family towards cancer, and their ways and strategies in confronting and coping with the disease (Ghazali et al., 2009; 2008). The visit, survey, interview and observation was held in 2006-2008, and the final report was submitted to MAKNA in mid-2009. While all 295 patients and family were involved in the survey, only 30 selected patients and family were involved in in-depth interviews and observation. Ethical consideration was taken into consideration to protect the respondents as a Research Subject, and thus their anonymity is sheltered under the pseudonyms of Respondent 1, 2, 3 and so on (Neutens and Rubinson, 1997; Bernard, 2000; Ghazali et al., 2009).

Results

Background

32.9 % (97 respondents) of the respondent in this study were the patients themselves whereas 67.1 % (198 respondents) were family members that were closest to the patients. These family members were chosen to answer the questionnaire because the patients were too sick or unfit to do so. Among the patients they were 57.7% (56 people) females and 42.3 percent males (41 people). Meanwhile family members representing patients were 52.5 percent males (104 people) and 47.5 percent (94 people) females. The respondents were reside in Pulau Pinang (102 people), Kedah (148 people), Northern Perak (26) and Perlis (19), which total up to 295 respondents.

The most common types of cancer that was suffered by the patients were:  
1) Leukaemia - 26.4% or 78 patients; 49 were males and 29 females  
2) Breast cancer – 14.9% or 44 patients; all are females  
3) Non-Hodgkins Lymphoma – 5.8% or 17 patients; 12 males and 5 females  
4) Nasopharynges Carcinoma – 3.4% or 10 patients; 7 males 3 females.

Other common types of cancer suffered were rectum, colon, lung and cervix. 61 women suffered women specific cancers including breast cancer (44), cervix (9), ovarian cancer (7 cases) and uterus (1 case). Lung cancer reported 13 cases.
Knowledge and awareness of the respondents in facing and coping with cancer according to the level of education

This section discusses knowledge and awareness of the respondents in coping with cancer. Knowledge and awareness is important because it helps patients and their family to take the correct measures when they realise the changes in their body and health status. Three basic questions which were asked: ‘Do you know what is cancer’, ‘in your case, what are the symptoms’, and ‘what can be done’. 59.3% respondents show that they are knowledgeable and aware about cancer in which they can answer or discuss the questions. Meanwhile 40.7% (175 respondents) showed hesitation and do not know how to explain them, or simply said ‘I don’t know’. This is worrying because more than a third of the cancer patients and their family were not knowledgeable and unaware of the signs, consequences, and correct measures to take.

It was found that the majority of respondents who were knowledgeable and aware about cancer were those with higher education level. Meanwhile, those who have little knowledge and awareness on cancer are those with lower education attainment (TABLE 1).

<table>
<thead>
<tr>
<th>Education level</th>
<th>Respondents have certain level of knowledge and awareness on how to face and cope with cancer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>No formal education</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>Primary school</td>
<td>21</td>
<td>38</td>
</tr>
<tr>
<td>Lower Secondary (Form 1-3)</td>
<td>56</td>
<td>48</td>
</tr>
<tr>
<td>Upper Secondary (Form 4 – 6)</td>
<td>86</td>
<td>18</td>
</tr>
<tr>
<td>College/Polytechnics/University</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>175</td>
<td>120</td>
</tr>
</tbody>
</table>

Knowledge and awareness towards cancer among respondents living in urban, semi-rural and rural areas

Our study found that knowledge and awareness towards cancer and coping strategies are higher among cancer patients and family living in urban areas compared to those living in rural areas. As shown in TABLE 2, those living in urban areas of Penang and Seberang Perai, Kedah, Perlis and north of Perak are more knowledgeable and aware of the issues relating to cancer compared to those living in the urban fringes and rural villages. Accessibility to information, supported by higher education level among urban respondents compared to those of rural, could have resulted in this situation.
TABLE 2: Respondents’ knowledge and awareness towards cancer according to residential areas (rural or urban)

<table>
<thead>
<tr>
<th>Residential area</th>
<th>Have certain level of knowledge and awareness on how to face and cope with cancer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes No. %</td>
<td>No. %</td>
</tr>
<tr>
<td>Urban</td>
<td>35 74.5 12 25.5</td>
<td>47 100</td>
</tr>
<tr>
<td>Semi-rural</td>
<td>91 65.5 48 34.5</td>
<td>139 100</td>
</tr>
<tr>
<td>Rural</td>
<td>49 45.0 60 55.0</td>
<td>109 100</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>175 52.9 120 45.0</strong></td>
<td><strong>295 100</strong></td>
</tr>
</tbody>
</table>

Knowledge and awareness towards cancer among the respondents according to gender

This section discusses knowledge and awareness of respondents towards cancer and how these affect their manners in handling and taking appropriate action to face cancer. 88.5% (261 respondents) claimed that they did not know cancer symptoms. They thought that the symptom they or their family member were experiencing was ordinary disease that would not affect their general health. They usually simply let the symptom without doing anything, which actually make the disease becoming worse (29.5% out of 261 respondents). Some of them seek alternative treatment such as homeopathy and traditional treatment (20.3%), or self-treated by buying the medicine from a pharmacy, sundry shops or mini market (10.2%). This worsened the cancer and delayed their opportunity in getting prompt treatment. This has resulted in the cancer becoming worst and approaching stage 3 or 4 when diagnosed. Some of the respondents even predicted that the disease were caused by a 'black magic'. Only 16.6% respondents went to the clinic and 6.1% went for general examination at the hospitals.

Comparison between the genders showed that more women ignored the early signs of cancer (38.1%) compared to men (19.3%). This contributed to low prognosis among women than men at the time of diagnosis. In terms of early action, both male and female respondents preferred to seek alternative treatment, get medical treatment at public clinics, or buy medication without consulting the doctor and seek medical check up in the hospital (TABLE 3).

TABLE 3: Early action when facing cancer symptoms according to gender

<table>
<thead>
<tr>
<th>Early action</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
<td>No.</td>
</tr>
<tr>
<td>Leave it until it gets serious</td>
<td>26</td>
<td>19.3</td>
<td>61</td>
</tr>
<tr>
<td>Seek alternative/traditional treatment</td>
<td>27</td>
<td>20.0</td>
<td>33</td>
</tr>
<tr>
<td>Seek medical check up at the nearest government clinic</td>
<td>27</td>
<td>20.0</td>
<td>22</td>
</tr>
<tr>
<td>Seek medical check up at the nearest government hospital</td>
<td>28</td>
<td>20.7</td>
<td>23</td>
</tr>
<tr>
<td>Seek medical check up at the nearest private clinic/hospital</td>
<td>4</td>
<td>3.0</td>
<td>14</td>
</tr>
<tr>
<td>Buy medicine without consulting the doctor</td>
<td>24</td>
<td>17.0</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>135</td>
<td>100.0</td>
<td>160</td>
</tr>
</tbody>
</table>
This study found that many women were afraid and hesitated in submitting themselves to medical examination. This situation causes them to ignore cancer symptoms. Poor knowledge about cancer caused them to refuse medical check-up even though they know women are more at risk of cancer. In addition, fear of treatment and the difficulty in facing reality if they are diagnosed with cancer caused them to refuse medical examination. A case is expressed by a female respondent in an informal interview as follows:

‘I’m scared. I heard in the TV that if there are lumps, it means that there is cancer. I’m afraid to undergo surgery....that’s the reason why I don’t want to see the doctor’ (Respondent 1, female, age 49. Informal interview 2008).

Only 52% of the respondents studied have knowledge on cancer screening, in which they could explain the purpose of cancer screening, and when they could get the screening. 48% of the respondents had never heard about cancer screening and had no idea what it is all about indicating insensitiveness of respondents to screening campaign which have been broadcasted through television, radio, newspapers and even posters. Indifference of respondents on the information provided by the relevant agencies reflected their unawareness of the importance of healthcare. 86.9% out of 145 male respondents have never had a cancer screening compared to 72.7% out of 150 the female respondents. This portrayed that most of the family members do not carry out cancer screening. It was found that women are more knowledgeable about cancer symptoms compared to men. Our study showed that women usually talk or discuss about their health problems with their women friends and neighbours, which then enable them to share knowledge. Of this matter, a female respondent reported:

‘At first I did not know that this is cancer...you know women usually share problems with women friends..but not with men..they (men) knew nothing about women diseases..so one day I told my women friends about this (the symptoms) and they suggested that probably it was cancer.’ (Respondent 2, female, age 57, informal interview 2007).

A man interviewed tends to ignore his health status, as the respondent - a cancer patient, said:

‘I haven’t got time to talk about diseases like this with my friends...and they have no interest to talk about any disease...we fishermen will feel tired when we come back from the sea, so we go home for a rest. Or if we have time, we will have tea together at the coffee shop. But we talk about things related to our work...such as our net now tear, our boat needs repair.. If we talk about ‘health’, it means about ‘being manly’. We don’t talk about disease like this (cancer). My wife maybe knows about this better...she usually goes to chit-chat with neighbours.’ (Respondent 3, male, age 54, informal interview 2008).

This difference in everyday social behaviour between women and men led to disparity in knowledge and awareness towards cancer between the two genders. Sharing knowledge about health and cancer between neighbours and friends helps generate awareness among the community, especially those who live in rural areas.
Respondents’ knowledge and awareness towards cancer according to place of residence

This section discusses respondents’ initial actions in dealing with cancer according to place of residence (rural – urban). The results showed that there are differences in the initial action according to place of residence, and this is influenced by the physical environment and the socioeconomic status of the respondents (TABLE 4).

**TABLE 4**: Initial actions in facing cancer symptoms according to place of residence

<table>
<thead>
<tr>
<th>Initial action</th>
<th>Place of residence</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urban</td>
<td>Sub-urban</td>
<td>Small town</td>
<td>Rural</td>
<td>Total</td>
<td>Urban</td>
<td>Sub-urban</td>
<td>Small town</td>
</tr>
<tr>
<td></td>
<td>No %</td>
<td>%</td>
<td>No %</td>
<td>%</td>
<td>No %</td>
<td>%</td>
<td>No %</td>
<td>%</td>
</tr>
<tr>
<td>Leave it until it gets serious</td>
<td>14</td>
<td>29.8</td>
<td>25</td>
<td>25.5</td>
<td>11</td>
<td>26.8</td>
<td>37</td>
<td>33.9</td>
</tr>
<tr>
<td>Seek alternative/traditional treatment</td>
<td>4</td>
<td>8.5</td>
<td>17</td>
<td>17.3</td>
<td>6</td>
<td>14.6</td>
<td>33</td>
<td>30.3</td>
</tr>
<tr>
<td>Seek medical check-up at the nearest government clinic</td>
<td>5</td>
<td>10.6</td>
<td>19</td>
<td>19.4</td>
<td>12</td>
<td>29.3</td>
<td>13</td>
<td>11.9</td>
</tr>
<tr>
<td>Seek medical check-up at the nearest government hospital</td>
<td>14</td>
<td>29.8</td>
<td>17</td>
<td>17.3</td>
<td>6</td>
<td>14.6</td>
<td>14</td>
<td>12.8</td>
</tr>
<tr>
<td>Seek medical check-up at the nearest private hospital/clinic</td>
<td>5</td>
<td>10.6</td>
<td>8</td>
<td>8.2</td>
<td>2</td>
<td>4.9</td>
<td>3</td>
<td>2.8</td>
</tr>
<tr>
<td>Buy medicine without consulting the doctor</td>
<td>5</td>
<td>10.6</td>
<td>12</td>
<td>12.2</td>
<td>4</td>
<td>9.8</td>
<td>9</td>
<td>8.3</td>
</tr>
<tr>
<td>Total</td>
<td>47</td>
<td>100.0</td>
<td>98</td>
<td>100.0</td>
<td>41</td>
<td>100.0</td>
<td>109</td>
<td>100.0</td>
</tr>
</tbody>
</table>

It is interesting to see that there was a consistent sequence of initial actions while facing cancer symptoms according to place of residence. Percentage of respondents who chose alternative/traditional treatment is highest at the rural area (30.3%). This percentage dropped to 17.3% for the suburbs, 14.6% for small towns and 8.5% for urban areas. This finding supported the argument of National Rural Health Association (2006) that many rural communities trusted traditional methods probably. They also felt more confident with traditional medication or alternative methods compared to modern methods provided by the hospital. Seeking traditional healers has become the norm for rural communities due to their beliefs; culture and their easy access to the alternative/traditional services compared to the hospital (see also Tripp-Reimer et al., 2001; Smith and Easterlow, 2005). Hence they preferred traditional methods compared to conventional treatment in a hospital or clinic which were further away from their homes. In relation to this, a respondent from a rural area said:

‘I still remember that since long ago this disease has already exist...people called this ‘swollen breast’...and we don’t have to go to the hospital, because traditional medication can cure this. So I went to see a village (traditional) midwife who knows how to treat this disease. After some time I feel that the swollen and the pain have decrease. It will be painful if we go to the hospital because they (the doctors/hospital’s staff) will inject some kind of medication. The traditional midwife gives me healing water in which she has read some prayer (doa) to it... and she also gives me medicinal herbs and roots to drink with water... Now I am slowly recovered from the disease’ (Respondent 4, female, age 46, informal interview 2008).

Another respondent, a father to a young patient, said:

‘I heard that many people went to get treatment from him (a massage healer), and they were cured. So I took
my child to the massage healer. Now I can see the swelling is decreasing. The reason why I brought her home (from the hospital) was that I don’t want her to get hospital treatment any more...because the doctors said that they have to cut my daughter’s hand off... (Respondent 5, male, age 36, informal interview 2008).

As previous studies have highlighted, financial and employment factors can lead to early action selection. For example, respondents with higher income are able to bear the cost of medical examination. They will seek for medical investigation and treatment in a hospital or private clinic despite relatively high charges. In addition, the treatment costs may be supported by the company where they work. This contrasted with the respondents who have relatively low and fluctuated income, especially those who live in rural areas and make a living on seasonal and agricultural works. Low and fluctuate incomes limit their capacity to pay for the cost of medical check-up at the private hospitals and clinics, or even to travel to a government hospital. Furthermore, health centres that provide services for critical diseases such as cancer were rarely established rural areas (Kerner et al., 2001; Reyes, 2007; Cavalli, 2006).

However, our study highlighted that socio-cultural factors influence the choice of action in getting cancer screening and treatment despite the place of residence (rural vs. urban) and also level of income. It was found that respondents of both urban and rural areas conform to traditional treatments due to culture and beliefs, although we agree that the greater number would be those from the rural areas, as shown in TABLE 4.

TABLE 5 details the information on social and cultural influences in the patients and family’s choice of early actions when they realise symptoms of cancer.

<table>
<thead>
<tr>
<th>Patients’ background</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent 6 Female, age 47 Nasopharyngeal Carcinoma Cancer stage II*</td>
<td>Respondent 6 knew only a little about cancer from which she watched in the television. When she realised the early signs of cancer, she ignored it. She said: ‘I got bleeding nose...I thought the weather was too hot. So I put betel leaves to stop the bleeding...my nose always bleed, therefore I went to a traditional healer for a ‘cut’ – in which the healer will remove the inner spell by reading a prayer (doa) - but my sickness did not heal. I didn’t want to go to the hospital...I didn’t want to stay many days there...my friends said that I must undergo surgery’. In the end the patient was admitted to a hospital after being persuaded by her husband. Once diagnosed with cancer, Respondent 6 refused treatment. She said ‘I watched TV, I knew cancer is dangerous...many died because of cancer. So I am scared to be treated by the hospital...they (friends, relatives) said that I will become bald...it will become worse.’</td>
</tr>
<tr>
<td>Respondent 7 Female, age 57, Breast Cancer Cancer stage II*</td>
<td>Respondent 7 is a housewife. She knew about cancer through talks and campaigns organised by her husband’s employer. However, she did not care much, and she said: ‘I don’t bother too much. I am just healthy at that time. So I did not realise I have it (the symptom). The swollen was there since one or two years ago, and I can feel the lump but it didn’t hurt or pain...so I let it be. I feel shy to go for a test or check-up because the lump is there (at the breast)’. She had a check-up after being persuaded by her daughter, who came to stay with her for a confinement after giving birth. The check-up was done by a nurse who came to the house to visit her daughter. The nurse advised her to have a full medical check-up at the nearby hospital.</td>
</tr>
</tbody>
</table>
| Respondent 8 Female, age 7 (represent by her father) | Respondent 8 is a child; she was represented by her father. Her early sign of cancer was that she always had epilepsy and her eyes became squint. Her parents took her to a traditional healer but there was no change. Her father said: ‘I took her everywhere I knew...
there was a traditional healer, but there was no improvement. Then I took her to a private hospital, and she was diagnosed cancer. I didn’t want her to have the surgery. I still want to try traditional healing. At that time I listened to my friends - they said that if she undergo surgery, the disease will become worst. They said that the government hospital is not good, my girl will become more painful. Therefore I took her to a private hospital even though it was expensive.’ However, upon diagnosed, it was already too late and the respondent had to underwent a risky surgery.

Respondent 9
Female, age 43.
Cancer Rectum
Cancer stage III*

The patient was a former production operator and she had to quit work when she was diagnosed cancer in 2006. During the early stages, she had to keep it a secret from her family because at the same time, her husband suffers from rectal cancer. Even though she knew that cancer is dangerous, she refused to get treatment because she wanted to take care of her sick husband. She said: ‘I refused to do the screening at that time even though I was at the hospital every day. I knew I have the same disease like my husband but if I go for a check up and then have to be hospitalised, there will be no one to take care of my husband. We will have to stay in a different ward.’ The patient’s husband passed away in 2005. After her husband’s death, she told her late husband’s doctor about the symptoms she was experiencing. The doctor conducted an examination and she was diagnosed rectal cancer stage three.

Respondents 10
Female, age 47
Parotid Tumour
Cancer stage II*

The patient is a teacher at a kindergarten. At first, she kept the disease a secret. She said: ‘The swelling on my neck had been there for 6 years but I didn’t care about it because it didn’t hurt. Furthermore, I’m wearing a hijab, therefore nobody will notice it’. Before she went for diagnosis, the patient had undergone a series of traditional treatment. ‘I sought traditional treatment quietly… I’m afraid that people would find out… I feel ashamed… I’ve even went for a massage to remove the swell’. She got married and then her husband saw the swell and asked her to go for a screening. At first, she refused because, ‘I didn’t want to go for a screening or a treatment. I’m ashamed because I’ve just got married and now I am already a burden for my husband’. However, her husband insisted in bringing her for a treatment and coincidentally, her husband’s family member is a doctor. She was diagnosed with cancer in 2005.

Respondent 11
Female, age 36
Acute Leukemia
Cancer stage II*

The patient is a housewife and in the beginning she knew nothing about the early signs of cancer. While experiencing the early signs of leukemia, she described it as ‘normal fever’. Therefore she bought medication at the sundry shops without consulting the doctor. She said: ‘Usually if I have fever, I would only buy medicine from the grocery stores’. She also sought traditional treatment due to the repeated and prolonged fever. She only sought treatment at the hospital when her fever did not cure. She was diagnosed with leukemia. She was hospitalised only for two weeks because her husband insisted her to try traditional treatment. She reported: ‘My husband didn’t allow me to stay longer at the hospital… he brought me home because he wanted me to try traditional healing… but in the end, I didn’t recover and we went back to the hospital’. Because of the delay in getting right treatment from the hospital, her disease worsened and the healing process becomes slower and harder.

*Note: Stage I and II refer to the early stages of cancer. Cancer stage III and IV refer to the advanced stage of cancer.

Study cases in TABLE 5 shows that several reasons could cause patients to delay their visit to hospital for medical screening. The reasons included: fear of hospital and its staffs such as doctors and nurses; lack of trust on doctors and hospitals; feeling ashamed of being scanned (especially among women); more confidence on traditional/alternative treatment; inferiority complex due to the feelings of incompleteness (as a woman) and thinking themselves as a burden to others. The delay in getting treatment has led to the worsening of their disease.

Conclusions

Knowledge and awareness on the importance of a regular check-up and immediate action after the detection of early cancer signs are highly influenced by

the socioeconomic and socio-cultural factors. These include level of education, place of residence, and accessibility to hospitals. This study also unveiled the importance of psychological factors, which play a role in the worsening of cancer amongst the patients. These psychological factors include the attitude of the patients and their family towards the disease, the hospital’s staffs, and the hospitals. The patients tend to stigmatise cancer as a disease that could not be cured using modern treatment, while the hospitals and its staffs are stigmatise as making cancer patients’ life after treatment even worst. Other psychological factors include feeling guilty, ashamed and inferior as a cancer patient, which made them avoid modern screening and treatment. This study supported Freeman’s (1991) model, in which socioeconomics, socio-cultural and accessibility factors are important in influencing the opportunities of getting screening and treatment, thus led to the higher survival amongst the patients. However, the present study improved this model by highlighting the psychological factors, including stigma, as of greater importance. This stigma has led to the delay in screening and treatment, thus lowering the survival rate of the patients. Our study offered guidelines to certain bodies such as hospitals, media and educators to understand the psychological aspects of the society, and thus makes campaign efforts towards screening and treatment of cancer less frightening.

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