EXPRESSIONS OF PERCEIVED SUSCEPTIBILITY TOWARD NASOPHARYNGEAL CARCINOMA

Jia-Yiing Ho^{1*}, Su-Hie Ting¹, Yuwana Podin²

¹Faculty of Language and Communication, Universiti Malaysia Sarawak, Samarahan City, Sarawak, Malaysia. ²Institute of Health and Community Medicine, Universiti Malaysia Sarawak, Samarahan City, Sarawak, Malaysia. Correspondence: Jia-Yiing Ho Email: hojiayiing@outlook.com

ABSTRACT

Introduction: Perceived susceptibility to diseases influences intentions to undertake health protective measures. **Methods:** The study investigated perceived susceptibility of nasopharyngeal carcinoma (NPC) among Malaysians, focusing on their expressions of disease susceptibility before and after reading an NPC health pamphlet. Method: A total of 65 participants in Kuching and Kota Samarahan, Malaysia, aged 13 to 65, were interviewed on their perceptions of their risk of getting NPC. **Results:** The thematic analysis of the interviews revealed several levels of perceived susceptibility to NPC, namely, 1) not susceptible to NPC, 2) may be susceptible to NPC, 3) susceptible to NPC, and 4) not knowing much about susceptibility to NPC. The expressions the participants used revolved around "living a healthy life", "second-hand smoker", "polluted air" and "eat preserved or salted food", indicating perceived risk factors of NPC. **Conclusion:** Some mentioned family history and ethnic background as risk factors. After reading the NPC pamphlet, the participants gave the same reasons but with more specific details on the symptoms and types of food associated with NPC. The study indicated that the NPC pamphlet can increase awareness of NPC because additional reasons given for NPC susceptibility after reading the pamphlet were signs of cancer, age, and NPC incidence in Malaysia.

Keywords: perceived susceptibility, nasopharyngeal cancer, nose and throat cancer, risk factors

INTRODUCTION

Perceived susceptibility is one of the five constructs of the Health Belief Model, an intrapersonal behaviour change theory designed to elucidate how beliefs predict commitment in adopting healthprotective behaviours such as undertaking regular screening. Perceived susceptibility to diseases influences adoption of health protective behaviour to minimise risk of getting the disease. For example, in the case of cancer, the public can go for regular cancer screening to detect cancer early so that there would be better treatment outcomes.

Nose and throat cancer is also known as nasopharyngeal cancer (NPC). When NPC is diagnosed before Stage 3, it has good prognostic outcomes but most of the NPC cases in Malaysia were detected at Stages 3 and 4 (63% for males, 60% for females) (Azizah et al., 2019). This suggests a lack of awareness towards NPC susceptibility. Regular screening is important to reduce mortality considering NPC that is sensitive to chemoradiotherapy and results in a two- and three-year survival rate of 84% and 78%, respectively, in cases of early detection (Fles et al., 2016). Worldwide, deaths due to NPC number 50,000 out of 86,000 cases while 71% of new NPC cases are from East and Southeast Asia (Chang and Adami, 2006). NPC is the fourth most common cancer in Malaysia. The lifetime risk for males was in 1 in 143, and it was 1 in 417 for females in the 2007-2011 period (Azizah et al., 2019). The latest data about NPC in Malaysia show 2,222 new cases in 2020 with 1,450 resulting in deaths (Sung et al., 2021).

Although causes of NPC cannot be definitely identified, reports show that Epstein-Barr virus infection, smoking, and frequent consumption of preserved food and salted fish are associated with a high incidence of NPC (Zheng et al., 1994). Non-environmental risk factors of NPC include family history, ethnicity and gender (Fles et al., 2010). Certain ethnic groups such as the Bidayuh (Devi et al., 2005), Cantonese (Wee et al., 2010) and Malaysian residents in Sarawak, Penang and Labuan have higher incidences (Azizah et al., 2019).

generally believed It is that awareness of NPC susceptibility can lead adoption of susceptibility-reducing to behaviours such as screening and reduced intake of NPC-causing foods. Interestingly, Malaysians living in Sarawak who have higher perceived risk of getting NPC also reported weaker efficacy beliefs and intention to enact self-protective behaviour (Ting et al., 2021). This may be due to taboos surrounding cancer. Taboos have been found to discourage screening for early cancer detection in various settings (Banning and Hafeez, 2010; Ting et al., 2018).

Thus far, research on NPC in Malaysia is mostly clinical studies on the epidemiology of NPC (Aziz et al., 2017; Tarone et al., 1990). Some studies examined the social impact of NPC (Armstrong et al., 2000) and the knowledge of primary care doctors on NPC (Balachandran et al., 2012). The existing findings on NPC susceptibility-reducing perceptions indicate that factors that predict perceived susceptibility among Malaysians is still not well understood.

The present study investigates perceived susceptibility towards NPC among Malaysians living in Sarawak, an East Malaysian state on Kalimantan Borneo Island, focusing on their expressions of disease susceptibility before and after reading an NPC health pamphlet.

METHOD OF STUDY Participants

This descriptive study involved data from 65 participants living in Kuching,

the capital of Sarawak. A demographic profile of the sample is provided in Table 1.

Instruments

The instruments used in the study were an NPC pamphlet and an interview guide.

The pamphlet on NPC produced by the Ministry of Health, Malaysia, was printed on an A4-sized paper and folded in half to produce four pages, as shown in Figure 1. Page 1 has the caption "*Kenali kanser nasofarinks*" ("Get to know nasopharyngeal cancer"). Page 2 has the headlines "*Kesan kanser pada peringkat awal*" ("Effect of cancer in the early stage") and "*Faktor Risiko*" (Risk factors").

The pamphlet informs the public that NPC is widespread in Asia and Southeast Asia and is number four cancer in Malaysia in terms of incidence. The risk factors are identified as practices (e.g., smoking, chewing of betel nut leaves, eating preserved food), family history, and Epstein Barr Virus infection. Page 3 shows six pictures of signs and symptoms accompanied by words: nosebleed, ringing sound in the ear, neck growth, numbness or pain on the face, double vision, and headache. At the bottom of Page 3, the public were cautioned to get their doctor's advice if they have any of these signs and symptoms. Page 4 extols the public to prevent cancer before it is too late and to practice a healthy lifestyle ("Cegah Kanser Terlambat", "Amalkan gaya Sebelum hidup sihat"). The logo and name of the ministry are placed on the first and last pages of the NPC pamphlet to show the authoritativeness of the information in the pamphlet.

An interview guide using the NPC pamphlet developed by Malaysian Ministry of Health was pilot tested on 10 participants to investigate if the interview questions were answerable by the public. The interview questions were as follows: (1) Have you heard of Nose and Throat Cancer? (2) Do you think you are susceptible to Nose and Throat Cancer? Why? and (3) After reading this NPC pamphlet, do you think you are susceptible to NPC? Why? The 10 respondents read the pamphlet for an average of 31 seconds and they were given the flexibility to refer back to the pamphlet for information when answering the interview questions. All of the 10 respondents could answer the interview questions with two participants enquiring if the NPC pamphlets were available in Mandarin and Malays versions.

Data collection procedures

Ethical clearance for the study was given by the medical ethics committee of Universiti Malaysia Sarawak (Ref.: UNIMAS/NC-21.02/03-02 Jld.4(53). Data were collected from a few places in Kuching, such as Borneo Convention Centre Kuching, Batu Lintang Secondary School, King's Centre, Imperial Hotel Conference Hall, University Malaysia Sarawak, Kuching City Mall, Howdy's Restaurant and Park Lane residential area.

The first researcher approached potential participants and asked if they would participate in a study on nose and throat cancer. Those who agreed were told their voluntary about the interview, participation and preservation of anonymity in reports based on the study. They were also told that the interview would be audio-recorded. Participants who consented to participate in the study filled in the consent form, and a form with their demographic details.

Participants were asked Question 1 and 2 in the interview guide. Then they were shown the NPC pamphlet produced by the Malaysian Ministry of Health (Figure 1). Following this, participants were asked Question 3 to find out if their perceived susceptibility towards NPC had changed after reading the NPC pamphlet. The mean time taken by the participants to read the pamphlet was 48 seconds.

Data analysis procedures

The interviews which were audiorecorded were transcribed verbatim into Microsoft Word documents. Thematic analysis of the interview transcripts was carried out following Rubin and Rubin (2012).



Figure 1. NPC pamphlet produced by the Malaysian Ministry of Health

RESULTS

In the results section, the participants are referred to as P1 for Participant 1 till P65 for Participant 65.

Table	1.	Demographic characteristic	cs of			
the participants (N=65)						
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Demographic Characteristic	~	0/
Demographic Characteristic	n	%
Gender		
Male	37	56.9
Female	28	43.1
Age (years)		
13 - 20	14	21.5
21 - 30	20	30.8
31 - 40	14	21.5
41 - 50	12	18.5
51 - 60	3	4.6
61 - 70	2	3.1
Ethnic Background		
Malay	20	30.8
Chinese	29	44.6
Indian	1	1.5
Bidayuh	4	6.2
Iban	5	7.7
Others	6	9.3
Education		

Education

Demographic Characteristic	n	%	
Elementary school		6.2	
Junior High School		9.2	
Senior High School		12.3	
College		4.6	
Bachelor		35.4	
Masters and PhD.	20	30.8	
Monthly Income			
Not working	19	29.2	
Less than RM2000		10.8	
RM 2000 - RM 3999		20.0	
RM 4000 - RM 5999		7.7	
RM 6000 - RM 7999		7.7	
RM 7999 - RM 9999		13.8	
More than RM 10000		10.8	

Perceived susceptibility to NPC

Table 2 shows the percentages of the participants' perceived susceptibility to getting NPC before and after reading the NPC pamphlet. Before reading the NPC (43.08%) out pamphlet, 28 of 65 participants stated that they were not at risk of NPC. A majority of the participants (18 or 27.69%) felt that they might be at risk of getting NPC. Only 12 (or 18.46%) participants were certain that they were susceptible to NPC while seven (or 10.77%) participants said that they did not know if they were at risk of getting NPC or not.

Table 2. Perceived susceptibility of NPC
before and after reading the
NPC pamphlet

Perceived susceptibility	Before reading the pamphlet	After reading the pamphlet
Not at risk	28	30
	(43.08 %)	(46.15 %)
May be at risk	18	15
	(27.69 %)	(23.08 %)
Yes, at risk	12	20
	(18.46 %)	(30.77 %)
Don't know	7 (10.77 %)	0 (0 %)
Total	65 (100%)	65 (100%)

However, after reading the NPC pamphlet, there was an increased awareness of NPC risk, seen in none of the

participants saying that they did not know if they were at risk of getting NPC. Before reading the pamphlet, 10.77% did not know much about their NPC risk (Table 2).

The NPC pamphlet was informative for the participants. Table 2 shows that the percentage who were sure that they were not at risk increased to 46.15% and those who were sure that they were at risk also increased (to 30.77%). Concomitantly, the percentage of participants who were unsure whether they were at risk decreased from 27.69% to 23.08%. The pamphlet was clear on the risk factors and signs of NPC, and from this information, the participants could assess their susceptibility to NPC more accurately. The NPC had clearly increased their general knowledge on the NPC disease.

Perceived risk factors of NPC

Figures 2 and 3 show the perceived risk factors of NPC given by the participants before and after reading the NPC pamphlet respectively. In this section, the risk factors are explained in connection to their assessment of their perceived susceptibility to NPC (not at risk, may be at risk, certain of risk, and not knowing risk).



Figure 2. Participants' perceived susceptibility of NPC before reading the NPC pamphlet



Figure 3. Participants' perceived susceptibility of NPC after reading the NPC pamphlet

Not susceptible to NPC

The reasons given by the participants for not being at risk of getting their NPC before and after reading the pamphlet were slightly different. Before reading the pamphlet, the participants mentioned clean environment to justify why they were not susceptible to NPC. After reading the pamphlet, the participants said that they were not susceptible to NPC because they had no symptoms of NPC and there was no family history of NPC, but they omitted mention of the environment. This is probably because the environment was not mentioned as a risk factor in the pamphlet.

However, two reasons for nonsusceptibility to NPC were mentioned both before and after reading the NPC pamphlet, namely, healthy eating and not smoking. Smoking seems to be a widely known risk factor of NPC among the participants. P3, a retiree initially replied, "No [not susceptible to NPC], I don't smoke". However, after reading the NPC pamphlet, he changed his mind and replied, "Probably, probably. If you avoid [the risk factors], then it [NPC] won't happen. If you don't avoid, and continue, then it'll happen".

The participants also generally believed that healthy living minimised their risk of getting NPC and reading the pamphlet did not change their views. Healthy living is seen as living in a clean pollution-free environment and having a healthy diet. A researcher on NPC, P59, said that she was susceptible to NPC due to the environmental factor, dating back to the time when she was a child and exposed to a lot of wood dust when she was helping her dad at his factory. However, P59 said that she was not susceptible to NPC because she ate healthy food and exercised.

Excerpt 1

(Before reading the NPC pamphlet)

If I eat a healthy diet, I'm fine. And do regular checkup. Exercise more. Eat healthy food. Try to ... if you're working in a carcinogenic environment, you try to follow the working procedures. (P59)

This educated participant also used the adjective "carcinogenic" to describe the environment based on her general knowledge of NPC. After reading the NPC pamphlet, P59 said that she was at risk of NPC because "Even though sometimes we lead a healthy lifestyle, there are still people who smoke, and there's family genetic issues". These are information present in the NPC pamphlet, and it added to what she already knew about NPC risk factors.

An unhealthy environment was perceived as one that had poor air quality. Excerpt 2 shows P22, a teenager, talking about the link between air pollution and NPC.

Excerpt 2

The air we're living in now. The quality of the air is not as clean as back then. So I may fear that the pollution that are happening around may cause nose and throat cancer. (P22)

There is a common perception that food is a risk factor for NPC. P49, a 13year-old student, initially said, "No, because I seldom eat fried food". After reading the NPC pamphlet, he reasoned that he might be at risk of NPC as he "did consume food that contained preservatives, such as cheese." The word "preservatives" under the heading of "Risk Factors" in the NPC pamphlet brought surprises to the participants as most of them consumed food that contain preservatives. Some preservatives are known to be harmful to the human body as some are classified as carcinogens or cancer-causing agents (Mirza et al., 2017).

The pamphlet also corrected some participants' misconceptions of NPC. For example, P62, a 14-year-old student gave a definite "No" when asked if she would be at risk of nose and throat cancer. She said, "I very take care of my nose". However, after she read the NPC pamphlet, she gained new understanding of what NPC meant. Excerpt 3 shows that P62 realised NPC was not about the cleanliness of the nose but a nose cancer. For this teenager, the pamphlet had succeeded in correcting her misconception of NPC.

Excerpt 3

My thinking is wrong. It's not about you can't smell and you can't breathe. Just that your ... your nose ... I don't know how to translate in English. 鼻喉炎 是吗? (Is it Nasopharyngeal Cancer? In Mandarin). I sometimes feel... (touches head) headache. 3 [some level of risk]. Because I usually eat the food that contains the preservatives and salted food. (P62)

The NPC pamphlet also alerted some participants to the early signs of NPC. Some of them gave the absence of NPC symptoms as a reason for not being susceptible to NPC. One of them was P25, a senior lecturer in her late forties, who said that she did not have the symptoms. The value of the pamphlet in alerting participants to the possible signs of NPC will be explained in the next section.

Possible susceptibility to NPC

As for participants who assessed themselves to be at some risk of getting NPC, Figures 2 and 3 show that the only reason that was mentioned by participants both before and after reading the NPC pamphlet was unhealthy eating. However, they were more informed after reading the pamphlet because they were specific on what they meant by unhealthy food. They talked about preserved and salted food, showing that the NPC pamphlet had increased their general knowledge on the food factor. Excessive intake of preserved vegetables and salted eggs are commonly thought to be associated with NPC.

Other than unhealthy eating, before reading the NPC pamphlet, some participants mentioned smoking, family history and the predisposition of the Chinese to getting NPC. Some participants already knew about the hereditary cause of NPC and research findings on certain ethnic groups being more susceptible to getting NPC. However, some learnt of the genetic factor through the pamphlet which mentioned "sejarah keluarga" (family history).

After reading the pamphlet, three new reasons were given by participants for saying that they were currently free of NPC but might be susceptible to NPC in future. At the time of the interview, they were avoiding risk factors of NPC, and did not have symptoms of NPC. In addition, one teenager said that she was still young, indicating her belief that NPC risk is higher among older people.

Next, excerpts are shown to illustrate how the participants used the symptoms of NPC shown in pictures and words in the pamphlet to assess their risk. For example, before reading the pamphlet, P48 said that she did not know her risk but after reading the NPC pamphlet, she assessed her risk as low and rationalised that she did not exhibit the signs of NPC.

Excerpt 4

Erm, I don't really have these symptoms. And some of these also (pointing to risk factors), I don't smoke and take those food. (P48).

Another participant (P46) had vague ideas on the symptoms of nose and

throat cancer before reading the NPC pamphlet. Excerpt 5 shows that after he had read the pamphlet, he concluded that he had two signs of NPC but not the other signs, which is why he said he might be susceptible to getting NPC.

Excerpt 5

Oh, I'm afraid of that [risk of NPC]. Because I've sinus. (After reading the NPC pamphlet, the undergraduate circled 2, low risk of NPC). I've two [symptoms]. But I don't have this, bloody nose. It's always painful at the nose, nose block. I have headache but no blurry. And this one also, no numbness. (P46)

The pamphlet listed "bloody nose", "blurred vision" and "numbness" as signs. In addition, "headache" and "ringing ears" were shown in pictures on page three of the pamphlet. Participants like P9, P52 and P55 noticed them. For P9. an undergraduate in his early 20s, it was the first time he heard about NPC. After reading the pamphlet, he said, "No, I don't have all of these symptoms. I only have toothache". He added that he experienced ear ringing (which was stated as a sign of NPC in the pamphlet) when he was young but it disappeared after the doctor scanned his nose and removed the mucous from his nose.

Certain susceptibility to NPC

For participants who were certain that they were susceptible to NPC, Figures 2 and 3 show that unhealthy eating and smoking were mentioned both before and after reading the NPC pamphlet. Similar to participants in the category of possible NPC risk, the participants gave more specific reasons after reading the pamphlet. They talked about unhealthy food as those containing preservatives. Some participants showed more specific understanding of the danger posed by cigarette smoke in that second-hand smoke was mentioned as a risk factor for people who were constantly in the company of smokers. Smoking and food are the same factors given by participants for assessing themselves to be at various levels of susceptibility to getting NPC. This shows the common understanding of smoking and unhealthy food as possible causes of NPC.

Although less common, family history and the polluted environment were also given as reasons for high NPC risk. Figure 2 shows that before reading the NPC pamphlet, some participants were certain that they were at risk of getting because of the genetic NPC and environmental factors. However, after reading the pamphlet, they brought up Chinese ethnicity, NPC symptoms and cancer incidence as reasons to explain why they were at high risk of getting NPC (Figure 3). NPC symptoms were clearly shown in the pamphlet in text and visual form.

The pamphlet provided the NPC incidence statistics ("fourth most common cancer in Malaysia") in the Introduction section, page 2, third bullet point. This catch phrase changed some participants' assessment of their own risk of getting NPC (e.g., P30, P43). For example, before reading the pamphlet, P43, a senior lecturer in his late forties was "not sure" whether he was susceptible to getting NPC but he changed his mind after he had read the pamphlet. P43 said that he had a "50-50" chance of getting NPC "because this is the number four type of cancer in Malaysia". P30 felt that he could be susceptible to getting NPC, adding that he was at greater risk because he is a Chinese (Excerpt 6).

Excerpt 6

First thing, I'm a Chinese. Second thing, it's the fourth highest cancer in Malaysia. Even if I don't smoke, the risk is still high. You look at the genetic is also one of the important factors. In other words, Malaysians are susceptible to NPC. (P30)

Indeed, numbers are effective in creating fear of diseases. The information on the greater susceptibility of the Chinese to NPC is not directly stated in the pamphlet, showing that P30 had general knowledge on this. They could have made an inference based on the statement that NPC occurs more frequently in Southeast Asia and South China than in Western countries.

In Excerpt 6, it is interesting how P30 switched from using the first personal pronoun "I" to "Malaysians" when assessing his risk of getting NPC ("Malaysians are susceptible to NPC"). He did not say "I am susceptible to NPC". By using a third person reference, he put a distance between himself and the NPC risk.

Susceptibility to cancer is not an easy topic for most people, and assessing personal risk of getting NPC may be a kind of taboo to some participants. From their interviews in urban and rural areas of Kuching, Sarawak, Ting et al. (2018) found hesitation among some people to estimate their risk of getting NPC. Some individuals believed that if they assessed their risk to be high, it is as if they have cursed themselves with the cancer but if they assessed their risk to be low, it is as if they did not believe in God's control over their lives.

Lack of knowledge on susceptibility to NPC

Before reading the NPC pamphlet, some participants said that they did not know if they were susceptible to NPC and had never thought of it. Most of them were relatively young. For instance, P2, a Malay executive in her twenties said that she did not know if she would be susceptible to NPC. She said, "I'm not sure. Ya, never thought of it. I hope I won't get it". Another participant, P13, an Indian investor relation who was in his midthirties admitted, "I don't know. I just don't know enough about this disease".

After reading the NPC pamphlet, both changed their views on their susceptibility to getting NPC as follows in Excerpts 7 and 8: Excerpt 7

(laughs) Yes, because I think I ... I surround with the ... the people who are smoking. Like secondary smoker. Family members and friends. I usually hang out with friends, right. So they always ... I'm just okay with them smoke in front of me. But okay, it's quite bad actually. (P2)

Excerpt 8

Er ... to some degree, ya ... I do have some level of headache, this one okay, this one okay (symptoms). Sorry, this means what ah? (double vision). Just a bit of headache, mild headache. (P13)

P64. 16-year-old а student explained that "I am not sure if I am at risk or not (of NPC) because I'm still young, but we should be aware of it". P27, a professor in a local university, did not give a definite answer when asked if he might be at risk of contracting nose and throat cancer. He said, "I'm scared of it, so that's why I think nowadays I'm having a healthier way of eating and living". The reasoning probably goes like this: If I take good care of my health now, then chances of me contracting the cancer will be lower.

Overall, the results showed that the participants used the information on the signs of NPC shown in images and text to assess their susceptibility to NPC. Some thought that they might have NPC but concluded that since they did not exhibit any of the symptoms, they did not have the cancer. On the other hand, some began to worry because they had one or two of those symptoms. Interestingly, the participants were first drawn to the images. However, they would read the captions to ensure they did not misinterpret the pictures.

DISCUSSION

The results showed that the participants had some general knowledge on the causes of NPC. Before reading the pamphlet, they assessed their susceptibility to NPC based on whether they were living a healthy life, smoking (second-hand smoker included), breathing in polluted air and eating preserved or salted food. Leading a healthy life is too general to be of relevance in self-assessment of NPC susceptibility but smoking have been identified as possible causes of NPC by researchers (Kumar and Mydin, 2019).

The additional risk factors of NPC that were known to only some participants before reading the pamphlet were family history and ethnicity. Research have established that NPC is hereditary, and incidence is higher among some ethnic groups (Salehiniya et al., 2018) and the participants were right in identifying the Chinese as susceptible although NPC incidence among the Bidayuh of Sarawak has also been documented (Linton et al., 2021).

In the context of public health, we sought to investigate if health risk messages can educate the public on risk factors and health protective measures. The NPC pamphlet was found to be useful in creating awareness of NPC risk factors because it made participants more certain when assessing their own susceptibility to NPC and eliminated the cases of participants not knowing whether they were at risk. In addition, after reading the pamphlet, more participants were able to give specific risk factors such as food preservatives, NPC signs and cancer incidence, which were in the pamphlet. None mentioned the Epstein Barr Virus infection. probably because the information was too technical for the lay public to handle.

Health risk messages such as fact sheets and videos can increase intention to undertake health protective behaviours, for example, for HPV vaccination (Song et al., 2021). However, knowledge uptake is influenced by the information design in health risk messages. Pictorial health information moderately increase knowledge and understanding and overall recall of health information especially for the lower health literacy populations (Schubbe et al., 2020). Some of the changes made to improve text coherence were clearer agency, increasing argument overlap and adding connectors to draw attention to consequences of diseases. An effective health risk message is one that succeeds in increasing intention to detect or treat the disease, which would lead to better treatment and survival outcomes.

Researchers have moved into investigating the effectiveness of webbased tailored interactive interventions targeting HPV (Pot et al., 2018) and drug abuse (Arabyat et al., 2019). Nevertheless, brochures are still useful to reach the less information technology-savvy segments of the community. Mobile health approach was effective in encouraging breast cancer patients to perform an exercise intervention but its superiority over the conventional brochure was not evident (Uhm et al., 2017). Public responses may varv depending on format of health risk messages, the type of diseases and sociocultural context.

CONCLUSION

Considering the high incidence of NPC among Malaysians, further research involving experiments should be conducted investigate knowledge uptake to in response to a range of educational interventions with manipulations of information design. In addition, further studies should investigate perceptions of barriers that may prevent individuals from engaging in regular cancer screening or seeking cancer treatment.

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