

Expressions of Perceived Severity towards Nasopharyngeal Cancer

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Abstract. *Perceived severity of diseases influences health protective behaviour. Although the causes of cancer are not definitive, the public can seek regular cancer screening to detect cancer early to bring about better treatment outcomes. The study investigated perceived severity of nasopharyngeal cancer (NPC) among Malaysians, focusing on their expressions of disease seriousness. The participants were 65 Malaysians aged 13 to 65. They were interviewed about their perceived severity towards NPC before and after reading an NPC pamphlet produced by the Ministry of Health, Malaysia in Malay. A majority of the participants perceived NPC as a severe disease linked to death, scary symptoms, and disruption to the quality of life. The analysis revealed that before reading the pamphlet, the participants said that the word “cancer” made them fearful, and it is associated with images of sick and suffering patients, side-effects of chemotherapy which includes loss of appetite and weight, and the despondence of “waiting for death”. This is based on their general knowledge of NPC. After reading the pamphlet, the participants’ knowledge of NPC severity increased, indicated by the highlighting of NPC incidence (“the fourth most common cancer in Malaysia”) and symptoms such as “blurry vision”, “double vision”, “lumps on neck” and “bleeding”. The study suggests that perceived severity of this cancer is affected by the words used in health pamphlets, which indicates the importance of disease risk communication materials in creating public awareness on health protective behaviour.*

Keywords: *perceived, severity, expressions, nasopharyngeal, cancer*

1. INTRODUCTION

Nasopharyngeal cancer (NPC), also known as nose and throat cancer, is the fourth most common cancer in Malaysia (Ministry of Health, Malaysia. (2016). Some ethnic groups have a higher likelihood of contracting NPC. In Malaysia, the Chinese have a higher risk of getting NPC because NPC ranks third for Chinese males and ninth for Chinese females. In comparison, among the Malay, NPC ranks seventh for Malay male but it is not common among Malay females. NPC is also not common among the Indian. However, NPC incidence is high among Malaysians in the Others category which includes the Sabah and Sarawak indigenous. NPC ranks second for male indigenous and eighth for indigenous female. Devi et al. (2004) identified the Bidayuh group from Sarawak to be more susceptible to NPC than other indigenous groups.

There seems to be lack of awareness towards NPC symptoms because a majority of NPC patients had the cancer diagnosed at Stages 3 and 4 (63% for males, 60% for females) (Ministry of Health Malaysia, 2017). Despite NPC incidence being high among Malaysians, ranking number four in cancer incidences, Ting et al. (in press) found that Malaysians view themselves to be at low risk to NPC and rated the

severity of NPC as marginally low. Their study was conducted using questionnaires and involved 215 Malaysians living in Kuching and Kota Samarahan areas of Sarawak. As perceptions of disease severity is sometimes hard for lay people to quantify, it is important to investigate perceived NPC severity using interviews.

The study investigated perceived severity of nasopharyngeal cancer (NPC) among Malaysians, focusing on their expressions of disease seriousness. The results presented in this paper are part of a larger study which also examined perceptions of NPC risk and intended health protective behaviour.

2. LITERATURE REVIEW

The theoretical framework used in this study is the Health Belief Model for describing and predicting health behaviours (Hochbaum, Leventhal, Kegeles, & Rosenstock, 1952). The predictive factors for the health behaviours are perceived susceptibility (beliefs about possibility of getting a disease), perceived severity (beliefs about consequences of the disease), perceived benefits (potential of health action to reduce disease consequences), and perceived barriers (obstacles to adopting recommended health action). Two additional constructs were later added to the Health Belief Model, that is, self-efficacy (perceived readiness to take health action, and response efficacy (confidence in effectiveness of health action). These factors influence adoption of a recommended health action but the direct cues to action are stimulus that trigger acceptance of a recommended health action such as physical symptoms of the disease or external cues (e.g., advice from others, illness of family member, newspaper article) (LaMorte, 2019).

In the present study, the only construct examined was perceived severity. LaMorte (2019) explains that perceptions of severity is not necessarily limited to medical consequences such as disability and death, but can include social consequences such as family life, and social relationships. In the Health Belief Model, disease severity is combined with perceived vulnerability to form "threat", and that perceived threat motivates health actions (Miles, 2020). Qualitative studies in Indonesia (Fles, 2016; Fles et al., 2017) found that the lack of awareness among the public on the severity of NPC caused them to defer getting treatment for the cancer. In Sarawak, Malaysia, Ting et al. (in press) found perceptions of low severity for NPC. Such perceptions may cause delay in seeking treatment. Therefore, it is important to investigate the public's understanding of disease severity with respect to NPC.

3. METHODOLOGY

A descriptive study was conducted to understand perceived severity of NPC among the public by analysing their expressions of disease seriousness in interviews. Considering that little is understood about perceptions of disease severity, a qualitative analysis of the interview transcripts would lead towards identification of characteristics and trends in how NPC is perceived among Malaysians.

The participants of the study were 65 Malaysians aged 13 to 65 living in Kuching and Kota Samarahan. The participants ranged from secondary school students to senior citizens, with varied educational background and ethnic backgrounds. Table 1 shows the demographic characteristics of the participants. Demographic characteristics such as educational level, ethnicity and religion were not used as the exclusion criteria because the purpose of the study was to understand how members of the public from all walks of life perceive the severity of NPC. Therefore, whether or not the members of the public had NPC or other types of cancer were also not in the selection criteria.

Table 1. Demographic characteristics of the participants (N=65)

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		
Primary 6	4	6.2
Form 3	6	9.2
Form 5	4	6.2
Certificate	3	4.6
Form 6	5	7.7
Bachelor	23	35.4
Masters and Ph.D	20	30.8
Monthly Income		
Not working	19	29.2
Less than RM2000	7	10.8
RM 2000 - RM 3999	13	20.0
RM 4000 - RM 5999	5	7.7
RM 6000 - RM 7999	5	7.7
RM 7999 - RM 9999	9	13.8
More than RM 10000	7	10.8

The material that was used in the study was an NPC pamphlet printed by the Ministry of Health Malaysia. The pamphlet 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 in Malaysia in terms of incidence. The risk factors are identified as practices of smoking, chewing of betel nut leaves, preserved food, family history, and Epstein Barr Virus. Page 3 shows six pictures of signs and symptoms accompanied by words: nose bleed, 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 practise a healthy lifestyle ("*Cegah Kanser Sebelum Terlambat*", "*Amalkan gaya hidup sihat*"). The logo and name of the ministry is placed on the first and last pages of the NPC pamphlet to show the authoritativeness of the information in the pamphlet.



Figure 1. NPC pamphlet produced by the Ministry of Health, Malaysia

The instrument used to elicit the participants' perceptions of NPC severity was a semi-structured interview guide and the responses to Questions 3, 7, and 9 are related to NPC severity and reported in this paper.

- Q1: Have you heard of Nose and Throat Cancer?
- Q2: How will you know if a person has Nose and Throat Cancer? Why?
- Q3: Do you think Nose and Throat Cancer is a serious disease? Why?

Q4: Do you know what are the causes of Nose and Throat Cancer?

Q5: Do you think you might be at risk of Nose and Throat Cancer? Why?

Q6: How do you think we can prevent Nose and Throat Cancer?

Now I'm going to show you a brochure by our Ministry of Health. You may take a look.

Q7: So based on this brochure, is there anything new you learnt about Nose and Throat Cancer?

Q8: When you look at this brochure, does it make you feel that you're at risk of Nose and Throat Cancer?

Q9: Based on this brochure, does it make you feel that Nose and Throat Cancer is a serious disease?

Q10: Based on this brochure, can you identify what does it recommend you to do to avoid Nose and Throat Cancer?

Q11: Will you consult a doctor if these symptoms show? Why?

Q12: Is it easy for you to consult a doctor? Why?

Q13: Would you lead a healthy lifestyle to avoid Nose and Throat Cancer? Why?

Q14: Do you think it's easy to lead a healthy lifestyle? Why?

Question 1 and 2 were warm-up questions to ease the participants into the interview. The participants were asked to talk about general topics related to NPC such as whether they had heard of NPC and how they knew if a person had NPC. The term "Nose and Throat Cancer" was used in the interviews instead of NPC to avoid medical terms that the public may not be familiar with.

The data collection took place in Kuching and Kota Samarahan, Malaysia for six months from March to December 2018. The second researcher identified potential participants from her social network. In addition, she went to two conferences and interviewed participants who consented to participate in the study in order to widen the selection of participants to members of the public outside her social network. Whenever she met a potential participant, the second researcher introduced herself and the study, and asked if they were willing to participate in the study and whether the interview could be audio-recorded. Those who consented filled in the demographic section of the questionnaire before questions were asked on what they knew about NPC and its seriousness. Field notes were also taken during the interview. After the first part of the interview, the participants were shown the NPC pamphlet. Questions 1-2 in the interview guide were posed, with the purpose of comparing their knowledge of NPC severity before and after reading the NPC pamphlet. The interviews lasted 13 to 56 minutes.

For the data analysis, the audio-recorded interviews were transcribed verbatim. To understand how participants perceived NPC severity, depth was achieved by referring to the context, which is obtained from the demographic details given by the participants at the beginning of the interview. The thematic analysis of the expressions used by participants before and after viewing the NPC pamphlet showed complexity of multiple, overlapping, and sometimes conflicting themes.

4. RESULTS AND DISCUSSION

In this section, the participants are referred to using codes, P1 for Participant 1 and P65 for Participant 65. Out of 65 participants, 87.69% (or 57) participants said that NPC was a serious disease. The other participants were unsure and their responses were "I don't know", "pretty common", "I think so" and "depends on the stage". For example, P25 said that the signs and symptoms of NPC such as running nose, red eyes, and ringing ears were like common flu, and therefore not serious enough to warrant attention.

Figure 2 shows the perceived severity of NPC before and after reading the NPC pamphlet. The main themes that emerged from the interview analysis were the perception of NPC as fatal, disruptive to the quality of life and associated with scary symptoms. Two themes on severity (fatality, disruptive) were mentioned by participants before viewing the NPC pamphlet while the two themes on scary symptoms and NPC incidence surfaced after they had seen the NPC pamphlet.

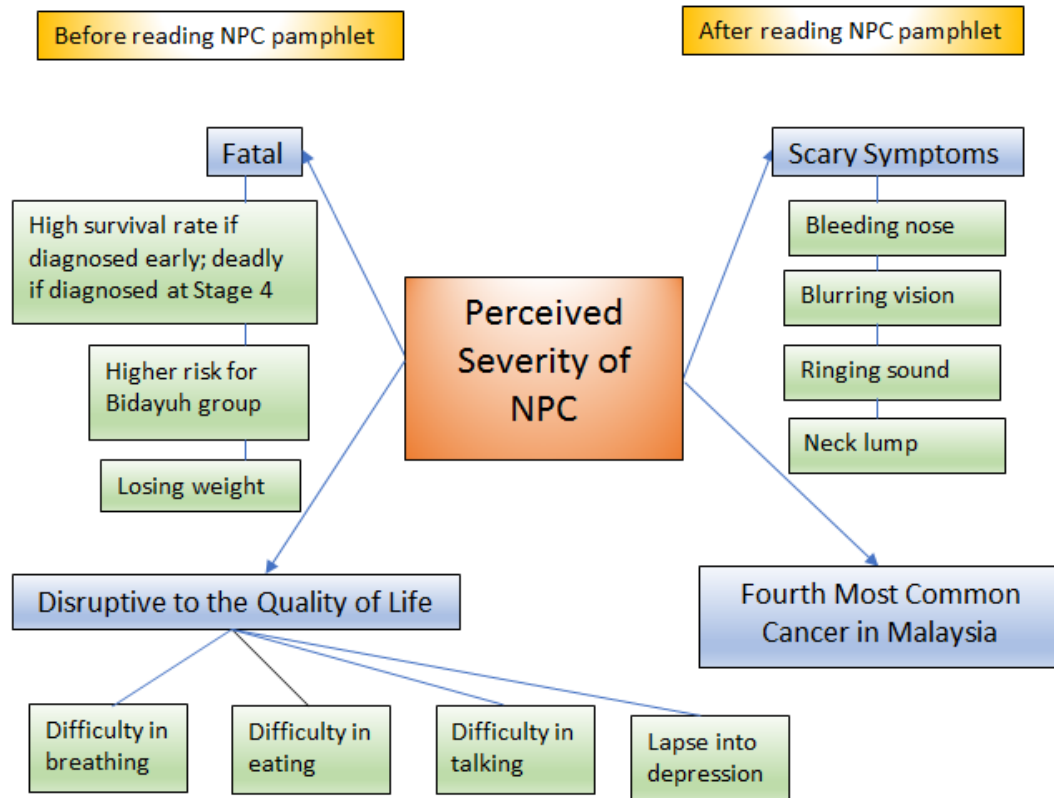


Figure 2. Perceived severity of NPC before and after reading the NPC pamphlet

4.1 Cancer causes death

A total of 17 participants reasoned that NPC was serious by virtue of it being a cancer. For example, when asked if he thought nose and throat cancer was a serious disease, P8 replied, “I think it is. All cancers is er ... serious.” After seeing the NPC pamphlet, P8 gave the same response regarding the perceived severity of NPC, “Yes [It is serious] ... because it can cause dying.” P11 stated, “Any form of cancer is a serious disease.” She further explained that “because er the rate of er what do you call that, the rate for you to be cured is very little for cancer.” The word “cancer” brings images of sick and suffering patients, undergoing chemotherapy, losing weight and lying on the death bed. P20, an Australian young teacher trainee in Kuching, also perceived NPC as a severe disease “because it is deadly”. The most frequently used justification to explain why NPC is perceived as a disease with severe consequences is that cancer causes death.

One scale down in disease severity from deadly is “terminal”. “A terminal illness is a disease or condition which can’t [cannot] be cured and is likely to lead to someone’s death” (Mariecurie, 2021, para. 1). The difference is that these participants did not stress that NPC would lead to death but focused on the debilitating nature of the disease. For example, P39 (an undergraduate) compared the severity of NPC to AIDS, diabetes and Alzheimer’s Disease as shown in Excerpt 1:

Excerpt 1

Just like AIDS. AIDS and diabetes. Diabetes is a very serious disease. Can spoil all your kidneys. You'll go to dialysis. Your legs can't move. And then, then ah....you turn to be depression. Then, lao ren chi dai zheng [Chinese for Alzheimer's Disease]. (P39)

P39 apparently knew more about diabetes and dialysis than NPC because he did not talk about the adverse effects of NPC on bodily functions.

Participants who had some knowledge of NPC were less pessimistic about the severity of NPC. A participant who had some knowledge of NPC (P51, a postgraduate student) was aware that NPC is only serious if it is discovered at an advanced stage and treated late, as shown in Excerpt 2.

Excerpt 2

It [nose and throat cancer] would be serious if it is not treated like on time. And if it were to be diagnosed at early stage, I think it is curable and maybe you can have like five years period of free disease. Five years free diseases time. Yeah. After the chemotherapy and everything. Once you have removed the cancer cells. Or maybe once you have already cured most of the cancer cells. (P51)

P31 who referred to Malaysian badminton player Lee Chong Wei's nose cancer also talked about the high survival rate of NPC if the cancer is diagnosed at an early stage but acknowledged that it is deadly if it is diagnosed at Stage 4 because it would have spread to other parts of the body (see Excerpt 3).

Excerpt 3

It depends when it is diagnosed. If the treatment is at an early stage, the survival rate is quite high; if the diagnose stage is quite late, basically nothing much can be done. Because the location of our nose is quite near to our brain. So, if it goes to stage 4, it'll spread quite fast, to our brain. It's something like liver cancer, it's surrounded by our everything, like lung also, you know the lung cancer. (P31)

Karamouzis (2012) described NPC as a rare but potentially curable disease, and it is more common in eastern Asia, northern Africa and Alaska than among Caucasians. This fact is also placed in the NPC pamphlet on page 2 under the Introduction section (the second bullet point). Some participants like P52, a master student who was coincidentally researching on this topic, were aware of the higher incidence of NPC among the Sarawak indigenous groups of Malaysia (Excerpt 4).

Excerpt 4

As a master's student, I focus on [NPC] ... I did quite an amount of literature review, so I think that in Sarawak, it's a very crucial issue that I think is awaited to be supported, because among the Bidayuh group especially, the risk of getting nasopharyngeal cancer is relatively higher. (P52)

The Cancer Registry produced by the Ministry of Health, Malaysia showed higher incidence among the Sarawak Indigenous groups and Devi et al. (2004) identified the Bidayuh as the most susceptible Indigenous group.

4.2 *Scary signs and symptoms of NPC*

Before reading the pamphlet, participants who did not have much general knowledge of NPC had a vague idea that it is a deadly disease because it is a cancer but the pamphlet educated them on the cancer death statistics and the specific signs and symptoms of the NPC.

After reading the pamphlet, the participants highlighted the scary symptoms as justification to support their view of NPC as a disease of high severity. The symptom that seemed to scare the public the most was bleeding. For example, P1 described the signs and symptoms of NPC as follows (Excerpt 5):

Excerpt 5

Yes, I learnt about the symptoms. I learn about the bleeding nose, mucous and this blurring vision, furthermore, the ringing sound...and this cramp at the face. (P1)

P16, a Bidayuh technician, also mentioned the bleeding. He said, "If you constantly have blood coming out from your body, it is serious. It is not normal." In total, six participants gave the "blood symptom" to explain why they considered NPC a disease with serious consequences (P1, P16, P32, P34, P39, P59).

The neck lump was possibly the second most visible sign and symptom of NPC to the participants. Before reading the NPC pamphlet, some participants like P1 and P2 had vague ideas on some problems at the neck and throat area (Excerpt 6).

Excerpt 6

Because it's the main organ in our body. Because it's for our breathing (noun). Breathing and eating. (P1)

I think...er...for the nose cancer, the... the nose itself is swollen. I think la ... ya, ya. Er... I saw it on TV, in international channel. Er...for the throat, I think... they feel hurt, for the throat but I don't know exactly. (P2)

However, the NPC pamphlet made it very clear what the signs and symptoms of NPC were. The cover page of the NPC pamphlet shows a picture of two hands pressing on a neck lump, and the image took up over half of the space on the page. As for Page 3 of the NPC pamphlet, the third picture (out of a total of six) showed a neck lump. P34 and P59 talked about the neck lump.

The images on the NPC pamphlet had a big effect on some participants like P3. The Chinese retiree commented on the cover picture, "see the hand, like choking". P3's father had died due to NPC two years ago. After he was diagnosed at Stage 3, he lived for about a year before succumbing to the cancer. P3 talked about how his family had seen the lump on his father's neck but thought that it was a normal growth because it was only half a size of a thumb. However, as his father had unusual weight loss, they asked their father to go for a medical check. The first two scans could not pick up the cancer and it was the endoscope which confirmed that his father had NPC. In the context of P3's experience with NPC, it is right that the cover page of the NPC pamphlet shows the neck lump. The public needs to be made aware that growths on the neck may spell danger and it may not be just an abnormal enlargement of the thyroid gland or a skin growth.

4.3 NPC affects the quality of life

Some other participants considered NPC as a moderately severe disease because it affects the quality of life. The four reasons for NPC affecting quality of life are it causes difficulty in breathing, eating, and talking. In Excerpt 7, P5 explained that NPC affects breathing and eating functions:

Excerpt 7

Because we are breathing using our nose and then we eat using our throat. So if that one erm...have *rosak* [Malay word for “not functioning”], you cannot eat properly, you cannot eat the food that you like.

Six other participants (P11, P23, P37, P42, P47, P53) demonstrated awareness that a growth in the nasopharynx area would result in breathing and eating difficulty. P11, a Chinese sales executive, also said that at a serious stage, the breathing difficulties may lead to death. P3 was the only participant who said that the gradual loss of body organs may cause the patient to lapse into depression.

4.4 NPC incidence

Cancer incidence was mistakenly brought up as evidence of the severity of NPC. NPC incidence is actually information on risk of getting NPC but the participants in this study understood it as disease severity. The NPC pamphlet informed the public that NPC is the “fourth most common cancer in Malaysia” (Introduction section, page 2, third bullet point). When asked whether NPC is a serious disease, P52 brought up the NPC incidence statistics as shown in Excerpt 8:

Excerpt 8

Yes, because the pamphlet mentioned it's the fourth most deadly cancer that is found in Malaysia. I feel that the public should be aware of this. (P52)

P52's view was shared by P43, P45, P48 and P51, showing that cancer incidence statistics are seen as conveying disease severity. The reasoning probably goes like this: If NPC is such a common cancer in Malaysia, then chances of contracting the cancer is high and I might suffer debilitating effects, if not death. In other words, NPC is considered a threatening disease.

Risk and disease severity together constitutes the threat presented by a disease (Miles, 2020). To researchers in public health and health risk communication, risk and severity are two different concepts but to the lay public, they are coalesced. This result on perceived disease severity is made possible because the present study employed interviews as a data collection technique. In studies using questionnaires, the public are guided by the questions to assess their risk to getting a disease and the severity of a disease separately but in their minds, these concepts are probably indistinguishable.

CONCLUSION

The study examined perceived severity of NPC among Malaysians by focusing on their expressions of disease seriousness. The results showed that before reading the NPC pamphlet the participants expressed fears of NPC by virtue of it being a cancer. They knew that cancer was a terminal illness and there may be relapses of the cancer despite undergoing treatment. They had vague ideas that the cancer had bad effects on their body but they could not explain the specific effects. However, after viewing the NPC pamphlet, they highlighted the bleeding and the lump as the two most common signs and symptoms of NPC. They also paid attention to the

breathing and eating difficulties which resulted from the growth of the neck lump, showing the effectiveness of images in getting the message across to the public. Interestingly, cancer incidence was mistakenly brought up as evidence of the severity of NPC although disease incidence is actually information on risk. However, the participants could be responding to the threat posed by NPC because risk and disease severity together constitutes the threat presented by a disease. The study showed that disease risk messages in pamphlets can educate the public about the specific signs and symptoms of NPC, or cancer in general, so that they can go for regular cancer screening to detect the cancer earlier and have better treatment and survival outcomes. However, further studies should investigate public understanding of risk and severity to attain a better understanding of disease threat because these are two separate aspects of a disease, and the information is useful for the formulation of health risk messages that can be understood by the lay people.

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