

## WHY ARE NASOPHARYNGEAL CARCINOMA PATIENTS DIAGNOSED AT LATE STAGE ?

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**ABSTRACT:** 100 consecutive newly diagnosed patients with nasopharyngeal carcinoma (NPC) since January 1994 were the subjects for studying various factors related to the delay in the confirmation of the diagnosis. 79 of them were males and the peak age of incidence was the 5th decade. 92% were Chinese, 7% Malay and 1% Indian. 76% were agriculture worker or labourers with 66% having either no formal education (16%) or only primary level education (50%). For 50% of patients neck swelling was the first symptom, 26% had nasal symptoms, 12% ear symptoms and 11% had symptoms due to intracranial extension of tumour. As many as 80% were at UICC Stage IV at the time of diagnosis. While the median delay, on the part of patients, in consulting a doctor was 2.5 days, the median delay on the part of the doctors to confirm the diagnosis of NPC was as long as 127 days, which was particularly worse when the patients presented with ear symptoms (266 days) followed by those with neck swelling (94 days). For those patients who were required to undergo more than one nasopharyngoscopy and biopsy the median doctor's delay was 144 days. Since 82% of patients had consulted general practitioners who remained the first-line health-service provider, it is suggested that their level of awareness with regards to NPC be significantly raised so that the delay on their part be greatly minimized. (*JUMMEC 1999; 1:39-42*)

**KEYWORDS:** Nasopharyngeal carcinoma, delay in diagnosis, patient's delay, doctor's delay.

### Introduction

Nasopharyngeal Carcinoma (NPC) ranks fourth among the most common cancers in Malaysia. It most commonly affects the ethnic Chinese in or originating from southern provinces of China, where the incidence(1) is as high as 30 per 100,000 per year. Natives (Malays, Kadazans, Ibans and Bidayus) in Malaysia and those in other Southern Asian countries as well as Maghrebians Arabs and Greenland Eskimos have an intermediate risk, while for the rest of the population in the world the incidence of NPC is as low as 1 per 100,000 per year. In Peninsular Malaysia it was noted(2) that the Chinese males, in the fifth decades of life, were at the highest risk (40.1 per 100,000 per year). With almost 90% of population at either high or intermediate risk of developing NPC, it is a major health problem in Malaysia.

While the problem of establishing the diagnosis of NPC has been resolved(3), and there has been remarkable improvement in the survival of NPC patients at early stages(4), (UICC5 Stages I & II), for whom "cure" seems achievable, it is unfortunate that almost 80% of our patients are diagnosed at advanced stage( UICC Stages IV), for whom the survival rate is still far from satisfactory.

The present study was undertaken to investigate into the factors responsible for the delay in establishing the diagnosis of NPC.

### Materials and Methods

One hundred consecutive newly diagnosed and histologically confirmed NPC patients seen at the University Hospital Kuala Lumpur from January 1994 onwards were the subjects for study. All the patients were interviewed by one of the authors (Pua Kin Choo). A properly designed pre-set questionnaire-form was filled up with relevant data obtained from the patients and their case folders.

The questions were set in order to obtain information concerning the patient's general characteristics (age, sex, race, education, occupation, personal habits), his state of awareness about NPC, first symptom noted by the patient, with its duration, first and subsequent doctors

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visited, difficulties encountered before confirming the diagnosis and date of final NPC diagnosis.

Data thus obtained were stored in a file under a programme "spread sheet" in Excel 7.0 of Windows 95, and analysed with a view:

1. to ascertain whether there was delay on the part of patient (Patients delay). This was noted as the time interval between the start of first symptom as observed by the patient and the date of first visit by the patients to see a doctor.
2. to ascertain whether there was delay on the part of the doctor (Doctor's delay). This was taken as the time interval between date of first visit by the patient to see a doctor (or the first doctor, if he had consulted more than one) and the date of confirmation of diagnosis.
3. to study the factors which could have caused the patient's and/or doctor's delay, if any, with special reference to patient's general characteristics as mentioned above, their awareness about NPC, the nature of first symptom noted by the patients, type of doctor first consulted and the kind of difficulties encountered by the doctor in confirming the diagnosis.

For both patient's delay and doctor's delay, the time interval was computed to denote "median" or the middle number, when the numbers were arranged in order or according to size. Median was chosen because the range of value was wide and the distribution was skewed to the left. Realizing the fact that several patients had problems recalling the date of first symptom or date of first visit to see a doctor most appropriate dates were selected based on patient's recollection.

Descriptive statistics was used in the presentation of the results.

## Results

### I. General characteristics:

#### a. Age and Sex (Table 1)

Largest number of patients (37) belonged to the age group 40 - 49. The overall median age of the patients was 49. There were 76 males and 24 females giving a male to female ratio of 3:1.

#### b. Ethnic and dialect distribution (Table 2)

92 patients were Chinese, with 37 (40.2%) belonging to the Cantonese dialect group (dialect of the patient's father was taken as patient's dialect even though mother spoke different dialect). 24 (26.1%) of them were Hokkien and 24 (26.1%) Hakka. There were 7 Malay

patients and 1 Indian patient in this group.

#### c. Distribution according to occupation (Table 3) and education.

Based on the Dictionary of Occupational Classification of Malaysia(7), it was noted that as many as 73 (73%) belonged to workers or labourers class. Those female patients who were housewives were classified under their husband's occupational class.

As for education, majority (66%) of them had either primary education (50%) or no formal education (16%) at all. 31 (31%) had studied up to secondary level and only 3 (3%) had received tertiary education.

#### d. Awareness of NPC Before Diagnosis

34 (34%) patients had come to know about NPC before

Table 1. Distribution of 100 NPC patients according to age and gender.

| Age Group<br>Years | Female |        | Male |        | Total |       |
|--------------------|--------|--------|------|--------|-------|-------|
|                    | N      | (%)    | N    | (%)    | N     | (%)   |
| 20 - 29            | 1      | (4.2)  | 3    | (3.9)  | 4     | (4)   |
| 30 - 39            | 6      | (25.0) | 17   | (22.4) | 23    | (23)  |
| 40 - 49            | 8      | (33.3) | 29   | (38.2) | 37    | (37)  |
| 50 - 59            | 4      | (16.7) | 21   | (27.6) | 25    | (25)  |
| 60 - 69            | 5      | (20.8) | 4    | (5.3)  | 9     | (9)   |
| 70 - 79            | 0      | (0.0)  | 2    | (2.6)  | 2     | (2)   |
| Total              | 24     | (24.0) | 76   | (76.0) | 100   | (100) |
| Median of age      | 49     |        | 46   |        | 49    |       |

N is the number of patients

Table 2. Distribution of 92 Chinese NPC patients according to dialect.

| Dialect   | N  | %      |
|-----------|----|--------|
| Cantonese | 37 | (40.2) |
| Hokkien   | 24 | (26.1) |
| Hakka     | 24 | (26.1) |
| Teochew   | 4  | (4.3)  |
| Hainanese | 3  | (3.3)  |
| Total     | 92 | 100    |

Table 3. Distribution of 100 NPC patients according to occupation

| Occupation     | N   | %   |
|----------------|-----|-----|
| Professional   | 2   | 2   |
| Administrative | 2   | 2   |
| Clerical       | 5   | 5   |
| Sales          | 11  | 11  |
| Service        | 4   | 4   |
| Agriculture    | 3   | 3   |
| Labourer       | 73  | 73  |
| Total          | 100 | 100 |

he/she was inflicted with this disease. Most of them (30 or 88.2%) got information through either friends and relatives (16 or 47%) or through newspapers (14 or 41.2%). 13 of them had positive family history of NPC. 4 obtained information from medical staff known to them.

### **e. First Symptom**

Presence of swelling in the neck (neck mass) was noted as the first symptom by 50 (50%) patients whereas there were 26 (26%) patients for whom the first symptom was nasal (in the form of blood stained nasal or postnasal discharge). There were 12 (12%) patients whose first symptom was aural, which included impairment of hearing with or without tinnitus in one ear. 11 (11%) had intracranial symptom; either headache (6%) or cranial nerve palsy (5%). There was one patient whose first complaint was generalised bodyache.

### **f. Stage of NPC at Diagnosis**

All the patients were staged according to UICC staging classification (5), after CT Scan of the nasopharynx, skull base and cervical region, and complete metastatic work up (Bone Scan, Liver ultrasound and Chest X-Ray) to exclude distant metastasis to bone, liver or lung. As many as 80 (80%) belonged to Stage IV with 14 (14%) in Stage III and 3 each in Stages II and I.

## **II. Patient's Delay**

It was revealing to find that 73 (73%) patients had consulted a doctor within 2 months of observance of the first symptom with as many as 47 (47%) visiting a doctor's clinic on the very first day they noticed a symptom. While there were 14 (14%) patients who took between 2 to 6 months and 13 (13%), more than 6 months to see a doctor. The overall median time to see a doctor (Patient's delay) was only 2.5 days.

### **a. In relation to age, sex, ethnic and dialect groups and awareness about NPC.**

No significant difference could be allocated between various subgroups

### **b. In relation to occupation and educational level.**

It was quite obvious that the worker/labourer group (76) took longer time (median delay of 12 days) to see a doctor; while those with no formal education (16) taking yet longer time (median delay 30 days) to do so.

### **c. In relationship to symptoms.**

It was interesting to note that for those patients with

nasal symptoms (26 patients) the median delay was 21 days, while for those with intracranial symptom (11) it was 14 days. However for those with neck swelling (50) the median delay was only 3 days and for those with ear symptom (12) there was no delay at all.

## **III. Doctor's Delay.**

It was shocking to note that the median delay on the part of the doctors was as long as 127 days or more than 4 months. There were only 9 patients for whom the diagnosis of NPC was confirmed within 2 weeks of seeing a doctor. For 19 it took up to 2 months, for 37 between 2 to 6 months and for 35 (35%) i.e. more than one-third, it took anything between 6 months to more than one year.

### **a. In relation to first Symptom:**

For those with nasal symptom (26 patients) the median doctor's delay was minimum (26 days), followed by those with intracranial symptoms (11) for whom it was 51 days. It was unbelievable to find that the median doctor's delay was more than 3 months (94 days) for those with neck swelling (50 patients) and for those with ear symptom (12) it was close to 9 months (266 days).

### **b. Doctor's delay in relation to type of doctor.**

While none among this group of 100 patients consulted an ear, nose and throat surgeon to start with, there were 82 who attended the clinics of general practitioners (inclusive of 20 who first visited a Chinese traditional doctor). 18 went to see either the general surgeons (8), general physician (7), dental or maxillo facial surgeon (2) or a neurosurgeon (1).

Although it was interesting to note that median number of doctors consulted by these patients was 3.5, it had no obvious relationship to the first symptom or the doctor's delay.

Among the doctors consulted were those who had graduated from United Kingdom, India, Australia, Bangladesh, however further details were not extracted.

### **c. In relation to difficult diagnosis.**

Difficulty in establishing the diagnosis was encountered in 18 patients who were subjected to nasopharyngeal biopsy more than once. 14 of them had biopsy taken twice and in 2 patients each it was done three times and four times respectively. The median doctor's delay was 144 days (close to 5 months) for those patients (14) who were biopsied twice and it was 576 days (about 1 1/2 year) for those with more than that (4 patients).

Nonetheless, it was surprising to find that even for those whose diagnosis was confirmed on first biopsy (82

patients) the median doctor's delay was as long as 92 days (more than 3 months).

## Discussion

Needless to say, early diagnosis is the key to effective control of cancer in general but for NPC, early diagnosis can lead to "cure". Fortunately NPC is both radiosensitive as well as chemo responsive, so much so that for those at early stages the "cure" seems possible and for those at advanced stage better survival results are forthcoming. In fact, according to our NPC data bank, since the last 10 years not a single case of histologically confirmed NPC at UICC Stages I & II and treated with radiotherapy (RT) alone has died. For those at UICC Stage IV (non-metastatic) who received a combination of RT followed by chemotherapy (CT) there has been considerable improvement in overall survival (8) (80% 3 year survival), however there is room for further improvement. The fact remains that the chance of attaining effective control is best if NPC is diagnosed early, which has been the problem in the past<sup>9</sup> and remains so at present (this study). It has been generally believed by oncologists in the developing world that cancer patients themselves visit the doctors at late stage, due to ignorance, lack of awareness, non-availability of medical services close by, financial difficulties, etc. The results of the present study has been an eye opener in the sense that in Malaysia so far as NPC patients are concerned, they did present themselves to their doctors within a very reasonable time (mean delay only 2.5 days), so much so that 47 (47%) of them consulted doctor on the very day they noticed a symptom. For those with ear symptom (12 patients), there was absolutely no delay while those with neck swelling the mean delay was only 3 days. Unfortunately for patients with these very important symptoms, which were clearly suggestive of NPC, the late diagnosis was due to doctor's delay. For those patients with ear symptom the median delay was close to 9 months (266 days) and for those with neck swelling it was more than 3 months (94 days).

If only the attending doctors had realised that the ear symptom in the form of unilateral hearing impairment with or without tinnitus, is one of the symptoms of NPC, which often comes on at its early stage, diagnosis for those 12 patients would not have been delayed to that extent. It was difficult however to ascertain as to why the median doctor's delay was to the extent of 3 months for those patients with neck nodes, which must be taken as secondary to NPC, particularly, if the patient is a Chinese, and in this series 92% of the patients were Chinese.

Although we did not go in depth investigating about the doctors who were responsible for the delay (82% of them were general practitioners), it was felt that those

doctors who had received their undergraduate education in countries where NPC is rare like U.K, India, Pakistan, Bangladesh, Egypt, Australia, etc. might not have been taught this subject in great detail and would not have been exposed to NPC patients as they are commonly seen in Malaysia.

The authors would like to urge those doctors who wish to know of the fundamental clinical aspect of NPC, to read the articles, (10,11) particularly written for that purpose.

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