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## **Nasopharyngeal Carcinoma: An Awareness and Screening Initiative in Boston's Chinatown**

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### **Authors' contributions**

Author ROW designed the study and wrote the protocol. Author MO was involved in execution of the study and compilation of the data. Author MM performed data compiling and analysis. Author JT performed data analysis and wrote the manuscript. All authors read and approved the final manuscript.

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### **ABSTRACT**

**Aims:** Our objective is to describe our institutional experience with nasopharyngeal carcinoma (NPC), and the initiation of a community education and screening program.

**Study Design:** Retrospective case series; academic medical center.

**Methodology:** All cases of NPC treated at our institution between 1995 and 2009 were included; in total, 63 consecutive cases. Initially a retrospective review of patient characteristics was performed (Phase 1). Information reviewed included stage at presentation, completion of primary treatment and follow-up greater than 1 year. Findings of Phase 1 were interpreted as demonstrating an issue in communication between the medical center and the community of patients at large. As such, a community education and screening program was instituted as part of an attempted community outreach program (Phase 2). The primary goals were to increase awareness about this disease, symptoms requiring evaluation and to educate patients about the resources available to them.

**Results:** At the time of diagnosis, 67% of patients with NPC presented with advanced-stage (III,IV) disease. Of the patients treated with curative intent, only 76% fully completed their plan of treatment. Also of note, only 60% of patients were seen in follow-up at 1-year post-treatment. A community education and screening program was initiated in order to address a presumed gap in provider-patient communication. To date a total of 176 patients have been screened; with approximately 10% warranting further diagnostic

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evaluations.

**Conclusions:** Although NPC is an unusual diagnosis in the United States, it is a common entity in the immigrant Cantonese population that live in Boston's Chinatown. A review of the characteristics of our patient population with NPC led to a community awareness and screening initiative, which has sought to achieve earlier diagnosis and improved continuity of care for patients.

*Keywords: Oncology; head and neck surgery; nasopharyngeal carcinoma; disease screening.*

## 1. INTRODUCTION

In the United States, nasopharyngeal carcinoma (NPC) is a rare malignancy of the upper aerodigestive tract and has an incidence of less than 1 per 100,000 [1]. However, this disease has a well-documented regional and ethnic distribution such that individuals of Southern Chinese and Southeast Asian descent are up to 20-40 times more like to develop NPC than individuals of European ethnicity [2]. NPC is epidemiologically and pathologically distinct from most other carcinomas of the upper aerodigestive tract. The World Health Organization (WHO) classifies NPC as Types I-III [3]. Type I includes keratinizing squamous carcinoma; this is the most common type in the United States [1]. Type II includes non-keratinizing squamous carcinoma and Type III undifferentiated carcinomas. Types II and III are associated with the Epstein-Barr virus. WHO type II and III are the most common type of NPC in endemic populations and worldwide [2,4].

Tufts Medical Center is located in the heart of Boston's Chinatown and cares for a large proportion of Cantonese-speaking patients that have immigrated from China. This represents a uniquely diverse community in which Asians represent more than 75% of the population, of which 90% are Chinese, with nearly 70% being foreign born. The language barrier is significant with 69.2% of Chinese Americans in Massachusetts over the age of 65 reported to speak English "not well" or "not at all". The median household income for Chinese Americans in Chinatown is \$13,046 and only 1 in 4 males attains a 9<sup>th</sup> grade or greater education [5].

In the US, NPC makes up a low percentage of head and neck cancer overall; however, at Tufts Medical Center NPC can represent up to 5% of head and neck malignancies in any one year [1,3]. The patient population with NPC at Tufts Medical Center (over a defined timeframe) was reviewed with an assessment of the diagnosis and treatment characteristics for our patients. This 'Phase 1' portion of our project enabled a performance improvement project that is ongoing and considered Phase 2.

## 2. METHODOLOGY

This study was comprised of 2 phases. Phase 1 involved a chart review of 63 sequential cases of NPC treated at our institution between 1995 and 2009. The electronic medical record was used in order to determine the following disease characteristics: stage at presentation, presenting complaint, patient age, patient sex, smoking history and family history. In addition the following outcome measures were recorded: completion of treatment, length of follow-up. This study was approved by the Tufts Medical Center Institutional Review Board.

Phase 2 was to institute an NPC community awareness and screening initiative. With guidance from local community leaders, informative handouts were created for distribution at

medical center and in the community. Postings were also placed in local Chinese-language periodicals. The information focused primarily on the presentation of this disease; features such as unilateral nasal obstruction and new onset epistaxis. Resources available to patients including medical care and interpreter services were highlighted. Free screening examinations were offered at the Department of Otolaryngology – Head and Neck Surgery. Screening involved a focused history and physical exam, as well as endoscopic nasopharyngeal examination. The target population in this case was patients of Chinese or SEA descent with any symptoms of nasal obstruction, epistaxis, or a family history of nasopharyngeal carcinoma. The screening exam, including the nasopharyngoscopy, was provided to patients free of charge with the help of volunteers from the Tufts Medical Center Department of Otolaryngology-Head & Neck Surgery and Interpreter Services. Informational pamphlets about the warning signs of NPC were provided to each individual screened written in both English and Cantonese. Patients participating in nasopharyngeal carcinoma screenings sign consent allowing for the de-identified use of statistical information generated from the program.

Fisher's exact test and Binary Logistic Regression were used to compare nominal variables. Statistical significance was defined as a  $p < 0.05$  and the analyses were performed using SPSS Statistics software v.20 (IBM, NY, U.S.).

### 3. RESULTS

Sixty-three patients were diagnosed with NPC in the period from 1995 to 2009. The findings of Phase 1 are displayed in Table 1. In summary, 67% of patients were diagnosed with Stage III/IV disease at presentation. Importantly only 76% of patients completed treatment of their disease and 40% had less than 1-year of post-treatment follow up. Female patients had a significantly lower average follow-up period than male patients controlling for all other variables ( $p = 0.019$ ).

**Table 1. Characteristics of patients diagnosed and treated for NPC at Tufts Medical Center (1995-2009)**

<b>Total patients</b>		63	
<b>Age in years mean (SD)</b>		52.5 (17.0)	
		<b>n</b>	<b>%</b>
<b>Gender</b>	Male	42	66.7
	Female	21	33.3
<b>Ethnicity</b>	Chinese	34	54
	SEA (non-Chinese)	7	11.1
	Other	22	34.9
<b>Other characteristics</b>	First gen. immigrant	24	38.1
	Smokers	33	52.4
<b>Symptoms (Median duration 3 months)</b>	Nasal obstruction	24	38.1
	Neck mass	23	36.5
	Ear discomfort	17	27

<b>Histology</b>	Type I	6	9.5
	Type II	32	50.8
	Type III	21	33.3
<b>Stage</b>	1	6	9.5
	2	12	19
	3	17	27
	4	25	39.7
		48	76.2
<b>Treatment completion</b>	yes	12	19
	no		
<b>Follow-up &lt; 1 year</b>		25	39.7

Phase 2 involved a community awareness campaign as well as free screening on designated days in the Otolaryngology Department. Six screening days were carried out in the time period from 2008-2009 and a total of 176 patients were screened. Approximately 10% of screened patients warranted further diagnostic evaluations. The most common abnormal findings on history, physical and nasopharyngoscopy were nasopharyngeal soft tissue asymmetry and neck lymphadenopathy. The most common further diagnostic study was computed tomography of the neck and nasopharynx. No new cases of NPC have been diagnosed at this point.

#### 4. DISCUSSION

The findings of Phase 1 indicated that a high percentage of patients initially presented with advanced stage disease (67%). This figure is comparable to that of other studies [4]. The most common WHO types diagnosed were types II and III, which was expected given that the population screened was predominantly of SEA descent. Perhaps the most clinically important findings of Phase 1 of this study were those regarding treatment completion and follow up.

All patients in this study underwent primary treatment with concurrent chemoradiation therapy. Only three quarters of patients completed treatment and 40% of patients had less than 1 year of follow-up. These findings were interpreted as indicative of the challenge of communication between health care providers and patients. A community outreach program was initiated (Phase II), with a focus on access to care. The goal of this program was to improve overall communication between the local community and healthcare providers.

Information in Chinese-language brochures was provided at the Departments of General Medicine, Medical Oncology, Radiation Oncology and Otolaryngology – Head and Neck Surgery. In addition, basic information of the presenting signs and symptoms as well as contact information for appropriate resources within the medical center were published in local Chinese-language periodicals. These included several community newspapers.

The incidence of NPC in individuals of Southeast Asian descent in endemic regions varies between an estimated 10-50/100,000 individuals and is considered rare in North America

[2,6]. Based on this figure our study would expect to screen 2,000 individuals in order to diagnose one case of NPC. However, the benefit of the screening program lies in communication and education. The Chinese population in Boston's Chinatown is composed of a large number of recent immigrants with poor English fluency rates, low levels of educational accomplishment and median household incomes of less than \$15,000 per year. A free screening and educational effort offers a substantial benefit to a population that one could consider "at risk" and potentially unwilling to seek care for symptoms of lymphadenopathy or a persistent serous otitis media.

Asian Americans represent the fastest growing ethnic group in Massachusetts with numbers growing more than 28% between 2000 and 2007. Asians currently represent 4.7% of the total Massachusetts population (305,057 individuals). Chinese ethnicity is the largest subgroup of Asian Americans in Massachusetts representing 36.6%. Filipino and Thai immigrants are the fastest growing subgroups with a 50% increase in their populations since 2000. Within Boston's Chinatown, Asian Americans currently comprise approximately 75% of the total population. More than half are foreign born. Chinatown remains the economic, social and cultural center for all the Chinese and other Southeast Asian populations living in the greater Boston area [5].

Screening minority populations in the US possesses special challenges. A deep understanding of their socioeconomic status, health literacy, social norms and beliefs and access to health care are all key to the success of any health related campaign. Immigrants are one-third as likely as non-immigrants to report a positive family history of cancer, even after controlling for demographic and cancer knowledge status [7]. Even in the case of a common cancer with a strong link to family history such as colon cancer, 20% of minority populations with positive family history were never recommended screening by their physicians and two thirds were never scheduled a screening [8].

Interventions targeting organizational changes such as provision of separate dedicated prevention clinics, use of a pre-planned prevention visits, or designation of supporting staff to do prevention specific tasks were previously found to be the most effective method of increasing participation in adult screenings.[9] Similarly, a recent meta-analysis also found that access enhancement, followed by community education and individual education, were the most effective method of increasing cervical cancer screening in minority women.<sup>10</sup> Using the Health Information and National Trends Survey, Rakowski et al identified insurance coverage and regular source of care combined as the strongest predictors of repeat screening for breast cancer [10]. The most recent study from the Behavioral Risk Factor Surveillance System (BRFSS) found only 1.6% uninsured rate within Asians living in Massachusetts, nonetheless 20.2% still declared not having a personal doctor or a health care provider [11].

## **5. CONCLUSIONS**

Although NPC is a rare disease in much of the United States, it is much more common in Boston's Chinatown community representing greater than 5% of head and neck malignancies at our institution. Even in this higher-risk population, the incidence of NPC is low enough that screening may not be a cost-effective method of improving treatment. However, screening as part of a broader community education initiative may help to identify those patients who are truly at the highest risk and aid communication with health care providers for appropriate diagnostic evaluation. It is hoped that this quality care initiative,

based on the findings from our institutional retrospective review, will allow for improved opportunities for community education, earlier diagnosis and facilitate continuity of care.

## **CONSENT**

Not applicable.

## **ETHICAL APPROVAL**

This study was approved by the Tufts Medical Center institutional review board.

## **COMPETING INTERESTS**

Authors have declared that no competing interests exist.

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