

Social Impact of Nasopharyngeal Carcinoma on Chinese Households in Selangor, Malaysia

R W Armstrong, M J Armstrong, M S Lye

ABSTRACT

Aim of Study: With a five-year survival rate of 20% in 1970 and 40-45% in 1990, and highest incidence and mortality in early and middle adult years, nasopharyngeal carcinoma (NPC) may have a severe social impact on families and households. The aim of this study was to measure the social impact of NPC in the Chinese population of Selangor, Malaysia.

Method: Cases were pooled from three epidemiological case-control studies conducted in 1973-74, 1980, and 1990-92 for a total of 442. They lived in households with a grand total of 2,598 persons. Interviewers collected data on household composition: number of residents; each resident's age, sex, occupation, and relationship to the head of the household; and position of the NPC case in the household.

Results: Ninety-four percent of cases supported 93% of household members in some way. Most cases were employed as income earners or homemakers and 80% had a key role as head of household and/or parent of dependent children.

Conclusion: The illness and death caused by NPC had a major social impact on immediate families and on extended family and non-kin households as well.

Keywords: nasopharyngeal cancer, Malaysian Chinese, social impact, household organisation

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INTRODUCTION

Any chronic illness in a member of a household has a social impact, especially on the other members of the household. Diseases with a high fatality rate have particular impact, especially when younger adult age groups are more affected. One example is nasopharyngeal carcinoma (NPC), a common cancer in Chinese with ancestry from the southeastern provinces of China, particularly Cantonese, Fukienese and Hakka. The Chinese population of the state of Selangor and the Federal Territory of Kuala Lumpur,

Malaysia, in Southeast Asia, is primarily of this ancestry and has an incidence of NPC of about 16 per 100,000 population in males, and 7 per 100,000 in females⁽¹⁾. Similar rates are reported for Chinese in Singapore⁽²⁾.

NPC is highly fatal and in Malaysia had an estimated five-year survival rate of only 20% in 1970, rising to 40-45% by 1990. There is no cancer registry in Malaysia capable of generating survival data. The estimates are based on information from local clinicians and pathologists, and with reference to studies on NPC survival in the Chinese populations of Singapore, Hong Kong, and Taiwan which are comparable to the Chinese population of Malaysia. In 1979, the five-year survival rate for all Singapore NPC cases following radiotherapy was estimated to be 25.3%⁽³⁾. For 1985, the rates for all cases after radiotherapy were estimated in Hong Kong as 45% and in Taiwan as 44%⁽⁴⁾.

The age specific incidence and mortality curves for NPC in high-risk Chinese populations rise rapidly after age 20 peaking around age 45 and then declining with increasing age. Those affected include a large proportion of younger and middle aged adults who are most responsible for young families and their social and economic support. Little is known about the social impact of NPC on households in which it occurs. This paper draws on three epidemiologic case control studies of NPC conducted in Selangor and the Federal Territory to report on the characteristics of cases and their households, and to examine the social impact of the disease on those households.

Our review of the literature reveals little research attention specific to the social impact of chronic illness, cancer or other, at the level of the household. Impacts at the level of society are a frequent topic of investigation and comment, especially as regards the medical and social service needs presented by growing prevalence of chronic disease and disability in the ageing societies of North America and Europe⁽⁵⁻⁷⁾. Research of impacts at the level of the individual on social roles and responsibilities has given considerable attention to work roles, but much less to other necessary and expected roles such as parent, grandparent, and household head^(5,8). At the level of the family there is an extensive

Department of
Community Health
University of Illinois at
Urbana-Champaign
1206 S. Fourth Street
Champaign, Illinois
61820, USA

R W Armstrong,
PhD (Illinois),
MPH (Michigan)
Professor

M J Armstrong,
PhD (Illinois)
Associate Professor

Division of
Epidemiology
Institute for Medical
Research
Jalan Pahang
50588 Kuala Lumpur
Malaysia

M S Lye,
MBBS (Malaya),
DrPH (Tulane)
Head

Correspondence to:
Prof R W Armstrong

research literature on the impact of chronic illnesses in terms of family as the social context within which most caregiving of persons with chronic illness occurs. The research has firmly demonstrated that the majority of long-term support and care provided to chronically ill and disabled persons comes from the family⁽⁹⁻¹²⁾. Outcomes of stress and burden in caregiving families have been well demonstrated and become a focus of intervention^(12,13). Research on the impact of cancer on families has similarly focused on family as a common and significant source of support⁽¹⁴⁻¹⁶⁾. The family caregiver burden and intervention issues specific to cancers are documented in research reviews by Lewis⁽¹⁷⁾, Pardue⁽¹⁸⁾, and Sales⁽¹⁹⁾.

For Southeast Asian societies, the health and social service resource impacts of development with industrialization and urbanization have been widely acknowledged in the services planning literature⁽²⁰⁻²²⁾. Issues relating to research of sociodemographic and economic factors in the epidemiological transition to a preponderance of chronic and degenerative diseases, including cancers, have been examined by Phillips⁽²³⁾. The Malaysian situation has been addressed in country profiles for the wider region⁽²⁴⁾, and in a comprehensive, multidisciplinary documentation and review sponsored by the Institute of Strategic and International Studies⁽²⁵⁾. The economic costs of injuries as a newly significant health concern have been examined by Arokiasamy and Krishnan⁽²⁶⁾, and the health implications of lifestyle changes by Kandiah and Ramlee⁽²⁷⁾. As in other Southeast Asian countries, health objectives and policies often specify the responsibilities of families⁽²⁸⁾. To the best of our knowledge, neither families nor households have been the primary focus of any of the research studies. The research on social aspects of cancer in Malaysian populations has been limited to relative risks of sociodemographic factors such as age, gender, and ethnicity⁽²⁹⁾.

METHODS

In 1973-74, 1980, and 1990-92, case-control studies were conducted in Selangor and what is now the Federal Territory of Kuala Lumpur to study associations between NPC and dietary and occupational exposures⁽³⁰⁻³²⁾. In the first two studies two of us (RWA and MJA) were the principal investigators and were joined by MSL for the third. In all three studies case and control participants, and other members of their households, were interviewed in their homes by specially trained local Chinese interviewers. One of the schedules used in all studies collected detailed data on the composition of the household: the number of residents; each resident's age, sex, occupation, and

Table I. Number of cases, households, and household members 1974, 1980 and 1990-92

Characteristic	1974	1980	1990-92	Combined years
Cases - total	60	100	282	442
- male	35	65	195	295
- female	24	35	87	147
Households	60	100	282	442
Persons - total	367	661	1570	2598
- male	180	310	769	1259
- female	187	351	801	1339
- mean per house	6.1	6.6	5.6	5.9
- range	1-21	1-27	1-19	1-27

relationship to the head of the household; and position of the case or control participant in the household. The use of a household composition survey in epidemiologic case-control studies is, as far as we know, unique. In this paper only data from case households are used to assess the social impact of NPC.

In all three studies, cases were histologically confirmed cases of NPC identified through medical records at all treatment centres for NPC in Selangor. All cases were classified as squamous cell carcinomas, but they had not been systematically typed for clinical stage using the TNM classification. At the time of interview all cases had received radiotherapy. Cases were excluded who were not residents of Selangor for at least five years prior to diagnosis, and for this paper, cases who were not of Chinese ancestry were also excluded.

In the three studies there were, respectively, 60, 100, and 282 Chinese NPC cases for a combined total of 442. They lived in households with, respectively, 367, 661 and 1,570 members, for a total of 2,598 (Table I). The mean number of persons per household for the three studies was 6.1, 6.6 and 5.6, with sizes ranging from 1 to 27 members (Table I). Data for sex and age distributions, occupations, household composition, household type, and role and relationship of the NPC case to the head of the household were all examined by study period separately. Given no important differences in the patterns for the three study periods, the data were combined for reporting here. The fact that there were no significant changes among the three periods speaks for the stability of household structure in this community across the 20 years represented, despite the pace and magnitude of socioeconomic development and change generally in Malaysia since 1970.

RESULTS

The age distribution of the 442 NPC cases and the 2,598 household members (including the cases) is

Table II. Percentage cases and household members by age and occupational group

Characteristic	Cases	Household members*
<i>Age Group</i>		
under 5	-	6.5
5 - 14	-	20.2
15 - 24	1.4	20.1
25 - 34	12.0	14.9
35 - 44	32.8	14.5
45 - 54	31.2	11.8
55 - 64	14.9	6.7
65 - 74	6.8	3.9
75 & over	0.9	1.4
Total percent	100.0	100.0
Total number	442	2598
<i>Occupational Group</i>		
Prof., tech., admin.	17.0	11.7
Sales, service	16.1	13.0
Agric., forest, fish.	0.9	1.2
Production workers	15.8	11.2
Transport workers	3.2	1.7
Between jobs	11.1	2.8
Homemaker	20.4	15.3
Retired	13.3	5.2
Student	0.2	26.7
Disabled, ill	2.0	0.3
At home	-	2.4
Preschool	-	8.5
Total percent	100.0	100.0
Total number	442	2598

* Includes cases

shown in Table II. The age distribution of the cases is typical for NPC with over 60% falling between 35 and 54 years. The households, on the other hand, reflect the general population with over 45% of members under age 24, and more even distribution of the remainder in later young and middle adult years. Occupational patterns reflect the predominantly urban nature of the population of Selangor and the Federal Territory, with professional, technical, administrative and clerical jobs, sales and service jobs, and production jobs being the most important occupations outside the home. Homemakers comprise 20% and retired persons 13% of cases (Table II). The pattern in the cases reflects their adult status, while the households reflect the inclusion of younger children, both preschool and school.

Households were classified by the authors into seven types: single person; married couple without children but with other kin or non-kin household members; nuclear family; nuclear family with other kin or non-kin; extended (multigenerational) family; extended family with other kin or non-kin; and other kin or non-kin assemblages. The types of household of which most people were members were the nuclear

family (35%), and the extended family with other kin or non-kin (30%) (Table III). The two other types of nuclear and extended families accounted for another 32% of household members. These four household types accounted for 91% of the households and 97% of residents. Chinese households in Selangor tend to include high proportions of relatives beyond the nuclear family and this is shown in the data for household composition where "other relatives of the head or head's spouse" comprise 22% of the all-households population (Table III). The size of household varied by type from single person to extended families, ranging from 1 to 27 members. The mean number of persons per household was 5.9, ranging from 4.9 to 7.9 across the four categories of nuclear family and extended family household (Table III).

The role of the NPC cases in their households was primarily as head of the household (60%), followed by spouse of the head (21%) and other supporting relative (10%) (Table IV). Only 4% were dependent on the household. These were cases who were no longer employed and due to seriousness of their NPC not able to contribute to household activities such as homemaking. Since 60% of cases filled the role of head in their households, the most common relationship of the case to the head of the household was as head (also 60%). However, there were other important relationships, namely, spouse (21%) and son (9%). Brother and other relative each accounted for 3% (Table IV).

The role of the NPC case in relation to other household members was examined in terms of all cases, and separately for those aged under 55 years. Age 55 is the age of retirement from government service, a major employer in Malaysia, and the beginning of a decade of general retirements. The role of the case was also classified into socioeconomic supporting roles and dependent or employee roles in the household (Table V). The most important supporting roles were as head of the household or as spouse of the head. Among the 442 cases, 264 were heads of households supporting 1,154 associated other persons in their households, and 92 were spouses of a head supporting 467 associated other persons. Together, these heads and spouses of heads comprised 81% of all cases and 79% of cases under 55 years of age. They supported 75% of all other household members in the study group, and 74% of all other members in the households of cases under 55 years. The proportion of NPC cases in all kinds of supporting roles was 94% for all households and 95% in those where the case was under 55 years of age. All cases supported 93% of all their other household members, and cases under 55 supported 94% of the members of

Table III. Percentage of persons by household composition and household type

Household composition*	Household type							
	Total comp.	Single person	Married couple+	Nuclear family	Nuclear fam.+	Extended family	Extended fam.+	Other kin+
Head of household	17.1	100.0	45.8	20.4	14.4	14.3	12.8	23.1
Spouse of head	14.4	-	45.8	19.0	13.1	11.9	9.7	-
Unmarried children of head	38.2	-	-	60.6	36.0	37.8	17.5	-
Parents of head and/or spouse	3.2	-	-	-	0.8	9.1	5.2	-
Brothers & sisters of head/spouse	2.9	-	-	-	8.5	-	4.7	23.1
Other relatives of head/spouse	22.5	-	2.1	-	20.8	26.9	48.0	53.8
Live-in servants	0.7	-	-	-	2.6	-	0.9	-
Non-kin boarders	1.0	-	6.3	-	3.8	-	1.2	-
Total percent	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
No. persons	2598	14	49	904	388	432	785	26
Percent persons	100.0	0.5	1.9	34.8	15.0	16.6	30.2	1.0
Mean no. persons	5.9	1.0	2.2	4.9	6.9	7.1	7.9	4.3
- range	1-27	1-1	2-4	2-9	3-15	3-22	3-27	2-7
No. households	442	14	22	184	56	61	99	6
Percent type	100.0	3.0	5.0	42.0	13.0	14.0	22.0	1.0

* Reference of relationships is to head of household + = Basic household type plus other kin and non-kin of head

their households (Table V). The mean number of persons supported by the cases was 4.8 for both total and under 55 years categories.

DISCUSSION

Nasopharyngeal carcinoma is a disease that affects primarily younger and middle aged adults and given its relatively high fatality rate removes most of these individuals from their households within five years. There are cases who survive many years after diagnosis and treatment, but they are exceptions. In Malaysia in 1970, with the five-year survival rate estimated as 20%, it could be expected that 80% of NPC case households would have lost a supporting member, in most cases a primary supporter, within five years of diagnosis. By 1990, with the five-year survival rate improved to an estimated 40-45%, between 55 and 60% of households could be expected to have lost a supporting member within five years of diagnosis. Compared to most other adult cancers, NPC has a higher number of years of potential life lost.

If the clinical stage of cases had been available according to the TNM classification, it would have been possible to explore the social impact of NPC by the five clinical stages representing progressively severe disease and prognosis. The five-year survival rates for NPC are

known to differ by clinical stage. For instance, in 1985 in Taiwan the rates were 21% for advanced tumours, 30-40% for intermediate, and 60-72% for least advanced⁽³³⁾. The clinical records of our Malaysian cases indicated that most of them were in the intermediate or advanced clinical stages but, as noted, no systematic data were available.

In high risk Chinese populations, such as in Malaysia, Singapore, Hong Kong and the southeastern provinces of China, a high proportion of incidence and mortality from NPC occurs in cases under 55 years of age. In these populations about 75% of all cases occur before age 55, with 60% between 35 and 54 years⁽²⁾. Other major cancers have higher proportions of incidence later in life; cancers of the stomach and lung, for example, have only 10-15% of their incidence in the 35-54 year age group. Cancer of the female breast resembles NPC in this respect with, in most countries, 35-50% of incidence in this age group but with a five-year survival rate of about 70%. Thus NPC compares as an especially severe cancer in its social impact on families and households.

At the time of interview, most of the Chinese cases in Selangor were either still at work (as income earner or homemaker), or were on leave from work outside the home because of their illness (Table II). Most were

Table IV. Role of case and relationship to head of household

Variable	Number	Percentage
<i>Role of Case</i>		
Head of household	264	59.7
Spouse of head	92	20.8
Dependent	19	4.3
Parent of sub-family*	16	3.6
Other supporting relative	42	9.5
Supporting non-kin	3	0.7
Employee	2	0.5
Other	4	0.9
Total	442	100.0
<i>Relationship of Case</i>		
Head of household	264	59.7
Spouse of head	92	20.8
Son	39	8.9
Daughter	7	1.6
Brother	13	2.9
Sister	3	0.7
Parent	7	1.6
Other relative	13	2.9
Non-kin	4	0.9
Total	442	100.0

* Parent of component nuclear family but not the head of household

seen shortly after completing a course of radiotherapy and were in reasonably good health. Most cases respond well to modern treatment prescriptions and can enjoy a better quality of life in the 1990s than cases did 20 years ago. However, mortality rates have not greatly changed⁽²⁾. Accurate information on survival is not yet available for Malaysian and other high risk Chinese populations.

Eighty percent of the NPC cases in this study had a key role in their household either as head

(60%) or as the head's spouse (21%). Male cases (67% of the total) accounted for most of the household heads with decision-making authority, were the fathers of most of the unmarried children, and held most of the income earning occupations. Female cases (33%) were most of the spouses of the household heads, the mothers of unmarried children, and homemakers. Ninety-four percent of the cases supported 93% of all household members in some way (Table V). Their illness and high probability of death is a major social impact, not only on immediate family members, but also on the memberships of large extended family households and on the non-family kin and non-kin that both types of household commonly incorporate.

It was not within the scope of this study to examine the long-term social impact of NPC on households. The specific adverse effects on households that could be associated with the periods of illness, treatment, and rehabilitation, or death, are unknown. Impacts of loss of role function by the NPC case in their respective households may be short or long-term, and the capacity of households to adjust and adapt to change or loss of support may vary considerably. These topics must await a longitudinal study.

Household composition was a unique inclusion in the three epidemiologic case-control studies conducted on NPC in Malaysia. Besides contributing data on the social impact of the disease on families and households, it also provided information on occupations and social contexts. The stability of household composition and household type across the 20 year period underlines the continuity of the social impact of NPC despite rapid national socioeconomic changes at the same time.

Table V. Role of case in relation to other household members

Role of case	All cases		Associated other persons		Cases under 55 years		Associated other persons	
	No.	%	No.	%	No.	%	No.	%
Head of household	264	59.7	1154	53.5	193	56.4	833	49.8
Spouse of head	92	20.8	467	21.7	78	22.8	400	23.9
Working relative	58	13.1	364	16.9	53	15.5	324	19.4
Working non-kin	3	0.7	25	1.2	2	0.6	16	0.9
Dependent	19	4.3	125	5.8	14	4.1	90	5.4
Employee	2	0.5	7	0.3	1	0.3	3	0.2
Other	4	0.9	14	0.6	1	0.3	6	0.4
Total	442	100.0	2156	100.0	342	100.0	1672	100.0
Total supporting	417	94.3	2010	93.2	326	95.3	1573	94.1
Mean no. persons supported by cases	-	-	4.8	-	-	-	4.8	-

CONCLUSION

The severity of illness and high probability of death associated with NPC have a major social impact on Chinese households in Selangor, Malaysia. The impact is not only on immediate nuclear family members, but also on the memberships of large extended family households and on the non-family kin and non-kin that both types of household commonly incorporate.

This study is the first to report on the social impact of NPC, in Malaysia or elsewhere. It is based on three case-control studies that were not primarily intended to research the social impact of the disease and future studies could be designed to focus on the topic. Comparative studies of the social impact of other cancers in these populations would help put the impact of NPC in perspective.

Different chronic illnesses, whether associated with disease, injury, or disability, have different social impacts on households depending on the characteristics and behaviour of the illness, the nature of households affected, and the wider sociocultural environment. Study of the nature of impacts such as those examined here will help to broaden understanding of the short and long-term effects of chronic illness in human populations. It draws attention to family and household as the contexts within which most chronic illness is experienced and managed and, thus, to the importance of care designed not only to address medical concerns of the chronically ill individual but also to involve family and household care.

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