

Long-term socioeconomic impact of the Nipah Virus encephalitis outbreak in Bukit Pelanduk, Negeri Sembilan, Malaysia: A mixed methods approach

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Abstract

Background and Objective: In 1998/99, an outbreak of Nipah virus encephalitis occurred in several pig-farming communities in Malaysia. It was associated with a high mortality rate and persistent neurological deficits among many survivors. This mixed method study aimed to examine the long-term socio-economic consequences of the illness on affected pig farmers and their families in Bukit Pelanduk, Negeri Sembilan. **Methods:** A quantitative cross sectional survey was conducted in 2008 on 78 former patients or their kin from 61 households (46.2% males, mean age = 48.7 years) in Bukit Pelanduk via face-to-face interviews. This was followed by qualitative in-depth interviews with 20 respondents. **Results:** The immediate treatment costs were not a major burden to most households. Majority of the patients (92%) required inpatient care and most obtained free care from public hospitals. Households relied mainly on savings and support provided by the public and family members during the outbreak. However, many former patients found their low educational qualifications prevented them from obtaining good alternative employment after their recovery. This had negatively affected their households' living standards. As a result, there had been a renewed appreciation of the value of education for their young, and one of their main concerns was the financial burden of educating their children.

Conclusion: Free public health care protected most households from high medical costs. However, household living standards had dropped due to limited alternative employment opportunities. Education has been identified as a key to improving the long term welfare of affected households.

INTRODUCTION

Major illnesses within a household can have significant negative economic impact on household welfare in the short and long term. This is especially so for poor households reliant on out-of-pocket payment for health care expenses where financial outlays for health care are sourced from a combination of savings, borrowings and sales of assets.^{1,2} Many households have been driven into and maintained in poverty through the need to finance health care.^{3,4} However, in countries where there exist adequate financial safety nets for health care, the direct illness cost to households can be significantly reduced or even abolished at the outset. Despite this, long term economic impact can still be felt by households from indirect costs such as loss of income from continuing ill health or deaths, forced sale of income-generating

assets and reduced investments into human capital through loss of educational opportunities for children in affected households.⁵

There have been several studies in low and middle income countries examining the extent and consequences of the direct cost of illness on households.⁶⁻⁸ However, the long term economic impact of illness episodes and the strategies that households employ to cope with these consequences have received less attention especially in countries where health care services are purportedly free. Russell and Gilson⁵, in their study of poor households in 2 urban areas of Sri Lanka, have shown that free public health services had been protective against high direct illness costs. However, other indirect costs of illness mainly from income losses, triggered households to employ coping strategies such as sale of assets, borrowings and delays in debt repayment. The

ability of the affected households to cope in the long run depended on factors such as the frequency and severity of illness episodes especially those affecting household breadwinners, availability of assets, existing debts, and stability of employment. The study was conducted on very poor households who lived near or below the international poverty line of USD 1.08 per person per day and whose lifestyle choices had already been significantly restricted prior to the illness experience. In such circumstances, the households' vulnerability to even minor illness costs is understandable. However, richer households' reaction to similar economic shocks may differ and subsequently their coping strategies may differ from those in lower income groups.

In this paper, we describe the long term economic impact of an episode of major illness on households in a setting of free public health services using as a case study the Nipah virus encephalitis outbreak in Malaysia which occurred from September 1998 to May 1999.⁹ The outbreak occurred amongst pig-farming households, most of whom had household incomes higher than the national average of USD 670 per month¹⁰ and would be illustrative of coping strategies employed by middle income households to major illness shocks.

Study Setting

Nipah virus encephalitis is a severe, rapidly progressive disease caused by the Nipah virus and was transmitted to humans via contact with infected pigs.^{9,11,12} It was associated with a high mortality rate and a large proportion of patients who recovered had persistent neurological deficits. Many patients required prolonged intensive hospital treatment at the initial stages and some survivors continue to require nursing care and assistance with daily living.

During the 1998/99 outbreak, affected patients came from predominantly Chinese households in several pig-farming communities in Peninsular Malaysia. One of the epicentres of the outbreak was Bukit Pelanduk, in the state of Negeri Sembilan.¹³ The pig farms in this area were largely family owned and workers consisted of family members supplemented by migrant workers from Bangladesh, India and Nepal and local Indian workers from the nearby village of Kampung India. At the time, this area had one of the largest concentrations of domesticated pigs in South East Asia which were farmed for local consumption and also for export to Singapore

and Hong Kong. As a result of the flourishing pig industry, the village could support local businesses such as shops and banks. Family owned pig farms provided employment opportunities for the local young and many remained working in family farms after schooling.

However, the pig farming industry in Bukit Pelanduk was decimated by the outbreak. Most of the patients were workers in the pig farms or related industries. Their deaths and in many instances, continuing disability affected their families' ability to sustain the standard of living they were enjoying prior to the outbreak. In addition to this, all pigs had to be culled to control the spread of the disease. Although the government provided a compensation of USD 32 per pig, this did not provide sufficient financial assistance to families especially since the pig farms were not permitted to re-stock. The government has since made a policy decision to relocate pig farming to approved pig farming areas which did not include Bukit Pelanduk. Former pig farmers were encouraged and given assistance to undertake other agricultural and livestock activities.¹⁴ Financial assistance also came from other sources. The Government provided free medical care which was made available in public hospitals and clinics. Public donations were also channelled to affected families through a local political party.¹⁵ On a wider perspective, the loss of the local pig industry resulted in closure of many local businesses.

This study involved visits to Nipah encephalitis patients in Bukit Pelanduk 10 years after the outbreak to document the long term economic impact of the outbreak on affected households.

METHODS

The study utilized a mixed methods approach. Mixed methods research involves the collection, analysis and mixing of both quantitative and qualitative data in a study.¹⁶ The core of this approach is to utilize the strengths of both quantitative and qualitative data leading to a more complete analysis that provide better understanding of the research problem than any one data type alone could produce.

The concurrent mixed methods study design (quantitative and qualitative data were weighted equally) used in this study was carried out in two parts from January to June 2008. In the first, a cross-sectional survey of former Nipah encephalitis patients, or the nearest kin of deceased patients, was conducted to obtain a profile of health

seeking behaviour during and after the outbreak, immediate and continuing illness costs, economic losses and coping strategies. All former patients, and if deceased, their nearest kin, who were living in Bukit Pelanduk and Kampung India at the time of the study were invited to participate in the survey. The patients had been identified from the database of Nipah virus encephalitis patients maintained by the University of Malaya Medical Centre, one of the 2 main centres providing hospital care during the outbreak, and the Ministry of Health, Malaysia. Out of a total of 88 invited participants, 78 former patients or their kin from 61 households participated in this study. Ethical clearance was granted by the University of Malaya Medical Centre Medical Research Ethics Committee.

The survey was conducted by trained data collectors via face-to-face interviews with former patients or their kin using a structured questionnaire. The questionnaire contained sections on the following: (i) Health seeking behaviour: Choice of health care provider and type of health care received during and after the outbreak for treatment of Nipah virus encephalitis; (ii) Illness costs: Estimate of treatment costs during and after the outbreak at various health care facilities and how these costs had been financed; (iii) Household coping strategies: Coping strategies of interest included sales of assets, borrowings, changes in income generating activities and loss of educational opportunities for household members.

The second part of the study was in-depth interviews with 20 selected former patients or their kin. Using the survey information as background, participants had been selected based on the following criteria; former patients who recovered completely, disabled patients or deceased patients (where a family member was interviewed by proxy). All in-depth interviews were carried out at the participant's home using a semi-structured interview guide. The sessions were audiotaped with participants' consent. The interviewers kept field notes, which included their observations, views and reflections about the interviews. These interviews were transcribed verbatim and checked by the researchers independently. Data was collected until it reached saturation and data collection ceased at 20 participants.

The transcripts and the researchers' field notes were used as data and managed by the NVivo 8 qualitative data management software. The data sets were analysed separately and independently by researchers at the first stage

of analysis and subsequently were combined for comparison and triangulation. Three researchers analysed the qualitative data independently and any disagreement were resolved through discussion and consensus. The data analysis used the framework approach to identify the range of experience and views of the participants.¹⁷ Researchers also interviewed 3 key informants concerning the general condition of the village before and after the outbreak.

Quantitative assessment of actual health care utilization and demographic data and qualitative assessment of social impacts related to the outbreak were collected to triangulate results from these two methods with a focus to further enhance the overall explanatory results of the study. Although data collection of both approaches was conducted in sequence (with household survey followed by in-depth interviews), the quantitative and qualitative components of the study were carried out independently and analysis was conducted separately at the initial stage. The researchers then pooled and synthesized the findings.

RESULTS

Description of sample

Among the 78 respondents (from 61 households), 46.2% were males and had ages ranging from 18-70 years (mean age= 48.7, SD= 11.2). The sample was predominantly Chinese (65.4%) and the rest were Indians. Of these respondents, 20.5% were survivors who recovered completely, 44.9% had some physical or mental disabilities and the others were next-of-kin of deceased patients. Many households had two or more members who were affected by the disease (21% of 61 households). All respondents were either full time or part time pig farm workers at the time of the outbreak. Of the surviving patients (n=51), a majority of them (72.5%) were employed as semi-skilled or unskilled workers at the time of the study. The rest were unemployed, mainly due to persisting disabilities.

Health seeking behaviour

During the Nipah virus encephalitis outbreak, most of the patients required hospital inpatient care (92% or 72 of 78 patients). The majority (88% or 63 of 72 patients) chose to receive care from public hospitals only. Few sought care from private hospitals only (7% or 5 of 72 patients), while the rest sought care from both public and private hospitals. Most of the patients admitted to

public hospitals received free care (87% or 58 of 67 patients). Patients treated in private hospitals faced much higher cost burden than those who sought care in public hospitals. Only one patient who received private care was covered by private health insurance. The average lengths of stay in private hospitals were shorter than stays in public hospitals. Patients who were admitted to both public and private hospitals stayed for less than 2 weeks in the private hospitals before being admitted for longer stays in public hospitals. One of these patients was admitted for 2 weeks in the private hospital and was later admitted for about 5 months in a public hospital.

Contrary to the pattern of inpatient utilisation, most of the patients who received outpatient care (82%, 46 of 56 patients) preferred private general practitioners although free medical care was provided in public clinics. One fifth of the patients also sought care from traditional medical practitioners. These practitioners charged much higher fees than public clinics for their services. One patient purportedly paid USD 2,400 (USD 1 = Ringgit Malaysia 3.60) for traditional treatment which was twice his reported household income at the time. The same patient had then received free inpatient care in two public hospitals for a combined period of about 6 months.

According to one of the key informants, early patients sought care from private general practitioners who then referred them to private hospitals when their conditions deteriorated. However, as Nipah virus encephalitis became more widely recognised in the community, later patients were sent by relatives direct to the two public hospitals which served as the main treatment centres during the outbreak. However, the higher cost of private care was also one of the reasons for choice of treatment in public hospitals especially in households with more than one affected member as related by one of the male caregivers;

“Just because before that... his brother (referring to the victim’s brother) had it... Although, I got some money... After using it to treat his brother (for Nipah encephalitis treatment), no more (money)...” (CAT, age 67, male, caregiver, unemployed)

Most of the surviving patients were no longer on regular follow-up for Nipah virus encephalitis at the time of the study. However, in the intervening period since the outbreak, many have developed chronic medical conditions

for which most received free or subsidised care from public clinics or hospitals. Many surviving patients reported regular purchase of vitamins and dietary supplements and 2 respondents reported purchases of adult diapers and other consumables for care of bedridden patients. In most cases, patients sought care in the private clinics for the occasional episode of ill health.

Sources of financial support

Many of the patients had to rely on their own savings to tide their families through the outbreak. However, the publicity generated by the outbreak also led to an outpouring of public sympathy and financial support for the victims. Most of the patients (91%, 71 of 78 patients) received about USD 6,950 each from a fund set up from these public donations. Half of patients who died also received USD 1,400 for funeral assistance. Half of the patients also received a share of the government compensation for pigs culled to prevent spread of the disease. However, many claimed that the amount paid, USD 32 per pig, was less than the market value of the pigs. Nineteen patients (24%) reported that they had to borrow money from relatives, friends or money-lenders during the outbreak or the period immediately after to support their families.

One of the strong impressions that came through the interviews was the support given by relatives to affected families. In many cases, relatives provided regular monetary assistance or supplies of daily necessities such as food. Relatives also provided care for incapacitated patients.

In addition to social networks, Malaysia has in place several social security mechanisms to look after the welfare of her citizens. However, in this case study, social security payments did not feature prominently in the long term financial support of the affected families. At the time of the study, only 5 patients received regular support from the welfare department. Two patients received payments from the Social Security Organisation (SOCSO), one of whom also received payment from the Employees Provident Fund (EPF). This finding is not surprising for this group of mainly self-employed pig farmers as their participation in the EPF would only be on a voluntary basis and they would have been exempted from contributing to SOCSO.

Only 19 patients (24%) reported that they had to sell assets to ensure adequate finances for day-to-day living expenses. Of these 11 patients reported

sales of jewellery over the years since the outbreak, 2 sold their houses and 6 sold part or the whole of their farms. As the farmers were no longer permitted to continue with pig farming, many with financial resources invested in alternative use of their farms such as rearing snails, raising chicken and planting dragon fruit. Some of these endeavours were provided with technical support from the government agricultural department. Unfortunately these investments did not take off and did not provide sustained returns. The latest ventures were oil palm and farming birds' nests. However, they have yet to yield returns.

Livelihood Changes due to the Outbreak

Prior to the outbreak, the employment opportunities for the young in Bukit Pelanduk were provided for by the family pig farms. Jobs in these farms did not require highly educated workers. As such the educational attainments of most of the pig farmers were not high. Almost half of the patients had no formal education or did not complete primary schooling. Most of the rest did not complete secondary schooling. After the outbreak surviving patients were either unemployed or could only obtain unskilled or semi-skilled positions which did not permit them or their families to assume the same level of living standard to which they had enjoyed prior to the outbreak. Many were frustrated by this turn of events. This is illustrated by:

"If I have the ability, I will still rear pigs. Because we are not highly educated or professionals, we can only rear pigs. Right? What else do we know?" (TMY, age 50, male, fully recovered, part-time worker)

"... we were good in raising pigs since we were kids, our knowledge is only.... our specialty is... pig farming. When pig farming industry collapsed at that time, our skills became useless. All that we learnt, now we do not have a place to apply. Have to start all over again. Now, we face a lot of problems..." (KPK, age 55, male, fully recovered, mini-market operator)

On another related issue, many spouses of male patients found that they had to assume the role of family breadwinners especially when their husbands were either physically or mentally incapacitated or had passed away due to the disease. Prior to the outbreak these spouses were either full-time housewives or were helpers in

the family pig farms. Due to their lack of formal education, many were unable to obtain high paying employment.

Heightened appreciation of the value of education

Another important theme that came across during the study was the change in the community's appreciation of the value of education for their children. Due to the lack of success of the alternative income generating activities, many families were required to change consumption patterns to deal with their reduced economic circumstances including reducing consumption of food and clothing and participation in social functions. However, as far as was possible, families tried not to cut back on educational expenses for their children. One female respondent related this;

"We have to save. Everything is expensive (price), every type (expenses) all must save. We do not spend extravagantly as far as possible. For children's education, no expenses are spared.....I seldom buy clothes, sometimes pick other people's clothes to wear (LCK, age 46, female, widow, plantation worker).

Prior to the outbreak, children could anticipate future employment in the family pig farms and many were in line to inherit these farms from their parents. The outbreak and decimation of the pig farming industry in Bukit Pelanduk gave rise to the realization of the need to find alternative employment and related to this the value of a good education. This sentiment was shared by many participants, including the following,

"Previously.....All depends on one household, children will inherit father's occupation. If those can study, they can continue. If they can't, they can rear pigsat least, we have an industry (pig-breeding) to pass it to them (young people)... Now, our children, they must receive education" (LKK, age 64, female, widow, shopkeeper)

The current major concern of many affected families was the question of their ability to financially support their children's higher education. Many families have had to borrow money to support their children's education. Many had expressed hopes that in view of their losses due to the outbreak, the government could step in to provide educational aid for their children.

Migration of younger working population

Due to the closure of the pig farms, the overall employment opportunities remaining in Bukit Pelanduk had decreased substantially. The young had started an out-migration to find work leaving behind the older members of the community.

“Now, (this place) has become an elderly village. This is because previously youngsters can work here, now there is no more work to do. Previously, our children do not have to work outstation.” (LBC, age 50, male, fully recovered, factory supervisor)

“In the past, this place was so prosperous. We reared pigs, all the young people were here, they could make money, everywhere full of people. Not like now, only two three people sitting around.” (TSW, age 45, male, minor disability, plantation worker)

Many interviewed gave appreciation to government assistance to help the patients and their families but commented that this was insufficient to spur development of Bukit Pelanduk.

DISCUSSION

The 1998/99 Nipah virus encephalitis outbreak in Bukit Pelanduk had a major socioeconomic impact on the lives of the patients, their families as well as the whole village in general. Living standards of most affected families had been reduced in the long term not so much due to catastrophic medical expenditures but mainly due to loss of income and employment in the pig farms. In this case study, free public health care was found to have protected households from high out-of-pocket payments at the time of the outbreak and probably played a mitigating role in preventing additional long-term decline in living standards. The role of free care was especially important in this community which relied mostly on savings, rather than insurance, for health care expenses. Similar beneficial impact of the provision of free public health care had been documented in Sri Lanka and as in this Malaysian case study, it was the provision of free inpatient care, rather than the less expensive outpatient care, that appeared to have the higher impact.⁵

The Bukit Pelanduk study households affected by the 1998/99 Nipah virus encephalitis had at least one saving grace, in that they were not poor prior to the outbreak and many had amassed

substantial assets and savings from pig-farming. This, combined with free health care, protected households from falling into a “medical poverty trap”, i.e. a vicious cycle of impoverishment due to high cost of care and maintenance in poverty due to the effects of poor health.⁴ However, the large differentials in standards of living pre and post outbreak had led to some unhappiness. Pig-farming in Bukit Pelanduk had provided a sustained source of economic prosperity and security for generations of families living in the village and which in turn had encouraged the development of the entire village. The families have yet to find a commensurate replacement for the loss of the farms and Bukit Pelanduk, as a whole, has not regained its former state of development. This has led to calls for more intensive government assistance to improve the lot of the families and the condition of the village.

This study among the predominantly Chinese pig-farmers has highlighted the issue of education in many different contexts. Culturally, the Chinese place education in high regard but against the backdrop of employment and financial security offered by the family pig farms, the attainment of high educational qualifications has had less impetus. This lack of formal qualification among surviving pig farmers had hampered their search for good employment opportunities after the cessation of pig-farming activities in Bukit Pelanduk. High fatality and disability rates among affected family breadwinners also meant that the financial burden of maintaining the households had to be passed on to other family members, many of whom were not in paid employment prior to the outbreak and due to lack of formal qualification again, their employment opportunities had been rather restricted. The outbreak has also led to a renewed appreciation of the benefits of a good education to provide for a brighter future for the younger members of affected families. Due to this development, although consumption patterns changed and living standards declined, families resisted reducing the educational opportunities for the young.

In conclusion, the main lesson that can be learnt from this case study is that free public health care has an important role in protecting families from the financial impact of major illness episodes. The Malaysian public health care system, mainly financed through general taxation, was able to provide an adequate safety net during the 1998/99 Nipah virus encephalitis outbreak. However, mitigating the subsequent socioeconomic effects of the outbreak will require a major paradigm shift

in the mindset of affected families. The loss of financial security from family farms will require them to be more resourceful in their search for higher living standards.

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REFERENCES

1. Leive A, Xu K. Coping with out-of-pocket payments: empirical evidence from 15 African countries. *Bull World Health Organ* 2008; 86:849-56.
2. McIntyre D, Thiede M, Dahlgren G, Whitehead M. What are the economic consequences for households of illness and of paying for health care in low- and middle-income country contexts? *Social Science & Medicine* 2006; 62(4):858-65.
3. van Doorslaer E, O'Donnell O, Rannan-Eliya RP, et al. Effect of payments for health care on poverty estimates in 11 countries in Asia: an analysis of household survey data. *Lancet* 2006; 368(9544):1357-64.
4. Whitehead M, Dahlgren G, Evans T. Equity and health sector reforms: can low-income countries escape the medical poverty trap? *Lancet* 2001; 358(9284):833-6.
5. Russell S, Gilson L. Are health services protecting the livelihoods of the urban poor in Sri Lanka? Findings from two low-income areas of Colombo. *Social Science & Medicine* 2006; 63(7):1732-44.
6. Roy K, Howard DH. Equity in out-of-pocket payments for hospital care: evidence from India. *Health Policy* 2007; 80(2):297-307.
7. Thuan NT, Lofgren C, Chuc NT, Janlert U, Lindholm L. Household out-of-pocket payments for illness: evidence from Vietnam. *BMC Public Health* 2006; 6:283.
8. van Doorslaer E, O'Donnell O, Rannan-Eliya RP, et al. Catastrophic payments for health care in Asia. *Health Econ* 2007; 16(11):1159-84.
9. Goh KJ, Tan CT, Chew NK, et al. Clinical features of Nipah virus encephalitis among pig farmers in Malaysia. *N Engl J Med* 2000; 342(17):1229-35.
10. Economic Planning Unit Malaysia. Eighth Malaysia Plan 2001-2005, Chapter 3 - Poverty Eradication and Restructuring of Society. Kuala Lumpur: Economic Planning Unit, Prime Minister's Department, Government of Malaysia, 2001:55 - 83.
11. Parashar UD, Lye MS, Ong F, et al. Case-control study of risk factors for human infection with a new zoonotic paramyxovirus, Nipah virus, during a 1998-1999 outbreak of severe encephalitis in Malaysia. *J Infect Dis* 2000; 181(5):1755.
12. Chua KB, Goh KJ, Wong KT, et al. Fatal encephalitis due to Nipah virus among pig-farmers in Malaysia. *Lancet* 1999; 354(9186):1257-9.
13. Chong HT, Kunjapan SR, Thayaparan T, et al. Nipah encephalitis outbreak in Malaysia, clinical features in patient from Seremban. *Neurol J Southeast Asia* 2000; 5:61-67.
14. Nor MN, Ong BL. The Nipah Virus Outbreak and the Effect on the Pig Industry in Malaysia. *JE/Nipah Outbreak in Malaysia*. Kuala Lumpur: Ministry of Health, Malaysia, 2001:128-33.
15. Ministry of Health Malaysia. *JE/Nipah Outbreak in Malaysia*. Kuala Lumpur: Ministry of Health, Malaysia, 2001.
16. Creswell JW, Plano Clark VL. *Designing and conducting mixed methods research*. 1st ed. Thousand Oaks: Sage Publications, 2006.
17. Pope C, Ziebland S, Mays N. Qualitative research in health care: Analysing qualitative data. *British Medical Journal* 2000;320:114-116.