



**CARE SEEKING EXPERIENCES OF  
HOUSEHOLDS IN SRI LANKA**

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## **INTRODUCTION**

This case study considers the experiences of four households, of different socio-economic status, where one of the family members suffers from a non-communicable disease. The objectives of the case study are to:

1. Develop an understanding of care seeking experience and health service access issues;
2. Consider the relevance of both direct and indirect costs of health care use; and
3. Develop an understanding of the household level impacts of illness and health care use and the strategies used by households to cope with these impacts.

You are asked to read the following background information and four narratives about individual household's experiences of seeking health care in Sri Lanka. In groups, consider the questions below.

## **BACKGROUND TO THE SRI LANKAN HEALTH SYSTEM**

In 2003 life expectancy in Sri Lanka was 74 years, similar to many European countries, despite having a national income under \$1,000 per capita. Under 5 mortality rate was 15 per 1,000 live births in Sri Lanka in 2003, compared with 87 for India, 69 for Bangladesh.

Sri Lanka has a publicly funded health system that is free at the point of access. Since before independence in 1948, equitable, free health care has been an ideological foundation of the health system and a subject of political concern. There is a wide-ranging network of public hospital spreading out to rural areas which are equipped to provide preventive health care, maternal and child health care and treatment for non-communicable diseases. Since the 1960s there has been a growth of the private sector in health care provision. Although care is free at the public clinics, today more than half of all outpatient visits take place in the private sector. This is due to patients trading the inconvenience of accessing public hospital out-patient care with out-of-pocket payments but lower indirect costs in accessing private out-patient care. However, a major part of inpatient care takes place in public hospitals and is free, although hospitals that do not have the necessary facilities may require patients to purchase drugs or tests privately whilst receiving inpatient care.

***Diabetes in a middle income household: Sena's experience***

Sena has suffered from diabetes for the past 15 years; he is 72 years old. He is from a middle income household and earned 11,500 rupees a month through his vegetable business. He lives with his wife in the suburbs of Colombo, the capital city. This is within easy access of public and private health care facilities, but despite this Sena has not managed keep his diabetes under control.

Sena was diagnosed when he was 57 years old. After fainting he had immediately gone to the National Hospital, a public hospital with free, high quality treatment. His diabetes was diagnosed and he was asked to follow a management regime of medication and tests with regular visits to the hospital clinic every month, which cost him 500 rupees for the taxi on each visit. However Sena was very dissatisfied with the treatment he received at the National Hospital. He complained that doctors did not have the time to discuss his condition with him or to explain ways to manage it, and that other staff were also not attentive. At the hospital, he had to wait in three queues from 7am to 5pm in order to see the doctor, get the tests done and receive the drugs he needed. So Sena stopped going to the hospital clinics and continued his treatment in a private clinic for 4 years. In the private clinic he found the service much better and more convenient, with more attention from the doctor and with less waiting in queues, so that appointments took up less of his time.

Although his diabetes was brought under control, the costs of consultation, tests and drugs at the private clinic were high, making the cost to him over 2,000 rupees at each visit, so he did not always adhere to the management regime. After some time his condition worsened significantly and he had to return to the National Hospital, where he continued to receive outpatient treatment. However, he was again dissatisfied with the long queues and the indifference and unkindness of some of the doctors and other staff. He therefore went back to receiving treatment in the private sector.

Then his wife had an accident, and whilst she was recovering he neglected to stick to his management regime. When his diabetes worsened again he had to return to the National Hospital. As he continued to be dissatisfied with the service he received he again sought treatment from a private doctor. By this time Sena was running out of money, and although he was advised to see the private doctor fortnightly he could not afford to do so, and was unable to purchase the drugs prescribed for him. When his wife fell ill again he stopped receiving treatment.

***Diabetes in a low income household: Hamina's experience***

Hamina is 43 years old and has suffered from diabetes for the past 6 years, and has poor eyesight as a result of her condition. She is from a low income family in Moneragala, a rural area, and has two sons. Her family make a living through agriculture, and a small store. The store brought in a cash income of Rs 3000 a month and the agriculture brought in about Rs 6000 at the harvest every three months if the crops were good.

She had been experiencing symptoms for 2 years without realising that she was suffering from diabetes. She attributed her fatigue to the hard agricultural work she was doing. She self-medicated using medicines bought from a local pharmacy for a while, then went to an Ayurvedic practitioner. When she fainted she decided to go to the district hospital, only a few kilometres from her home. However the government district hospital did not have the facilities necessary to diagnose or treat her condition, so she was transferred to the government provincial hospital in Badulla, where she was an inpatient for 14 days. This cost her family 230 rupees a day due to the costs of visiting her and providing special food whilst she was in hospital. After she was discharged she was told to attend clinics at the provincial hospital every two weeks.

The provincial hospital is very far from Hamina's home. She found it hard to abandon her agricultural work and domestic duties for the amount of time required to travel to the hospital and wait in queues to see the doctor, and the costs of transportation were too high. Each visit was costing her around 430 rupees. She therefore stopped attending clinics at the provincial hospital and visited the district hospital near her home instead, costing only 120 rupees per visit. However, she did not receive appropriate treatment due to the lack of facilities to manage diabetes at the district hospital and had to buy some of her drugs privately as the hospital could not provide them – this cost a further 250 rupees per visit. But Hamina was happier attending this hospital as she no longer had to miss the full day's work to attend the clinic, so the indirect costs were lower. She had to seek treatment for a wound that she got from her agricultural work that was not healing properly. She was advised to follow a special diet, but has been unable to because the recommended foods were not available locally and were expensive. Her health deteriorated and eyesight began to fail, but the district hospital was unable to treat it.

As a result of her worsening health Hamina was not able to continue her agricultural work. When the family had spent what savings they had, they borrowed money. At the time of the interview they owed about Rs 3000 to a village store owner, and owed family members more money. She pawned her jewellery until the next harvest, then sold some of the agricultural land to raise money. Eventually her son gave up school and started working as an agricultural labourer to supplement the household income. Hamina was upset that he had given up his education just prior to sitting his exams, which would have opened up doors to employment or higher education for him.

***Cancer in a low income household: Seela's experience***

Seela is 66 years old and lives in Moneragala, a remote rural area of Sri Lanka. She has been a cancer patient for the past 4 years. She is a widow and lives with her married son and daughter-in-law and their children. They cultivated their own paddy land of 3 acres and 1 acre of chena land (highland). They had a seasonal income averaging Rs 3,000 a month and engaged in casual labour to supplement their earnings, averaging a further Rs 3,000 each month.

Seela suffered headaches and back pains, but for three years she purchased painkillers from the pharmacy and used herbal home remedies and continued with cultivation work since she did not wish to worry her son. When she fell very ill she was taken to the government district hospital 15 kms away but was transferred by ambulance to different hospitals twice, since none of the hospitals had the necessary diagnostic facilities. In the Colombo National Hospital, she was diagnosed with leukaemia and she was finally sent to the Cancer Hospital in Colombo, the capital city, 300kms from her home. She was hospitalised in the cancer hospital for one month, where she was given blood transfusions. By then she had been an inpatient for over 2 months.

After being discharged from hospital she was directed to attend the clinic at the cancer hospital in Colombo twice a month. She had to stay overnight in Colombo every time she visited the clinic, which was expensive and caused her to miss a lot of the time she would otherwise have been cultivating. She did this for 7 months until they ran out of money and she was forced to interrupt her treatment. Her condition worsened and she was admitted to the cancer hospital again, then directed to attend clinics every month. However, her attendance was not regular and in the next one and a half years she was hospitalised twice. She has attended clinics till the present time.

The family incurred heavy direct and indirect costs over this period. The total of 5 months inpatient care that she received had cost the household around Rs 40,100, largely due to the 25 family visits to the hospital, which cost a total of Rs 27,700, and also due to the cost of special foods (Rs 2,000) and paying donors for blood transfusions (Rs 10,400). The costs of outpatient clinic visits were also high, as travel and overnight accommodation were required for Seela and her son, who accompanied her, and cost around Rs 1,500 per month. Seela and her son were also not able to spend as much time cultivating, or conducting casual labour due to her illness and frequent visits to the clinic, resulting in income losses of around Rs 900 per month. The household had built up debts, and owed about Rs 25,000 to the grocer. Seela had to pawn her jewellery to raise further money, and Seela's son's children had to give up school too. Their house needed extensive repair, but they could not afford it. Seela is devastated, and said, "I wish I would die soon because the children are destroying themselves to give me a few days more of a life that is slowly fading away. I know that cancer kills but for us, a family that lived well with wealth produced with their hard labour, it kills the family as well and I do not want to see that happen. Sadly it has happened already."

***Cancer in a high income household: Banda's experience***

Banda is currently 65 and has been a cancer patient for the last 6 years. He lives in Moneragala, a remote rural area. Before his illness he had a stable income from paddy cultivation and vegetable cultivation, a total of four acres of cultivated land from which he drew an average monthly income Rs 5000. He lived with his wife, son and daughter-in-law, both of who were in formal sector occupations and together they had a monthly salary of Rs 12,000. They had one son who attended school.

His illness began with a severe pain in the mouth for which he consulted the government doctor but had no relief from his pain. He then went to the District hospital 10 kms away, and was directed to go to the Badulla provincial hospital 75 kms away. He was diagnosed as having throat cancer and hospitalised for 22 days. He was then transferred to the cancer hospital in Colombo for radiotherapy, where he was an inpatient for a further 25 days. Although inpatient care was free, he was required to purchase some medicines and special foods, and the costs of his family visiting him were high. The total direct cost of inpatient care was 31,500. When he was discharged, he was directed to attend clinics at the Badulla hospital once a month.

He attended clinics uninterrupted for 3 years and 8 months, at a total direct cost of Rs 14,000 for this period. He had to arrive early at the clinic in order to get a "number" for a place in the queue to see the doctor. He remarked, "On clinic days I start at 4.30 in the morning to get the bus and spend the entire day. If I delay they say the numbers have run out and I have to go another day. Some days if I find someone I know I give them some money and get a number." When he felt better he stopped going to the clinics because it was such a wearing experience. The illness surfaced again and he was admitted for 14 days to the Badulla hospital, where they had recently opened a cancer ward, so he did not have to go to Colombo for radiation treatment. He was then told to continue with visits to the clinic twice a month.

His wounds in the mouth made it unpleasant to go to the clinic and even to mix with his family. He is embarrassed to be seen in public. He has been going to a private doctor for medication because he fears being shunned by patients at the public clinic. Over the 6 years of his illness, special foods have cost him Rs 72,500; by the time of the interview he could eat only curd. But he stubbornly continues to chew betel. He sells the milk powder packets he receives as gifts to buy betel chew. He sees no point in giving up something he likes for the sake of an incurable disease.

Throughout his illness, Banda has lost time that he would otherwise have spent cultivating, costing him on average Rs 5000 a month. His daughter-in-law had been earning money through private tutoring, but children came to classes less because of the unpleasantness of his disease. The household pawned jewellery and sold some paddy land below their market value to raise money. At the time of interview there were family conflicts due to these strains on the household economy, and Banda keeps to his room and rarely comes out. He is thus totally isolated from his family and from society.

## *Care seeking experiences of households in Sri Lanka*

### **Questions**

Discuss the following questions and the issues they raise, in groups. Consider both cancer and diabetes when answering the questions.

1. What types of treatment do people use?
2. Why do people use these types of treatment?
3. Do the types of services used differ by the socio-economic status of the household?
4. What are the main barriers to care in terms of
  - a. Availability of care,
  - b. Affordability of care, and
  - c. Acceptability of care?
5. What direct costs of seeking health care do patients face?
6. What indirect costs of seeking health care do patients face?
7. Calculate:
  - a. The proportion of the household income that Seela's households spent on the direct costs of inpatient care for the total 5 months;
  - b. The proportion of the household income that Seela's household spent on the direct costs of outpatient care each month; and
  - c. The proportion of income that the Seela's households lost each month through the indirect costs of her illness.
8. List the coping strategies for health care costs that were most commonly used by households and the impact of illness costs on household livelihoods.
9. Consider the potential policy options to reduce household's barriers to health care in Sri Lanka.