

IMPACTS OF TOBACCO USE IN NEPAL:

How the tobacco epidemic is increasing health costs and affecting the lives of tobacco users and their families



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Foreword

Tobacco use is a global public health problem. It's a burden to an individual and its effect on the economy is enormous. It is a second risk factor for deaths in Nepal killing around 27,100 people each year. Tobacco use causes different kinds of non-communicable disease (NCDs) including Cardio Vascular Disease, lung diseases and other respiratory diseases, Coronary Obstructive Pulmonary Diseases (COPD) and cancer. These illnesses not only affects a person's health but their catastrophic financial, socio-economic, and psychological impacts on a person and their family members/ caretakers is inevitable. Among these, CVDs and cancer pose significant aforementioned impact on individuals, families and the nation as a whole.

Therefore, understanding the economic burden of tobacco use to a person and to the whole economy is very important to evaluate the adverse effects it is causing and the dire need to reduce its consumption. This becomes more evident at the time when COVID-19 is posing serious effects on people suffering from NCDs and tobacco users with impaired lungs.

NDRI in collaboration with the Nepal Cancer Relief Society (NCRS) have make an attempt to produce this report to shed light on the intensity of the impacts of tobacco-related illness, specifically due to cancer. This report includes case studies of tobacco-related cancer patients that give a glimpse of the financial, socio-economic and psychological impacts that tobacco attributable illness can have on an individual and their families. The case studies demonstrating the adversities faced by patients amid COVID-19 are also highlighted.

We are delighted to share this piece of work with you all and hope that the findings of this study will provide the policy makers with a glimpse of the real scenarios caused by the comprehensive effects of tobacco attributed diseases on patients and their families. In addition, we anticipate that this will be of help to concerned stakeholders and policy makers in taking the right decisions at the right time to reduce increasing consumption of tobacco products. Furthermore, we expect stories of cancer patients will help to raise awareness amongst current tobacco users and motivate them to quit, and persuade non-users to avoiding using tobacco. NDRI and NCRS would also like to recommend the government of Nepal to raise tobacco taxes and reduce its affordability.



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The vital input of Kivu International team on design, implementation and formulation of report of this study is acknowledged. We express gratitude to Ms. Becky Hatch, Ms. Sally Brunton, and Mr. William Klemperer for their contribution to this report.

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Executive Summary

Background

Tobacco claims more than 27,000 lives each year in Nepal, and is the single greatest avoidable risk factor for cancer mortality. Despite these risks, a national survey conducted by NDRI in 2020 found that almost one third of Nepalis – and more than half of Nepali men – consume some form of tobacco products.

The World Health Organization (WHO) further estimates the percentage of Nepalis who smoke is almost double the average across the South Asian region, and of all the South Asian countries only Bangladesh has a higher rate of smoking than Nepal.

This report uses a literature review and case studies to highlight some of the ruinous financial impacts and painful health costs endured by individuals. The report also seeks to calculate the direct and indirect costs of tobacco not only upon the Nepalese economy as a whole, but also upon affected individuals and their families.

National Impacts of Tobacco

The direct and indirect costs of smoking – through health expenditure and productivity loss – are enormous, with the WHO estimating annual costs of USD \$1.4 trillion per year globally, equal to 1.8% of the world's GDP. Due to its high rates of smoking, it is no surprise that Nepal suffers acutely from these costs, with NDRI estimating a loss to Nepal's economy of approximately NPR. 39.25 billion (USD \$334 million) in 2020 – approximately 1.5% of the country's GDP. This figure is likely to be an underestimate, as it does not incorporate costs related to smokeless tobacco or include non-health care costs such as transportation or time spent by caretakers and family members.

Individual Impacts – Financial Costs

The costs of smoking should not only be measured in billions of dollars and GDP figures. Tobacco also imposes very real costs upon individuals, their families, and their livelihoods. In Nepal, an estimated 48-69% of health costs in general are covered by individuals. This is true of cancer care, with the Government of Nepal only providing financial assistance of NPR. 100,000 to cancer and cardiovascular disease (CVD) patients to help meet healthcare costs – and this support is only available to certain patients from deprived family backgrounds, eligible through the *Bipanna Nagarik Kosh* (Deprived Citizens Fund).

Although this financial support is welcome and much needed, a study of 294 cancer patients undergoing treatment at Bhaktapur Cancer Hospital found that the mean cost of cancer care was NPR. 387,000. This is almost five times the average annual income of NPR. 78,900 and almost four times the amount covered by the government. Therefore, 86% of those surveyed experienced financial hardship and in order to meet the costs of treatment 78% had to obtain loans and 48% were forced to sell assets.

A second study of 103 patients suffering from tobacco-related cancers found that the mean cost of treatment for patients and their families was NPR. 981,370 in 2019. Direct medical costs comprised almost 73% of this sum, with the indirect costs of wage loss and absenteeism making up the remainder. Of these patients, only 14% of patients were able to meet the cost of treatment on their own, with 16% selling their land or buildings, and 27% borrowing money from relatives to cope.

The situation is similar for patients suffering from CVDs – a study of 97 patients suffering from CVDs found that the mean cost of cardiovascular treatment for patients and their families was NPR. 791,000 in 2019. Direct medical costs comprised almost 72% of this sum, with the indirect costs of wage loss and absenteeism making up the remainder.

Individual Impacts – Social Costs

Tobacco-related illnesses also have significant non-financial impacts on patients and their families, including stress, anxiety, depression and stigmatization. Patients with tobacco related illnesses often suffer significant long-term social impacts, such as stigmatization or feelings of shame and guilt, which can damage a patient's personal and social life, and harm their economic standing.

Cancer patients undergoing treatment and survivors are often left unable to work due to health impairments. Hence cancer and heart disease patients are at especially high risk of mental health disorders, such as depression and anxiety due to physical inability. Patients with chronic diseases often report that low self-esteem and persistent stress leave them psychologically vulnerable.

The impacts are greatest on poorer Nepalis in particular, who have been found to suffer greatly from stigmatization and hazardous social environments. Financial stress resulting from high treatment costs can affect all dimensions of family life and cause knock-on effects for younger generations, especially for poorer families. Concerns about loan repayment often leads family members dropping out of education so as to earn money from the youngest possible age to meet the costs.

Case Studies

In order to illustrate the devastating impacts that tobacco-related illnesses – and cancer in particular – can have on patients and their families, NDRI collaborated with the Nepal Cancer Relief Society (NCRS) to conduct a number of interviews over the period August – November 2020.

The results of these interviews are set out in seven case studies that shed light on the financial, socioeconomic and psychological damage done to patients and their families by tobacco-related illness. Note that names and other identifying features of patients have been changed in order to maintain the anonymity and privacy of patients.

The seven case studies showcase the full range financial, emotional and mental hardships that cancer patients regularly experience. All of those interviewed suffered negative financial impacts. Several interviewees were left unable to work by their cancer diagnosis, further affecting families already struggling to manage high treatment costs. In some cases the sons of patients were forced to take financial responsibility for their fathers; other families took out loans or borrowed from family and friends. The interviews reveal the impacts have been greatest for those families from lower socio-economic backgrounds, with three interviewees facing poverty as a result of their illness.

Non-financial impacts are equally apparent, with many stories of physical pain, mental distress, and social stigmatization both during and after treatment. One cancer patient was suffering so much from his cancer that he was unable to speak; his wife told his story instead.

These case studies show that while each individual's story is different, they share common characteristics, and taken together they reveal the full breadth of damaging health, social, and financial consequences caused by tobacco. Two examples in particular highlight the diversity and intensity of these impacts:

Mr. Kishor Manandhar (name changed to preserve privacy), is a 45 year old oral cancer patient from Jhapa. Mr. Manandhar's symptoms of cancer appeared in June 2020 when he developed a non-healing ulcer in his mouth where he used to regularly place chewing tobacco. After the wound became infected and painful, he was eventually diagnosed with oral cancer at Patan Hospital, where he now undergoes courses of chemotherapy.

He is suffering significant physical pain and mental stress from this life-threatening disease: the tumor inside his mouth prevents him from fully opening or closing his mouth, and hampers his speech, feeding, and breathing.



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“I cannot have any solid food. I am feeding on liquid food through syringe since 6 months. Because of this my stomach never gets full”.

Cancer has also been financially ruinous for Mr. Manandhar, who has already spent more than NPR. 150,000 (almost USD \$1,300) on treatment within just three months of the diagnosis. As the only earning member of his family, and now being unable to work because of the disease, his family now rely on their scant savings, and donations provided by relatives and neighbors, for basic necessities:

“I have a huge financial burden due to cancer. I have no other source of income, so it is really hard to arrange money for my further treatment.”

With his family fearing imminent financing crisis, Mr. Manandhar says ***“I want to make people aware about the harmful effect of tobacco and ask everyone not to use such harmful product.”***



This is a stock photo for illustration purposes only

Mr. Shailesh Tamrakar (name changed to preserve privacy), is a 63 year old lung cancer patient from in Kathmandu, who smoked cigarettes during gatherings and parties as a social smoker for almost 32 years. Since his stage 3 lung cancer diagnosis in 2017, Mr. Tamrakar has undergone 12 cycles of chemotherapy, which has caused physical exhaustion and gastritis. With his cancer being incurable, and his illness only controllable, the impacts on his working and social life have been severe. He was forced to retire from his job early, and felt it was the end of his life as he knew it:

“I was not prepared to face the cancer when I learned about the confirmation of my cancer. I felt insecure about my family and children”.

Previously a very social person, he has struggled to socialize at gatherings, and his diagnosis has caused psychological, social and mental stress. Family and friends treat him as a very ill patient and bid farewell to him as if they are never going to see him again. Repeated enquiries about his health

condition, the invasion of his personal life and being treated as if he is about to die cause irritation and stress.

The financial impacts have been enormous: CT scans every two months, visits to three different hospitals in India, and 12 cycles of chemotherapy have so far cost almost 20 lakhs (USD \$17,000). As a sufferer of cancer due to tobacco use, Mr. Tamrakar has a strong message to convey:

“The first message I would like to give to all the people out there is avoid nicotine and tobacco products completely, as using such products do not give any advantage and only cause health problems”.

While these are just two of the seven case studies in the report, together they describe a range of health, social, and financial consequences. From family financial ruin and continuous physical pain, to mental stress and the inability to work, the impacts of tobacco-related disease are as severe as they are varied.

Taken alongside compelling scientific literature, these studies highlight the urgent need for the Government of Nepal to prioritize tobacco control in order to reduce rates of tobacco use, including through an increase in taxation on tobacco products. Such policies will significantly benefit the wider economy by reducing the direct and indirect costs of tobacco-related illness while increasing taxation can also increase government revenues. Most importantly, however, stronger tobacco control policies, including an increase in tobacco taxes, change will save lives, improve health outcomes, and help prevent further tragic stories like those recounted in the case studies.

Background and Context

The tobacco epidemic is a huge threat to public health. It is estimated to kill more than 8 million people every year across the globe, accounting for more deaths each year than HIV/AIDS, tuberculosis, and malaria combined, and 80 percent of these premature deaths are taking place in the developing world.¹ It claims 1.6 million lives in the South East Asia Region alone,² and in Nepal, it is claiming 27,100 lives every year.³ Tobacco use is the single greatest avoidable risk factor for cancer mortality.⁴

Levels of tobacco consumption in Nepal are high. NDRI's 2020 National Survey on Socioeconomic and Policy Aspect of Tobacco Use (NSEPT) found the prevalence of any type of tobacco use among 18+ aged people to be 31.7% on average: men 51% and women 13.7% as shown in Chart 1 below. The overall prevalence rate of tobacco use was found to be 28.9% among 15-69-year adults by STEPS survey 2019 carried out by Nepal Health Research Council (NHRC).⁶

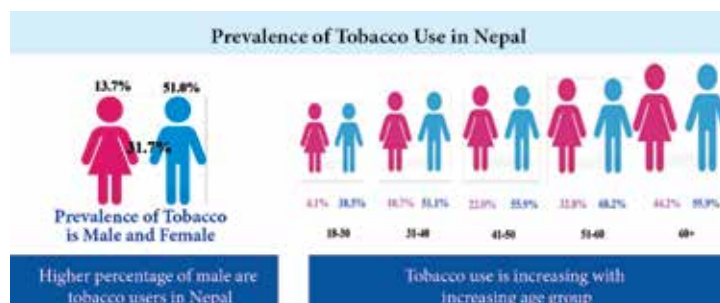


Chart 1: Gender and age prevalence of tobacco use in Nepal (Source: NSEPT 2020)

The prevalence rate is significantly higher in comparison to the average for other low-income countries: The World Health Organization (WHO) estimate that in 2015 the percentage of Nepalese smoking was 21.6% compared with 11.6% for all low-income countries as shown in Chart 2 below.

Nepal also has a higher prevalence of tobacco consumption (whether smoking or smokeless) than all South Asian countries apart from Bangladesh. The data was sourced from WHO website and constructed by NDRI, as shown in Chart 3 below.

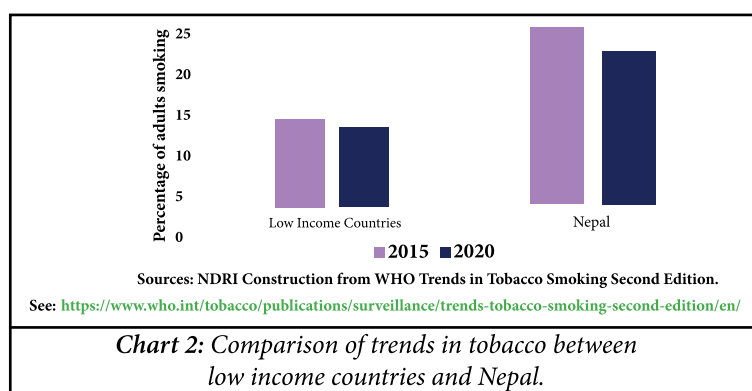


Chart 2: Comparison of trends in tobacco between low income countries and Nepal.

Chart 4 below (sourced from NDRI's 'Tobacco in Nepal: The current context') shows the trend in smoked and smokeless tobacco use: overall tobacco consumption rates have been broadly steady over time – while they are not getting worse, they also do not appear to be improving. Chart 4 also shows that smoked tobacco use is decreasing in different age groups while smokeless tobacco use is increasing.

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The impacts of tobacco use on society are significant. This report will explore two categories of impacts: firstly, it will consider the costs that tobacco use can have for Nepalese society as a whole by focusing on the health costs it can create. It will then look at the more personal financial, health and social impacts that tobacco use can have on tobacco users and their families and friends. To demonstrate this, a series of case studies conducted with patients suffering from tobacco-related cancers will then be presented.

¹<https://www.worldbank.org/en/topic/tobacco>

²<https://www.who.int/southeastasia/health-topics/tobacco/tobacco-control-in-the-south-east-asia-region>

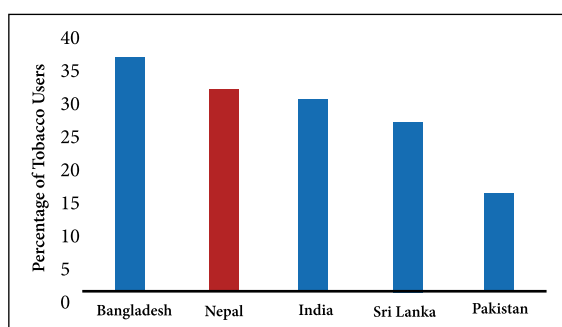
³<https://tobaccoatlas.org/>

⁴<https://www.who.int/activities/preventing-cancer>

⁵Nepal Development Research Institute. National Survey on Socio-economic and Policy Aspects of Tobacco Use (2020)

⁶Government of Nepal, National Health Research Council: Tobacco Fact Sheet, Nepal STEPS Survey 2019

⁷Nepal Development Research Institute. Tobacco in Nepal: The Current Context 2019, NDRI



Sources: NDRI construction from WHO data (<https://www.who.int/tobacco/surveillance>).
Nepal data based on STEPS Survey 2013

Chart 3: Tobacco prevalence in South Asian Countries

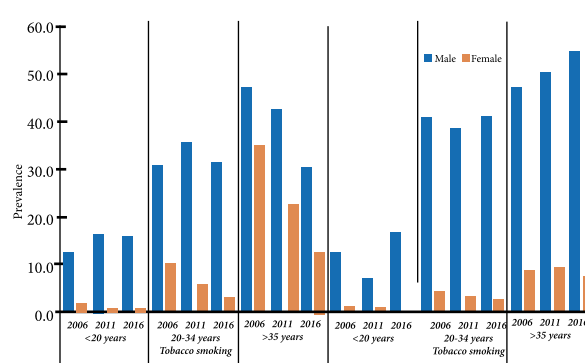


Chart 4: Trends of Tobacco use in last 10 years

The Health Costs Associated with Tobacco Use

The health costs of tobacco use are high: tobacco use causes economic loss due to the treatment of disease and loss of productivity in life due to premature death and disability. Such costs must be borne by the public sector and healthcare system, or by individuals and their households. Using the cost of illness approach that distinguishes economic costs of tobacco use into direct and indirect costs, according to the WHO the direct cost of tobacco use refers to the expenditures made on goods and services as a result of tobacco use and related illnesses.⁸ It consists of healthcare costs (e.g. medical supplies, medicine, treatment, doctors visits etc.) and non-healthcare costs

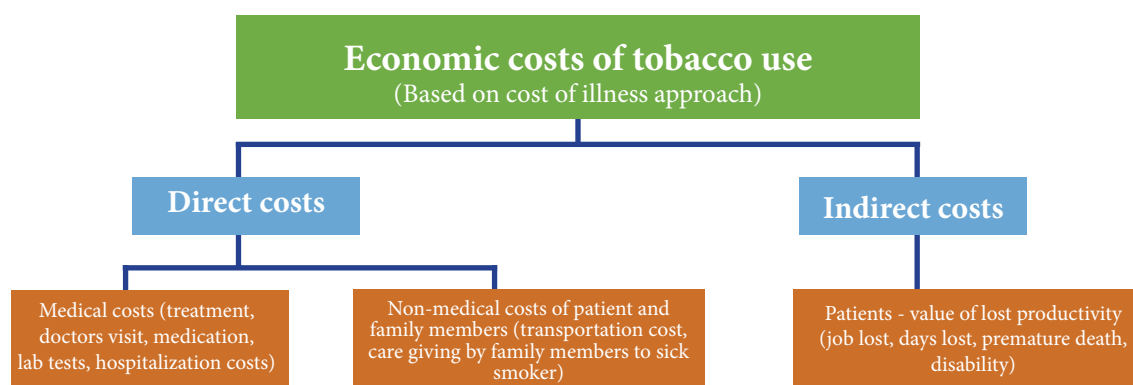


Chart 5: Economic costs of tobacco use

Source: Prepared by NDRI based on the information from Economics of tobacco toolkit (2011), WHO.

to health providers, care-giver/family members time provided to sick smokers. Indirect costs include the value of productivity loss, disability, lives lost due to the tobacco-related illness of patient as depicted in Chart 5 above. This section will consider the wider economic impact of the cost of treatment for tobacco-related illness.

According to the WHO, globally smoking causes total economic costs (from health expenditure and productivity losses together) of around US\$1.4 trillion per year (in 2016), which is equivalent to 1.8% of the world's annual gross domestic product (GDP). Almost 40% of these costs occurred in the developing world, indicating the substantial burden these countries suffer.⁹ This huge economic burden of smoking is shown across different contexts: for example, economic costs equate to approximately 1% of GDP in the United States and approximately 0.7% of China's GDP.¹⁰ Smoking related illness in the United States costs more than US\$300 billion each year including nearly US\$170 billion for direct medical care, and more than US\$156 billion in lost productivity (which includes US\$5.6 billion in lost productivity due to second hand smoking exposure).¹¹ In the UK, the direct

costs of smoking to the National Health Service have been estimated to be £30,424 million pounds (US\$40 billion)¹² and the total cost of smoking in Australia in 2016 was AUD 136.9 billion (US\$99.92 billion).¹³

These significant economic costs are also felt in low- and middle-income countries. According to the WHO, tobacco is closely linked to poverty and development in the South East Asia region. A study in Vietnam shows the total economic costs of smoking in 2011 was 24,679.9 billion Vietnamese Dong (US\$1.173 billion), accounting for 0.97% of that year's GDP. The direct cost of patient care was US\$592 million while indirect costs (productivity loss) due to morbidity and mortality were US\$121.1 million and US\$454.6 million respectively. These indirect costs of smoking accounted for 49.5% of total costs.¹⁴ In Thailand the cost of smoking in 2015 was 74.88 billion Baht (US\$2.18 billion) which accounted for 0.78% of the country's GDP. The majority of the cost burden was due to productivity loss at 62.24 billion Baht (US\$1.81 billion), followed by direct medical costs of 12.64 Baht (US\$0.37 billion).¹⁵ Similarly, in Indonesia – which is the top tobacco using country in the South East Asia Region – the health cost due to tobacco-related illness is significant: the treatment cost of smoking was estimated to be US\$2,177 million accounting for 2.5% of the country's GDP in 2015.¹⁶

According to 'The Tobacco Atlas' report published in 2018,¹⁷ the economic cost of smoking in some South Asian countries ranged from US\$22.5 million to US\$34.4 billion (calculated in 2012), which is 0.68% to 1.8% of GDP of the respective countries as shown in Chart 6 below.¹⁸

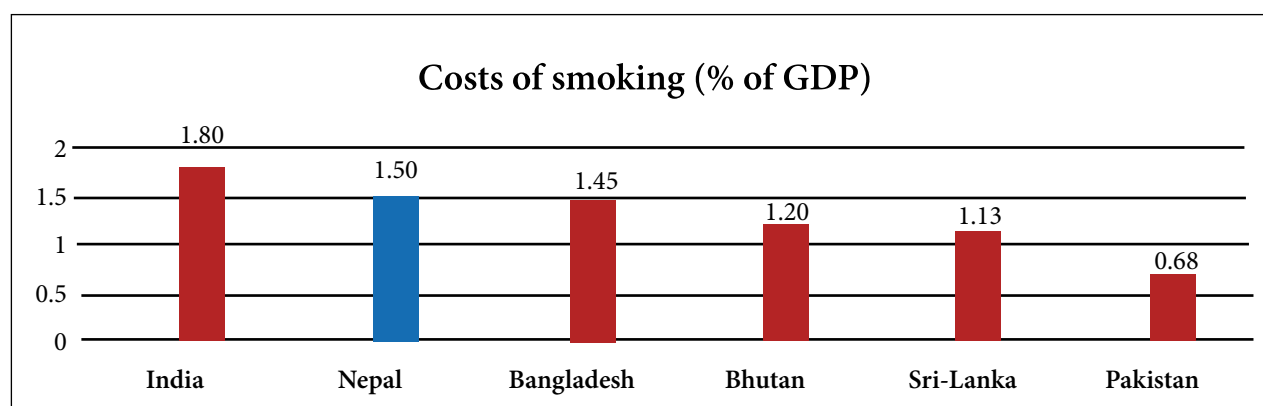


Chart 6: Economic cost due to smoking attributable disease in South Asia

It is clear that there can be significant economic costs arising from tobacco use, and the high prevalence of tobacco use in the South Asian region is putting an additional burden onto economies.¹⁹ Nepal is no exception: as shown in Chart 6 above, Nepal has high economic costs attributable to smoking and in 2012 lost NPR. 22.94 billion (US\$258 million) – which accounted for 1.5% of its GDP – due to smoking related illness in that year. If we adjust those costs for inflation, we get an estimated cost of smoking in Nepal of around NPR. 39.25 billion (US\$334 million)²⁰ in 2020.²¹

⁸WHO. Economics of tobacco toolkit (2011)

⁹https://www.who.int/health-topics/tobacco#tab=tab_2

¹⁰Ekpu, V. and Brown, A. (2015), 'The Economic Impact of Smoking and of Reducing Smoking Prevalence: Review of Evidence', Tobacco Use Insights, Volume 8: 1-35. doi:10.4137/TUI.S15628.

¹¹https://www.cdc.gov/tobacco/data_statistics/fact_sheets/economics/econ_facts/index.htm

¹²<https://tobaccoatlas.org/country/united-kingdom/>

¹³National Drug Research Institute (2019), 'Identifying the social costs of tobacco use to Australia in 2015/16'

¹⁴Hoang Anh, P.T., et al. (2016), 'Direct and Indirect cost of smoking in Vietnam', Tobacco Control, Volume 25, Issue 1. <http://dx.doi.org/10.1136/tobaccocontrol-2014-051821>

¹⁵Bundhamcharoen, K., Aungkulanon S., Makka N., and Shibuya, K. (2016), 'Economic burden from smoking-related diseases in Thailand', Tobacco Control, Volume 25, Issue 5. <http://dx.doi.org/10.1136/tobaccocontrol-2015-052319>.

¹⁶Kristina S. A. et al. (2018), 'Health Care Cost of Noncommunicable Diseases Related to Smoking in Indonesia, 2015', Asia-Pacific Journal of Public Health, Volume 30, Issue 1: 29-35. doi:10.1177/1010539517751311.

¹⁷<https://tobaccoatlas.org/>

¹⁸GDP of each country sourced from World Bank.

Further, this cost only includes costs for smoking related illness and does not include costs related to smokeless tobacco (due to a lack of data and literature). Furthermore, this cost calculation has been limited to direct healthcare costs only and excludes non-health care costs such as transportation and time spent by caretakers/family members.²² This suggests that the estimated health costs of tobacco-related illnesses are significantly underestimated.

The Personal Impacts of Tobacco-related Illness

Financial Impacts on Patients and Their Families

The cost of purchasing tobacco diverts the income of families which could have been used for other purposes. But when a tobacco user becomes ill, the costs of this illness fall on both the government/wider society (as shown above) and on individuals. In Nepal, an estimated 48-69% of health costs in general (so not simply those related to tobacco-related diseases) are covered by individuals. This includes out of pocket (OOP) expenditures which are those costs borne by individuals and households (rather than the government) away from medical facilities, as well as the cost of hospitalization²³. Medical expenses associated with treatment of tobacco-related conditions can be catastrophic, especially for Nepalese belonging to the lower socioeconomic status. At the household level, illnesses can result in a loss of earnings, household savings, and investments.

Realizing the potentially catastrophic health expenses due to cancer and CVDs, the government of Nepal has been providing financial assistance of NPR. 100,000 to cancer and CVD patients to meet healthcare expenses, including medicines required for disease management. This is only provided to those belonging to poor and deprived family backgrounds from the Bipanna Nagarik Kosh (Deprived Citizens Fund) since 2006.²⁴ In addition to this, NCRS has been providing airfare support to cancer patients for up to 3 trips: the first trip=100% off to the patient and 50% off to the caretaker; the second trip=50% off to the patient and 25% off to the caretaker; and the third trip=25% off to patient only).²⁵ These financial support and airfare services provide the cancer patient with help to meet the costs of their treatment, however the government provided assistance seems insignificant when considering the total costs of treatment.

A quantitative cross-sectional study done among 294 cancer patients receiving treatment from Bhaktapur Cancer Hospital to estimate direct and indirect costs associated with the treatment of cancer found that the mean direct cost of cancer care was NPR. 387 thousand which was far above than average annual income of a person of NPR. 78.9 thousand, enough to have catastrophic financial impacts. This study also revealed that 86% of those surveyed experienced financial hardship and they managed the cost of treatment by getting loans (78%) and selling properties (48%) to manage costs.²⁶ Similarly, another study carried out by Action Nepal among 103 patients suffering from tobacco-related cancers has shown the mean cost of treatment to the patient and their family was NPR. 981,370 per patient in 2019. The direct costs accounted for 73% and the indirect costs such as wage loss, absenteeism due to sickness accounted for 27% of the total cost. The study also revealed that 16% of patients sold their land and buildings to meet the cost of treatment of their cancer and 27% borrowed money from relatives, and only 14% of the patients have managed the expenses from their own income.²⁷ Another study carried out by Action Nepal among 97 patients suffering of any kind of Cardio Vascular Diseases (CVDs) from two specialized hospitals of Nepal has found that the mean cost of CVD treatment to the patient and their family was NPR. 790,995 per patient in 2019. The direct costs accounted 72% and indirect costs such as absenteeism/wage loss due to illness was 28%. Based on this study, the extrapolated tobacco attributable cost of CVDs is around NPR. 33.35 billion per year.²⁸

¹⁹<https://www.who.int/southeastasia/health-topics/tobacco/tobacco-control-in-the-south-east-asia-region>

²⁰Calculated by NDRI incorporating the inflation rates sourced from Nepal Rastra Bank; 1 USD = 117.52 on 12 January 2021.

²¹Note that the WHO FCTC investment case study of Nepal report has shown the total economic loss due to tobacco use has further increased since 2012: this study used a different methodology to the Tobacco Atlas report and suggested the cost was NPR. 47 billion (USD \$458 million) in 2017, accounting for 1.8% of national GDP. And if we inflate this amount to 2020, then it is NPR. 54.6 billion (USD \$464 million). This shows the costs may range up to NPR. 54.6 billion per year.

²²Goodchild, M., et al. (2016), 'Global economic costs of smoking attributable diseases', Tobacco Control, Volume 27, Issue 1: 58-64; <http://dx.doi.org/10.1136/tobaccocontrol-2016-053305>.

²³<https://apps.who.int/iris/bitstream/handle/10665/205319/B0575.pdf?sequence=1&isAllowed=y>

Non-financial Impacts

Tobacco-related illnesses like cancer can also have significant non-financial impacts on the lives of the patient and their family including stress, anxiety, depression and stigmatization.

Patients with tobacco-related illnesses are often found to be stigmatized with significant after-effects including defamation, leading to guilt and shame, and such stigma may risk the patient's personal and social life, as well as their economic opportunities - it can profoundly affect families.²⁹ The financial impacts of tobacco-related illness can also lead to stigmatism. For example in Nepal poor people living in rural areas have been found to be exposed to hazardous social and physical environments: underprivileged families struggled to manage the cost of treatment of tobacco-related chronic diseases, and patients with chronic diseases had low self-esteem and lived in stress in order to manage finance for treatment, leaving them psychologically vulnerable.³⁰ Additionally, patients with tuberculosis (in Kathmandu) were found to be unjustly stigmatized and discriminated by health workers and the community at home, in the workplace and in hospitals due to lack of knowledge and feared of being 'infected' with those diseases.³¹

The stressful nature of diseases like cancer and others caused by the consumption of tobacco is widespread and inescapable, not only for the patient but also their family members. During the course of treatment of tobacco-related ailments, the financial and mental status of the patient and their family may worsen.³² And this financial burden can add a burden onto family members as well as the patient because their minds may be occupied in thinking about the way to manage the cost for the treatment and medication.³³ Financial stress can also affect other dimensions of family life, including for example concerns about how to repay loans taken out to finance treatment costs, and family members dropping out of school as well as working for income generation at a young age to help meet the cost of treatment.³⁴ And there are many other non-financial impacts of tobacco-related illnesses. For example, patients with cancer, particularly those in active treatment and those with advanced stages of the disease, may experience severe symptom distress, which may influence social and physical as well as mental functions.³⁵ It can also add a heavy emotional and physical burden on the primary family caregiver when patients are bedridden. Patients with heart disease are at high risk for mental health disorders, such as depression and anxiety due to physical inability.³⁶ And cancer patients undergoing treatment and survivors are often left unable to work due to health impairment and disability induced due to the treatment and onset of cancer, in turn leading to emotional distress, as well as mental health and social problems.³⁷

²⁴<https://www.mohp.gov.np/eng/program/medical-treatment-deprived-citizen>

²⁵http://www.ncrs.org.np/page/48/programme/other_activities

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Case Studies: How Tobacco-related Cancers Have Impacted the Lives of Tobacco Users in Nepal

In order to illustrate the impacts tobacco-related illnesses, and specifically cancers, can have on patients and their families, NDRI in collaboration with the Nepal Cancer Relief Society (NCRS) conducted a number of interviews over the period August – November 2020. Case studies based on these interviews are set out below, and help shed light on the intensity of the impacts of tobacco-related illness, specifically focusing on the impacts of cancers mostly attributable to tobacco use on the financial, socioeconomic and psychological well-being of patients, their families and their care givers in Nepal. Note that names and other identifying features of the patients have been anonymized for the purposes of this report.

The case studies of cancer survivors and those currently fighting with cancer presented here showcase the range of financial, emotional and mental hardships they experienced. All of those interviewed suffered negative financial impacts: the cost of cancer treatment is high and can deplete savings and weaken the economy of the family. A number of the interviewees were no longer able to work after their cancer diagnosis, including Mr. Chandra Neupane, Mr. Kishor Manandhar and Mr. Narayan Tharu; and Mr. Shailesh Tamrakar was forced to take early retirement. This severely impacted the income of their families, already under strain due to the high costs of treatment. In some cases, other family members were forced to take on financial responsibility for the family: the respective sons of Mr. Chandra Neupane, Mr. Narayan Tharu and Mr. Lalit Balami all had to take on this responsibility. Some interviewees mentioned taking out loans and getting help from family and friends to meet the costs of their cancer treatment and care (for example, Mr. Narayan Tharu); and a few also confirmed they had received government support – Mr. Narayan Tharu, Mr. Diwash Thapa, Mr. Lalit Balami and Mr. Kishor Manandhar.

But whilst all interviewees suffered financially, the impact has arguably been greater on those families from lower socio-economic backgrounds who found it harder to bear the financial costs. Those from higher income families (such as Mr. Rajan Devkota and Mr. Shailesh Tamrakar) did have to meet the costs of treatment and felt that these resources could have been utilized for other productive things instead of being diverted to meet the costs of their cancer, but this was more manageable for them than for other, less well-off patients who are suffering from more catastrophic impacts. As shared by Mr. Narayan Tharu, Mr. Lalit Balami, and Mr. Kishor Manandhar, the huge cost of cancer treatment and care has depleted their savings and is pushing them towards a poverty trap.

When reading these case studies, it is also clear that patients suffered from other, non-financial impacts. The interviewees spoke about the physical pain and distress caused by their cancers and the treatment, including Mr. Diwash Thapa who was unable to participate directly in the interview due to the physical effects of his ongoing treatment – his wife had to conduct the interview on his behalf – and Mr. Kishor Manandhar who has been forced to eat only liquid food for over 6 months. And whilst Mr. Shailesh Tamrakar and Mr. Rajan Devkota remain financially, emotionally and mentally strong after their triumphs over cancer, they suffered other non-financial impacts like stigmatization and they are also fed up with society treating cancer patients as if they are destined to die. Mr. Shailesh Tamrakar in particular stressed that his lifestyle and social life has changed significantly since his diagnosis. In the case of Mr. Diwash Thapa, cancer treatment has affected the physical and mental status of both him as a patient and his wife – who acts as his caretaker – too, and Mr. Kishor Manandhar spoke about the mental challenges and depression he has faced since becoming ill. And Mr. Chandra Neupane - who got cancer at the age of 78, the age when he has to take rest and care of his quality of life – is now loaded with medicine and treatments which are leading to a deteriorated quality of life: this is due to his past tobacco use habit.

As these case studies show, each individual's story is different. But what is clear is that tobacco-related cancers have significant negative impacts on both patients and their families. And in particular, the cost of treatment and care can have a catastrophic financial impact on those patients from lower-socio economic households.

Case Study 1: Mr. Kishor Manandhar (45), oral cancer patient

Mr. Kishor Manandhar³⁸ (original name changed), 45, is a patient of oral cancer, originally from Jhapa, and currently residing at Lalitpur. He is a driver by profession and lives in a nuclear family with his mother, wife and 3 children. He had his cancer diagnosed in September 2020 and currently he is being treated at Patan Academy of Health Sciences (Patan Hospital). Mr. Manandhar comes from a lower middle class family with a poor educational background (under SLC) and has a history of using chewing tobacco (khaini) for around 32 years.



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Mr. Manandhar's symptoms of cancer appeared in June 2020, when he developed a non-healing ulcer in his mouth where he used to regularly place chewing tobacco. The wound persisted for months but was painless, but it soon became painful and infected after Mr. Manandhar gargled with cow's urine following the advice of a local religious person.

Suffering from infection and pain, Mr. Manandhar tried to visit hospitals but due to the COVID-19 pandemic he could not, and ended up consulting a local medical shop. The medicine and mouthwash prescribed caused further deterioration of his wound. Afterwards, following the advice of his family members, relatives and neighbors, he visited Patan Hospital for treatment. He is now undergoing episodes of chemotherapy in the same hospital.

Cancer has caused significant physical pain and mental stress

Within a 3-month period of treatment, Mr. Manandhar has completed two cycles of chemotherapy and still has two cycles are left to do, after which he will have a further diagnostic test and a surgical removal of the mass. He is suffering from both physical and mental stress due to this life-threatening disease: the tumor inside his mouth is not just painful but is also creating difficulty in his day to day life by hampering his speech, feeding habits, and breathing. He has been feeding only on liquid food through syringes for over 6 months. He also shared that he cannot open or close his mouth completely due to the mass:

"It's obvious to have difficulty with the tumor inside mouth. I cannot have any solid food. I am feeding on liquid food through syringe since 6 months. Because of this my stomach never gets full."

³⁸<https://www.flickr.com/photos/77356400@N00/40320781283>

In addition to these physical challenges, Mr. Manandhar faced enormous mental stress in the beginning of his cancer and had undergone two to three depressive episodes. After consulting his doctor, family and friends he is now gaining the strength required to fight against cancer. His illness was a shock for whole family at the initial stages, and since then there has been a tremendous downfall in his and his family's quality of life.

The financial burden is a tragic part of cancer battle

After only 3 months since his cancer diagnosis, Mr. Manandhar had spent NPR. 150,000 (approximately USD \$1,275) on his treatment.³⁹ As he is from a poor economic background he is getting financial help from his relatives and neighbors: he is getting minor financial support worth NPR. 10,000-20,000 (USD \$85-170) from relatives. He has also received financial help worth NPR.100,000 (USD \$850) from his municipality.

Despite this help, the increased financial burden he is facing has been a tragic part of his cancer battle. He was the only earning member of his family, and because of his illness he can no longer continue his driving profession. Due to his cancer, his family members also cannot do other income generating work because they have to stay with him to take care of him. He is therefore worried about his family, as there is no direct source of income. They have been relying on savings and donations provided by their relatives and neighbors even for basic necessities such as food. Panicking about his current situation and future he said:

"I am having a huge financial burden due to cancer. I have no other source of income so it is really hard for me to arrange money for my further treatment."

Until now Mr. Manandhar's family have been managing their expenses in whatever way they can, but there are still many phases of treatment left ahead. His family fear financial crisis in the near future due to the dangerous and unpredictable nature of the disease, and the high costs of treatment. Mr. Manandhar plans to create awareness among people about the side-effects of using tobacco and request every tobacco user to quit the tobacco-related habits. He added:

"I want to aware about the harmful effect of tobacco and ask everyone not to use such harmful product."

Case Study 2: Mr. Narayan Tharu (49), nasopharyngeal cancer patient

Mr. Kishor Manandhar⁴⁰ (original name changed), 45, is a patient of oral cancer, originally from Jhapa, and currently residing at Lalitpur. He is a driver by profession and lives in a nuclear family with his mother, wife and 3 children. He had his cancer diagnosed in September 2020 and currently he is being treated at Patan Academy of Health Sciences (Patan Hospital). Mr. Manandhar comes from a lower middle class family with a poor educational background (under SLC) and has a history of using chewing tobacco (khaini) for around 32 years.

Mr. Manandhar's symptoms of cancer appeared in June 2020, when he developed a non-healing ulcer in his mouth where he used to regularly place chewing tobacco. The wound persisted for months but was painless, but it



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⁴⁰<https://www.flickr.com/photos/35943421@N00/141637089>

soon became painful and infected after Mr. Manandhar gargled with cow's urine following the advice of a local religious person.

Suffering from infection and pain, Mr. Manandhar tried to visit hospitals but due to the COVID-19 pandemic he could not, and ended up consulting a local medical shop. The medicine and mouthwash prescribed caused further deterioration of his wound. Afterwards, following the advice of his family members, relatives and neighbors, he visited Patan Hospital for treatment. He is now undergoing episodes of chemotherapy in the same hospital.

Cheap cigarettes and social prestige in the past have turned into a heavy burden and worry

Mr. Tharu was diagnosed with stage 1 nasopharyngeal cancer in 2019. He has completed five cycles of chemotherapy and has one cycle left to be done. Until he was diagnosed with the disease, none of his family members were aware of the deadly impact of smoking and rather took it as a sign of big personality. He shared:

“The cost of cigarette was cheaper and it was our social habit to smoke as a prestige. For this reason, I used to buy a packet of cigarette at that time.”

After he was diagnosed with cancer, he had a realization and fear that his son might also get cancer in the future as his son is also a smoker who has smoker friends. Despite these worries, Mr. Tharu is afraid to impose his advice not to smoke on his son since Mr. Tharu is financially dependent on his son and thinks he is an adult and enjoying using his own money. He shared:

“I also used to smoke cigarette from my early age from the influence of friends and now my son is also doing the same. If I impose him to stop smoking, he might get upset since he is using his own money to enjoy.”

The cancer has affected Mr. Tharu's work and lifestyle. He was engaged in agriculture before his cancer was diagnosed and had to give up working in field after he got sick with cancer. Since they are from a lower middle-class background, his family members are worried about his health and they are also suffering from other problems in their social life. Besides this, Mr. Tharu is also weak physically and has a frequent vomiting tendency due to the chemotherapy. This has left him feeling bad about his past habit, and he shared:

“When I am weak, I feel sorrow over my disease and my bad habit in the past.”

Health crisis has invited financial crisis due to highly-demanding treatment costs

Mr. Tharu along with his family members are worried about his health due to their poor economic condition, not least because his treatment demands a lot of money and their only source of income is from his only son. He has spent around about NPR. 800,000 (approximately USD \$6,800) till date for the treatment of cancer. He also has to spend NPR. 5,000 (USD \$42.50) per month as a rent in rent in Dudhpati, Bhaktapur near the hospital.

To help meet these costs Mr. Tharu has received NPR. 100,000 (approximately USD \$850) provided by the Government of Nepal for cancer patients. He has also taken a loan of NPR. 300,000 (USD \$2,550) from his married daughter, and NPR. 115,000 (USD \$980) from his son-in-law. The rest of

the money required for his treatment is provided by his son, and this is very difficult. He says:

“We are striving because of our lower middle-class background. Somehow, we are able to manage the cost of treatment but it is very difficult for us.”

Mr. Tharu therefore has to rely completely on his son for his living and treatment costs. His son is now the single source of income in the family. His profession is driving and he earns about NPR. 30,000 (USD \$255) per month. But given the high costs of treatment, his income alone is not enough. Mr. Tharu has not got any property or other assets to sell for his treatment, and so due to these high economic costs he feels it is challenging for them to deal with this disease. He said:

“This disease is a great challenge to my health as it needs more money for the treatment.”

Case Study 3: Mr. Lalit Balami (52), lung cancer patient

Mr. Lalit Balami⁴¹ (original name changed), 52, is a lung cancer patient from Bhaktapur. His cancer was diagnosed in mid-2020. He has a history of smoking cigarettes (15 sticks per day) and drinking alcohol for almost 15 years. He was a heavy smoker and was influenced by his friends to smoke cigarettes at a very young age, before giving up smoking almost 20 years ago. He lives in a nuclear family with his wife and two sons. He was the only source of income for the family when he was healthy, but the onset of cancer has transferred the financial responsibility of the family to his two sons. This responsibility is heavy with the added costs of cancer treatment.



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Physical pain and profound life transformation after cancer

Mr. Balami's cancer was diagnosed after series of tests at Bhaktapur Cancer Hospital in May 2020, but the stage of his cancer has not been finalized yet. His cancer has spread to the bone area as well, causing him shoulder pain. Currently, he is undergoing treatment in the same hospital. He has completed nine cycles of chemotherapy which has made him physically weak and ill. In addition, he was mentally disturbed thinking about his illness and could not continue his driving work. He said:

“I continuously have to visit the hospital for my chemotherapy and due to its side effect, I suffer many health problems. Due to this, I cannot think of continuing my work.”

After the family members learnt about his cancer, they were stressed mentally. His suffering from pain during chemotherapy has made all the family members worry about him. After the onset of cancer, Mr. Balami's quality of life has been greatly affected, as have the lives of his associated family members. Because of this his sons have been managing their own time to take care of their father. Mr. Balami shared:

“My quality of life has also deteriorated. Before the diagnosis of cancer, I used to work enduring the pain but now I can't work due to health issues. I came here to treat my shoulder pain but the pain has not decreased. It has been 6 months since I have been taking treatments but my shoulder is still aching. Due to this pain, I can't enjoy my life like I used to do before.”

⁴¹<https://search.creativecommons.org/photos/1f3e307-0262-4452-9360-243e723617ae>

He along with his son regret his habit of smoking which has led to cancer. Both of them conveyed a message that health is wealth, and smoking is injurious to health. He said:

“If I had not smoked or drank alcohol in the past then I might not have suffered from cancer. I want to give message to people not to smoke and drink alcohol.”

Financial burden for the family: cancer could push the family into poverty

After his diagnosis of cancer and associated health problems, physical pain, and mental stress, Mr. Balami has not been able to continue his work. At the time of the interview it had been seven months since he left his driving job from which he used to earn NPR. 15,000-20,000 (USD \$125-170) per month. After leaving his job, he is now fully dependent on his two sons' earnings who earn same amount as he used to earn. Both sons are using their earnings, savings, and their time for their father's treatment and care.

Till now Mr. Balami has spent NPR. 400,000 (USD \$3,400) on his cancer diagnosis and treatment. He has utilized the government's fund worth NPR. 100,000 (USD \$850) for cancer patients. But the family have been using their savings to meet the costs, and these savings are depleting day by day. Since he is unable to make earning, Mr. Balami's sons are now facing a heavy financial burden. He is very worried about the financial state of his family since he was the backbone and main source of income of his family before his cancer diagnosis. He said:

“I also fear and worry that we might have financial problems as cancer is a dangerous and expensive disease. I would not have worried if it was other disease but this is cancer which is unpredictable.”

Case Study 4: Mr. Chandra Neupane (79), lung cancer patient

Mr. Chandra Neupane⁴² (original name changed), 79, is a lung cancer patient from a middle-class family originally from Baglung, and currently residing in Kathmandu. He was engaged in subsistence agriculture for living with normal literacy. He had his cancer diagnosed when he was 78 years old (in November 2019) and is currently being treated at Bhaktapur Cancer Hospital.



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Mr. Neupane has a history of smoking cigarettes: he smoked 8-10 sticks per day for around 42 years. In addition to cigarettes, he used smokeless chewing tobacco like surti, khaini and gutkha occasionally. His cancer was diagnosed when he exhibited the symptoms of hemoptysis (started to cough up blood) which lasted for quite long time. His ailment was confirmed after visiting two hospitals in Kathmandu and he has started the treatment in the third hospital – Bhaktapur Cancer Hospital. Since he is old and was a subsistence farmer in his whole life, he is now dependent on his son, who runs a business, for this treatment. This has had significant financial impacts for the family, and his son's savings are running out. Mr. Neupane's health is also increasingly vulnerable during the COVID-19 pandemic, which causes him and his family stress and worry.

⁴²<https://search.creativecommons.org/photos/1f3ce307-0262-4452-9360-243e723617ae>

Cancer diagnosis has made his health more vulnerable, particularly during COVID-19 pandemic

Mr. Neupane was diagnosed with stage 3 lung cancer at the age of 78. Due to his age, after the confirmation of cancer he searched for effective methods of treatment and tried ayurvedic medications for 3 months which costed him and his family around NPR. 50,000 (USD \$425) per month. Later he shifted to chemotherapy, and he has now completed four cycles of chemotherapy with two cycles yet to be completed.

Cancer has affected Mr. Neupane's daily and working life, and those of his family members. He was carefree before the diagnosis of cancer but now he says:

“My health has become very sensitive. I also have to be extra careful in my eating habits. The things which I could eat before my cancer got diagnosed cannot be eaten by me now.”

Further, unlike before he can no longer go out in a carefree way but instead has to think a lot about his health. The current COVID-19 pandemic has also made him vulnerable since it attacks people with low immune systems and people with non-communicable disease like cancer. So, he shared,

“Due to chemotherapy, my antibodies are affected to some extent, so I have to take high precaution before going out.”

Since he and his family also have to frequently visit hospital for chemotherapy during this pandemic, they all are frightened of infection and this makes them stressed.

Worried about finance: savings are depleting

After only 10 months since his cancer diagnosis, Mr. Neupane has spent NPR. 500,000 (USD \$4,255) for his treatment. All the cost has been borne by his son, who owns a business in Kathmandu. His son is spending his savings to meet the cost of his father's treatment, and these savings are running out now. Besides the expense for the treatment, Mr. Neupane has to spend some money to travel from Kirtipur, Kathmandu to Dudhpati, Bhaktapur for his treatment (and his son has to take time off work to accompany him for the treatment). The cancer has therefore affected his family's financial activities. He shared:

“Before my cancer was diagnosed, my elder son used to have small savings left from our monthly expenses but now, he does not have any savings left from our household expenses and my cancer treatment.”

Till now Mr. Neupane's family are managing their expenses in whatever way they can, but if the cancer treatment continues they fear a financial crisis in the near future due to the dangerous and unpredictable nature of the disease. He says:

“Until and unless the cancer is treated completely, I feel like I still have lots to spend in my treatment. It can be said that I and my family members have faced a bit of financial problems.”

Case Study 5: Mr. Diwash Thapa (46), oral cancer patient

Mr. Diwash Thapa⁴³ (original name changed), 46, is a stage 3 oral cancer patient originally from Jhapa, Nepal and currently residing in Pepsicola, Kathmandu in rented accommodation. He is a businessman making his living from a consultancy business. He has a history of drinking alcohol, smoking cigarettes (4-5 sticks per day), and chewing smokeless tobacco products. He started smoking at the age of 16 years under the influence of his circle of friends. Later in life his friends introduced and got him addicted to chewing smokeless tobacco. Now he has quit both forms of tobacco consumption after his cancer was diagnosed in May 2020. He and his family have been left shocked, anxious and stressed following his diagnosis.



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He and his family have been left shocked, anxious and stressed following his diagnosis.

Mr. Thapa visited three private hospitals in Kathmandu for the diagnosis of his illness. Due to the COVID-19 pandemic, his illness was not properly checked and he had to follow various medications and perform various diagnostic laboratory tests in two of the hospitals. After his cancer was confirmed in third hospital, he started his treatment at the public Bhaktapur Cancer Hospital to minimize the cost of treatment. The patient was not able to speak during the interview due to the ongoing treatment of his oral cancer. Therefore, his wife on his behalf presented his experiences.

Cancer shattered the patient and family members into pieces

Mr. Thapa was diagnosed with stage 3 oral cancer in May 2020. Till now he has completed three cycles of chemotherapy and 30 fractions of radiotherapy, and still has three cycles of chemotherapy and five cycles of radiotherapy is left to be done. Since he did not have any other health issues and had no history of cancer in the family, his suffering from cancer was a shock to the family. His wife said:

“After my husband was confirmed with cancer, whole family and friends were in shock for a week. We all were stressed out. Everyone at home were silent and depressed for a week. We gradually adopted to it and started getting back to normal.”

In Nepal, the male is considered the pillar of the house who feeds the household. After Mr. Thapa was diagnosed with oral cancer, everyone in his family including the children became anxious about finances at home and were depressed. Though his illness was a shock for whole family at the initial stage, later he received full support from family with his parents, wife, brother, and two children. His wife is very supportive and takes care of him, including planning his diet meticulously. But sometimes, Mr. Thapa feels bad about his habit. His wife shared:

“My husband sometimes gets guilty that due to his bad habits, he and his family members are suffering.”

In addition to the psychological impact, he has also had some negative physical effects due to the chemotherapy which was evident since he could not speak for the interview.

⁴³<https://search.creativecommons.org/photos/1f5ce307-0262-4452-9360-243e723617ae>

Financial impact of cancer treatment worsened during COVID-19 pandemic

Only 6 months after his cancer diagnosis, Mr. Thapa has spent around NPR.700,000–800,000 (USD \$5,960–6,810) on the costs of diagnosis, treatment (chemotherapy and radiotherapy) and medication including his diet. He has additional spending of NPR. 15,000 (USD \$125) per month for the rent in temporary residence at Pepsicola. He has utilized NPR. 100,000 (USD \$850) provided by Government of Nepal for cancer patients. But his business has been affected greatly due to the COVID-19 pandemic and his working hours have been diverted to his treatment and regular visits to hospital over the last 6 months.

But it is not just Mr. Thapa's time which has been taken up by the disease: along with him, his wife has also dedicated her time to his treatment and welfare. She accompanies him to hospital and takes care of him fully. She has been investing her time and energy to help improve his quality of life, exploring healthy food habits and ways of being well physically and mentally too.

After experiencing the enormous impact of cancer, his wife on behalf of him has conveyed the message to the public warning of the risks of tobacco use:

“To be aware of any symptoms of cancer and stay away from any forms of tobacco.” She also emphasized that “The government should strictly monitor the rules on import and use of tobacco products in Nepal.”

Case Study 6: Mr. Shailesh Tamrakar (63), lung cancer patient

Mr. Shailesh Tamrakar⁴⁴ (original name changed), 63, is a retired professor living with lung cancer in Kathmandu. He is well educated and belongs to prosperous family. He lives in a family with two children and his mother. He earns NPR. 40,000 (USD \$340) as a monthly pension from his previous institution. He sparingly smoked cigarettes during gatherings and parties as a social smoker, which would sometimes be zero sticks and sometimes reached up to 3-4 sticks per day for almost 32 years.

Though only a social smoker, in 2017 Mr. Tamrakar was diagnosed with stage 3 lung cancer that required oral chemotherapy. The symptoms of cancer began when he started experiencing distress in his stomach. After 12 cycles of chemotherapy his cancerous lump size has decreased and now he is on oral medication and receives a bimonthly CT-scan test. The many cycles of chemotherapy he experienced made him exhausted physically, and he suffered from gastritis due to the oral chemotherapy. His cancer is not curable but only controllable, and the impacts of his illness on his working and social life have been severe. He has faced physical, mental and psychological struggles associated with cancer. He also faced significant economic costs associated with the treatment of his illness.



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⁴⁴<https://search.creativecommons.org/photos/1f5ce307-0262-4452-9360-243e723617ae>

Impacts of cancer on working life

Mr. Tamrakar was shattered to the ground when he learned his cancer was not treatable, but instead could only be controlled. He felt it was the end of his life as he knew it:

“I was not prepared to face the cancer when I learned about the confirmation of my cancer. I felt insecure about my family and children.”

Mr. Tamrakar had to take sick leave from work to receive his treatment, and he also had to retire a year before his actual retirement due to the cancer.

His working life has changed with the early retirement and his cancer: for example, he would have to take on projects with flexible deadlines since he is unable to work under pressure like before. Since his cancer he has therefore been less active in work than before, and has stopped visiting his project field sites and limited his work to indoors only. This has severely affected his life:

“After my retirement, I still keep on getting calls for a lot of consulting works but I have cut down workloads. I do not go to fields but give consulting support in report produced from the field instead. Like before, I am not able to give full time to consulting works, I only work in free time which takes a bit long time in finishing my task.”

Forced to make lifestyle and social changes

Along with the changes in his working life caused by his cancer, Mr. Tamrakar has also had to change his lifestyle, including his social life. After the diagnosis of cancer he chose a healthy lifestyle, quitting smoking and drinking along with changes in his food habits. He has shifted to healthy food habits with less spicy, oily and salty foods. Before his illness he was very social person and loved to hang out with friends and family, but cancer has lessened these activities and his involvement in the gatherings. He along with his family members have also experienced some psychological, social and mental stress following his cancer diagnosis. After learning about his cancer, Mr. Tamrakar's family and friends treated him as a very ill patient and would bid goodbye to him as if they were never going to meet him again. He shared:

“Before anyone was aware of my cancer, we used to have casual chit-chat and have fun but as they learned about my cancer, they preferred to meet me in my home and from their talks, I got a sense that they had a feeling that we might not meet each other and that this might even be our last meeting”

This stressed both him and his family members. Though arising out of concern, the repeated enquiries about his health condition, the invasion of his personal life and being treated as if his existence is very short caused him irritation and stress.

Finance diverted to the treatment

The diagnosis of cancer not only affected Mr. Tamrakar's working, personal and social lives, but it has impacted him financially as well. He had an enormous amount of cost for the diagnosis and treatment of his cancer which reached almost 18-20 lakhs (USD \$15,300-17,000). To diagnose and confirm his cancer, Mr. Tamrakar had lots of expenditure on different tests and then after confirmation through the tests he started oral chemotherapy at Nepal Cancer Hospital and Research Centre. With hope of better treatment, he also visited three different hospitals in India which incurred further costs.

As treatment progressed, his costs continued: CT scans conducted every 3 months to check the decreasing size of the lump were costly, and two years later his costs continued to rise as he had to

undergo oral chemotherapy because the lump was increasing again. He then shifted to chemotherapy and has completed 12 cycles of chemotherapy to minimize the size of lump in lungs – again, this has demanded a big sum of money. At present and over three years since his diagnosis he is still spending on his treatment - on oral medicines and CT scans every two months to keep track of the size of lump in his lungs.

Mr. Tamrakar emphasized that the costs incurred for treating his cancer could have been invested in other more beneficial works if he did not have cancer.

He says *“The treatment of cancer is an additional expense in my life. In other way, I feel like my expenses for drinking and smoking has been shifted to my cancer treatment. Had I been healthy I could have spent those expenditure for travel and tour around the world.”*

Being a sufferer of cancer due to tobacco use, Mr. Tamrakar has a strong message to convey to others:

“I would like to give the first message to all the people out there is to avoid the nicotine and tobacco products completely as using such products do not give any advantage and only cause health problems.”

Case Study 7: Mr. Rajan Devkota (64), throat cancer survivor

Mr. Rajan Devkota⁴⁵ (original name changed), 64 is a throat cancer survivor. He is currently residing in, Kathmandu. He is involved in a business of electrical vehicles and is also an active social worker. He was a previous ward chair of Kathmandu living in nuclear family with sole monthly income of around NPR. 50,000 (USD \$425).



This is a stock photo for illustration purposes only

Mr. Devkota has a history of using smoked tobacco, smoking cigarettes 6-8 times in a day for 30-35 years. He quit the habit after his diagnosis of cancer. Although he survived cancer, Mr. Devkota has experienced a decreased quality of life after his cancer treatment, and the treatment itself had significant physical impacts: as a result of his cancer his voice has been distorted to such an extent that it has affected his political career. Furthermore, he also suffered huge economic loss due to the cost of treatment.

The mental and physical impacts of cancer treatment

Mr. Devkota was diagnosed with cancer in 2010 when he was 54 years. He suffered physical distress due to his chemotherapy and radiotherapy and, despite his strong character, he was scared during his treatment:

“I was scared when the results of chemotherapy and radiotherapy appeared.”

⁴⁵<https://www.flickr.com/photos/147139101@N07/27831007318>

His treatment has also left him with a distorted voice, due to radiation therapy. This has negatively affected his political career: being a politician he was fond of public speaking and used to give speeches in different talk programs, but various cycles of radiation therapy made him physically weak for few months and his voice also changed. Even today his throat keeps drying and his food pipes become congested, so he has had to alter his lifestyle to adopt healthier habits, including taking care of his throat with warm water, eating warm food with less spices and doing more physical activities.

It was not only Mr. Devkota who suffered as a result of his cancer: his wife also felt negative impacts on her working career when she had to take long leave to treat Mr. Devkota. And Mr. Devkota has also faced stigmatization: he finds the repeated question from his well-wishers inquiring about his state annoying and he does not want to replay his memories of cancer and wants the well-wishers instead to perceive him as a healthy person. This shows existing social stigma in our society towards cancer survivors.

Significant financial impact due to costs of cancer treatment

During the cancer treatment, Mr. Devkota had huge economic costs to bear. He had approximately spent NPR. 20,00,000 to 25,00,000 (USD \$17,000–21,300) since his diagnosis along with treatment and follow ups including travel, food and accommodation of his and his family member who accompanied him. For Mr. Devkota, this amount was manageable by himself with his earned money – Mr. Devkota was a business person, had a house to rent, and a working wife, so the cost of cancer treatment was more easily managed by him without any stress to borrow loans or sale properties. However, the cost of his treatment is a huge amount for a normal income family in Nepal, and it may take a whole lifetime to earn this much. This shows that the financial impact of treatment costs can be catastrophic for those on lower incomes than Mr. Devkota.

Mr. Devkota's story is a lesson for lots of tobacco users who are certainly not willing to go through same. And although Mr. Devkota surely is an inspiration for present cancer patients to conquer the disease, he emphasized:

“Cancer not only takes away your money and time but also the life.”

Conclusion

Tobacco use is an increasing public health problem in Nepal. Various studies, including NDRI's study, have shown that the prevalence of tobacco use is high and is increasing among new generation youths therefore demanding strong political and social efforts to curb the problem. It is well known that tobacco use is harmful for human health and is associated with significant economic costs, both for the wider economy and for the individuals (and their families) who are affected by tobacco-related illnesses. Tobacco-related illness can also have significant impacts on the mental health of sufferers, and can cause social stigmas and force other lifestyle changes amongst the sufferer and their family. Cancer in particular can exert tremendous physical, emotional, and financial strain on individuals and families. The stories of cancer patients and survivors set out in this report provide further evidence on how strong the negative impacts of tobacco-related illnesses, particularly cancer, can be. Therefore, to help address this the reduction of tobacco consumption through raised taxes should be a priority program for the Government of Nepal.

To find out more, please read NDRI's upcoming policy briefs on:

- ☑ **"Enforcement of Tobacco Policy Implementation in Nepal"**
- ☑ **"Tobacco Control: Comparative Experiences of India and Nepal"**
- ☑ **"Understanding Economic Costs of Tobacco Use in Nepal"**
- ☑ **"Smokeless Tobacco vs Smoked Tobacco: Possibilities of Substitution"**

Please also see the accompanying literature review produced by NDRI:
"Impacts of Tobacco Use in Nepal: Literature Review".

Further information about NDRI's Tobacco Control Program can be found online at:
<http://www.ndri.org.np/tobacco-control-program/>



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