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AN ANALYSIS OF SOCIO-ECONOMIC CONSEQUENCES OF CANCER IN NEPAL

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AN ANALYSIS OF SOCIO-ECONOMIC CONSEQUENCES OF CANCER IN NEPAL

by

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DISSERTATION

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Dedication

To my parents Sushanta Roy Chowdhury and Ranju Roy Chowdhury who have always shown immense faith in me and in all my independent decisions of life ...

Acknowledgement

My utmost appreciation goes to my dissertation committee chair, Professor Alok K. Bohara. Not only in the process of dissertation, but his guidance throughout my Ph.D., years had immensely helped me in exploring my capabilities. Thank you for the faith that you have shown in my abilities. Thank you for the exposure that you gave me through various research initiatives of Nepal Study Center. I deeply appreciate all your help.

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I would like to thank Dr. Dipesh Tamrakar of Katmandu University for providing the logistical support throughout the survey. Special mention should go to the enumerators who spent months in hospitals communicating with the patients. But most importantly, I owe my study to all the patients who responded to the survey even being in such a critical phase of their life.

I came to Albuquerque knowing no one, but as I leave, I see so many of my friends wishing me luck. I thank you for all the amazing trips and get together we did. You helped me find a balance in my professional and personal life.

Finally, I rest tremendous faith in Almighty. I thank God everyday for making me capable enough to go through uncertain situations with strength and dignity. To my parents and sister, I always wanted to make you proud knowing that irrespective of success or failure, you do accept me as is. I know that you are way more excited than me in my success and way calmer in my failures. Same goes with my in-laws who are always praying for my betterment. My best friend also my husband, Deepak Singhania is the biggest source of strength and sadly enough has always been at the receiving end when my academic days are not going great. My deepest apologies for that. I owe to each and every one of you for being by my side in all my decisions.

An Analysis of Socio-Economic Consequences of Cancer In Nepal

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Abstract

This dissertation investigates the socio-economic burden of cancer patients using a primary survey in Nepal. Given the low uptake rate of cancer screening facilities in developing countries, my study covers three important issues: the need of information dissemination on cancer prevention among asymptomatic individuals, the emotional stress of cancer patients in relation to a control group of patients, and the severity of economic burden due to premature cancer related deaths measured at the national and individual levels. In developing countries with low level of information and awareness, it is difficult to communicate the importance of cancer preventative measures to the healthy population. It is only those who have a deeper understanding of the state of world and of the extent of disease adversities can truly value a cancer preventative program.

With this background, Chapter 2 studies the retrospective preference of cancer patients in valuing an annual comprehensive cancer screening program. Conventional contingent valuation models and a structural equation modeling framework under mediation analysis not only determines how current health status affect preferences, but also unravel mediating linkages between different psychosocial factors of patients. For example, patients' perceived chances of cancer re-occurrence may lead them to prefer screening services, but it can also leave an opposing effect on screening preferences through higher pessimism among patients. The second chapter is a case-control comparison of mental burden. I extended the mental health literature by studying the differential impact of gender and cancer sites on patients' experience of emotional stress. Using propensity score matching methods, binary, and multivalued treatment effect weighting strategies, I found that cervical cancer is not only the most prevalent cancer in Nepal, but they also face the highest mental burden pointing to dysfunctional familial relationships. The objective of my third chapter is to highlight the magnitude of economic burden that low resource-setting countries face due to cancer. Mortality cost measured in the number of life years lost and the amount of productivity loss constitute the highest proportion of economic burden. Understanding the severity is important to provide insight into the need of a cancer control policy in the country.

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Chapter 1
Introduction

The global burden of diseases is slowly shifting from infectious to chronic diseases. According to the World Health Organization (WHO), chronic conditions such as heart disease and stroke, cancer, respiratory diseases, diabetes, visual, and hearing impairment are becoming the leading causes of death worldwide especially in low and middle income countries (Gross, 2012). It implies that over the next 20 years, mortality from communicable conditions such neonatal, diarrhea, and malaria will be replaced by global epidemic of chronic diseases. It is therefore important to address this epidemic with prevention and control approaches. The dissertation conducts analyses to highlight the socio-economic burden of one such chronic disease 'cancer' in a developing country, Nepal. It highlights the magnitude of financial and non-financial loss of cancer on an individual and national level. The study advocates the uptake of cancer screening facilities to asymptomatic individuals which can help mitigate the amount of loss associated with cancer diagnosis.

1.1 Prevalence of cancer in developing countries

The global burden of cancer is increasing at an alarming rate. The American Cancer Society (ACS) reports that cancer accounts for one in every seven deaths worldwide. The figure is higher than HIV/AIDS, tuberculosis, and malaria combined. The burden is expected to increase further in future to the point that by 2030, we can see 21.7 million new cancer cases and 13 million cancer deaths worldwide (Torre et al., 2015). Cancer mortality is sharply shifting towards the middle and low income countries. In 2008, of the worldwide 7.6 millions cancer deaths, developing economies accounted for 63% of the total deaths which thereafter increased to 65% in 2012. The value is expected to be 85% by 2030, where simultaneously developed countries are going to see a 30% reduction in cancer related deaths in future. However, population based study and epidemiological surveys on cancer patients are mostly available for developed countries (Coleman et al., 2008; Henson and Tarone, 1977; Collin et al., 2008; De Angelis et al., 2014; Coleman et al., 2011; Rahib et al., 2014). The share of literature on cancer is only growing in the middle and low income countries (Horton and Gauvreau, 2015; Sankaranarayanan et al., 2010; Abegunde et al., 2007). With exception to some national and international surveys (Dikshit et al., 2012; Torre et al., 2015; Fitzmaurice et al., 2017), research on cancer in the developing economies is primarily focused on increasing the awareness, uptake, and cost effectiveness of cancer preventative measures (Saha et al., 2010; Goldie et al., 2005; Okobia et al., 2006; Joy et al., 2011; Kim et al., 2008; Levin et al., 2010). The unavailability and lack of information therefore remain as a constraint to understanding the severity of cancer. There are no preventative programs in place (Binu et al., 2007) or national level cancer database to analyze the accessibility, barriers, treatment procedures, and sufferings of a patient. Most of the South Asian countries such as Maldives, Nepal, Afghanistan, and Bangladesh do not have any cancer registry system; available information is limited to selected hospital level facts and figures (Dikshit et al., 2012; Poudel et al., 2016; Carr et al., 2001).

1.1.1 Cancer Status in Nepal

A standard method of cross country comparability of World Health Organization (WHO) revealed that chronic diseases had accounted for 42% of all deaths in Nepal, and 7% of which was related to cancer alone (Piya and Acharya, 2012). In 2008, the International Agency for Research on Cancer (IARC) estimates a total of 27,800 newly diagnosed cancer cases and 20,000 cancer deaths in the country. By compiling hospital level information across seven cancer hospitals of Nepal, Poudel et al. (2016) found that the magnitude and trends of cancer cases has overwhelmingly increased over the last 10 years.[1] The crude incidence rates for males increased from 12.75 in 2003 to 25.27 in 2012, the rates are even higher for females, 15.09 in 2003 and 28.06 per 100,000 in 2012. Similarly, the age standardized cancer rates (ASR) increased from 20.47 (17.33) in 2003 to 33.97 (30.16) per 100,000 in 2012 for females (males). Lung cancer followed by oral cavity among males and cervical and breast cancer among females remained the most prevalent cancer types (Pradhananga et al., 2009). The increasing incidence of lung cancer can be traced back to higher smoking and tobacco consumption, household air pollution, poor quality of health education, and socio-economic conditions of the patients (Binu et al., 2010; Hashibe et al., 2010; Raspanti et al., 2016). On the other hand, lack of information on Human papillomavirus (HPV), scarce screening resources, and poor uptake of screening (Pap test) are associated with increase in cervical cancer incidences in Nepal (Johnson et al., 2015; Ranabhat et al., 2014; Ranjit et al., 2016). Increase mortality from cervical cancer is unwarranted

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[1] The hospitals are B.P Koirala Memorial, Bhaktapur cancer hospital, Bir hospital, TU teaching hospital, Kanti children hospital, BP Koirala institute of health science, and Manipal teaching hospital

because screening can easily identify the precancerous lesions preventing the potential progression to cervical carcinoma (Mishra et al., 2011). But, on the contrary, Nepali women never undergo screening and are most often diagnosed at a very late stage of the disease (Ranjit et al., 2016).

1.1.2 Types of Interventions for Cancer Control

The World Health Organization has devised national strategies to be adopted by the countries to fight against cancer (Brown ML, 2006; WHO, 2002). The four broad intervention measures include:

> Primary Prevention: This involves reducing the exposure to cancer causing factors through immunization, tobacco control, reduction of alcohol consumption, and changing lifestyle and habits related to nutrition and physical activity.
>
> Secondary Prevention and Early Detection: This involves detecting the disease at a treatable stage. There are two types of interventions that allow secondary prevention: (a) Early diagnosis, when patients are made aware of signs and symptoms of cancer leading to consultation and (b) participating in national or regional cancer screening programs to detect abnormal growth in tissues or pre-cancerous lesions.
>
> Diagnosis and treatment: There is a greater emphasis on having cancer specialized centers with accessibility to treatment facilities such as surgery, chemotherapy, and radiotherapy. Treatment procedures aimed at curing the disease and improving the quality of life of patients post diagnosis with cancer.

Palliative care: This encompasses the quality of life and psychological aspects of cancer patients as well as their family caregivers. Palliative care are extended to patients who are at their advanced stages of disease and have low chances of being cured. This is also for those who are unable and unwilling to undergo specialized treatment facilities.

Of the above described four different types of cancer control interventions, in my dissertation, I focus on ways to promoting the 'Secondary Prevention and Early Detection' of cancer through dissemination of cancer screening information.

1.2 Research design and data

Seven hospitals located in the southern and central region of Nepal cater to most cancer patients of the country (Pradhananga et al., 2009; Bhatt et al., 2009; Subedi and Sharma, 2012). Understanding the importance and inflow of patients to these hospitals, I surveyed five of them namely Bir Hospital, Birendra Military Hospital, Bhaktapur cancer hospital, Dhulikhel hospital, and B.P Koirala Memorial hospital. I interviewed 600 cancer patients using random sampling techniques.[2] In deciding the sample size, I based our estimates following the GLOBOCAN Data of International Agency of Cancer Research. In 2012, there were approximately 20,000 incidences of cancer been reported in Nepal. Using this figure as the cancer population with 95% confidence interval and allowing for 4% margin of error, the total sample size recom-

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[2] Randomization was done in two stages, first in randomly selecting the patients from the hospitals and second in randomly assigning the willingness to pay bid amounts which will be discussed in Chapter 2.

mended was 583. Also, as common in a face to face survey, most of the individuals who were asked to participate in the study did participate which gave us a response rate as high as 97%. Adult patients of more than 18 years of age under specialized cancer treatments were included in the survey. Based on our consultations with doctors and nurses, patients who were critically ill and were not deemed mentally capable of being interviewed were excluded from the survey. I also interviewed 200 adult control group of inpatients who were suffering from different chronic health conditions but had no prior history of cancer.[3] All the patients interviewed had provided their participation consent under the ethical guidelines of the Institutional Review Board requirements of the University of New Mexico, USA as well as the National Health Research Council, Nepal. The five different hospitals and their location in the central developmental region of the country are shown in Figure 1.1.

[Figure 1.1 here]

Figure 1.2 plots the residential address of our sampled cancer patients by different types of cancer. The most prevalent ones among males are Lung cancer (18%) and Stomach cancer (15%), whereas for female it is Breast cancer (28%) and Cervical cancer (18%). The estimates corroborate that of the other hospital specific and Global Burden of disease study for Nepal (Fitzmaurice et al., 2017; Poudel et al., 2005; Pradhananga et al., 2009). Owing to the fact that most of the hospitals are situated in the central region, I find a significant clustering of cancer incidences in the Kathmandu municipality followed by Lalitpur and Bhaktapur municipalities. The

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[3] There were some patients with acute to chronic conditions.

spatial concentration of cancer incidences are statistically tested using the Getis-Ord Gi* tool under the ArcGIS. The Getis-Ord Gi* tool is used to identify significant hot spots or clustering of cancer cases in the country.

[Figure 1.2 here]

Cancer patients selected for the study represents that of the general population on their socio-demographic characteristics. Majority of our sample reported their monthly income as NPR 10,000 or less ($100). This when compared to the National Living Standard Survey (NLSS), 2011 data shows that the mean and median household income is NPR 16,000 ($160) and NPR 10,606 ($106) respectively. Also, when compared against the Demographic Health Surveys (DHS), 2011 data, I find patients with no education or incomplete primary education comprises of 59% of our sample versus 62% in DHS 2011, also the highest educational attainment beyond Class 10 and above is 20% (in sample) versus 13% (in DHS, 2011). The mean age of our sampled patients however is significantly higher (52.37 years versus 26.25 years). This is expected given the occurrence and diagnosis of cancer usually happen at later years of one's life. Finally, when compared against DHS, 2011, our sample reflects a higher percentage of Brahmins (24.75% versus 15.4%) and Dalit (16% versus 13.8%) population.[4]

In this section, I provide descriptive on perceptions and beliefs of cancer patients on different causes of cancer. Patients identified smoking as the primary cause of

---

[4] Brahmins belong to the most advantaged class of the society in Nepal, whereas Dalits are the most disadvantaged section of the society. Also NLSS and DHS are nationally representative secondary data sources of Nepal.

the disease (22.7%) followed by ‘Unknown’ factors (15.1%). It is also interesting to note that 9% of the patients consider cancer as punishment of their wrong doings. To them, cancer caused because of the sins they have committed in life indicating unawareness on the disease. A majority of the patients also believe that awareness on cancer is very low (51.1%) and there is indeed a higher stigma associated with having cancer (60%).

1.2.1 Cancer patients versus control groups

The socio-economic consequences of any disease is measured in terms of the financial and non-financial burden faced by the patients. Financial burden includes direct treatment cost and indirect cost through loss of employment after diagnosis. The monthly average treatment expense for one cancer patient is NPR 97,571, which is significantly higher than NPR 38,356 of the control group ($p< 0.000$). Indirect burden caused by loss of employment due to disease disability is also higher among cancer patients ($26\% > 13\%$, $p< 0.0001$). The magnitude of economic burden increases under lack of safety nets when financing treatment involve borrowing or selling off properties. Majority of the cancer patients (51%, $p < 0.000$) have resorted to these aggressive means of financing treatment. Not only them, but a higher percentage of control patients have also suffered financial hardships due to inadequate health insurance coverage [Figure 1.3].

[Figure 1.3 here]

Non-financial burden measures mental, emotional, and family related stress that patients face. I compared the distribution of mental burden across the two groups of patients through a non-parametric Kolmogorov-Smirnov test as shown in Figure 1.4. The distribution of burden faced by cancer patients stochastically dominates the distribution of the control group. Also, the Mann-Whitney test comparing the median of the two distributions yields similar findings.

[Figure 1.4 here]

The financial and non-financial burden can be mitigated if proper cancer preventative measures are introduced in the country. Routine screenings are preventative measures which help detect any abnormalities in the growth of tissues likely to be carcinogenic. Early diagnosis not only enhances their survival chances, but can also save patients from adversities post diagnosis. In order to uptake any prevention strategy such as cancer screening tests, individuals need to be aware of the availability of screening and the benefits that screening can bring in. But, as in case with most of the developing economies, individuals in general are not aware of the cancer screening facilities. The state of knowledge is low in both the cancer and control groups of individuals. However, with diagnosis, cancer patients reflect a relatively better understanding of state of the world and of the available cancer preventative measures shown in Figure 1.5. Also only 1% (n=2) control patients said that they had screened before for cancer whereas 17% of cancer patients recollect screening during their course of diagnosis.

[Figure 1.5 here]

1.3 Description of the chapters

A number of coexisting factors in the developing countries including the growing burden of cancer, the low level of information on cancer prevention, low uptake of cancer screening facilities, existing poverty, and inaccessibility of specialized treatment facilities contribute towards inadequate cancer management in these countries. But it is important that we start acknowledging the growing epidemic of cancer so that comprehensive and integrated approaches can be developed to fight against it. Dissemination of information on cancer among the yet healthy individuals is one step towards cancer management.

Significant research points to the fact that a timely screening can detect cancer early or sometimes it can also prevent the abnormal growth of cell tissues before it become carcinogenic. International organizations such as American Cancer Society, National Cancer Institute (NCI), and country specific cancer research organizations have screening guidelines advising people on specific tests, the age at which screening should start, and the frequency at which individuals should be tested. Despite of these recommendations and significant evidences that screening reduces cancer mortality, the uptake rate of screening in the developing countries remains inadequate. This brings up the question as to why individuals are agreeing to face the risk of a health shock if there is a way to identify and mitigate the effects of shock? Whether they understand the financial and emotional distress following a cancer diagnosis? What is the existing state of knowledge on cancer among the general individuals? Whether they are aware of some available prevention mechanisms? If not, how do we inform them about the benefits of cancer screening facilities?

The present research motivated by these puzzles goes beyond the existing state of literature to find out an appropriate way of disseminating these information to the yet healthy individuals. I argue that if the healthy individuals are told about the experiences of the current cancer patients, the extent of their adversities, and their revelation on what they should have done differently, they may consider this a viable source of information. In Chapter 2, I focus on gathering information on cancer screening preferences. Specifically, through a primary survey, I asked the diagnosed cancer patients their retrospective preference of an annual comprehensive cancer screening program in Nepal. The policy goal is to use their stated preferences to inform the asymptomatic individuals about better health choices.

The retrospective preference is studied using the contingent valuation estimation techniques under several econometric applications. Traditional WTP methodologies and structural equation modeling framework is used to analyze how the current state of an individual's health shape their preferences. First, using conventional models of contingent valuation such as interval regression, probit, and Lopez- Feldman model, I studied the individual factors determining a patient's willingness to pay (WTP) for screening. I built on these conventional models to allow for inter-linkages between different psychological factors affecting preferences. For example, more information on screening may lead them to prefer the same, as well as, can make them optimistic about their future. This multidirectional network is analyzed through structural equations modeling framework (SEM). The conventional models showed evidences that individuals who evaluate their survival chances to be higher or rate their health better are more encouraging of the proposed intervention. Pessimism and aggressive means of financing treatment decreases whereas information and risk of cancer re-occurrence increases the likelihood of paying for the annual cancer screening program. In addition to confirming to the above stated results, under SEM, I find evidences of mediation between variables. For example, risk of cancer re-occurrence can directly and positively influence screening, but can also indirectly impact WTP through a higher pessimism. Whereas, Optimism can indirectly impact WTP through a higher perceived chances of survival.

For individuals to undertake preventative measures, they need to believe that the disease has a reasonable impact in their life. In the following Chapter 3 and Chapter 4, I study the emotional stress called 'Mental Burden' and financial stress 'Economic Burden' of cancer patients. Physical pain and side effects of treatment, family level distress, survival risks and uncertainty, stigma of having cancer, and loss of self-esteem might contribute to growing anxiety and depression among patients. In Chapter 3, I measure this holistic lack of well-being of cancer patients with reference to the control group. Also, I hypothesize that emotional stress can vary within cancer patients. This is specially when some cancers have side-effects not limited to physical disabilities. I used the propensity score matching methods and treatment effect weighting strategies to find that the risk of experiencing mental burden is twice as higher in cancer patients than in the control group. The likelihood of burden further increases with a lack of familial support and higher medical expenditure. This study extended the literature to examine if localization of cancer leaves a differential impact to different types of cancer patients. Multivalued treatment effect estimators reveal that cervical cancer patients undergo significantly higher mental burden when compared against all other female cancer patients, male cancer patients, and control patients respectively. This brings up the question as to what is specific about cervical cancer that separates it from all other types of cancer. In the absence of household data in our survey, I fall back to the literature to find that cervical cancer patients are more prone to facing domestic consequences and vice-versa. Also, treatment of cervical cancer can affect the fertility and intimate relationship among couples in a marital relationship leading to more psychological stress.

Following the earlier chapter, where I calculated the non-financial burden, in Chapter 4, I present national and individual level estimates of cancer-related economic burden. Any premature death is a public health concern where societal loss gets magnified if deaths happens at earlier ages. Hence, economic burden is not only the excessive treatment expenses of cancer, but for a country, it is the the number of life years lost (YLL) and the amount of productivity loss (YPLL) following a premature cancer related death. On a national scale, to measure productivity loss, I used the GLOBOCAN 2012, IARC data on cancer related age and sex specific mortality figures of Nepal. Using the national averages of income, unemployment rate, and expected future growth rate, I found that premature cancer deaths can yield to \$149 million and \$121 million loss in productivity for males and females respectively in

2012; the amount varies by different types of cancer. In the second half of the paper, I used my survey data to measure the foregone wages and excessive treatment expenses borne by a cancer patient compared to the control group. I found that control patients are less likely to quit their job because of the disease disability which means that cancer patients forego a significant amount of wage income and simultaneously borne a higher treatment expenses. Both the treatment and forgone wages impose a monthly burden of NPR 82,684 and NPR 68,731 to the cancer patients. This chapter projects the severity of the problem to policymakers. Understanding the magnitude of monetary loss will justify the introduction of a national cancer control policy in Nepal.

Finally, in the concluding chapter (Chapter 5), I have tried to build a narrative by providing a summary of findings from different chapters. Also I have highlighted the directions to future research. Two additional phases of cancer research is underway in Nepal which will not only extend the current study but will also explore additional research interests.

1.4 Contributions of my dissertation

My dissertation fills in the gap of literature by providing a comprehensive survey of cancer patients. Not only in the context of Nepal, but it serves to understand cancer adversities in middle and low income countries. To the best of my knowledge, this is a first kind of study encompassing information on economic and emotional hardships of cancer patients in developing countries. Further, a comparative analysis from a group of control patients have situated the results in context.

The retrospective preferences of cancer patients is consequential and can be a viable source of information to the policymakers. Patients with a deeper understanding of disease adversities have stated their preference for a cancer control measure which should be assessed as important. Also, the dissertation contributes to the awareness literature by providing the direct account of cancer patients as new source of information to the asymptomatic individuals.

Beyond adding value to the existing literature, my dissertation identifies promising areas of future research on cancer. Towards this, two additional grants have been approved by the American Cancer Society (the funding agency for the current project) to continue cancer research in Nepal. The second phase of the project will be a discrete choice experiment study on 'Quality of Life' following EuroQol living standard measures. Also, an in-depth association of cervical patients and familial dynamics will deconstruct the reasons behind certain types of cancer patients facing higher mental burden. Finally, the third phase of the project has been designed as a randomized controlled trial with informational intervention. Information generated from my study as well as specific screening guidelines will be introduced to the general population whose screening behaviours will then be tracked in future.

Figures and Tables

Figure 1.1: Location of cancer hospitals

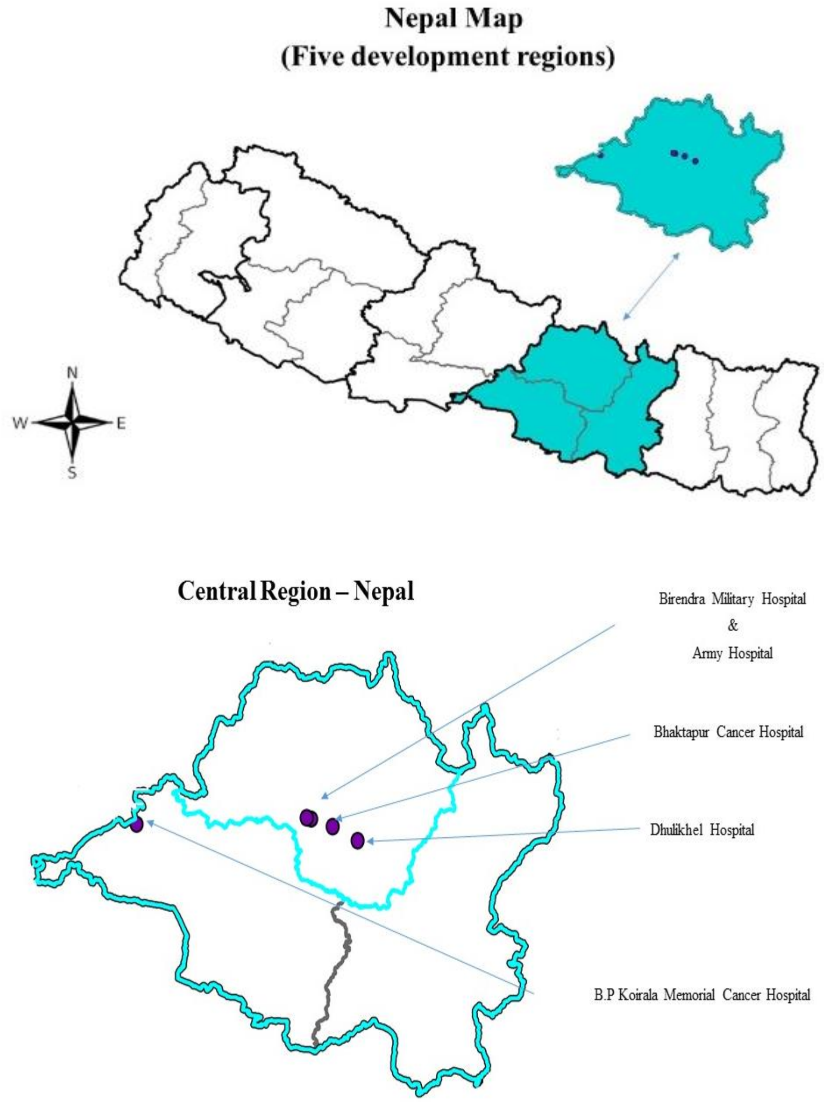


Figure 1.2: Clusters and Types of cancer in Nepal

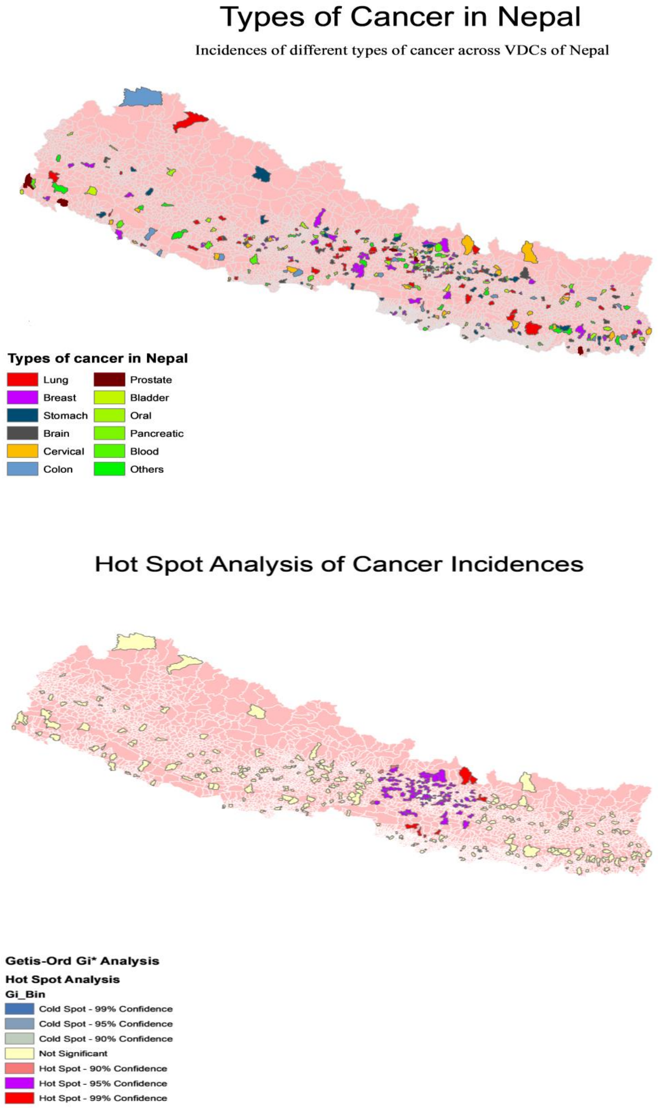


Figure 1.3: Different types of economic burden faced by patient
(Cancer vs Control groups)

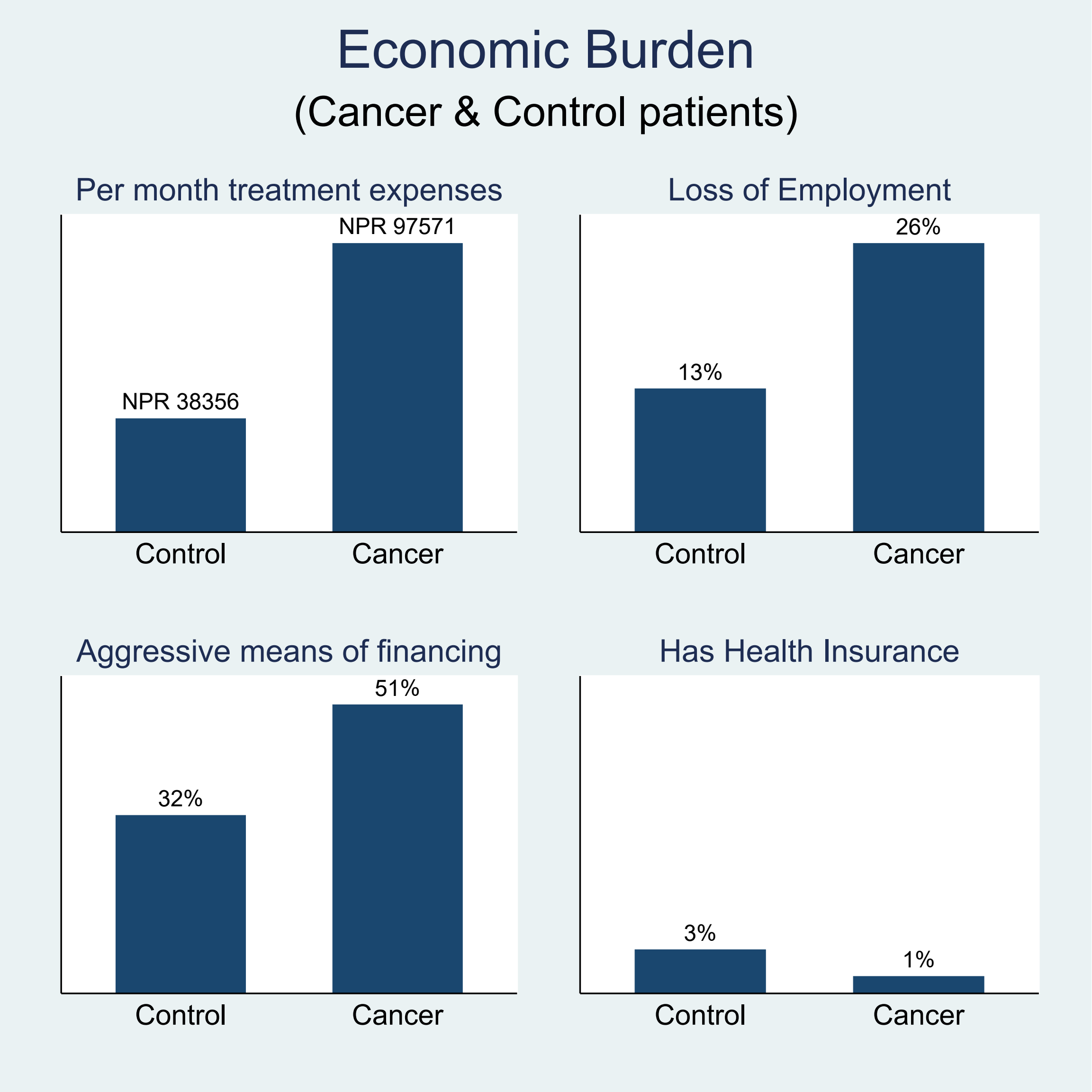


Figure 1.4: Distribution of mental burden by patients
(Cancer vs Control groups)

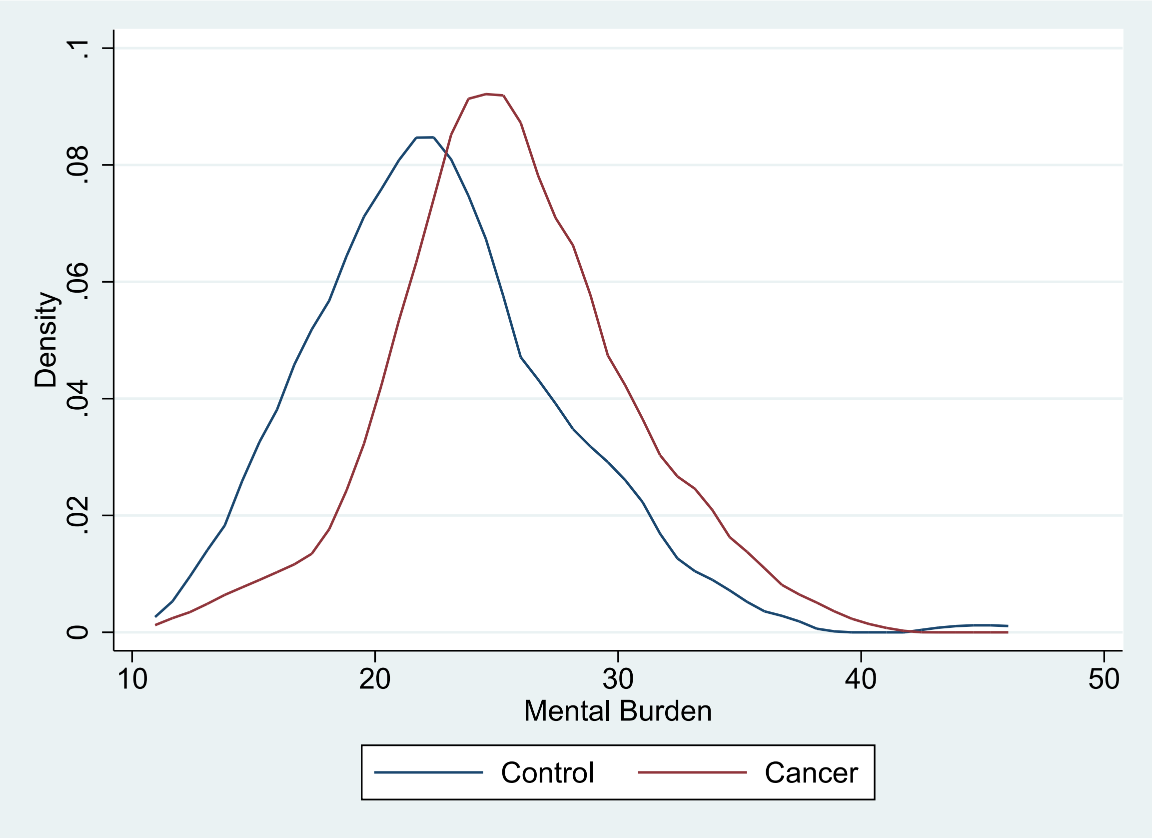
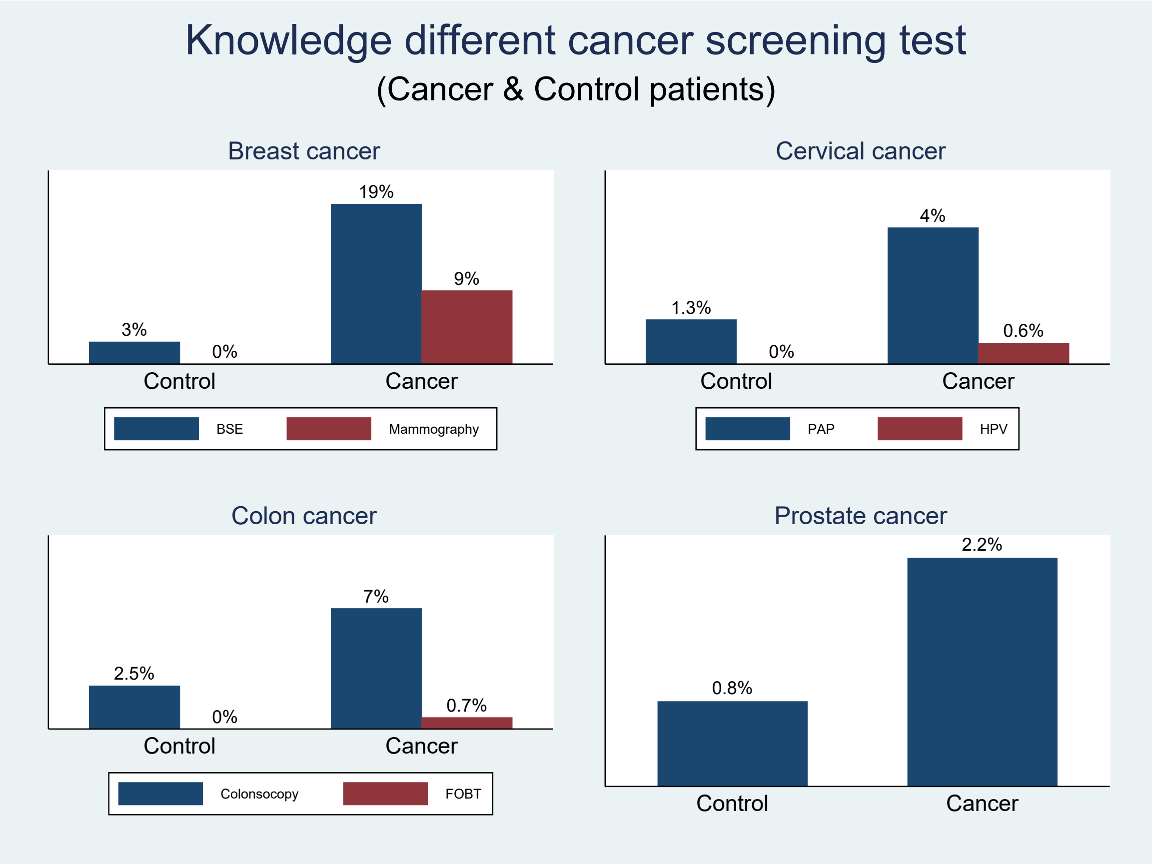


Figure 1.5: Knowledge of cancer screening tests
(Cancer vs Control groups)



Note: BSE- Breast Self Examination, PAP-Papanicolaou test, HPV -Human Papillomavirus (HPV) test

Chapter 2

It's better to learn than to suffer! Cancer patients' preferences as a guide to cancer prevention

2.1 Introduction

Non-communicable diseases comprising mainly of cardiovascular, cancer, diabetes, and chronic lung disease constitute almost two-thirds of all deaths that occur globally. According to the World Health Organization, 80% of these deaths take place in low and middle income countries (WHO, 2011). Cancer is recognized as one of the five chronic diseases which has emerged as a global epidemic and is a leading cause of death worldwide. The International Agency for Research on Cancer through their GLOBOCAN project reports worldwide incidences and mortality rates of cancer in 2008 and 2012. In 2008, cancer accounted for 7.6 million or 13% of the total deaths. The mortality is higher than worldwide HIV/AIDS, malaria, and tuberculosis deaths combined (WHO, 2006; Gross, 2012). According to the estimates of the American Cancer Society, the figures are expected to grow to 21.7 million incidences and 13 million cancer deaths by 2030 (Torre et al., 2015).

Cancer being a health shock implies that the low resource setting countries will experience significant amount of financial and non-financial burden in the next decade. But the lack of information and unavailability of population based cancer registry system in these countries put a constraint in understanding the magnitude and severity of the problem (Torre et al., 2015; Varughese and Richman, 2010). It also constrains the formulation of any cancer control management program in those countries (Hanna and Kangolle, 2010).

One of the primary predictors of mortality from cancer is a late stage diagnosis of the disease (Ortiz-Ortiz et al., 2016; Pruitt et al., 2013; Allgar and Neal, 2005; Macleod et al., 2009; Baldwin and Callister, 2016; Gynewali et al., 2014; Handayani et al., 2016). The prognosis of tumors leading to cancer is so slow that individuals are unlikely to feel any symptoms until the disease reaches their advanced stage (Frew et al., 2001). Late detection of cancer increases patient management expenses and decreases their chances of survival. Consequently, the introduction of preventative measures aimed at detecting the abnormalities in cell growth before tumors become carcinogenic has become crucial. Significant clinical evidences demonstrates the effectiveness of cancer screening test both in developed (Baldwin and Callister, 2016; Saslow et al., 2002; Zavertnik et al., 1992) and developing countries (Lee et al., 2017; Rohner et al., 2017; Sankaranarayanan et al., 2007; Tebeu et al., 2015).

Patients in developing countries undergo diagnostic testing once they are identified with disease symptoms. Diagnostic tests referred to as opportunistic screening occurs under doctor's recommendation (Campos et al., 2017). However, routine screenings are voluntary measures taken irrespective of medical conditions, i.e., when an individual is free of disease symptoms. The obvious concern is however the low uptake of screening in the developing countries (Chidyaonga-Maseko et al., 2015; Dhendup and Tshering, 2014; Idowu et al., 2016; Shrestha, 2017). Numerous demand and supply side factors influence the poor utilization of screening. On the demand side, screening expenses (Cazap et al., 2016; LeMasters and Sambamoorthi, 2011; Miller and Champion, 1997; Stein et al., 1992; Trivedi et al., 2008), lack of information and awareness (Abiodun et al., 2014; Ndikom and Ofi, 2012; Sudenga et al., 2013), inability to perceive the benefits of preventative measures (Al-Dubai et al., 2013; Baskaran et al., 2013), and socio-demographic characteristics (Al-Dubai et al., 2013; Baskaran et al., 2013) deter an individual from undergoing screening. On the other hand, inadequate resources in the health industry (Li and Shao, 2015) including insufficient health workers (Aluttis et al., 2014; Willis-Shattuck et al., 2008), and poor organizational structure of hospitals (Kotilainen, 2001) are supply side constraints. Especially in emerging economies, reduced access to basic health needs (Jacobs et al., 2012; Strasser, 2003) coupled with lack of health insurance coverage (Mills, 2014; Mishra et al., 2015) make the provision and uptake of preventative services even more difficult.

As the case with most of the developing countries, Nepal also does not have a national cancer registry system to track patients. Most of the available information on cancer come from hospital level case studies with only limited demographic information on patients (Bhatt et al., 2009; Binu et al., 2007; Bohara and Roy Chowdhury, 2016; Chataut et al., 2015; Piya and Acharya, 2012; Pradhananga et al., 2009). A standard method of cross country comparability of World Health Organization (WHO) revealed that chronic diseases had accounted for 42% of all the deaths in

Nepal, and 7% of which was related to cancer (Piya and Acharya, 2012). In 2012 alone, the estimated incidences of cancer in Nepal is 20,000 and the total number of deaths recorded is approximately 15,000 (Ferlay et al., 2014). Information collected from seven cancer hospitals have shown that cancer incidences in Nepal is overwhelmingly increasing over the last 10 years (Poudel et al., 2005). Uniformly over every year, it is the lung and oral cancer among males, whereas cervix uteri and breast cancer among females which are reported as the most prevalent ones in the country (Pradhananga et al., 2009).

This ever-increasing trend of cancer incidences in countries like Nepal is going to impose a significant financial and non-financial burden to the society. This calls for a strategy where it is important that asymptomatic individuals understand the benefits associated with uptaking of a preventative screening program. Through this study, I propose an annual comprehensive cancer screening program where healthy individuals with no symptoms of the disease should also be encouraged to undergo screening. However, availing the services by general individuals or provisioning of screening facilities requires understanding of the relevance of the good. Individuals who have no information or awareness about the good or those who do not perceive the benefits of screening will not be able to understand the true importance of having such a preventative measure. It is only those who have a deeper understanding of the state of the world and of the extent of disease adversities can communicate the true value of a cancer preventative program (Haefeli et al., 2008). In order to value a good, it is important that the respondents perceive the consequentiality of the proposed intervention (Vossler and Watson, 2013). If a proposed intervention is relevant to the sample of study, then the respondents may be more serious while stating a value of the good. This is because they will perceive the survey as an opportunity to influence government's decision (Carson, 2012). Potential users who is not familiar or are uncertain of the derived benefits may not be able to understand the importance of screening in totality. With this background, my objective is to study the retrospective preference of cancer patients in valuing a preventative measure such as an annual comprehensive cancer screening program. Also, I studied if the current status of health of cancer patients influence their monetary importance of the good. Under this program individuals will have the facilities to screen for the most widespread cancer annually in the hospitals. The program will not only make the general individuals aware of available facilities but a direct account of cancer patients showing preference for screening will be instrumental in informing asymptomatic individuals about better health choices. Already been diagnosed with cancer, the respondents may not be able to reap the benefits of screening but they may influence the policy makers and help prevent the future generation from going through an equivalent level of suffering. Introduction of mass screening in the country is possible if individual hospitals initiate screening program within their annual scope of operations ensuring better cancer management of the country.

I took the help of contingent valuation (CV) techniques while studying their preferences (Diener et al., 1998; Frew et al., 2001; Klose, 1999). Using a double bounded willingness to pay (WTP) methodology, I obtained the quantitative estimates of a cancer patient's preference for cancer screening program. The empirical analysis is based on a psychological model called Health Belief Model (HBM) under the Sick Role Behavior (SRB) framework. HBM model attempts to predict and explain health behavior by focusing on the attitudes and beliefs of individuals. SRB framework is the application of HBM model with already diagnosed ill patients. The HBM is tested under several econometric techniques. First, using the conventional CV models such as interval regression, binary probit, and Lopez- Feldman model, I predicted the likelihood of individual variables in determining the preference for cancer screening. But individual variables may be correlated with each other and hence it is not easy to establish a direct causality of different aspects of human behavior with relation to their willingness to pay for the good. To be able to unravel some of the inter-linkages between variables, Structural Equation Modeling (SEM) is applied to the data.

2.2 Conceptual Framework

The Health Belief model (HBM) is a conceptual model used to predict an individual's decision to engage in or avoid a variety of health-related preventative actions (Becker, 1974; Chapman Lambert et al., 2017; Janz and Becker, 1984; Leavitt, 1979; Rosenstock, 1974; Stein et al., 1992; Strecher and Rosenstock, 1997). The origin of HBM was however on the grounds where individual actions towards preventing the occurrence of the disease is studied (Rosenstock, 1974). For an individual to take up any preventative health measures, he needs to believe that he is personally susceptible to the disease and it will at least have a moderate influence in his life. These models are called Preventive Health Behavior Models (PHB). But, Becker (1974) pointed out that the foundations of HBM can also be applied to Sick Role Behavior Models (SRB) framework, where patients are already diagnosed as ill or have already been contaminated to the disease. According to Rosenstock (1974), HBM is tested under both PHB and SBM forms of applications producing strikingly similar results (Chu et al., 2015; Janz and Becker, 1984; Leavitt, 1979; Mirotznik et al., 1995, 1998). The model was traditionally formulated based on four constructs: perceived seriousness, perceived susceptibility, perceived benefits, and perceived barriers towards undertaking a preventative services. Perceived seriousness is an individual's belief that the disease is going to bring in a moderate level of adversity in his life. If an individual believes that he is at a risk for a disease, he may likely be taking up measures to avoid the disease happening to him. But his actions will also be guided by the perceived benefits and barriers in adopting the new healthy behavior.

The sick role behavior models are modified version of traditional HBM to account for current health status of diagnosed patients. The SRB models comprise of variables including the patient's perceived beliefs in the accuracy of the proposed intervention, their perceived likelihood of re-occurrence of the disease, and their subjective feeling to the illness in general (Becker, 1974). These additional variables being added to the traditional model gives us a modified HBM. Further, my paper closely resembles that of (Bosompra et al., 2001, 2000), where mediating psychological variables are introduced influencing the preference of cancer screening test. I adopted a schematic representation of HBM model from (Bosompra et al., 2001) and present it in Figure

2.1. As we can see in the figure, HBM consists of three broad classes of variables such as: ‘Background variables’ which are the socio-demographic information of the patients affecting the ‘Mediating variables’ which in turn affect the ‘Behavioural variables’.

[Figure 2.1 here]

2.3 Data and Measures

Seven hospitals located in the southern and central region of Nepal cater to most of the cancer patients of the country (Pradhananga et al., 2009; Bhatt et al., 2009; Subedi and Sharma, 2012). Patients from five of these hospitals namely Bir Hospital, Birendra Military Hospital, Bhaktapur cancer hospital, Dhulikhel hospital, and B.P Koirala Memorial hospital were surveyed for the present study. The geographical location and spread of the hospitals are shown in Figure 2.2.[1]

[Figure 2.2 here]

At these hospitals, 600 adult cancer patients were surveyed. The cancer patients were randomly selected from the hospitals over a span of three months. Enumerators involved in data collection process visited the hospitals to track cancer patients (both inpatients and outpatients). The total number of patients selected for interview from each hospitals depend on the volume of new cancer patients that a hospital receives in

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[1] I also approached the Teaching hospital of Tribhuvan university for the study. However, all their cancer patients are referred to either Bir or Bhaktapur hospitals made it redundant to include it in the survey.

a cycle of treatment year.[2] Table 2.1 gives the number of patients from each hospital included in the present study.

[Table 2.1 here]

2.3.1 WTP elicitation

Respondents were asked to state if they were willing and able to pay a given amount in Nepali rupees per year (out-of-pocket) for a new cancer preventative program. The enumerators were trained to introduce a brief narration about the good and the factors patients should consider while making their decisions to pay. The narration started with a brief description of the disease itself highlighting the fact that in recent years, there has been a major increase in the number of cancer cases in Nepal. Cancer is a disease that develops from abnormal cell growth in a body. This abnormal growth does not happen overnight, it is a steady process, which develops over years. At the onset, an individual may not realize that any abnormality exists because symptoms of cancer develop after the cell growth has matured and has taken the shape of a tumor. However, with all the preventative measures in the health sector today, it is not difficult to track any abnormality in the growth of cells. This does not need a monthly tracking, but can be done on an annual basis. If any irregularities show up during the tracking period, they can be treated immediately before developing into cancer. Detection at initial stages can result in significant increase in survival rates of

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[2] B.P Koirala Memorial hospital is the first and biggest national cancer center in Nepal with an estimate of 5442 new cancer patients admitted for treatment in the year 2010. Patients in Bhaktapur and Bir hospitals significantly increased with 1387 and 686 new patients in Bhaktapur and Bir respectively in the same year.

patients. A hospital can initiate an annual comprehensive cancer screening program where individuals can get screened for the most widespread cancers. The study tries to analyze if cancer patients put a retrospective value on early screening facilities. They were also reminded that accessing these services would involve opportunity costs and benefits. On one hand, they may have to spend time and money to visit the hospitals, wait to be screened, take leave from work, manage domestic chores, or adjust their total monthly expenditures. On the other hand, they are valuing a good that may lead to a greater benefit to the society. If such a service is provided, it may help future generations with improved cancer detection, higher survival outcomes, and reduced amount of economic and mental burden. Given they are already diagnosed with cancer and are currently facing the perils of the disease, they are in a better position to understand what a preventative measure can do. The stated value will indicate the importance they place on having such a program prior diagnosis. Their perspective on the good will then be used to inform the asymptomatic individuals about the importance of screening and the need for it. Specifically the script says that: Individuals will need to pay each time they take a cancer screening test in addition to their annual medical expenditure. They may have to go on doing the test for their entire life given they are never diagnosed with cancer or they may get their cancer diagnosed at early stages and significantly increase the chances of survival. Now if such a screening program existed before they were diagnosed with cancer and if they were asked a yearly fee (Select from the bids). Would they have paid for it? [Yes, No] . Each of the individuals was offered one random bid amount to choose from the range of bids (NPR 500, NPR 1000, NPR 3000, NPR 6000, and NPR 10000). Based on the respondents answer, a follow-up question were posed proposing either the half (if the initial answer is 'No') or double (if the initial answer is 'Yes') of the first sets of offered bids. So depending on the responses, four sets of WTP responses can be observed (Yes-Yes, Yes-No, No-Yes, No-No) ranging from 0 to infinity (Wooldridge, 2010; Milligan et al., 2010). [3]

In a contingent valuation study, there are many methods of measuring the WTP for a good, such as single bounded, double bounded, payment card technique etc. Hanemann et al. (1991), for the first time, proposed that the statistical efficiency of a conventional dichotomous model can be improved by asking the respondents to engage in two rounds of a bidding process known as double bounded WTP. The respondents are first presented with a bid amount for the good and depending on their responses, they are presented with either a lower or a higher amount for good. Hence, the follow-up amount of the second bid is contingent upon their responses to the first bid. A double bounded elicitation technique is statistically more informative and efficient than single bounded dichotomous choice methods (Hanemann et al., 1991). But, they are also usually criticized on some grounds. Respondents presented with a higher follow up bid may feel that the interviewer has reneged on the initial deal or those who were presented with a lower follow up bid may feel it obligatory to

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[3] If a person says 'Yes' to the initial bid of NPR 500 (say), then the minimum WTP is NPR 500 and if he says 'NO' to the follow up amount of NPR 1000, then a maximum WTP value of NPR 999 will be assigned. Whereas, if he is ready to pay the follow-up amount, then the maximum WTP will tend to infinity. Whereas, for someone who says 'No' and 'No' to both the assigned and follow up bids, WTP is assumed equal to NPR 0. Respondents were never asked if they would like to have a free preventative service; and so the lowest bound should have been coded as a negative infinity rather than $0. However, I assume that a persons utility will not decrease by accepting the preventative measure; hence, the lowest bound is set to be $0 for the analysis.

accept the amount out of guilt (Bateman et al., 2001; Milligan et al., 2010).

2.3.2 Independent variables

This section describes the types of explanatory variables used in the study. These are mediating and socio-demographic variables from the HBM framework indicating patients' subjective feeling of vulnerability to the disease or their perceived chances of survival. *Stigma* is the mark of disgrace/embarrassment that a patient feels after diagnosed with cancer. It is an individual feeling associated with familial or societal response to cancer. Patients' *Stigma* is measured using three variables, if attitudes of family member has changed since they got diagnosed; if they feel embarrassed in public because of cancer; and if they wanted to hide the fact that they have cancer from others. All these variables range from one to four, where one indicates facing no stigma at all and four is the highest exposure to stigma. Patients are asked about their general understanding of cancer: if they consider cancer as a treatable disease and that people with cancer usually survive. Patients faith in the curability of the disease known as *Optimism* is assigned a value of one, or zero otherwise. It is however important to distinguish *Optimism* from *Chances of cure* where I believe that *Optimism* captures the ex-ante perception of patients, whereas *Chances of cure* are their perceived survival chances from the current state of the disease. Patient's perceived *Chances of cure* from cancer is composed of absolute or relative chances of cure. Absolute chance of cure is measured using an 11-point scale on how certain are they about getting completely cured of cancer. The higher the scale is, the higher is their absolute perception of getting cured. Whereas, relative chances of cure comes from the belief that they have a comparatively higher chances of getting cure relatively to other cancer patients. A higher value of *Chances of cure* is indicative of better certainty about their chances of survival. Depending on their perceived severity, they may rate their own survival chances lower even when they were generally optimistic about the curability of the disease or vice versa. *Pessimism* defines a state of mind with the worst future aspirations where they feel bad about themselves and for letting their family down. They consider their life unworthy to live for and have lost all hopes of survival. All these variables are measured on a scale of one to four where one indicates that they do not feel pessimistic at all and four indicates highest level of pessimism. *Self Rated Health* is defined through two observed indicators, if they are feeling very energetic or if they are content with individual's quality of life right now. For both of the variables, a higher value represents a better rating of individual health. Furthermore, cancer patients face a higher *Barriers* if they needed to travel longer distances to avail medical care or if they had to sell their properties to finance treatment expenses. In the regression analysis, I created a binary variable for distance equals one if a patient has traveled more than three hours for cancer treatment facilities. The measure of awareness and dissemination of knowledge regarding various causes and symptoms of cancer is captured in *Information.* Individuals are asked, if they had heard of any of the screening tests for cancer before or prior to diagnosis or have they received any information from hospitals (through campaigns or posters) related to symptoms, screening, and consequences of cancer. A patient's estimate of disease re-susceptibility is also significantly used in the sick role behavior models. The likelihood that a disease is going to re-occur (*Risk of re-occurrence*) is measured through how certain are they that cancer can come back after getting completely cured? A higher value of the variable is associated with higher risk of cancer getting relapsed. For modeling purposes, again I created a binary variable of *Risk of re-occurrence* which is one if patients are 70% or more certain of cancer re-occurring. All of the above responses are based on patient's experience of cancer following their diagnosis. *Perceived susceptibility* or *Perceived benefits* respectively evaluates if patients ever perceived the risk of getting cancer before diagnosis and if they believe that screening for cancer would have helped.

As a measure of robustness checks, I did a principal component analysis to reassure that the observed variables loads into individual corresponding components. Below, I provide two sets of empirical applications. First, an item level analysis, where observed individual variables are regressed under conventional contingent valuation techniques. Based on the findings of the conventional models, a structural equation modeling framework is conceptualized where I formally tested the constructs through confirmatory factor analysis and used the latent endogenous and exogenous factors to establish linkages and interrelationships between them.

2.3.3 Summary Statistics

The distribution of the respondent's preference for the good against the bid value is presented in Table 2.2. Respondents have either said 'Yes' or 'No' to both the initial and follow up bids or have said 'Yes' to the initial amount followed by 'No' in the follow-up amount or vice-versa. About 32% of the sample have positively responded to both the initial and follow up bids, whereas 31 % of the patients have said ‘No’ to both the initial and follow up amounts.

[Table 2.2 here]

The initial responses of the patients were plotted to found a downward sloping demand curve for the annual cancer screening program in Figure 2.3. The proportion of patients’ who are willing to pay for the good is plotted against the random bid values. As the price of the screening program goes up, it decreases the percentage of people who agreed to pay for the program. There are 87% of the respondents who are willing to pay the lowest bid amount of NPR 500 and 28% are willing to pay NPR 10,000 or above.

[Figure 2.3 here]

I present the descriptive statistics for all the observed variables under different constructs in Table 2.3. Most of the patients reported periodically facing phases of stigma or pessimism. The experiences get extreme when they acknowledge facing them on a daily basis. For example, about 17% of the sample always feel that they have lost hope against survival from cancer. Only about 11% of the patients respectively feel energetic and content with their QOL on an everyday basis. Not all the patients have access to cancer facilities and travel long distances to avail care. It is not only the barriers of accessibility, but patients also resort to aggressive means of paying for cancer. Lack of information and fear of cancer re-occurrence is high among the patients. On the other hand, they have also reported a higher absolute (mean=7.5) and higher relative chances (83%) of survival from cancer. Many patients fall back on their family as a means of coping (37%) and believe that screening test would have been beneficial if undertaken before (87%).

[Table 2.3 here]

In Table 2.4, I presented the descriptive statistics of the socio-demographic variables used in the study. The sample mostly represents patients with 65% reported income below NPR 10,000 and only 5% have an income level more than NPR 30,000. Majority of the patients have no formal educational level; only a 4% have degrees above Class 12. The average age of the cancer patients is 52.37 years and 16% represents the minority Dalit population group.

[Table 2.4 here]

2.4 Empirical Models

2.4.1 Conventional Models

The conventional contingent valuation empirical strategy include binary probit regressions for single bounded and interval regressions for double bounded survey formats.[4] Under the interval regressions, we do not observe a respondents' actual willingness to pay value, instead, we see a range where an individual's WTP for this

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[4] Under double bounded contingent valuation models, there are four possible responses of individuals: Π^{yy} (Yes-Yes), Π^{yn} (Yes-No), Π^{ny} (No-Yes), and Π^{nn} (No-No). The log likelihood function can be written as the following: $\ln \mathrm{L}^{D}(\theta) = \sum d_i^{yy}\Pi^{yy}(\mathrm{B}_i, B_i^u) + d_i^{nn}\Pi^{nn}(\mathrm{B}_i, B_i^d) + d_i^{yn}\Pi^{yn}(\mathrm{B}_i, B_i^u) + d_i^{ny}\Pi^{ny}(\mathrm{B}_i, B_i^d), d_i^{yy}, d_i^{nn}, d_i^{ny}$,$\mathrm{d}_i^{yn}$ are binary indicator variables.

good falls. The item level responses help in exploring the importance of individual variables that contribute to the stated preferences. I employ Interval regressions to the double bounded nature of data following previous literature (Lang et al., 2012; Milligan et al., 2010; Werner, 1999).

The interval model assumes that for respondent i, the natural log of WTP_i is a linear function of a vector of exogenous explanatory variables X_i and an error term ϵ_i. Thus, the proposed econometric model of the WTP is given as:

$$WTP_i^* = X_i\beta + \epsilon_i \tag{1}$$

I maximize the following likelihood function where true WTP is bounded by two individual-specific thresholds, t_j and t_k, such that $t_k > t_j$. Some of the responses are left censored ($WTP_i{}^* \leqslant \mathrm{t}_j$) or right censored ($WTP_i{}^* \geq \mathrm{t}_k$) and some lie in the interval ($t_j \leqslant \mathrm{WTP}_i{}^* \leqslant \mathrm{t}_k$). The conditional mean of predicted WTP can be estimated as exp $(X_i\beta + \sigma^2/2)$ and median as exp $(X_i\beta)$.

$$\begin{aligned} ln(L) = \sum_{j\epsilon L} \log\phi\left\{\frac{t_{Lj}-X\beta}{\sigma}\right\} + \\ \sum_{j\epsilon R} \log\left\{1-\phi\ \left(\frac{t_{Rj}-X\beta}{\sigma}\right)\right\} + \\ \sum_{j\epsilon I} \log\left\{\phi\left(\frac{t_{Lj}-X\beta}{\sigma}\right) - \phi\left(\frac{t_{Rj}-X\beta}{\sigma}\ \right)\ \right\} \end{aligned} \tag{2}$$

In addition, as measures of sensitivity checks, I also estimate a probit model for single bounded and Lopez-Feldman model for double bounded sensitivity analysis. The Lopez-Feldman model also uses the maximum likelihood techniques to estimate the double bounded dichotomous choice models. In Lopez-Feldman model, both initial and follow up bid amounts offered to the respondents are used as dependant variables whereas the response dummies to both the bids are used as third and forth variables in the regression equation. The remaining are covariates or control variables of the model.

2.4.2 Structural Equation Model (SEM)

In a social science research, many variables are intertwined and affect each other simultaneously. Thus, it is important to consider the mediating effect of one variable on another and vice versa. A structural equation modeling framework is generally suitable for survey research with extensive set of variables that are generally collinear and are hard to write as a causally well-defined regression equation. In my study, the structural linkages between health status, risk factors, demographics, financial, and emotional stress may have to be treated as a multidirectional network instead of a bi-directional causal regression model. Hence, there is a need to introduce econometric models which can detect and unravel complex socio-economic and health linkages. The SEM model under Mediation Analysis has an advantage over other conventional models because it allows for complicated paths with mediating variables between the dependent and independent variables (Baron and Kenny, 1986; Bollen and Stine, 1990;

Imai et al., 2010; Kraemer et al., 2002; Hoyle and Kenny, 1999; MacKinnon et al., 2007; Bollen, 1987). Through SEM, I will be able to estimate the simultaneous impact of the latent and manifest variables together on the primary variable of interest. The total effect on the structural variables can be decomposed into direct and indirect effects. Furthermore, unlike linear models that assume all observed variables are obtained without error, under SEM, all the variables that feed into latent constructs are measured with error and so are the endogenous variables. However, SEM has some disadvantages in the sense that it lacks the ability to estimate a dependent variable in their interval form. Thus, I need to estimate the model only with the maximum WTP values. In creating the maximum WTP, I constrained the infinite WTP of interval models with the amount equivalent to one month of the patient's individual income.[5]

A SEM is composed of two types of models: measurement models and structural models. Measurement models construct latent factors from observed variables through confirmatory factor analysis (CFA), whereas the structural model measures the causal relationship between the latent and outcome variables. The observed variables follow a multivariate normal distribution and are measured with error. In this paper, I am estimating a recursive structural model where all the causal effects are unidirectional and there is no feedback loops between the endogenous variables implying the error covariance between different latent endogenous variables to be zero. Also, the vector of errors defining the measurement equations are assumed to be un-

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[5] WTP for screening is an additional yearly expenditure that individuals will incur. When I constrained the yearly WTP by their monthly income, it accounted for 8% of their monthly income.

correlated. The estimation of a SEM model requires additional assumptions to be met (Kline, 2012): (a) There is a temporal precedence where the presumed cause [independent variable (X)] must occur before the presumed effect [dependent variable (Y)] (b) There is a significant association between X and Y. (c) There are no confounders and that all the common causes between X and Mediator (M), M and Y, X and Y are measured and controlled, and (d) There is no reverse causal effects from M to Y and M must not cause X.

A SEM model is written as the following (Huber, 2014):

$$Y_{n\times 1} = B_{n\times n}Y_{n\times 1} + \Gamma_{n\times j}X_{j\times 1} + \alpha_{1\times n} + \zeta_{n\times 1} \tag{3}$$

$Y_{n\times 1}$ = Endogenous variables in the model

$B_{n\times n}$ = Coefficient of endogenous variables on endogenous variables

$$Y_{n\times 1} = \begin{bmatrix} y_{k\times 1} \\ n_{j\times 1} \end{bmatrix}$$

$y_{k\times 1}$ = Observed endogenous variables[6]

$\eta_{k\times 1}$ = Latent endogenous variables[7]

$X_{j\times 1}$ = Exogenous variables

$\Gamma_{n\times j}$ = Coefficient of exogenous variables on endogenous variables

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[6] Cancer Treated, Cancer Survive, Absolute chances, Relative chances, Knowledge of tests, Information, Feeling Bad, Lose Hope, Hurting Oneself, Attitude change, Stigmatized, Hide-cancer, Content-qol, Energetic, ln(MaxWTP)

[7] Optimism, Chances, Information, Pessimism, Self Rated

$$X_{j\times1} = \begin{bmatrix} x_{c\times1} \\ \\ \xi_{d\times1} \end{bmatrix}$$

$x_{c\times1}$ = Observed exogenous variables [8]

$\xi_{d\times1}$ = Latent exogenous variable [9]

α =Intercept of the endogenous variable

$\zeta_{n\times1}$ = Represents all errors of observed and latent endogenous variables

2.5 Results

2.5.1 Conventional Model Results

A number of individual variables grouped under specific constructs are regressed with conventional models such as Interval regression, Lopez-Feldman, and Probit to predict WTP in Table 2.5. A significant positive relationship has been found with variables representing *Self Rated* health status and *Chances of cure*. Patients rate their relative and absolute chances of survival based on their perceived severity of the disease.[10] Also, people with higher perceived chances of survival are more likely to have faith in treatments. Hence, they are likely be supportive of any new medical intervention that will only serve to enhance the cancer care management of

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[8] Perceived benefits, Perceived susceptibility, Age, Income; Family history of cancer, Dalit, Barriers (Distance), Aggressive payments, Risk of re-occurrence, Communication Family, ln(expenses)

[9] Stigma is the only latent variable which is exogeneous to the model.

[10] Given that majority of the patients did not know about their stages of cancer, I explicitly did not control for the severity of the disease. But I believe that patients through responses to questions on their chances of survival, feeling of pessimism, or self rating of health status have already factored in their perceived feeling of severity from cancer.

the country. In contrast, patients for whom the survival chances are lower, they did not find it worthy to contribute towards any further initiative. Next, awareness and information regarding the good in question are of particular importance when it comes to voluntarily paying for the good. It is not the knowledge of the screening test but dissemination of relevant information from hospitals *(Information)* is associated with higher likelihood of paying for the good. Family interactions *(Communication with Family)* indicate higher social support leading to higher WTP. For a cancer patient, if they believe that cancer can re-occur even after they survive through their current phase *(Risk of re-occurrence)*, it is likely that they would be willing to have detection measures early on which will save them from the current level of suffering.

On the other hand, *Pessimism* is associated with lower likelihood of paying for the good in concern. The disease has brought the patients to such a mental state that they consider themselves as failures and are suicidal in their thoughts. This pessimistic attitude make the health intervention seem unworthy to them. Similarly, patients that resort to aggressive means of paying for treatment perceive their limited resources as inability to contribute monetarily towards any medical intervention.

I have not found any strong statistical significance of *Perceived susceptibility*, *Perceived benefits*, or *Stigma* on their decisions to screen. The models were also ran with Income and social constructs as additional variables with no significant change to the main variables of interests.[11]

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[11] Results with socio-demographic variables are not shown in the paper and are available upon request. However, I found that individuals who fall in the higher income category are more likely and those who belong to the lower strata of the society *(Dalits)* are less likely to incur any cost

[Table 2.5 here]

2.5.2 SEM results

Unlike in the interval regressions where I estimate one equation, the SEM allowed for six structural and 14 measurement equations. The SEM model is estimated with maximum likelihood robust estimators, and it fits well with the data. The model fit was ascertained using the standardized root mean squared residual (SRMR) and the coefficient of determination (CD).[12] A small value of SRMR (0.05) and the model coefficient of determination close to one (CD=0.93) indicates a good fitted model. Through CFA, the factor structure of a set of observed variables are verified. The measurement models tested the hypotheses that the relationship between the observed and their corresponding latent constructs are significant. The factor loadings of the manifest variables to their latent constructs are provided in the Addendum 2.1. This in turn reconfirmed the earlier groupings of variables in reduced form models. For brevity, I do only present the results of the structural equations.[13] Given the cross sectional nature of the data, the decomposition of total effects is more correlational in nature rather than being causal. So the direct and indirect effects which might appear to suggest causality is infact correlational in nature (Bosompra et al., 2001).

I present the standardized coefficients of the structural equation model in Table 2.6. The values reflect the total effect of independent variables on respective outcome

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towards the program.

[12] Since I present the robust estimates of the model, SRMR and CD are the only valid measure of the goodness of fit.

[13] Results of the measurement equations are available upon request.

equations. As we can see the willingness to pay for cancer screening is positively and directly associated with *Self Rated Health* ($\beta = 0.25$) and *Chances of cure* ($\beta = 0.14$). Factors such as *Communication with Family* ($\beta = 0.14$), and *Perceived Susceptibility* ($\beta = 0.08$) are positively correlated with ones chances of paying for the good. This concurs with my earlier findings; it is the healthy state of mind or perceived chances of curability that encourages medical intervention. Patients who have a better familial support to cope with disease adversities are more likely to be supportive of any medical intervention. Contrary to my beliefs, people who are facing *Stigma* have a direct and positive association on willingness ($\beta = 0.11$). It is the strong desire to avoid their current embarrassment from the disease that lead them to pay more for a preventative technique. Whereas, when people are pessimistic *(Pessimism)*, they are inherently discouraged towards any positive step of cancer care ($\beta = -0.14$). As expected, patients belonging to the higher economic category are more likely to pay more for the good [*Income* ($\beta = 0.13$)], whereas those who belong to the lowest demographic strata of the society are willing to pay less. Being *Dalit* has both direct ($\beta = -0.10$) and indirect adverse effects ($\beta = -0.04$) on willingness to pay for the good. Likewise, if an individual has already resorted to borrowing or selling properties to finance their treatment, they perceive any intervention in the light of their current resource limitation. This discourages them from paying towards the screening program [*Aggressive payments*, $\beta = -0.10$]. Finally and importantly, if there are higher chances of cancer re-occurrences, the immediate direct response would be paying higher for the preventative mechanism ($\beta = 0.09$) to avoid repeating their present circumstances.

The results of SEM in its association with WTP not only reconfirms the item level reduced form findings, but it also explored the interrelationships between different constructs through direct and indirect effects. As seen before, patients with general perception on cancer as being any other normal diseases where survival chances do not necessarily need any intervention are not willing to pay any higher ($\beta = -0.15$). However, when *Optimism* is correlated with a higher chances of getting cure or a better self rating of one's health, then it is the indirect effect ($\beta = 0.10$) of *Optimism* through *Chances of cure* ($\beta = 0.41$) and *Self Rated Health* ($\beta = 0.14$) that lead to higher *WTP*. This indirect positive effect in turn increased the total magnitude of *Optimism* on *WTP* ($\beta = -0.05$) as can be seen in Figure 2.4.[14]

[Figure 2.4 here]

A similar interpretation can be derived from the variable that measures *Risk of re-occurrence*. If the patients believe that cancer is expected to relapse, then they are likely to have a higher willingness to pay for any cancer prevention measures. The direct effect of *Risk of re-occurrence* on *WTP* is positive ($\beta = 0.08$). But, *Risk of re-occurrence* is also associated with lower *Chances of cure* ($\beta = -0.18$) and higher *Pessimism* ($\beta = 0.22$). Lower perceived curability and increased pessimism both have a negative indirect relationship on willingness *WTP* ($\beta = -0.05$). This in turn reduced the total effect of *Risk of re-occurrence* on willingness to pay by the amount of negative indirect effect as can be seen in Figure 2.5.

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[14] The total effect is $c = c^{'} + ab$, where c = total effect, $c^{'}$ = Direct effect, ab is Indirect effect. When $c^{'}$ = -0.15 and ab = 0.10, the total effect is increased by the amount of positive indirect effect, c = -0.05 [> -0.15]. Under the absence of indirect effect [when ab = 0] , c = $c^{'}$

[Figure 2.5 here]

Both of the cases as described above, *Optimism* and *Risk of re-occurrences* have opposing direct and indirect effects on the outcome variable. These independent constructs contain two sources of variance reflecting two opposing channels through which they affect the outcome variable suggesting mediation with suppression (MacKinnon et al., 2000). In mediation with suppression, one of the channels through with X affects Y include the indirect pathway of the mediator M, whereas, the other channel influences Y in the opposite direction once M is accounted for in the model.

The influence of *Dalit* on *WTP* is negative both on direct and indirect accounts. Being *Dalit* is correlated with lower *Self Rated Health* ($\beta = -0.15$) and less availability of *Information* ($\beta = -0.14$) which in turn leads to a negative indirect effect of *Dalit* on WTP ($\beta = -0.04$). Given the direct effect of *Dalit* on *WTP* was negative ($\beta = -0.10$), the total effect remained significant and the magnitude of *Dalit* on *WTP* increased in absolute terms ($\beta = -0.14$).

Other linkages include *Barriers*, here barriers indicate distance to the nearest cancer specialty. Facing *Barriers* lead to lower *Optimism* ($\beta = -0.20$) among patients. More *Information* make individuals optimistic ($\beta = -0.23$) which indirectly increases their perceived chances of survival, it does not have any direct or indirect relationships with other psychosocial elements of my study. Perceiving the benefits of screening *(Perceived Benefits)* makes people more optimistic ($\beta = 0.18$) and with age, availability of information decreases ($\beta = -0.37$). Finally, it suggests that a family history of cancer more likely to have taught the patients to manage the stress and associated effects of cancer better.

The bootstrapped mean willingness to pay estimated from the predicted values of a SEM model is NPR 5527 per year ($53) [CI 5288-5757] for a comprehensive cancer screening. This translates into an approximate monthly payment of $4. The mean monthly willingness to pay is similar to what I have also found earlier in probit ($3) and Lopez-Feldman ($3) models.

[Table 2.6 here]

2.5.3 Sensitivity Analysis

Sensitivity Analysis are ran with additional variables such as severity of cancer which can also impact patients' preference to screening. I ran a sub-sample analysis to include stages of cancer as an indicator of severity. Given a majority of the patients (52%) did not know their current stage of cancer, it limits the inclusion of this variable in the main model. I do not find any significant association of stages of cancer with their perceived chances of survival or their self rating of health. Nor did it have any significance on the mean WTP value for the good.

In addition to having cancer, if a patient is also suffering from any other comorbidities, it might also influence their willingness to pay for any health intervention. I controlled for comorbidities among the patients like Diabetes, Heart disease, COPD, Epilepsy, Asthma, Alzheimer's and few others. Incorporating this did not alter the sign and significance of the model nor did it have any influence on WTP.

I trimmed the maximum WTP in SEM model to varied percentages of income (2.5%, 5%, or 10%) to robust the mean WTP value. There was no significant change in the relationship between variables apart from the marginal variation in mean value. Finally, employment status of the patients is also not significantly correlated with stated WTP.

2.6 Discussion

This project is the first of a kind that attempted a comprehensive individual level survey of cancer patients in Nepal. The literature was limited with only demographic information of patients extracted from hospital records. This study brings in the first direct account of cancer patients on their perceptions, beliefs, and experience of adversities through the course of disease. Thus, it fills in the gap of data limitation in the literature. Also the good, an annual screening program in Nepal has a wider policy applicability. Previous WTP studies of an imaginary pill completely effective in remission of cancer (Lang, 2010) or a hypothetical drug guaranteeing 100% prevention from cancer (Milligan et al., 2010) are hypothetical in nature and are limited in their application.

Also, I believe that this paper will act as a source of information to the general individuals as well as to the policymakers on the importance of screening. The 'tips' or 'advices' of cancer patients will potentially yield to more demand and uptake of screening. Policymakers should also view the perspective of cancer patients as a guidance to bring in cancer control measures in the country. Initiation of such programs in the hospitals in itself will spread awareness regarding service availability.

It is however important to acknowledge that though screening is advocated nationally and is named as one of the four important steps to cancer management (Brown ML, 2006; WHO, 2002), the darker side of screening is usually overlooked (Grimes and Schulz, 2002). On one hand, screening can improve health outcomes and increase the survival rates of patients, whereas on the other hand, it can be inconvenient, unpleasant, expensive, and most importantly inaccurate. Screening tests can have false positive results where the test may be indicating that cancer is present even though it is not. This ability of a test to correctly identify patients without disease (true negative) is called specificity. A false-positive result can lead to anxiety and unnecessary expenses following the treatment of a nonexistent condition. Tests can also give false negative results, where the test may be indicating the absence of cancer even in the presence of carcinogenic cells. The accuracy with which a test correctly identifies patients with disease is called sensitivity. All the screening test differs by degrees of inaccuracy. A false negative will delay the process of diagnosis and lower the survival outcomes of the patients (Grimes and Schulz, 2002; Croswell et al., 2009). The conclusions on specificity and sensitivity of tests further varies by studies with no definitive conclusion. Therefore, the proposition to build cancer screening policies should be evaluated in light of the above mentioned issues. It is important to understand that screening cannot prevent cancer from occurring, it can help detect cancer in their early phases to prevent delays of treatment. Further, optimizing screening in resource constrained economies may need targeted screening policies on high risk individuals. If adequate supply of resources is not available in the countries to undertake a national cancer screening program, targeted screening policies can benefit individuals with modestly increased risk of cancer. They should be prescribed specific investigations based on clinical symptoms and signs (Kumar and Bhasker, 2014).

My analysis highlights the hardship of the patients in financing the treatment process. This urge for a policy where safety nets such as health insurance policy is required to be introduced in the country. This would prevent the patients from borrowing or selling off of properties to pay for treatment. Steps should also be taken to disseminate the information on screening to the disadvantaged section of population. Less availability of information brings in more pessimism among the patients, which in turn make any health intervention less preferable. Hence, along with information dissemination, steps should be taken to address pessimism among individuals.

2.7 Conclusion

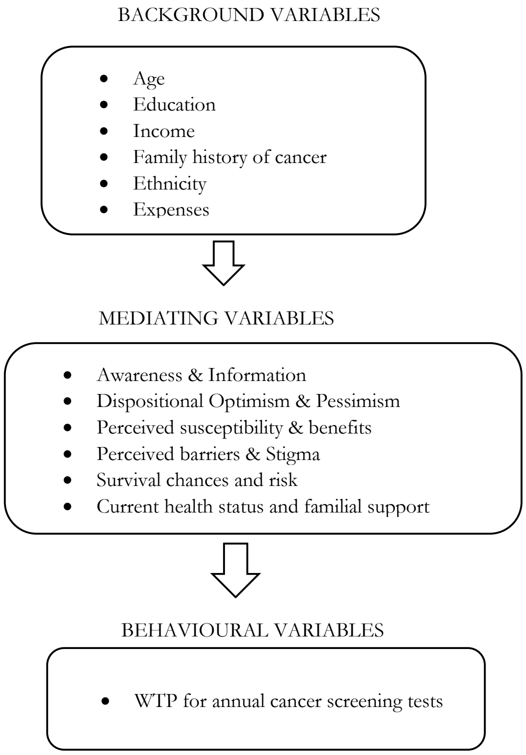
In the absence of a national cancer registry in Nepal, it is challenging to understand the gravity of the need of cancer care management in the country. For a resource poor economy like Nepal, significant compromises in other areas would be required to cover the expenses of new treatment facilities especially if it is a non-obligatory preventative measure. Cancer screening is a preventative approach to early diagnosis of any abnormality in the growth of cells that lead to cancer. A substantial number of factors contribute to one's decisions to screen. Individuals who have faced through the extreme adversities of cancer are the best stakeholders to communicate the value of screening. Thus, I aimed to study a cancer patient's retrospective preference of a cancer preventative program. I surveyed cancer patients to understand how their present health status, beliefs, and perceived susceptibility to the disease shape their preference for the good. Through the application of contingent valuation method such as Interval regression, Lopez-Feldman, and binary probit models, it is found that individuals who evaluated their survival chances to be higher or rated their health better are more encouraging of any medical intervention. Whereas, when they are pessimistic or have already resorted to aggressive means of paying for their treatment, they are less likely to pay for cancer screening. Information dissemination and risk of disease re-occurrence also increases their probability of paying for the good.

A psychosocial analysis of individuals WTP needed a much more flexible empirical approach to address interrelationships between variables. This is possible in a SEM framework where multiple endogenous variables are modeled simultaneously. Simple regression models limit any examination of direct and indirect effect of variables on other endogenous variables; this is feasible to do under SEM. Individual variables in association with their preference for the good yield similar findings. In addition, under SEM, I find instances where latent constructs impact the outcome variable through two opposing channels. For example, when people generally perceive cancer as any other treatable disease (optimistic), they are not encouraging enough towards any additional treatment intervention (direct effect), but if that sense of optimism increased their perceived chances of survival or their self rated health status, that in turn led to a positive indirect effect on their willingness. Similarly, as individuals believed that there is a higher chance of cancer re-occurrence, their direct response include paying more for the preventative measures, but if fear of cancer re-occurrence made them more pessimistic, they had retorted indirectly by showing a lower likelihood of paying for the good. This opposing direct and indirect effects are called mediation with suppression. Indirect effects also magnified the total effect of dalit on willingness to pay. Besides, accessibility to information or perceiving the benefits of screening program also significantly improve patients' perceived survival chances. Socio-economic variables such as income, aggressive means of financing treatment, and belonging from a disadvantaged section of the society also predicts one's decision to uptake preventative measure. Both types of models provide sufficient evidences that patients are ready to pay a positive amount towards the good. The estimated mean WTP of cancer patients is NPR 5527 per year ($53) under SEM.

I would like to conclude with acknowledging some limitations of the empirical analysis, First, both the SEM and interval regressions follow different approaches to the construction of variables used in the models. The dependent variable under interval regression signifies a range of minimum and maximum WTP values, whereas SEM exploits a continuous dependent variable. Hence, we should be cautious while deriving any direct comparisons between the two different models. Second, as mentioned before, the effects of structural model in a cross sectional data do not signify causality unlike in the longitudinal study. We should look at the relationship as being correlational in nature, and finally the study could not predict if there is a demand for a cancer preventative program in Nepal. In other words, the mean WTP amount is only reflective of cancer patients' positive preference for the good. The valuation does not project the existence of demand among the potential users of the good. Instead the study wanted to appeal to the healthy population about the importance of screening.

Figures and Tables

Figure 2.1: Theoretical framework of Modified Health Belief Model



Source: Adapted from Bosompra et al. 2001

Figure 2.2: Development regions & locations of sampled hospitals

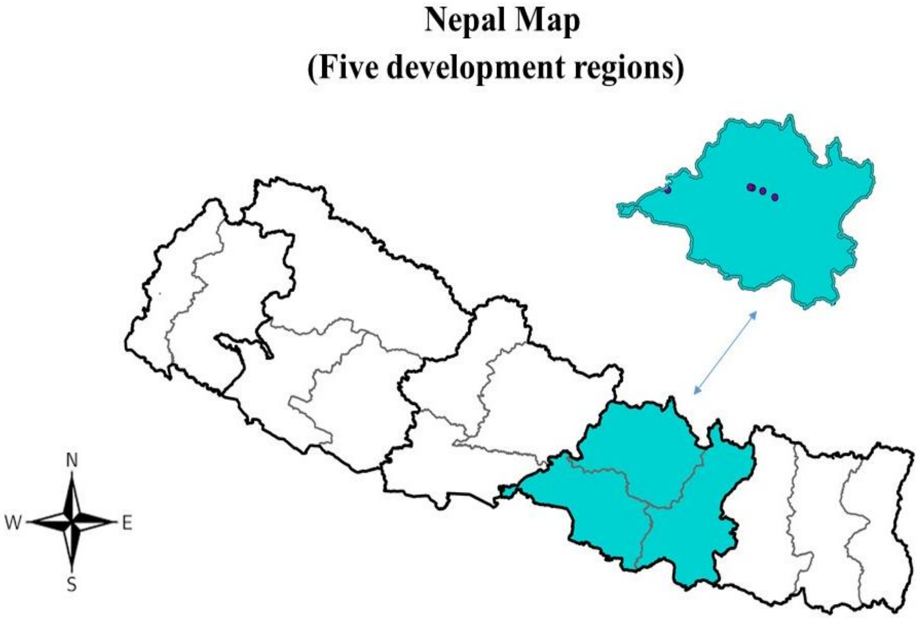


Figure 2.3: Proportion of patients saying ‘yes’ to the bid amounts

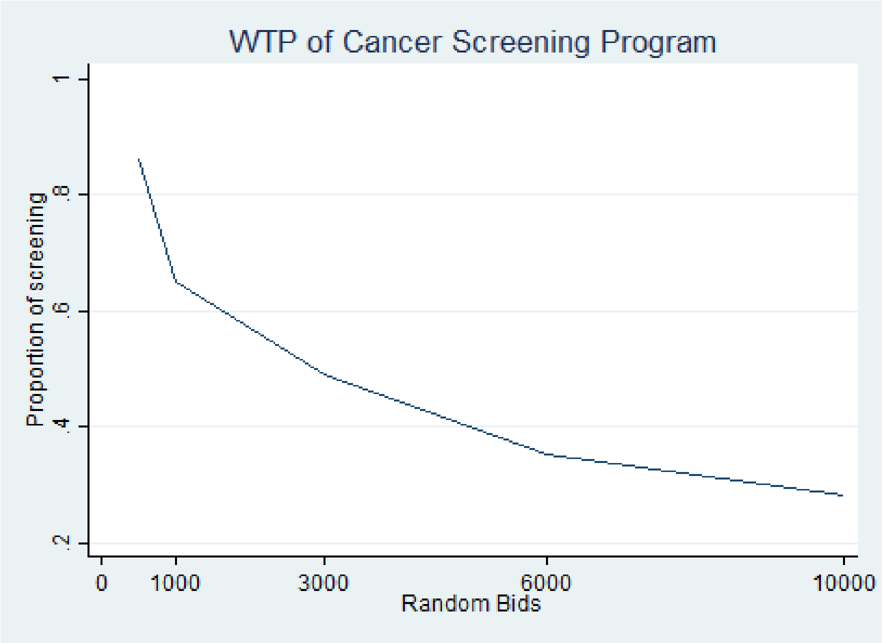


Figure 2.4: Mediation Analysis: Pessimism and WTP

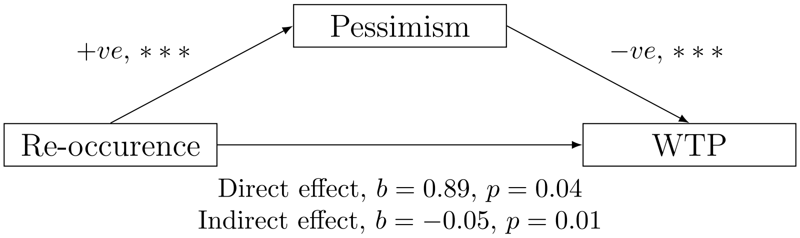


Figure 2.5: Mediation Analysis: Optimism and WTP

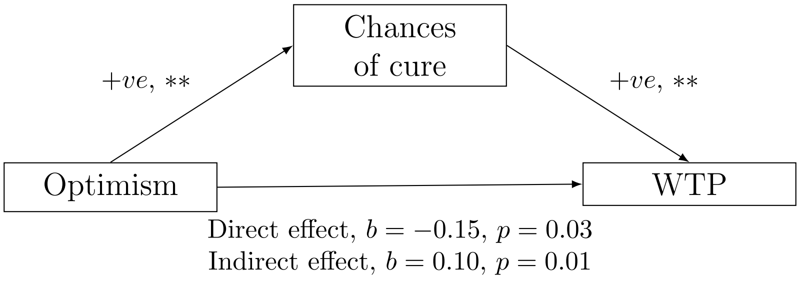


Table 2.1: Distribution of cancer patients across cancer hospitals

Serial No.	Name of the hospitals	Cancer patients
1	Bhaktapur Cancer Hospital	186
2	Bir Hospital	119
3	Dhulikhel Hospital	62
4	Birendra Army Hospital	24
5	B.P Koirala Memorial	209
	Total	600

Table 2.2: Distribution of respondents by bid amounts

	Yes-Yes		**Yes- No**		**No-Yes**		**No-No**		**Total**	
Bids	**N**	**(%)**	**N**	**(%)**	**N**	**(%)**	**N**	**(%)**	**N**	**(%)**
500	67	58.2	32	27.82	8	6.9	8	6.9	115	100
1000	47	40.17	27	23.07	27	23.07	15	12.82	117	100
3000	38	29	26	19.8	28	21.3	39	29.77	131	100
6000	19	15.5	24	19.6	24	19.6	55	41.98	122	100
10000	17	14.91	15	13.1	17	14.91	65	57.01	114	100
Total	**188**	**31.39**	**124**	**20.70**	**104**	**17.36**	**182**	**30.38**	**599**	**100**

Table 2.3: Definition of the observed variables

Variables	**Not at all**	**Several days**	**More than half days**	**Nearly every day**
Energetic	54.64	24.45	9.78	11.13
Content QOL	45.7	23.44	19.22	11.64
Feeling Bad	39.12	37.1	14.5	9.27
Lose Hope	46.88	22.93	12.98	17.2
Hurting Oneself	51.77	27.49	14.84	5.9
	< 1-3 hours	**3-5 hours**	**5-10 hours**	**>10 hours**
Distance	44.61	13.64	20.37	21.38
	Definitely False	**Probably False**	**Probably True**	**Definitely True**
Stigmatized	63.51	20.44	9.63	6.42
Hide cancer	68.92	16.05	7.77	7.26
Attitude	62.16	22.13	9.29	6.42
	10-30%	40-60%	70-90%	100%
Risk of reoccurrence	36.09	27.49	24.79	11.64
	Mean		**S. D**	
Absolute chances	7.5		2.01	
Relative Chances	0.83		0.38	
Cancer Survive	0.47		0.5	
Cancer Treated	0.58		0.49	
Aggressive payment	0.52		0.5	
Information Hospitals	0.22		0.42	
Knowledge of test	0.22		0.41	
Communication Family	0.34		0.47	
Perceived susceptibility	0.13		0.34	
Perceived benefits	0.87		0.34	

Table 2.4: Socio-demographic variables

Variables	Definition	Mean	S.D
No Education	Have no formal education in school	0.59	0.49
Education 1-8th	The highest level of educational attainment is Class 8	0.2	0.4
Education 9-12th	The highest level of educational attainment is Class 12	0.16	0.37
Education > 12th	Education beyond Class 12	0.04	0.2
Income <10k	Individual Income <NRS 10,000	0.65	0.47
Income 10-20k	Income between NRS 10,000 & NRS 20,000	0.19	0.39
Income 20-30k	Income between NRS 20,000 & NRS 30,000	0.11	0.31
Income >30k	Income between NRS 20,000 & NRS 30,000	0.05	0.21
Age	Age of the patient	52.37	14.09
Dalit	Belongs to the Dalit section of the society	0.16	0.36
Ln(Expenses)	The logged value of the total treatment expenses	11.02	0.92
Family history of cancer	Any immediate member had a family history of cancer	0.12	0.32

Table 2.5: Conventional Models: Effects on WTP

Variables	Interval regression	Probit regression	Lopez-Feldman model
Bids	--	-0.00017***	--
		(-9.65)	
Stigma			
Stigmatized	0.0947	0.0903	671.8
	(0.99)	(1.11)	(1.61)
Hide cancer	0.171**	0.101	579.4
	(2.06)	(1.31)	(1.49)
Attitude change	-0.0399	-0.0172	-305.1
	(-0.47)	(-0.24)	(-0.83)
Optimism			
Cancer Survive	-0.374**	-0.268*	-1849.7**
	(-2.30)	(-1.89)	(-2.53)
Cancer Treated	0.167	0.186	1299.1*
	(0.99)	(1.28)	(1.72)
Pessimism			
Feeling Bad	-0.258***	-0.125*	-984.8***
	(-3.13)	(-1.72)	(-2.66)
Lose Hope	-0.0911	-0.0432	-532.0*
	(-1.34)	(-0.77)	(-1.86)
Hurting Oneself	0.0172	0.0201	217.5
	(0.20)	(0.27)	(0.57)
Chances of cure			
Absolute chances	0.117***	0.111***	554.0***
	(2.87)	(3.31)	(3.21)
Relative chances	-0.239	-0.348*	-1552.3*
	(-1.08)	(-1.94)	(-1.71)
Self-Rated			
Energetic	0.0717	0.0629	558.5*
	(1.02)	(1.02)	(1.77)
Content-QOL	0.248***	0.126**	1090.6***
	(3.78)	(2.08)	(3.52)
Barriers			
Distance	-0.259*	-0.283**	-1018.9
	(-1.86)	(-2.28)	(-1.62)
Aggressive payment	-0.511***	-0.319***	-2627.2***
	(-3.69)	(-2.64)	(-4.21)
Information			
Information	0.367**	0.197	1722.4**
	(2.24)	(1.39)	(2.35)
Knowledge of tests	-0.0343	0.0135	-425.3
	(-0.24)	(0.09)	(-0.58)

conventional models contd...

Others HBM variables			
Risk of re-occurrence	0.252*	0.227*	1252.2*
	(1.73)	(1.79)	(1.91)
Perceived benefits	0.0318	0.219	658.9
	(0.17)	(1.25)	(0.75)
Communication Family	0.489***	0.296**	1955.4***
	(3.40)	(2.31)	(2.98)
Perceived susceptibility	0.274	0.0733	736.4
	(1.60)	(0.41)	(0.80)
Constant	6.974***	-0.211	-487.7
	(14.66)	(-0.50)	(-0.23)
N	592	592	592
Log Likelihood	-697.0	-328.2	-858.5
Chi Squared	122.5	163.1	123.8
AIC	1437.9	700.4	1761.0
BIC	1534.4	796.9	1857.4

t statistics in parentheses * p<0.1, ** p<0.05, *** p<0.01

Table 2.6: SEM Results

	Structural Models	ln(WTP)	Chances of cure	Optimism	SelfRated	Information	Pessimism
LATENT	Stigma	0.11^{***b}	--				--
	Optimism	(-/+) 0.05$^{**\ a,b}$	0.41^{*b}		0.14^{**b}		
	Pessimism	-0.14^{**b}	--				
	Chances of cure	0.14^{**b}					
	Self-Rated	0.25^{***b}					
	Risk of re-occurrence	(-/+) 0.03$^{**\ a,b}$	-0.18*				0.22^{**b}
POLICY	Barriers	0.04	--	-0.20^{***b}	--		
	Information	0.04	0.29^{*a}	0.23^{*b}	0.30^{*a}		--
	Perceived Benefits	-0.01	--	0.18^{***b}	0.03^{*a}		
SES	Income	0.13^{***b}	--	0.10^{*b}	--	--	
	Dalit	-0.14^{***a,b}	--	--	-0.15^{**b}	-0.14^{**b}	--
	Age	-0.02	--	--	--	-0.36^{**b}	--
OTHERS	Aggressive Payments	-0.10^{**b}	--				
	CommunicationFamily	0.14^{***b}	--				--
	PerceivedSusceptibility	0.08^{*b}	--	0.05^{*a}	--	0.23^{**b}	--
	Family history cancer	0.02	--	0.12^{***b}	--		-0.16^{**b}
	Ln(Expenses)	0.01					

Note: 'a' indicates Indirect effect: 'b' indicates Direct effect, '(+/-)' Opposite direct and indirect effects, only '*' indicates that the indirect and direct effect of risk of reoccurrence on Chances is not significant but the total effect is significant. A dash (-) means that the paths are not significant. The cells are kept empty if there are no direct and indirect paths linking the corresponding variables. The model effects should be read horizontally, e.g. The direct effect of Pessimism on WTP is negative & significant or Optimism had opposing direct and indirect effects on WTP, both of which are statistically significant

Addendum 2.1: Confirmatory Factor Analysis

Confirmatory Factor Analysis	Factor Loadings
Stigma	
Attitudes of my family member has changed since I have cancer	0.39
I feel embarrassed in public / stigmatized because of cancer?	0.88
I want to hide the fact that I have cancer disease from others?	0.67
Optimism	
People with cancer generally survive	0.70
Cancer can be treated	0.76
Pessimism	
Feeling bad about himself that he is a failure and let his family down	0.69
Thoughts that it would be better off dead and hurting myself	0.48
Do you feel that you lose hope in fight against the illness	0.70
Chances of cure	
How certain do you think you will get completely cured of cancer?	0.70
Comparatively higher chances of getting cure relatively to other cancer patients	0.62
Self rated health	
Feeling very energetic	0.54
I am content with the quality of my life right now	0.57
Information	
Have you heard of any of the screening test for cancer	0.51
Available information from the hospitals (through campaigns or posters)	0.28

All the factor loadings are significant at p<0.000

Chapter 3

A case-control comparison of mental burden across and within different types of cancer patients in Nepal

3.1 Introduction

A cancer diagnosis is a life-changing phenomenon, which can lead to a considerable amount of psychological and emotional stress in any individual. Cancer affects the overall functional well-being of patients. In this paper, I study mental burden from the perspective of this lack in functional well-being. Following diagnosis, patients experience disruptions in their personal lives through unmet physical challenges or in their social lives through isolation from friends and family (Zebrack et al., 2014). Inability to take care of one's personal needs, financial distress from higher treatment expenses, and the associated societal stigma takes an emotional toll in the lives of the patients. This holistic measure of mental burden is a point of departure from the earlier stream of literature studying clinical depression. Precisely, I approach the issue from the point of view of functional disabilities at different domains of life giving rise to mental burden. However, it is not only cancer, but localization of cancer, age and stage of the disease have heterogeneous impact on the magnitude of burden. Burden can even be more for women specific cancer due to specific gender effects.

The magnitude of depression or anxiety among patients has varied considerably across recent studies (Linden et al., 2012; Hinz et al., 2010; vantSpijker et al., 1997).

These studies are however not comparable in their settings and/or in their instruments to measuring depression (Vodermaier et al., 2009; Stommel et al., 2004; Brintzenhofe-Szoc et al., 2009; Hinz et al., 2010). They also differ in their sample size (Brintzenhofe-Szoc et al., 2009; Zabora et al., 2001; Sharpe et al., 2004), age (Groenvold et al., 1999; Crawford et al., 2001), stage and trajectory of disease (Vodermaier et al., 2009, 2011), and other socioeconomic dimensions (Chen et al., 2009; Ell et al., 2005).

Depression among cancer patients differ by cancer sites (Linden et al., 2012; Vodermaier et al., 2011; Neron et al., 2007; Castelli et al., 2009) and gender (Stordal et al., 2001; Cleeland et al., 1994). Linden et al. (2009) and Linden et al. (2012) however stated that even though the mean depression of cancer patients do not differ significantly from general population, but there are distinct groups of patients who experience greater depression. Unlike vantSpijker et al. (1997), where female cancer patients are found with lower rates of emotional distress, (Linden et al., 2012) showed that prevalence of anxiety and depression is particularly higher among females. Also, breast or any gynecological cancer are found closely associated with high pain and low health-related quality of life (Ell et al., 2005).

In another stream of literature, there has been a number of studies that measure distress of cancer patients in comparison to those of general population (Groenvold et al., 1999; Hadi et al., 2009; Hinz et al., 2010; Piccinelli and Wilkinson, 2000). Hinz et al. (2010) studied depression and anxiety separately over two years in Germany and found that the risk of psychiatric distress was nearly twice as high in the cancer group than the general population. The inter-individual variation in psychological distress propagated by age and gender differences plays a much stronger role than that caused by localization of cancer. In contrast, Groenvold et al. (1999) and Hadi et al. (2009) find that cancer patients do not show significant differences in their levels of anxiety and depressions compared to control groups. In fact, the patients facing breast cancer indicated significantly less stress than those in the general population. Also, it is the age and educational level that most significantly correlate with levels of depression. On the magnitude of depression, Desplenter et al. (2012) found patients with cancer are ten times more likely to be suffering from emotional distress, where Khan et al. (2010) through multivariate regression analysis shows no significant difference in the consultation behavior for depression and anxiety between cancer and control patients giving ambiguous relationship.

There has not been much work on the level of familial isolation and its association with mental burden among the cancer patients. Social isolation is the lack of interpersonal support from family that patients experience post diagnosis with cancer. Studies have found that there is an excessive risk of mortality associated being socially isolated (Elovainio et al., 2017). After adjusting for demographic characteristics, loneliness and social isolation are found to have a robust and positive association with greater risk of inactivity, smoking, as well as multiple negative health outcomes (Shankar et al., 2011). Umberson and Montez (2010) find that absence of social relationships has both immediate, long-term, and cumulative effects on mental and physical health behaviors. Thus, it is important to account for social ties when studying mental burden. Overall, I found that a number of factors such as age, gender, socioeconomic status, cancer site, and social isolation have differential impacts on the well-being of patients which also varies by differences in research design and measurement issues.

All of the above findings taken together have motivated me to focus on two objectives for the paper. First, I undertook a comparison of mental health conditions between cancer and control (non-cancerous) patients to see and estimate if there are statistically significant differences in the level of mental burden faced by the two groups. (b) Also, I wanted to study the differential impact of gender and cancer sites across patients. Specifically, I compare cervical cancer patients to other female cancer patients, all male cancer patients, and control patients in the sample. I employed propensity score matching techniques to match the case and control individuals. Different matching methods such as nearest neighbor, radius, kernel, and stratification methods are used to quantify the average treatment effects (ATE). Different groups of patients are evaluated through multivalued treatment estimators which uses probability weights to measure the causal effects of different types of cancer on mental burden. After balancing the covariates across groups, I find that cancer patients experience higher mental burden compared to patients without cancer. The results are robust across different measures of burden and estimation techniques. Gender and localization of cancer are also significant contributing factors to patients' mental burden, for example, cervical cancer which is uniquely a gynecological cancer is significantly associated with higher intensity of mental burden relative to all other categories of patients.

The study contributes to the growing attention to mental illness in the developing countries. Policymakers in low and middle income countries do not yet consider mental illness as a public health concern. The Mental Health Atlas, a recent global survey shows the inadequacy of developing countries to tackle mental health problems. The allocation of resources or investment in mental health is less than one percentage in developing countries. With majority of burden on poor countries, more than 90% of the global mental health resources are available in high income countries. The lack of policy attention is also driven from lack of research; only six percentage of all the published research on mental disorders was from low and middle income countries (Patel, 2007). Poverty, health shocks, experience of violence, lack of social networks are the primary determinants of growing mental illness. Also, any health shock can bring in poverty or can contribute to the determinants of mental problems. In my study, specific to cancer, depression is found to be one of the factors contributing to cancer mortality. In a meta analysis, Pinquart and Duberstein (2010) found that the relative risk for mortality increases by 19% among the depressed cancer patients. Through my primary survey on patients, I am trying to appeal to the limited available evidences of mental burden in the developing world. Also, as a point of departure to the oncology literature where studies on clinical depression is common, my paper addresses the holistic wellbeing of cancer patients.

3.2 Data & Measures

Seven hospitals located in the southern and central region of Nepal, cater to most of the cancer patients of the country (Pradhananga et al., 2009; Bhatt et al., 2009; Subedi and Sharma, 2012). Understanding the importance and inflow of cancer patients to these hospitals, I surveyed five of these hospitals namely Bir Hospital, Birendra Military Hospital, Bhaktapur cancer hospital, Dhulikhel hospital, and B.P Koirala Memorial hospital.[1] At these hospitals, I surveyed 600 cancer patients who are 18 years and older. The cancer patients were randomly selected from the hospitals over a span of three months. Enumerators involved in data collection process visited the hospitals to track the cancer patients (both inpatients and outpatients). The total number of patients selected for interview from each hospital depends on the volume of new cancer patients that a hospital receives in a cycle of treatment year.[2]

I compare cancer patients to a control group. Bhaktapur cancer hospital and B.P Koirala Memorial hospitals are cancer super-specialty hospitals, so the control patients are sampled from the remaining Bir, Dhulikhel, and Army hospitals. The 200 control patients are (a) Inpatients with chronic medical conditions and some acute conditions which may lead to being a chronic syndrome (b) Have no current or past history of cancer (c) 18 years or older, and (d) Hospitalized for more than three days

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[1] I also approached the Teaching hospital of Tribhuvan university for the study. However, all their cancer patients are referred to either Bir or Bhaktapur hospitals made it redundant to include it in the survey.

[2] B.P Koirala Memorial hospital is the first and biggest national cancer center in Nepal with an estimate of 5442 new cancer patients admitted for treatment in the year 2010. Patients in Bhaktapur and Bir hospitals significantly increased with 1387 and 686 new patients in Bhaktapur and Bir respectively in the same year.

and done more than two diagnostic testings. Hospitals and the associated number of observations collected from each of them are given in Table 3.1.

[Table 3.1 here]

3.2.1 Descriptions of the variables

In this section, I describe the dependent and independent variables of the study. Both cancer and control patients have responded to the following questions with respect to their own disease adversities.[3]

Dependent variable

My primary dependent variable of interest is *Mental Burden-Disease 1*. This index is measured using five different variables: if patients are worried about their financial conditions due to illness, face family level distress, feel concerned/ awkward regarding appearances, feel that they have lost hope in the fight against illness, and are worried about physical disabilities. I measure all these variables on a four-point scale where four indicates facing such situations on an everyday basis and one indicates that they do not face a situation like this at all. This is a disease related measure of burden. A continuous index is created where a higher value represents a higher intensity of mental burden faced by the patients.

Mental Burden-Disease 2 includes additional depression variables such as: they have little interest or pleasure in doing things, feeling down, depressed, or hopeless,

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[3] The questions measuring general and disease specific mental burden are extracted from PHQ-9 and FACT-G questionnaires.

feel like hurting themselves or consider themselves as better off dead. This measure is more stringent compared to *Mental Burden-Disease 1* and represents a higher severity of mental stress.

Manifestation of mental burden can also be assessed through the following questions: do their heart pound fast in most of the days, feel like vomiting, or have chest pain. Individuals who face all these conditions on everyday basis suffer from the highest intensity of burden [*Mental Burden-Disease 3*].

Finally, I also tried to capture the self-assessed health status of individuals. *Self-Assessed health* is measured using two variables, how good they consider their general life is and if they are content with their quality of life. Both the variables are measured on a four-point scale where one represents not good at all, and four represents in a very good state. This index ranges from two to eight, where eight accounts for a higher self-rating of individual's health and two indicates a poorer health rating.

Independent variables

Social Support

An interpersonal social support indicates social network or familial ties of individuals. I measure social support using eight different indicators: if patients have several people to talk to when lonely, have trustworthy people to help solve their problems, meet with family or friends on a daily basis, have someone to help with daily works, have someone to share most private worries and fears, have close family members to support through diagnosis, do not feel embarrassed nor do they want to hide their disease from public.

All these indicators are measured on a four-point scale where one indicates definitely true and four as definitely false. The higher the number is, the higher is the social isolation and lower social support and vice-versa. I created three different binary variables *(Higher support, Moderate support, Low support)* using the above responses. *Higher support* implies stronger familial ties and less social isolation whereas *Low support* indicate greater social isolation. The variable Social Support is a post treatment effect. It affects the outcome variable but does not predict the likelihood of cancer or control diseases.

Lifestyles and Habits

The covariates that define life style and individual habits may predict cancer as well cause mental burden. I assess these behaviors through their drinking and smoking habits, physical activities, and their routine screening for diseases. Also, indoor pollution, use of wooden fuel for combustion, and whether they are exposed to outdoor pollution directly or indirectly contribute to individual's susceptibility to diseases and mental burden.

Economic Expenses

Economic expenses include direct and indirect cost of treating the disease. The components of direct cost for cancer patients are expenses related to screening, hospitalization, surgery, chemotherapy, radiation therapy, physician visit, drugs, and medical devices. For a control patient, I asked about their expenses for X-rays, hospitalization, outpatient charges, doctor's visit, drugs, nursing fees, and charges on medical devices during the last month. Similar to the social support indicator, expenses result from treating the diseases, hence does not affect the likelihood of treatment.

Socio-Economic Indicators

Socioeconomic indicators such as Income, Education, Ethnicity, Occupation, Marital status, and age are included as confounding variables. Income is a categorical variable where *Income<10k*, *Income 10-20k*, *Income 20-30k*, *Income >30k* represents an income level less than NPR 10,000, between NPR 10,000- 20,000, between NPR 20,000-30,000, and finally more than NPR 30,000 respectively. Similarly, I have four categories of educational level such as no form of formal education *(No Education)*, highest level of education till Class 8 *(Education class 1-8)*, educational attainment of Class 12 *(Education class 9-12)*, and finally patients who have received educational level of more than Class 12 *(Education class >12)*. Under occupational status, I categorize individuals as *Unemployed*, engaged in agricultural activities *(Agriculture)*, *Self-employed*, administrative or executive jobs *(Ad-Ex jobs)*, *Laborers*, and finally *Housewife*. Other demographic characteristics include *Marital status*, *Age*, *Family history of cancer* and ethnic groups.

3.3 Descriptive Statistics

Figure 3.1 provides the distribution of mental burden across cancer and control groups. The equality of the two distributions are tested using Kolmogorov-Smirnov test (K-S test) to find that mental burden of cancer patients stochastically dominates the distribution of control groups. Further, through Mann-Whitney test, I found that the median value of the two distributions are also statistically different.[4]

[Figure 3.1 here]

In Table 3.2, I provide the descriptive statistics of independent variables that serve to distinguish individuals belonging to cancer and control groups. The groups differ in their experience of mental burden as well as on various other factors such as age, index of social isolation, education, and income to name a few. Thus, it is important to establish a balance of the covariates between the two groups before establishing any causal relationship with mental burden. The mean intensity of burden ranges from 12.13 units to 20.54 units for cancer patients. Patients belonging to the control groups have 1.13 units higher *Self-Assessed Health* status than the cancer patients. The differences in the intensity of burden between the two groups are statistically significant across all the indicators.

Patients from both the control and cancer groups demonstrate a relatively better connection with their family. Nevertheless, a significantly higher percentage of control patients receives *High Support* post diagnosis with their disease. Smoking and alcohol-

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[4] The statistical test of the two distributions is done using *Mental Burden Disease-1* variable.

use are prevalent in both groups of patients. Not surprisingly, treatment expenses significantly differ between the groups. Cancer patients do incur higher amount of economic burden (10.70 vs 8.97 for controls). The socio-economic indicator of the sample reflects a lower strata of society with low educational attainment and income level. Moreover, the cancer group of patients seem to be poorer as 65% of them self-reported an income of NPR 10,000 or less. Only 5% of the patients have reported an income of more than NPR 30,000. In addition, majority of the cancer patients have no educational attainment (59%). Finally, the percentage of married individuals is significantly higher in the treatment group.

[Table 3.2 here]

3.4 Empirical model

3.4.1 Propensity Score Matching

In the evaluation literature, where data are not developed out of randomized controlled experiments, estimation of the effect of treatment may be biased due to presence of confounding factors. Randomized controlled experiments are ideal for comparative studies where the two groups (treatment and control) are often directly comparable. Random treatment allocation ensures that the two groups are measured on similar baseline characteristics. Thus, effect of treatment on outcomes is measured directly by comparing the results of treated and untreated subjects (Bullen et al., 2013; Jacka et al., 2017). But for studies which use observational data (non-randomized experiments), such direct comparisons can be misleading because the baseline characteristics of treated and untreated groups can differ systematically (Rosenbaum and Rubin, 1983; Norgaard et al., 2017). Estimating treatment effects using linear regressions will provide bias estimates under the presence of confounding variables leading to endogeneity issues. Therefore, one must account for these differences before determining the effect of treatment on outcome.

Propensity Score matching techniques (PSM) are a better way to handle the confounding effects (Rosenbaum and Rubin, 1983). They relax the parametric assumptions associated with regressions and provide balancing scores used to group treated and control units so that direct comparisons become meaningful. For an unbiased estimation of the causal effect, I need to establish the balance in the distribution of covariates between the treatment and control groups. Subjects of the treatment groups which are not comparable to control groups are excluded from the analysis. The application of propensity score in an observational data involves estimating the propensity score through a matching algorithm, assessing covariate balance following matching, calculating the causal effects, and finally performing sensitivity checks. Before applying PSM, three key underlying assumptions are needed to be followed: (a) Conditional independence: After conditioning on the covariates, there should not be any observables which can affect both treatment assignment and potential outcomes b) Overlap assumption: This assumption requires that for each individual, there should be a positive probability of receiving the treatment level, i.e., everyone is likely to receive any of the treatment levels. c) i.i.d: Under this assumption, the potential outcome and treatment status of each individual are assumed to be unrelated to the outcome and treatment status of all other individuals in the population.

Estimating Propensity Score and effect estimates

The PSM is explained through the equation below:

$$Y_i = Y_{0i} + T_i(Y_{1i} - Y_{0i}) \tag{1}$$

$$p(X) = Pr(T_i = M|X_i) = E(T_i|X)$$

Y_{1i} = The potential outcome of unit ‘i’ if exposed to the treatment;

Y_{0i} = the potential outcome of unit ‘i’ if not exposed to the treatment;

$T_i \epsilon 0, 1 =$ treatment received by unit ‘i’ (binary treatments)

$T_i \epsilon 1, 2, M =$ Multivalued treatment received by unit ‘i’.

X = the set of pre-treatment characteristics.

I match the two groups of patients using pre-treatment characteristics only. Explanatory variables that are affected by the treatment such as *Social Support* and *Ln(Expenses)* are excluded from the matching equations. All other ‘Life styles and Habits’ and ‘Socio-economic indicators’ covariates are used in estimating the propensity scores. After estimating the propensity scores [p(X)], I match the individuals with similar propensity scores in order to compare their mental burden.

Propensity score involves running a logistic regression to model the probability of receiving a binary treatment given X in the following way:

$$ln\left[\frac{Pr(T_i = 1|X_i)}{1 - Pr(T_i = 1|X_i)}\right] = \alpha_0 + \alpha_1 x_1 + \alpha_2 x_2 + ... + \epsilon \tag{2}$$

For multivalued treatment categories, I run a multinomial logistic regression. It models the probability that a treatment assignment equals each of its possible values as a function of a linear combination of the covariates (McCaffrey et al., 2013). The extracted probabilities from the above regression is used as weights in the outcome equation. The weights are reciprocal of the probability of receiving the treatment they received.

$$Pr(T_i = t|X_i) = \frac{e^{\beta'_t X_i}}{1 + \sum_{t'=1}^{M-1} e^{\beta'_{t'} X_i}}$$

$$Pr(T_i = M|X_i) = \frac{1}{1 + \sum_{t'=1}^{M-1} e^{\beta'_{t'} X_i}}$$

The effects of being in the treatment and control groups is measured through average treatment effects (ATE) and average effect of treatment on the treated (ATT). The ATE evaluates the impact of a program over the population. It is the difference between the potential outcome means for the treated and control groups.

$$E(Y_{1i}|T_i = 1) - E(Y_{0i}|T_i = 0)$$

Most often, we would like to compute the average treatment effect on the treated (ATT).[5]

The ATT is the average effect of treatment on those subjects who ultimately received treatment and is given as follows:

$$\tau = E(Y_{1i} - Y_{0i}|T_i = 1)$$

$$E(Y_{1i}|T_i = 1, p(X_i)) - E(Y_{0i}|T_i = 0, p(X_i))$$

Matching Algorithm and covariate balance

The propensity score p(X) is a continuous variable; hence, the probability that two units of each group will have the exact matching score is almost zero. Thus, there are several matching methods based on which we match the treatment and control subjects. I used the nearest neighbor, radius/caliper, kernel, and stratification matching method to match the treatment and control group of individuals.[6] Balancing property

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[5] The ATT is given by the formula:

$$\tau^{ATT} = \frac{1}{|N|}\sum_{h \epsilon N}\left(y_h - \frac{1}{|j_h|}\sum_{j \epsilon j_h} w_j yj\right)$$

where J$_h$is the number of treated households, $J_h$is the set of comparison units matched to treated household h, $|J_h|$is the number of matched households inJ_hy is the outcome of the treated and matched households; and w_j is the weight assigned to matched household j

[6] Nearest neighbor matching (NM): An individual from the comparison group who is closest to a treated individual regarding their propensity scores is chosen to be included in the sample for estimation. The process continues until all the treated are matched, and the remaining unmatched control patients are dropped from the analysis. Radius matching: This method needs

measures the extent to which the distributions of propensity scores in the treatment and comparison groups overlap, i.e I measure the range of common support. The stratification method test if the mean propensity score is equal in the treatment and comparison groups within each quintile of the samples. The process continues until the balance is achieved. I also ensured if the covariates are balanced between the treatment and comparison groups within each block of propensity scores.

Sensitivity Analysis

Given there are few controls in comparison to the treated individuals, earlier I matched the two groups with replacement, where an untreated individual is used for more than once as a match to each treated units. When replacement is allowed, the average quality of matching increased and the bias decreased, but it also involved a trade off between bias and variance given the matched controls are used more than once under replacements (Stuart, 2010; Caliendo and Kopeinig, 2008). There are two possible ways to address these concerns. First, by doing matching without replacement (one to one matching) where one cancer patient is matched with one control while estimating the causal effect (Smith and Todd, 2005; Caliendo and Kopeinig, 2008). Second, through weighting strategy, where weights are assigned to balance the treated and untreated observations which in turn retained the entire bulk of sample (Starks and

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to pre-specify a caliper distance, which is a tolerance level on the maximum propensity score range. For a treated subject one would identify all those untreated subjects whose propensity score is within a specified distance of the treated subject and hence are included in the analysis. Kernel matching is a nonparametric estimator that uses weighted averages of all individuals in the comparison group. Untreated units with propensity scores closer to the treated individuals are given higher weights. Stratification matching. Stratification involves stratifying the subjects into mutually exclusive subsets based on their propensity scores and calculating the impact within each interval through the mean difference in outcomes between treated and control observations

Garrido, 2004). It gives more weights to the proximal matching and less weights to the distantly matched observations. The four weighting estimators are Regression Adjustments (RA), Inverse Probability Weighting estimators (IPW), Augmented Inverse Probability weight (AIPW), and Inverse-probability-weighted regression-adjustment (IPWRA).[7]

3.5 Results

3.5.1 Binary Treatments

The propensity scores are estimated through modeling the likelihood of treatment with a set of covariates.[8] The common support property between the groups is assessed through sufficient overlap of the range of propensity scores across treatment and comparison groups [Figure 3.2]. In addition, I determine if the covariate balance is sufficiently achieved between the two groups under study.[9] In Figure 3.3, the groups that were not similar before matching, achieved covariate balance under propensity score matching estimators.

[Figure 3.2 here]

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[7] (a) Regression Adjustments (RA): RA models the outcome equation without making any assumptions about the probability of treatment. (b) Inverse Probability Weighting estimators (IPW): IPW estimators model the probability of treatment without making any assumptions about the functional form of the outcome model.(c) Augmented Inverse Probability weight (AIPW): AIPW models both the treatment and outcome equations separately. AIPW, known as doubly robust.(d) Inverse-probability-weighted regression-adjustment (IPWRA): Similar to AIPW, IPWRA are also doubly robust estimators, which models both the outcome and treatment status.

[8] The results are not shown in the paper. They are available upon request

[9] An optimal number of six blocks ensured that the mean propensity score is not different for treated and controls under each blocks

[Figure 3.3 here]

In Table 3.3 below, I present the average effect of treatment on experiencing mental burden.[10] After controlling for the confounding variables such as *Social Support*, *Lifestyles and habits*, *Economic Expenses*, and *Socio-demographic variables*, I found that having cancer can be associated with a maximum of 2.69 units higher mental burden compared to the control individuals. The average treatment effects are found to be significant across all the propensity score matching techniques. As the treatment and control subjects are matched based on the minimum distance of propensity scores (NM matching), the cancer patients are found to suffer mental burden in the range of 1.99 to 2.29 units higher than the control groups across different measures of burden. Radius matching is a relatively conservative method with a permissible caliper distance of 0.01 between the two groups. Under this matching method, cancer patients face mental burden as high as 2.19 to 2.69 units higher to the control group. With Kernel matching all treated are paired with a weighted average of all controls with a maximum ATT estimated to be 2.08 units higher than the control group. Finally, under the stratification method, which stratifies the sample based on the propensity score, I find having cancer can lead to 2.08 to 2.54 units higher burden. The Self-Assessed health status on the other hand is negative and significant for the cancer patients indicating a poorer rating of individual health.

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[10] Mental Burden Disease-1, Mental Burden Disease-2, Mental Burden Disease-3, Self-Assessed Health are explained in ‘Data and Measures’ section.

[Table 3.3 here]

Sensitivity analysis: Binary Treatment

In this section, I present a sensitivity analysis of four pairs of regression models each estimated under 'with' and 'without replacement' techniques. The results are presented in Table 3.4. In this table, the first column for all the mental burden indicators represents one to one matching (without replacement) and the second columns are regressions with replacement (more than one comparison units are matched with one treated unit). The treatment indicator is significant and positive for all the mental burden models and negative for the *Self-Assessed* health status reinforcing the earlier findings that cancer patients do experience a significantly higher amount of mental burden compared to their counterparts and their self-report of health status is significantly low. Both the estimation techniques with or without replacement have similar ATT across all the measures of mental burden.

The extent of social isolation also seem to affect the likelihood of mental burden among the patients. Higher social isolation indicates low support from the family. Relative to having greater familial support, if a patient experience *Moderate support* or *Low Support*, it significantly increases their emotional stress. The sign and significance of *Social Support* remain uniform across different specifications. Physical activity such as *Exercise* decreases whereas higher treatment cost [*Ln(Expenses)*] is reflective of higher mental burden and less self-assessed health. Overall, both types of models, with or without replacement exhibit similar estimates and significance levels of the parameters except those of the *Socio-Demographic characteristics*. Higher income, better education level, and age seems to decrease mental burden only after allowing for replacement.

[Table 3.4 here]

In addition, as a part of robustness analysis, I also estimated the causal effect of cancer using four different treatment effect estimators such as RA, IPW, IPWRA, and AIPW. Table 3.5 gives the ATE and ATET estimation results. It also provides the potential outcome means (POM) of the control groups of patients relative to different estimation techniques.[11] As can be seen from the table, the POM for a control patient is in the range of 10.05 to 10.56 for the first index of mental burden. The ATET values reflect that the average treatment effect of cancer patients is 1.63 to 1.98 units higher to the POM of the control patients under different estimation techniques. All the ATET and ATE values under different indicators of burden are significant and positive indicating that cancer patients are significantly higher in their measures of burden. The values are negative and significant for *Self-Assessed Health*. The results shown in Table 3.5 reconfirms the findings of Table 3.3 and Table 3.4. It says that irrespective of the measures of mental burden and methods used for matching or weighting the two groups, cancer patients face significantly higher mental burden and rate their health poorly when compared against the control groups.

[Table 3.5 here]

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[11] POM refers to the means of the potential outcomes for a specific treatment level

3.5.2 Multivalued Treatment effects

In addition to studying heterogeneity of mental burden across cancer and control groups of patients, I looked into mental burden from gender perspective. In an attempt to do it, I extended the current state of literature by comparing female specific cancers to male cancer patients and control patients. Through this, I am not only distinguishing female with male cancer patients, but also comparing mental burden within female patients. Cervical and breast cancer are the two types of female specific cancers, both of them have unique gender implications which can lead to excessive burden. Both of these cancers have been the predominant ones for the last 10 years in Nepal (Poudel et al., 2016). I hypothesize that cervical cancer is even more invasive in the life of the patients since it gives rise to sensitive gynecological issues affecting interpersonal relationships. Therefore, this group is closely studied under multivalued treatment effect indicators. As in the binary case, the estimation started following a covariate balance. To assess the balance, I estimated the weighted regressions of the treatment effects onto different independent variables. The regressions are weighted with the inverse probability weights calculated from multinomial logistic regressions of the treatment model. Higher weights are given to better matches and vice versa. In Addendum 3.1, I presented the weighted and unweighted regressions for all the covariates as a function of different treatment indicators. No significant differences remained between different groups of patients after weighting; i.e the distribution of covariates across different groups of patients is same and the covariate balance is achieved. The effect estimates for different categories of mental burden calculated under RA, IPW, IPWRA, and AIPW are given in Table 3.6. The treatment effect captures the deviation of mental burden faced by other group of patients in relation to the POM of cervical cancer patients. The treatment effects are uniformly negative for all other categories of patients across different measures of burden. According to the doubly robust IPWRA estimator, all other female cancer patients, male cancer patients, and control patients experience significantly lower intensity of mental burden in the range of 1.83, 2.63, and 3.31 units respectively. With regards to the third measure of mental burden (*Mental Burden Disease-3*), not the localization, but a significant gender heterogeneity in burden is evident. Finally, *Self-Assessed Health* does not differ significantly within groups of cancer patients.

[Table 3.6 here]

My findings suggest new avenues for future research. It will be important to delineate the relationship further in future to see what unique characteristics of cervical cancer lead to such a higher magnitude and heterogeneity of burden within them. With cross sectional data, causal relationships cannot be validated. Hence, I resort to two approaches: (a) Item level analysis to see which component of the mental burden mattered most for cervical cancers (b) Validating the findings with help of existing literature.

3.5.3 Item level analysis

I measure effect size using the statistical technique Cohen's d, which is a standardized mean difference of *Mental Burden Disease-1* between cervical and non-cervical cancer patients.[12] The mean scores of the two groups by different indicators of burden and the 'd' statistic is given in Table 3.7. Most of the items show higher mean scores for the cervical cancer group. The greatest difference between the two groups, expressed in effect size is found for *Family distress (d=-0.47)*, followed by *Worried about finance (d=-0.35)*. This indicates that the non-cervical cancer patient face 0.47 SD lower familial distress than their counterparts. The value is 0.35 SD in case of finance related worries.

[Table 3.7 here]

The highest value for family level distress gives an indication that cervical cancer can be intrusive to familial relationship. Specially, the nature or characteristics of cervical cancer are such that it disrupts the intimacy among couples (Bergmark et al., 1999). In the absence of household data on the dynamics of domestic relationships, I resort back to literature to see what variables might explain the mental burden. However, this is only a discussion for future research and with the present data limitations, I am unable to test them empirically.

3.5.4 Literature on cervical cancer and emotional stress

Violence as a risk factor to cervical cancer

There is a growing literature linking domestic and sexual abuse with the risk of developing cervical cancer. Abuse of any nature increases the mental and emotional

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[12] The effect size is a sub-sample analysis of only the cancer patients. It is the difference in the mean mental burden of the two groups divided by the pooled standard deviation (SD) for the entire group.

burden in the patients. According to Hindin et al. (2015), there can be three various pathways through which violence can increase the risk of cervical cancer. First, sexual violence affects a womens control over her choice to engage in sexual intercourse and use of condoms, which make them prone to sexually transmitted diseases like Chlamydia and Human papillomavirus (HPV). STI in turn may lead to cervical cancer (Coker et al., 2009; Ramaswamy et al., 2011; John et al., 2004; Loxton et al., 2006; Modesitt et al., 2006). HPV is the most important risk factor for cervical cancer spread from a partner infected with HPV infection. In a sexually abusive relationship with multiple partners, the likelihood of contracting genital infection increases. Women infected with high-risk types genital HPV (HPV 16/ HPV18) can eventually develop cervical cancer (American Cancer Society, 2016).

Second, victims of any form of violence may resort to smoking, psychological stress, and adhere to risky health behaviors as a means to cope with their experience of violence. All these are risk factors to cervical cancer through damaging the DNA of cervix cells and contributing to the development of cervical cancer.

Finally, it may be the low resources and authority imposed by an abusive husband to proper screening for STIs or the delay and discontinuation of treatment due to limited financial help and inability to seek cancer services that may eventually lead the STI take the shape of cervical cancer.

Cervical cancer patients face higher interpersonal violence (IPV)

As discussed before, abuse and violence can be a risk factor to cervical cancer, also cervical cancer can lead to violence. As defined by The Center for Disease Control, one in four women has experienced severe physical violence by an intimate partner in their lifetime (Black et al., 2011). If we expand our definition of IPV to include sexual violence and assaults, we see that women with cervical cancer faces sexual violence twice compared to women who never had cancer before (Coker et al., 2009). The side effects of cervical cancer treatment can lead to anatomic and physiological changes to one's genital organs giving rise to dysfunctions in an intimate relationship (Basen-Engquist et al., 2003).

Bergmark et al. (1999) found that women with cervical cancer undergo changes in their vaginal anatomy including decreased lubrication, genital swelling, vaginal bleeding, and reductions in perceived vaginal length and elasticity during intercourse. In addition, women of childbearing age reported moderate or much distress because of the infertility that resulted from the disease. These negative effects on their sexual functioning ultimately is a source of higher level of distress faced by the patients. Even among the survivors of cervical cancers, sexual worry and dysfunction are evident, which impact their QOL (Le Borgne et al., 2013). Sexual distress between partners is studied in (Vermeer et al., 2015). They found that half of the cervical cancer survivors reported professional healthcare needs for their sexual concerns. This lack of sexual satisfaction between partners can therefore give rise to higher violence.

Treatment side effects: Radiation

Low quality of life can also be a result of the treatment process. During radiation therapy, it is recommended that women do not have a sexual relationship with their partners. It could hamper their treatment process and can be physically painful for the women. Studies have shown that irradiated cervical cancer patients had a significantly worse sexual functioning as compared to surgical patients or control patients after taking into account their tumor size, histology and stage of cancer (Frumovitz et al., 2005). All these symptoms taken together creates a lower QOL among these patients (Greimel et al., 2009). In a study of 26 couples with the women suffering from cervical cancer, couples admitted disruptions in their relationships and lack of intimacy. The instrumental life domains are said to have been interrupted due to the prognosis and the treatment of the disease (de Groot et al., 2005).

Treatment side effects: Hysterectomy

Hysterectomy is a surgical procedure for cervical cancer patients where the uterus is removed from the women's body as a process of treatment. For a young cervical cancer survivor, this sudden and unexpected event brings in infertility. Hysterectomy is found to complicate mental health illness and can significantly lead to post traumatic stress disorder among the patients (de la Cruz et al., 2016).

3.6 Conclusion

In this paper, I have attempted to measure the extent of the differences in mental burden experienced by cancer patients in comparison to their counterparts. I surveyed 600 cancer and 200 control patients and applied propensity score matching techniques to arrive at a comparable sample. After assessing the covariate balance, four different matching methods of PSM such as nearest neighbor matching, radius matching, kernel, and stratification methods are employed to compute the effect of having cancer on mental burden. Separate regression analysis on different indicators of burden shows that cancer patients face a significantly higher intensity of emotional stress than control groups as demonstrated in some other studies (Osborne et al., 2004; Hinz et al., 2010).

My analysis is extended to include different types of cancer patients. Specially, cervical cancer patients are studied in relation to other female cancer patients, all male cancer patients, and control patients. I concluded that cervical cancer patients face a significantly higher amount of burden, which is particularly true for *Mental Burden Disease-1*, and *Mental Burden Disease-2*. Attempts have been made to explain these findings with the support of previous literature and item level responses. Both the approaches give evidences that cervical cancers patients face higher magnitude of familial distress. The literature claims sexual violence as one of the predictors of cervical cancer (Coker et al., 2009; Basen-Engquist et al., 2003) which in turn also leads to higher mental burden. Other factors that contribute most to emotional stress include lack of social support and higher medical expenditure.

The cervical cancer approach as a gender aspect is an important contribution of my paper. Most of the studies in previous literature have studied gender heterogeneity comparing male vs female patients. However, in this paper, I am studying gender components in more detail by teasing out female specific cancer on different measures of burden. In addition, the exhaustive empirical approach and the uniformity in results across different econometric specifications contribute to validate the findings.

But, there are some limitations of the paper which should also be addressed. First, mental or emotional distress can be transitory or persistent. Therefore, we should be cautious while interpreting the results. Due to the lack of longitudinal data, it was only possible to reflect on their current state of health. I do not have information on their pre-cancer stress levels or late-term survivor effects to study long-term individual outcomes (Occhipinti et al., 2015; Perez et al., 2001; Stommel et al., 2004; Zabora et al., 2001; Duijts et al., 2016). Second, due to the unavailability of relevant information, I could not explore the different channels impacting a cervical cancer patient. A comprehensive household survey with a module on domestic violence is needed to rigorously delineate such relationships. These shortcomings suggest avenues for future research.

Nevertheless, the findings of the study lead to the following policy recommendations. Counseling services should be readily available and accessible for cancer patients. Hospital authorities should be proactive in delivering such services as a part of their treatment procedures. Counseling as a part of medical treatment is practiced in different countries (Copur et al., 2015; Kowalski et al., 2016, 2015; Kadan-Lottick et al., 2005). Similar consultations should be made available in the hospitals of Nepal. (b) Also, the present study is instrumental in identifying specific cancers whose side-effects are not limited to physical disabilities but may lead to dysfunctional relationships yielding to even higher mental burden. Female patients especially those who have cervical cancer should be given special attention because they appear to be the most vulnerable group. Cervical cancer is highly linked to family related challenges. Therefore, authorities should make concerted efforts to hold discussions with both the husband and wife explaining them about the common side effects of cervical cancer.

Figures and Tables

Figure 3.1: Distribution of mental burden across cancer and control group of patients

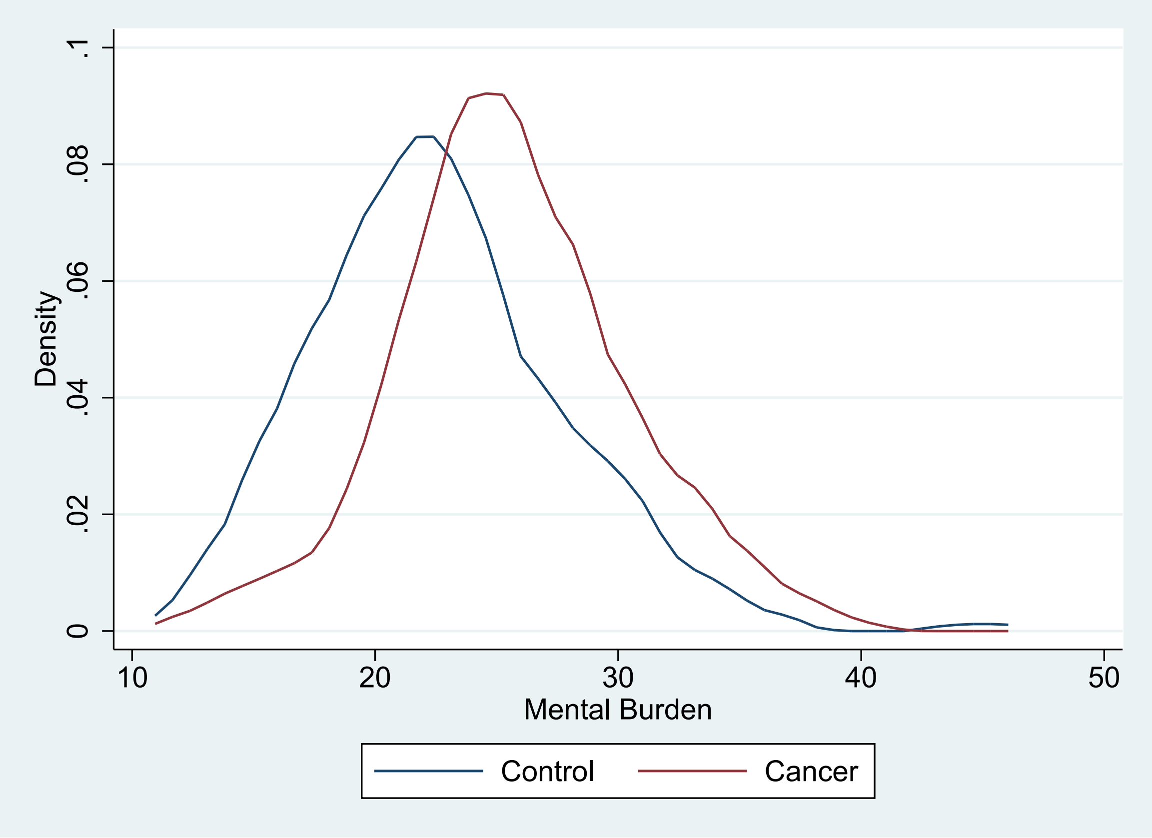

Figure 3.2: Common support region by treatment groups

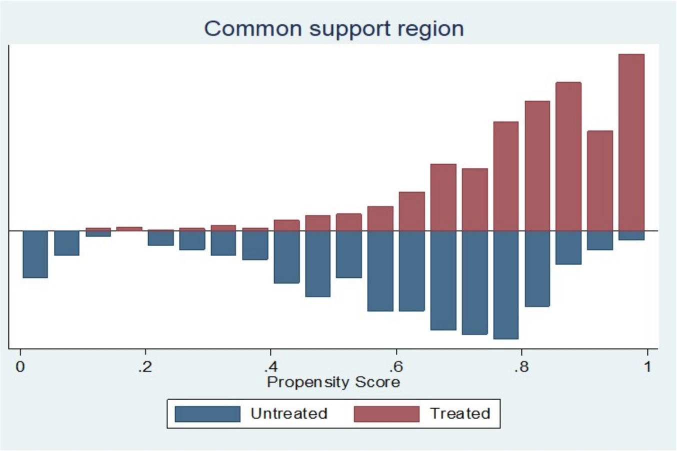

Figure 3.3: Balance density plot : Raw and Matched sample

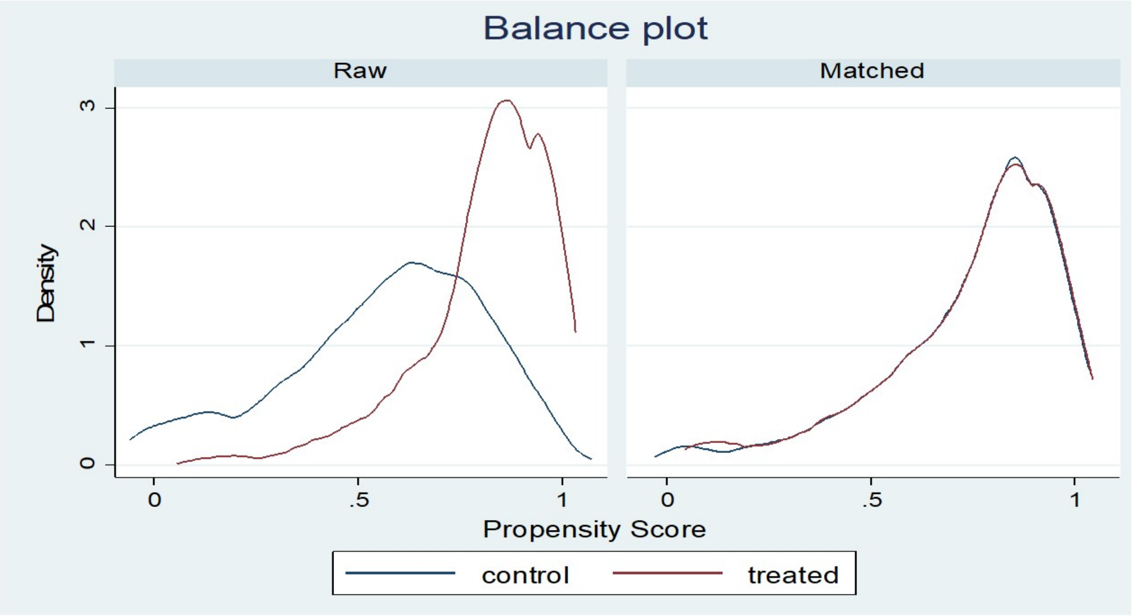

Table 3.1: Distribution of cancer patients across cancer hospitals

Serial No.	Name of the hospitals	Cancer patients	Control patients
1	Bhaktapur Cancer Hospital	186	0
2	Bir Hospital	119	105
3	Dhulikhel Hospital	62	65
4	Birendra Army Hospital	24	30
5	B.P Koirala Memorial Hospital	209	0

Table 3.2: Descriptive Statistics of Treatment and Control groups

Variables	Treatment	Control	p value
Dependent variables			
Mental Burden- Disease1	12.13 (0.14)	9.62 (0.22)	0.00
Mental Burden- Disease2	18.38(0.20)	15.11(0.32)	0.00
Mental Burden- Disease3	20.54(0.20)	17.82(0.35)	0.00
Self-Assessed Health	3.90(0.07)	5.03(0.13)	0.00
Social Support			
High Support	0.50(0.02)	0.59(0.04)	0.03
Moderate Support	0.38(0.02)	0.32(0.03)	0.11
Low Support	0.10(0.01)	0.08(0.02)	0.36
LifeStyle / Habits			
Alcohol	0.25 (0.01)	0.35 (0.03)	0.0063
Smoke	0.30 (0.01)	0.33 (0.03)	0.38
Exercise	0.34(0.01)	0.48 (0.003)	0.0003
Kitchen-inside	0 .75 (0.01)	0.80 (0.02)	0.15
Wooden Fuel	0.62 (0.01)	0.62(0.03)	0.96
Live_Mainroad	0.40 (0.02)	0.33 (0.03)	0.1
Screening for cancer	0.17(0.01)	0.01(0.007)	0.00
Economic Expenses			
Ln(Expenses)	10.70 (0.08)	8.97 (0.23)	0.00
Ethnicity			
Brahmin	0.24(0.01)	0.26(0.03)	0.53
Chhetri	0.17(0.01)	0.22 (0.02)	0.11
Newar	0.17(0 .01)	0.16 (0.02)	0.85
Janajati	0.24 (0.01)	0.18(0.02)	0.08
Dalit	0.15(0.01)	0.15 (0.02)	0.92
Income Level			
Income_<10k	0.65(0.02)	0.52(0.04)	0.002
Income_10-20k	0.20(0.01)	0.20(0.02)	0.93
Income 20-30k	0.10(0.01)	0.21(0.03)	0.0003
Income >30k	0.05(0.008)	0.07(0.02)	0.18
Educational Level			
No Education	0.59(0.02)	0.43(0.03)	0.0001
Education class 1-8	0.20(0.02)	0.21(0.02)	0.8
Education class 9-12	0.16(0.01)	0.29(0.03)	0.0001
Education class >12	0.03(0.007)	0.065(0.01)	0.13
Occupation			
Unemployed	0.36(0.02)	0.37(0.03)	0.75
Agriculture	0.24(0.02)	0.12(0.02)	0.0002
Self-Employed	0.09(0.01)	0.11(0.02)	0.46
Ad_ExJobs	0.04(0.008)	0.14(0.02)	0
Laborers	0.07(0.10)	0.11(0.02)	0.07
Housewife	0.16(0.02)	0.14(0.02)	0.32
Other Socio-economic			
Married	0.94 (0.009)	0.85(0.02)	0
Age	52.18 (0.58)	44.79 (1.29)	0.00
Family history of cancer	0.12 (0.01)	0.08 (0.01)	0.16

Table 3.3: PSM across different Mental burden measures
(Cancer and Control groups)

Dependent variables / Matching estimators	**Cancer**	**Controls**	**ATT**	**Bootstrapped Std. Err**	**t statistics**
Mental Burden Disease-1					
Nearest Neighbor matching	591	134	1.99***	0.35	5.72
Radius Method	549	185	2.19***	0.31	6.96
Kernel Matching Method	591	189	2.08***	0.30	6.99
Stratification Method	591	189	1.88***	0.31	5.96
Mental Burden Disease-2					
Nearest Neighbor matching	591	134	2.29***	0.44	5.22
Radius Method	549	185	2.69***	0.42	6.39
Kernel Matching Method	591	189	2.54***	0.42	6.04
Stratification Method	591	189	2.34***	0.37	6.29
Mental Burden Disease-3					
Nearest Neighbor matching	591	134	2.03***	0.52	3.87
Radius Method	549	185	2.29***	0.52	4.36
Kernel Matching Method	591	189	2.13***	0.52	4.09
Stratification Method	586	189	2.03***	0.43	4.76
Self-Assessed Health					
Nearest Neighbor matching	591	134	-1.08***	0.25	-4.34
Radius Method	549	185	-0.95***	0.18	-5.29
Kernel Matching Method	591	189	-0.96***	0.17	-5.58
Stratification Method	591	189	-1.13***	0.15	-7.23

Table 3.4: Different measures of mental burden under with and without replacement (Cancer and Control groups)

	Mental Burden Disease1		Mental Burden Disease2		Mental Burden Disease 3		Self-Rated Health	
	W/O	With	W/O	With	W/O	With	W/O	With
Treatment indicator	1.268***	1.537***	1.840***	1.783***	1.406***	1.766***	-1.061***	-1.017***
	(4.04)	(8.42)	(4.19)	(7.19)	(2.72)	(6.11)	(-5.55)	(-9.74)
Social Support								
Moderate support	1.032***	1.126***	1.463***	1.934***	1.772***	2.381***	-0.344*	-0.0192
	(3.09)	(5.69)	(3.13)	(7.19)	(3.22)	(7.60)	(-1.69)	(-0.17)
Low Support	1.723***	1.791***	3.030***	2.918***	4.039***	3.914***	-0.588*	-0.379**
	(3.10)	(5.61)	(3.89)	(6.73)	(4.41)	(7.74)	(-1.74)	(-2.08)
Economic Expenses								
Ln(Expenses)	0.214***	0.241***	0.278***	0.301***	0.264***	0.199***	-0.106***	-0.0871***
	(3.57)	(5.67)	(3.32)	(5.21)	(2.67)	(2.96)	(-2.90)	(-3.59)
Life Styles/ Habits								
Exercise	-1.155***	-1.12***	-1.72***	-1.17***	-1.90***	-1.393***	0.343*	0.195*
	(-3.76)	(-5.90)	(-3.99)	(-4.53)	(-3.76)	(-4.60)	(1.83)	(1.78)
Kitchen-Inside	-0.290	-0.0975	-0.599	-0.665**	-0.597	-0.450	0.524**	0.446***
	(-0.73)	(-0.45)	(-1.08)	(-2.26)	(-0.91)	(-1.31)	(2.17)	(3.60)
WoodenFuel	0.971***	0.329	1.336***	0.598**	1.078*	0.390	0.131	0.228*
	(2.70)	(1.59)	(2.65)	(2.13)	(1.81)	(1.19)	(0.59)	(1.94)
Live -Mainroad	0.337	0.206	0.296	-0.160	-0.00302	-0.463	0.211	0.322***
	(0.90)	(0.98)	(0.57)	(-0.56)	(-0.00)	(-1.39)	(0.93)	(2.67)
Screening for cancer	-0.450	0.488*	-0.113	0.503	-1.127	0.598	0.787	0.662***
	(-0.21)	(1.81)	(-0.04)	(1.37)	(-0.32)	(1.40)	(0.61)	(4.29)
Occupation								
Agriculture	0.635	1.179***	1.892**	1.601***	2.217**	2.301***	0.357	0.554***
	(0.99)	(4.42)	(2.11)	(4.42)	(2.10)	(5.45)	(0.91)	(3.63)
Self Employed	1.007*	0.544	1.988**	0.717	2.121**	0.702	0.592	0.661***
	(1.68)	(1.52)	(2.37)	(1.47)	(2.15)	(1.23)	(1.62)	(3.22)
AdminExecutiveJobs	0.346	-0.129	0.748	0.0235	0.248	0.0564	0.0914	0.593**
	(0.56)	(-0.27)	(0.86)	(0.04)	(0.24)	(0.07)	(0.24)	(2.13)
Laborers	0.610	0.743*	1.260	1.239**	0.467	0.297	0.406	0.757***
	(1.00)	(1.91)	(1.47)	(2.34)	(0.46)	(0.48)	(1.09)	(3.40)
Housewife	0.463	-0.247	0.649	-0.125	0.216	-0.513	0.492*	0.0299
	(0.96)	(-0.87)	(0.96)	(-0.32)	(0.27)	(-1.14)	(1.67)	(0.18)
Socio-Demographic Characteristics								
Income_10-20k	0.660	-0.178	0.0134	-0.829**	-0.338	-1.150***	0.0897	-0.382**
	(1.30)	(-0.67)	(0.02)	(-2.31)	(-0.40)	(-2.75)	(0.29)	(-2.53)
Income 20-30k	-0.205	-0.476	-0.813	-0.946**	-0.797	-1.306**	0.169	0.0458
	(-0.41)	(-1.44)	(-1.15)	(-2.11)	(-0.96)	(-2.50)	(0.55)	(0.24)
Income >30k	-0.761	-1.178**	-1.292	-1.707**	-1.671	-2.282***	0.366	-0.207
	(-1.04)	(-2.30)	(-1.26)	(-2.46)	(-1.38)	(-2.82)	(0.82)	(-0.71)

Table 3.4 contd...

Education class 1-8	-0.105	-0.123	-0.0994	-0.207	-0.231	-0.112	0.309	-0.198
	(-0.25)	(-0.49)	(-0.17)	(-0.61)	(-0.33)	(-0.28)	(1.20)	(-1.39)
Education class 9-12	0.236	-0.538*	0.397	-0.738**	0.596	-0.531	0.000805	-0.133
	(0.51)	(-1.95)	(0.61)	(-1.96)	(0.78)	(-1.21)	(0.00)	(-0.84)
Education class >12	0.971	-0.308	1.741*	0.000884	1.906	0.337	-0.132	-0.101
	(1.36)	(-0.61)	(1.74)	(0.00)	(1.62)	(0.42)	(-0.30)	(-0.35)
Age	0.0108	-0.0137*	0.0244	-0.0218**	0.0361*	-0.0209*	-0.00257	-0.00459
	(0.90)	(-1.93)	(1.44)	(-2.26)	(1.81)	(-1.86)	(-0.35)	(-1.13)
Family history of cancer	-0.800	-0.863***	-1.418*	-1.449***	-1.397	-1.901***	0.322	0.423***
	(-1.46)	(-3.35)	(-1.85)	(-4.14)	(-1.54)	(-4.66)	(0.96)	(2.88)
_cons	6.972***	8.326***	11.31***	14.43***	15.90***	19.79***	5.452***	5.219***
	(6.60)	(11.19)	(7.63)	(14.28)	(9.12)	(16.79)	(8.46)	(12.27)
N	396	1182	396	1182	396	1182	396	1182
log_likelihood	-965.5	-2907.4	-1099.4	-3270.2	-1163.9	-3451.5	-770.0	-2247.1
AIC	1991.0	5874.8	2258.8	6600.4	2387.9	6963.0	1599.9	4554.3
BIC	2110.4	6027.0	2378.3	6752.7	2507.3	7115.2	1719.3	4706.5

Note: 'W/O' indicates models without replacement and 'With' indicates models with replacement.

Table 3.5: Different treatment effects estimator across measures of mental burden (Cancer and Control groups)

Outcome variables	**RA**		**IPW**		**IPWRA**		**AIPW**	
	ATE	**ATET**	**ATE**	**ATET**	**ATE**	**ATET**	**ATE**	**ATET**
Mental Burden Disease-1	1.92***	1.98***	1.99***	1.97***	1.73***	1.63***	1.80***	-
Mental Burden Disease-2	2.29***	2.27***	2.43***	2.31***	2.08***	1.88***	2.13***	-
Mental Burden Disease-3	2.00 ***	2.01***	2.10***	2.00***	1.74***	1.52***	1.86***	-
Self-Assessed Health	-0.99***	-0.97***	-1.12***	-1.09***	-1.04***	-1.03***	-1.03***	-
POM- Controls								
[Mental Burden Disease-1]	10.05	10.20	10.02	10.16	10.26	10.56	10.18	-
[Mental Burden Disease-2]	15.90	16.17	15.84	16.07	16.13	16.56	16.07	-
[Mental Burden Disease-3]	20.58	20.48	20.56	20.81	20.86	21.33	20.74	-
[Self -Assessed Health]	4.91	4.87	5.00	5.00	4.95	4.93	4.94	-

Table 3.6: Average treatment effect across different measures of mental burden (Multiple treatment categories)

Outcome variable	**RA**		**IPW**		**IPWRA**		**AIPW**
	ATE	**ATET**	**ATE**	**ATET**	**ATE**	**ATET**	**ATE**
Mental Burden Disease-1							
Cervical cancer [Base]							
All Females	-1.01**	-1.50***	-1.26**	-1.56***	-1.05***	-1.69***	-0.93*
All Males	-1.05**	-1.86**	-1.50**	-1.64***	-1.40***	-2.19***	-1.11**
Control	-2.67***	-3.31***	-3.18***	-3.30***	-2.72***	-3.05***	-2.50***
Mental Burden Disease-2							
All Females	-0.95	-1.56***	-1.32**	-1.66**	-0.93	-1.83***	-0.80
All Males	-1.19*	-2.29***	-1.90***	-1.91**	-1.62***	-2.63***	-1.29*
Control	-2.97***	-3.62***	-3.84***	-3.73***	-3.04***	-3.31***	-2.74***
Mental Burden Disease-3							
All Females	-0.23	-0.99	-0.62	-0.96	-0.06	-1.21**	-0.03
All Males	-0.64	-1.92***	-1.30*	-1.44*	-0.90	-2.34***	-0.66
Control	-2.05***	-2.87***	-2.83***	-2.89***	-1.85***	-2.41***	-1.70**
Self-Assessed Health							
All Females	-0.25	-0.18	0.04	-0.009	-0.26	-0.07	-0.19
All Males	-0.11	-0.43	0.04	-0.30	-0.17	-0.44*	-0.09
Control	0.95***	0.70**	1.29***	1.03***	1.01***	0.83***	1.06***
[Cervical cancer]	12.70	13.61	13.29	13.63	12.97	13.80	12.73
[Mental Burden Disease-2]	18.82	19.97	19.78	20.01	19.16	20.23	18.88
[Mental Burden Disease-3]	22.59	23.84	23.52	23.8	22.71	24.06	22.54
[Self -Assessed Health]	3.94	4.12	3.7	3.95	3.93	4	3.89

Table 3.7: Item Level analysis of mental burden
(Cervical versus all other cancer patients)

Items / MentalBurdenDisease1	Cervical cancers	Other cancers	Cohen's d
Worried Finance	3.3	2.95	-0.35
Family Distress	3.25	2.76	-0.47
Awkward Appearances	2.2	2	-0.17
Lose hope against illness	2.3	1.97	-0.29
Unable to Personal care	2.37	2.22	-0.12
Little interest in things	2.37	2.24	-0.11
Depressed	2.47	2.19	-0.28
Feeling like hurting self	1.78	1.74	-0.04
Heart pounding fast	1.3	1.43	0.18
Vomiting	1.33	1.47	0.18
Chest pain	1.37	1.56	0.22
Content with QOL	1.97	1.98	0.01
General life is good	1.97	1.94	-0.03

Addendum 3.1: Weighted and Unweighted regressions on multivalued treatment categories

Regressions	Variables	Female	Male	Control	Variables	Female	Male	Control
Unweighted	**Social Isolation**	-0.06	-0.16	-0.27*	**Agriculture**	-0.10	0.28	-0.79**
Weighted		0.12	0.24	0.10		0.10	0.19	-0.11
Unweighted		0.28	1.33***	1.26***	**Self -Employed**	0.38	1.10*	0.92
Weighted	**Alcohol**	-0.90	0.33	-0.31		-0.80	-0.35	-0.75
Unweighted		0.37	1.13***	0.82**	**Ad_Ex Jobs**	0.24	1.16	2.27**
Weighted	**Smoke**	-0.75	-0.49	-0.45		2.38	1.67	1.61
Unweighted		0.06*	0.63	1.14***		-0.72	0.13	0.31
Weighted	**Exercise**	-0.77	-0.53	-0.42	Laborers	-0.11	0.65	0.40
Unweighted		0.09	0.32	0.42		-0.20	-2.53***	-1.07***
Weighted	Kitchen Inside	0.47	0.54	0.11	**Housewife**	0.33	-0.58	-0.10
Unweighted		-0.04	-0.42	-0.18		0.20	0.21	0.28
Weighted	Wooden Fuel	-0.75	-0.33	-0.34	Brahmin	0.11	-0.22	0.55
Unweighted		0.11	0.09	-0.19		0.77	1.01**	0.79
Weighted	Live-Mainroad	0.48	0.46	0.22	**Newar**	-0.62	-0.46	-0.52
Unweighted	**Screening for cancer**	-0.16	-0.55	-3.29***		-0.82**	-0.67**	-0.32
Weighted		-0.87	-0.74	-0.65	**Chettri**	0.18	0.41	0.17
Unweighted		-0.05	0.03	-1.74***	Janajati	0.28	-0.10	-0.28
Weighted	**Ln(Expenses)**	0.03	-0.07	-1.37***		-0.37	-0.19	-0.39
Unweighted	**Aggressive Payment**	0.47	-0.08	-0.69**	Dalit	-0.25	-0.16	-0.19
Weighted		-0.26	-0.50	-0.76		0.83	0.69	0.12
Unweighted	**Income**	-0.16	0.60***	0.58***	**Relative-Cancer**	-0.75*	-0.51	-0.98**
Weighted		0.09	-0.006	-0.13		0.007	0.11	1.09
Unweighted	**Education**	0.05	0.90***	0.88***	**Married**	-0.72	-1.14	-2.31**
Weighted		0.08	0.76	0.01		-1.08	-1.24	-0.15
Unweighted		0.34	0.31	0.33	**Age**	1.65	4.95***	-4.85**
Weighted	Unemployed	0.34	0.31	0.33		0.09	-0.81	1.43

Chapter 4

Measuring the economic burden of cancer due to premature cancer-related mortality in Nepal

4.1 Introduction

In the previous chapter, I have shown that cancer diagnosis can bring in a significant amount of mental burden to the patients. Also, the burden varies across different cancer sites and gender. In this chapter, my focus is in estimating the economic burden of cancer. Growing mortality from cancer not only affects the lives of those diagnosed but it also leaves a wider impact on the economy as a whole.

Economic burden of cancer arises from cancer related premature mortality or morbidity, where the former comprises of the largest proportion of productivity loss (Hanly et al., 2015). Premature mortality is the premature death of a person following cancer. Any premature death is a public health concern, and the societal loss gets magnified if deaths happen at an early ages. An early death would also imply a higher productivity loss for the society. Therefore, while measuring burden, it is important to move beyond the crude mortality rate and consider number of life years lost (YLL) and number of productive life years lost (YPLL) as more succinct indicators measuring economic burden (Brustugun et al., 2014). A similar perspective is shared by the National Cancer Research Institute who identified a greater mismatch between mortality and research spending of cancer. Often funding based on mortality rates remains under-provided for cancers with the highest burden (Burnet et al., 2005). Numbers of life years (YLL) lost depend on the expected life expectancy for each age group at the time of death which is different from the number of productive life years lost (YPLL). YPLL is based on working life expectancy and not on the expected life expectancy in general. YPLL is used to measure the foregone income that an individual could have earned otherwise.

Economic burden of premature mortality measured in the number of life years lost has been studied before (Thun et al., 2010; Carter and Nguyen, 2012; Soerjomataram et al., 2012; Pham et al., 2009; Mariotti et al., 2003; Brustugun et al., 2014). According to Soerjomataram et al. (2012), an estimated 169.3 million years of healthy life were lost due to cancer worldwide in 2008. It is the colorectal, lung, breast, and prostate cancer that contribute to 18-50% of the total burden. Also, the low resource setting countries register a relatively higher YLL than the developed nations. A cohort study in Japan recorded cancer as the leading cause of death with stomach, liver and lung cancer as the three most frequent cancers in both sexes. They found that a total of 517 and 322 deaths led to 7035.3 and 5627 life years lost in men and women respectively (Pham et al., 2009).

The productivity loss of cancer from loss of employment has also been widely researched in the literature. Specially in Europe, The Commission of European Communities recognized the need of estimating the magnitude of burden to facilitate policies on cancer management. In response to this, a series of studies came out (Broekx et al., 2011; Blomqvist et al., 2000; Macioch and Hermanowski, 2011; Hanly et al., 2012, 2015) and the total cost of cancer-related premature mortality in Europe was found to be $75 billion representing 0.58% of the total GDP of Europe in 2008 (Hanly et al., 2015). The amount varies across cancer sites, age, and sex of the population. In the United States for the year 2000, the total estimated loss was $115.8 billion dollars which is expected to increase to $147.6 billion in 2020. Lung cancer makes the highest portion of this burden. It is also interesting to see that a 1% reduction in lung, colorectal, breast, leukemia, pancreatic, and brain cancer mortality can reduce the productivity costs by $814 million per year in the USA (Bradley et al., 2008).

In a low resource country like Nepal, cancer is a health shock and the burden of premature deaths can be very severe for the country. With no cancer registry in the country, it is difficult to understand the severeness of the problem in totality. However, the only national figures released by the International Agency for Research on Cancer (IARC) is an estimated incidence and mortality data of Nepal. I use this database to study YLL and YPLL due to cancer. Especially, the monetary loss in productivity is calculated after adjusting for the labor force participation rate and predicted growth rate of the country. In the next half of the paper, I took into account our surveyed data to measure the monthly health benefits of a non-cancerous patient. The total productivity loss can be $149 million and $121 million for male and female respectively calculated for the year 2012. Also, when burden is compared against a cancer patient, health benefits for not having cancer can be as high as NPR 82,684 for males and NPR 68,731 for female control patients.

4.2 Data and Measures

4.2.1 Definition of Cancer Types

The Globocan-IARC 2012 data consist of age and sex specific cancer incidence and mortality information for all the cancer sites classified under the International Classification of Diseases, 10th revision (ICD-10). The cancer sites are oral cavity and pharynx (ICD-10 C0014), oesophagus (C15), stomach (C16), colorectum (C1821), liver (C22), gallbladder (C2324), pancreas (C25), larynx (C32), lung (including trachea, C3334), melanoma of skin (C43), female breast (C50), cervix uteri (C53), corpus uteri (C54), ovary (C56), prostate (C61), kidney (including renal pelvis and ureter, C6466), bladder (C67), brain and central nervous system (C7072), thyroid (C73), Hodgkin disease (C81), non-Hodgkin lymphoma (C8285, C96), multiple myeloma (C88, C90), leukaemia (C9195) and all cancers combined, excluding non-melanoma skin cancer (C0096 but C44). The data is disintegrated across different age groups such as [0-14 ; 15-39 ; 40-44; 45-49 ; 50-54; 55-59 ; 60-64 ; 65-69 ; 70-74 ; 75+].

4.2.2 Statistical Life Table

The age and sex specific statistical life tables are extracted from the Global Health Observatory repository database of the World Health Organization (WHO), 2012. The statistical tables tell the expected number of life years remaining to individuals of a specific age group.

4.2.3 Economic data

Estimation of productivity loss needs to account for the market wage rate and rate of labor force participation separately for female and male population. The estimated gender specific gross national per-capita income, 2011 PPP$ comes from the Gender Development Index (GDI) of the UNDP-Human Development Report of 2016. Whereas, The Population Monograph of Nepal provides age and sex specific information on labor force participation rates in economic activities for the year 2011.

4.2.4 Others adjustments

Finally, costs associated for each cancer sites are corrected to include the future wage growth of the country. The average GDP growth rate of Nepal from 2000 to 2016 is 3.9% which is used as a proxy to the potential future growth in wages. Also, the future cost were discounted at 3.5% per annum (Hanly et al., 2015).

4.3 Methods

Human capital approach (HCA) is the traditional method of measuring productivity losses (Hanly et al., 2012). It assumes that individuals are potentially eligible to produce a stream of outputs over their working life. A premature death leads to lost productivity by the amount of time working life is reduced due to illness. A work time is valued at the market wage in a competitive market and the resulting losses were adjusted to account for the labor force participation and unemployment rate. Under HCA, I measure the potential loss in productivity rather than the actual loss. HCA is usually criticized subject to having an upward bias in the value of productivity loss. This is because HCA assumes an uniform earning across all the groups of individuals which may not be the case; the earning patterns for young individuals and socially disadvantaged groups are typically less than the mean earning of the economy.

The number of life years lost (YLL) is calculated based on the number of deaths by each age group of individuals and the number of expected years remaining at the time of death. I calculated YLL through the formula below (Brushaptugun et al., 2014):

$$\sum_{i=15}^{75+} \text{deaths at age(i)} \times \text{expected remaining life years at age(i)} \tag{1}$$

The loss in productivity, on the other hand, is calculated from the number of productive life years lost to cancer (YPLL). I estimated YPLL by multiplying the number of cancer specific deaths for a given age group by the expected productive life years remaining at the mid-point for each group. The working life expectancy or the retirement age is assumed to be of 65 years. This YPLL is then multiplied with gender specific annual wages and the value is corrected for the labor force participation rate of Nepal for the year 2012. Finally adjustments were made to account for the future wage growth; I assumed the future growth rates in wages will closely confirm to the country specific GDP growth rates from 2000 to 2017. The value is also discounted at 3.5% per annum. The same process is repeated for different cancer sites among male and female patients separately. The estimation is done following the published literature (Hanly et al., 2015).

$$\sum_{i=15}^{65}[YPLL \times Y_g \times E_g(n)]\frac{(1+p)^{n-y}}{(1+r)^{n-y}} \tag{2}$$

YPLL = the number of productive years lost (upper limit of 65 years)

Y_g = mean annual earning of an employed person of gender g

$E_g(n)$ = employed proportion of population of gender g and age n

y = age of the person at present

n = working life expectancy (assumed to be 65 years)

g = gender of the individual

r = real discount rate

4.4 Results

4.4.1 Mortality Estimation

Table 4.1 gives the total number of life years lost to cancer by age group both for male and female population separately in 2012. The cancer related deaths are higher for female at the younger ages giving away more number of life years. Females share 59% of the total YLL lost due to cancer. So it is not only the number of deaths but deaths at younger ages leave more impact to the society. For example, female mortality is highest for the age group of 75+ but deaths at 50-54 years inflict the highest burden through loss in life years. I provide below a pictorial representation of mortality and YLL by different age groups in Figure 4.1. As we can see from the figure below, deaths at early ages lead to a higher YLL. The total YLL to cancer in Nepal amounted to 280 (in thousands) which in comparison to other communicable and non-communicable diseases gives a insight into the magnitude of loss. The number of lost life years in Nepal (measured in thousands) is highest for lower respiratory infections like pneumonia (846) followed by diaarhea (677), neonatal complications among the infants (407), preterm births complications (329), tuberculosis (295), and heart disease (277) in 2010. It is also important to note that compared to 1990, in 2010 all the above diseases except for Ischemic heart conditions register a significant decrease in the number of YLL. The burden of chronic non-communicable heart disease has seen a 95% increase in YLL and the value of which is comparable to our estimates of cancer (GBD, 2017).

[Table 4.1 here]

[Figure 4.1 here]

Average years of life lost (AYLL) due to cancer is calculated which is the total YLL divided by the number of deaths due to cancer. AYLL tells how much a patient's life is likely to get shortened if diagnosed with cancer (Burnet et al., 2005). The AYLL is 19.64 years both sexes combined in Nepal, where on average females tend to lose 22.2 years compared to 16.8 years by males. The figures from Nepal are compared with available information from literature. The value of AYLL for males and females are 13.6 and 17.5 years in Japan (Pham et al., 2009), 12.8 and 14.4 years in England (Syriopoulou et al., 2017), and 12.7 and 14.9 years in Norway (Brushaptugun et al., 2014). The highest AYLL however being registered in the USA. On an average, the number of years lost by males are 19.3 years and 23.1 years by females in the USA (Ekwueme et al., 2008).

In Figure 4.2, I calculated the age-specific YLL as a percentage of total YLL for different types of cancer. Lung cancer among males incurs the highest burden, accounting to 7% of the total YLL. This is followed by Stomach, and Oral cancer. Whereas, cervical cancer with 12% of the burden contribute to most of the YLL among females followed by Lung and Breast cancer. The findings are similar to other south asian countries (Mallath et al., 2014). In contrast, the percentage of YLL is infact the lowest for cervical cancer in Norway, whereas Breast, Lung, and Colon cancer are the highest contributor of the total cancer related YLL (Burnet et al., 2005; Brushaptugun et al., 2014). Variation is also seen in England with Breast cancer recorded the lowest and Lung and Stomach cancer recorded the highest loss to the society (Syriopoulou et al., 2017).

[Figure 4.2 here]

4.4.2 Productivity loss estimation

The total amount of lost productivity in Nepal is \$149.41 and \$121.80 million dollars for males and females respectively for the year 2012 as can be seen in Table 4.2[1]. I see that deaths at younger ages when the national labor force participation rate is higher yields to a greater loss. The value differs by gender due to variation in their market wage rate and unemployment rate.

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[1] Any mortality before 15 years of age and beyond 65 years of age do not account in calculating YPLL.

[Table 4.2 here]

As the productivity loss by cancer sites is disaggregated, I find that five cancer sites account for almost half of the total productivity (49.75%) loss among males Table 4.3. Lung cancer is most expensive ($19 million , 12.62% of total loss), followed by Leukemia ($18 million, 11.91%), Stomach ($15 million, 10.33%), Oral ($8 million, 12%), and Lymphoma cancer ($10 million, 6.89%).

[Table 4.3 here]

The relative share of five most prevalent cancers among females is 63.63% as shown in the Table 4.4. Cervical cancer account for the highest burden ($24 million, 19.99%). This is followed by Breast ($20 million, 16.30%), Lung ($16 million, 13.15%), Liver ($9.5 million, 7.88%), and Ovarian cancer ($7.8 million, 6.42%). Overall, both sexes combined, the total cost of cancer-related premature mortality in Nepal is $270 millions in 2012 indicating a significant loss to the economy.

This productivity loss calculation is biased downwards because of three reasons: a persisting gender gap in wages under which females of all ages earn less income than males. With this wage differential, even with higher number of cancer related deaths and more number of life years lost, females register a lower productivity loss. Second, the household work of females does not come under the realm of productivity. A premature morbidity or mortality due to cancer implies that females are unable to undertake household work, also an adverse cancer consequences. Ignoring the household productivity undermines the magnitude of total loss. Finally, it is not only the cancer patient but in developing countries, family members serve as immediate care givers to the patients. Depending on the severity, physical, and mental health of the patients, a caregiver often has to leave out of the labor market to take care of the patient. Therefore, a societal loss should also take into account the productivity loss of the patients and their caregivers. Inadequate data in my study limits us to extend the human capital approach to include the caregiver consequences.

[Table 4.4 here]

When the results are compared with reference to other countries, I find the value is as high as $93 billion dollars in Europe for the year 2008 (Hanly et al., 2015). The USA incurred the highest productivity loss of the amount of $115 billion in 2010 (Carter and Nguyen, 2012). But, in the recent years, with a shift in cancer mortality rates towards developing economies, there is a growing attention among the low-middle income countries to estimate a yearly loss. Pearce et al. (2018) recently published an analysis of BRICS countries and the results suggest that these five countries together account for $46 billion productivity loss accounting for 0.33% of their combined GDP. China ($28 billion) followed by India ($ 6.73 billions) record the highest loss of all the BRICS countries. To put my results into perspective, a total of $270 million loss comprise of 0.10% of Nepal GDP in 2012. [2]

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[2] BRICS- Brazil, Russia, India, China, and South Africa.

4.5 Opportunity cost of Cancer

In the second half of the paper, I used my primary data give a micro perspective of the productivity loss. In comparison to cancer patients, control patients are 31.5% less likely to withdraw from the labor market due to disease related disability shown in Table 4.5. The marginal effect is higher for male population than for female population. Also, in a sub-sample analysis, cancer patients who undergo all the three types of treatments such as surgery, chemotherapy, and radiation therapy are 19.7% more likely to miss out on jobs. Other variables with a significant impact include educational attainment. People with higher level of education retain their jobs better. Also the lower strata of society represented by Janajati and Dalit ethnic groups are most likely to lose out on job prospects, so are the older adults.

[Table 4.5 here]

Using the marginal effects of the probit model, in Table 4.6, I provided an average monetary estimates of health benefits. If a control patient is less likely to miss out on days at work, then evaluated at a market wage rate, the control patients will retain NPR 16,018 (for males) and NPR 13,034 (for females) of monthly wages which would otherwise be foregone by cancer patients.[3] This foregone income along with the excessive treatment cost of cancer patients give rise to NPR 82,684 (males) and NPR 68,731 (females) amount of economic burden per month.

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[3] A male control patient will miss out on 9.6 work days which is 7.2 work days for female per month. This yields to NPR 16,018 and NPR 13,034 of monthly wages for male and female control patient that would be foregone by cancer patients.

[Table 4.6 here]

4.6 Conclusion

In the first section of the paper, I give a macro estimates of lost YLL due to premature cancer related deaths in Nepal using the human capital approach. The age and sex specific cancer incidences and mortality figures are extracted from the Globocan-IARC 2012 dataset. Mortality at younger ages leaves behind the maximum burden when significant numbers of life years get lost to cancer. I calculate YLL by multiplying the number of disease related deaths with the expected life years remaining for each age group of females and males. Females contribute to the maximum years lost and share the highest burden (59%). There is however a difference between years lost (YLL) to productive years lost (YPLL). The productivity lost is calculated using the working life expectancy of 65 years. So any cancer related deaths during 15-64 years of individuals shorten their productivity by the expected remaining years of working life expectancy. The dollar amount of foregone productivity loss is calculated at a sex specific market wage rate adjusted by age and sex specific labor force participation rate and the expected increase in the future growth rate of a country. I found that the total loss in productivity is equivalent to the amount of $149 millon and $121 million dollars for the year 2012. This is infact a 0.1% of Nepal GDP for the same year. In the next section of the paper, the survey data is exploited to find that control patients are less likely to quit jobs which evaluated under market wage rate can bring in significant amount of savings for them. Not only in terms of foregone wages, but cancer patients also incur a significant out of pocket expenditure during their treatment process.

The contribution of the paper is in highlighting the magnitude of the problem of cancer in Nepal. Given the paucity of data, there have been no studies till date which provides a monetary estimate of the burden that cancer imposes on Nepalese economy. This is the first paper that presents an estimated economic loss to the society. The amount of economic burden pointed to the fact that policy makers need to be proactive in issues of cancer management in the country through cancer control policies. Secondly, there is no safety nets or insurance policies in Nepal that can support patients faced with this health shock. The only facility extended by the government involve a one-time NPR 50,000 monetary transfers which is half of the average monthly treatment expense of a cancer patient. In light of this, a safety net for financing cancer treatment should be established through health insurance policies to save families from the burden of poverty. A financing structure will improve the quantity and quality of human capital leading to productivity increase and long term economic growth.

However, I do also want to acknowledge some of the limitations of the paper. The human capital approach of measuring productivity loss gives a ‘potential’ amount of loss which may be different from the ‘actual’ loss to the society. This is because by using a national average of some indicators such as labor force participation rate or market wage rate, I am giving equal weightage to different sections of the population. This may bias our estimates because the poorer sections of the population most likely receive lower wages and have high unemployment rates.

Figures and Tables

Figure 4.1: Mortality and YLL by age groups (Male and Female)

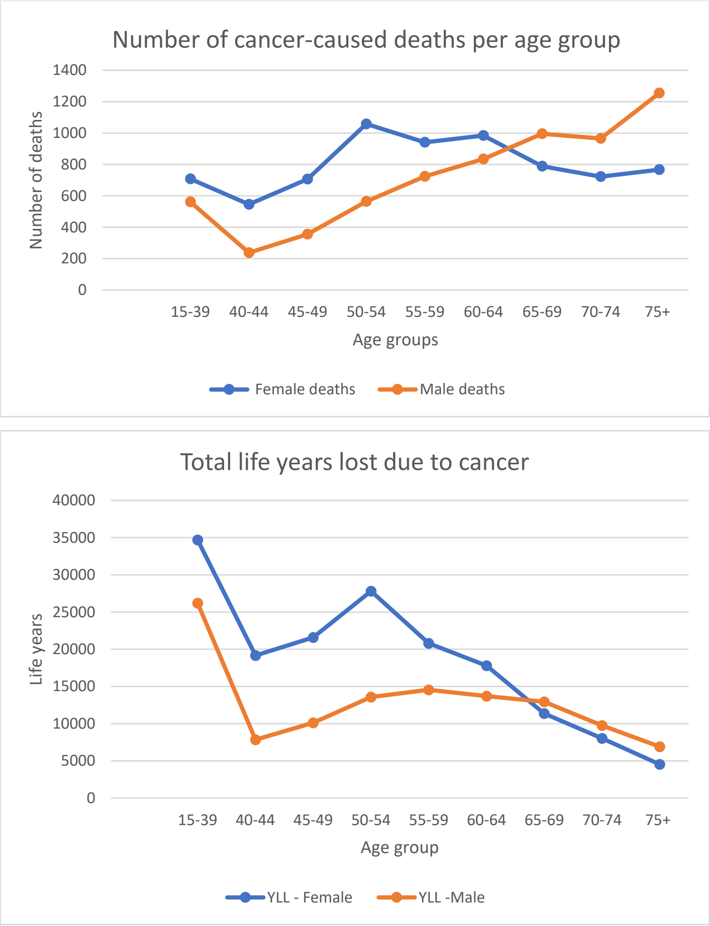

Figure 4.2: YLL per Cancer Types : Male and Female

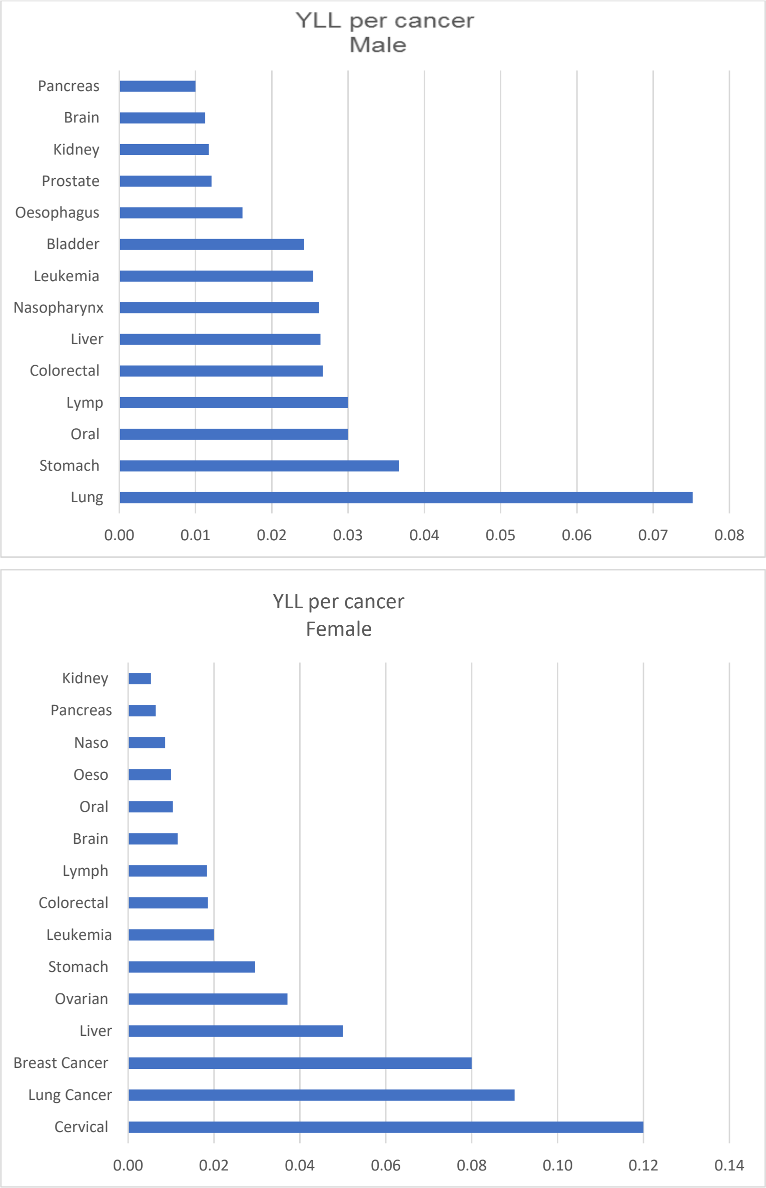

Table 4.1: Number of life years lost to cancer

Age Groups	**YLL - Female**	**YLL -Male**	**Total- YLL**
15-39	34692	26198.7	60890.7
40-44	19164.6	7830.2	26994.8
45-49	21603.6	10110.4	31714
50-54	27825.4	13592.4	41417.8
55-59	20796.1	14552.4	35348.5
60-64	17810.4	13694	31504.4
65-69	11361.6	12948	24309.6
70-74	8025.3	9746.5	17771.8
75+	4525.3	6897	11422.3
YLL (%)	59%	41%	100%

Table 4.2: Productivity Lost (in dollars)

Age Groups	Total Male deaths	Total Female deaths	Premature mortality Cost Male [In millions]	Premature mortality Cost Female [In millions]
15-39	561	708	70.17	46.14
40-44	238	546	17.49	21.33
45-49	356	706	19.55	20.45
50-54	564	1058	21.02	20.66
55-59	724	941	15.41	10.05
60-64	835	984	5.77	3.17
Total mortality cost			$149.42	$121.80

Table 4.3: Top five cancers with highest economic burden (Males)

Cancer Sites	Productivity Loss (in millions)	Burden of Productivity loss (in %)
Lung	19	12.62
Leukemia	18	11.91
Stomach	15	10.33
Oral	12	8
Lymphoma	10	6.89
Burden of top 5 cancers	74	49.75

Table 4.4: Top five cancers with highest economic burden (Females)

Cancer Sites	Productivity Loss (in millions)	Burden of Productivity loss (in %)
Cervical	24	19.88
Breast	20	16.30
Lung	16	13.15
Liver	9.5	7.88
Ovarian	7.8	6.42
Burden of top 5 cancers	77.3	63.63

Table 4.5: Loss of employment due to disease disability

Variables	**All Quit working**	**Male Quit working**	**Female Quit working**	**Treatment Types Quit working**
Control patients	-0.315*** (-5.86)	-0.323*** (-5.23)	-0.242* (-1.95)	
All types of treatments				0.197* (1.77)
Education class 1-8	0.0363 (0.54)	0.0722 (0.81)	0.00318 (0.03)	0.0304 (0.37)
Education class 9-12	0.0408 (0.54)	0.0278 (0.28)	0.140 (1.12)	0.0674 (0.73)
Education class >12	-0.392*** (-4.67)	-0.333*** (-3.24)	0 (.)	-0.439*** (-3.47)
Chherti	0.139* (1.75)	0.119 (1.20)	0.243** (2.05)	0.244** (2.49)
Newar	0.126 (1.58)	0.131 (1.39)	0.113 (0.87)	0.210** (2.21)
Janajati	0.227*** (3.11)	0.126 (1.25)	0.364*** (3.63)	0.296*** (3.56)
Dalit	0.238*** (2.78)	0.220** (2.10)	0.180 (1.14)	0.232** (2.31)
Married	-0.0701 (-0.57)	-0.189 (-1.51)	0 (.)	-0.172 (-0.70)
Age	0.00435* (1.93)	0.00237 (0.82)	0.0118*** (2.95)	0.00354 (1.24)
Agriculture	0.0311 (0.54)	0.117 (1.63)	-0.0632 (-0.70)	0.0821 (1.19)
N	315	200	107	222

Table 4.6: Opportunity cost calculation

Indicators	Male	Female
Marginal effect of a control patient on quitting jobs	-0.323***	-0.242*
Average missing work due to cancer	30	30
Missing days at work for control patients	0.32*30 =9.6	0.24*30 =7.2
Control patients continue working for the days not missed	30-9.6 =20.4	30-7.2 = 22.8
Opportunity cost per missing day	23556/30	17151/30
Monetary Benefit of avoiding cancer	785.2*20.4 =16018.08	571.71*22.8 =13034.99
Average medical cost of cancer	107611	90450
Average medical cost of control patients	40945	34753
Saved Medical cost of a control patient	66666	55697
Total Health Benefit for not having cancer		
[Monetary Benefits + Saved Medical cost]	NRS 82,684	NRS 68,731

Note: GDP PPP per capita $ 2718 for male and $1979 for female,
The exchange rate 1$ =NRS 104

Chapter 5
Conclusion

5.1 Dissertation Summary

The overall theme of the dissertation is to study the socio and economic consequences of cancer in a less developing country of Nepal. The motivation of the study came from the fact that cancer has emerged as one of the chronic epidemic diseases globally. Especially in a low resource setting country with no safety net to finance health care, cancer can be a major health shock affecting not only the patients but also family members. Through all the three chapters of this dissertation, I have emphasized the magnitude of economic and mental burden that cancer inflicts on the society. Also, I have tried to propose ways through which this burden can be mitigated. A national cancer preventative plan through provision of cancer screening tests should be implemented to detect any growth of carcinogenic cells. Detection of cancer at early stages would simultaneously enhance patient's survival probability as well as would save them from excessive amount of economic and mental burden. There are however concerns regarding the uptake of screening tests. Women in Nepal never undergo screening and are most often diagnosed at a very late stage of the disease leading to a higher mortality. Mortality from cancer is unwarranted when it can be prevented. Hence, the question lies in why individuals are not up-taking cancer screening when it can lead to significant health benefits. The answer is in low awareness and information among general individuals regarding various aspects of cancer.

Hence, it is important to communicate the value of screening to an asymptomatic individual.

Chapter 1 is an introductory chapter with a basic profiling of cancer incidences in Nepal. The comprehensive nature of data overcame the limitations of cancer information in Nepal. I observed different types of cancer across the country with Lung and Oral cancer among males and Cervix and Breast cancers among females being the most popular ones. Using ArcGIS hot spot analysis, I found significant clusters of cancer incidences in the Kathmandu valley. Both cancerous and non-cancerous group of patients displayed low level of information and poor uptake of screening test. For example, no one from the control group knew about the existence of Breast self-examination (breast cancer screening), Colonoscopy (Colon cancer screening), or HPV test (Cervical cancer screening). Cancer patients post diagnosis are marginally more aware of the nuances of cancer.

Further, I compared the financial burden of cancer patients with the control group to find that the direct treatment expenses was significantly higher (NPR 97,571 versus NPR 38,356 , $p<0.000$) among the cancer patients. The economic burden magnifies with a higher percentage of cancer patients withdrawing from the labor market due to disease disabilities ($26.2\% > 13.1\%$, $p<0.000$). Not only economic costs, but extreme manifestation of mental burden among cancer patients was also evident. They displayed suicidal characteristics; frequent thoughts of hurting themselves because they felt not worthy of living anymore.

The extent of economic loss and emotional stress can be mitigated if proper preventative measures such as routine screening practices are introduced. Asymptomatic individuals irrespective of their perceived susceptibility to cancer should take up preventative measures to get diagnosed early of any abnormalities. However, individuals who have no information or awareness about the good or those who do not perceive the benefits of screening will not be able to understand the true importance of having such a preventative measure. With this objective, Chapter-2 aimed to communicate the value of screening to the healthy population. Precisely, I believe that cancer patients who have a deeper understanding of the state of the world and of the extent of disease adversities can understand the consequentiality and are better able to portray what preventative measure can do. The preference of cancer patients is studied under contingent valuation techniques. Through the application of conventional WTP models and a structural model (SEM), I found that individuals who evaluated their survival chances to be higher or rated their health better were more likely to pay for screening. Pessimism and aggressive means of financing treatment decreased whereas information and risk of cancer re-occurrence increased the likelihood of paying for the good. With our SEM model, I was able to disentangle the direct and indirect effects of explanatory variable on the outcome variable (WTP). Perceived risk of cancer re-occurrence had a positive direct effect (as also seen in conventional models), but a negative indirect effect on WTP after accounting for pessimism. Similarly, cancer patient's perceived chances of cure acted as a mediating factor between Optimism and WTP. These opposing but significant channels of independent variable on the outcome variable are called mediation with suppression. Socio-economic variables such as income, aggressive means of financing treatment were also significant predictors to their decisions to screen. Both types of empirical models provided sufficient evidence that cancer patients have a positive preference towards introducing a cancer screening policy to address the growing incidences of cancer mortality in Nepal.

In Chapter 3 and Chapter 4, I aim to estimate the magnitude of mental and economic burden faced by cancer patients. Mental burden arises from the holistic disability that patients face post diagnosis with cancer. It is their concern over finance, physical inabilities, emotional agony, and family level distress that give rise to mental burden. I matched the control and cancer patients through propensity score estimation techniques and treatment effect estimators. The ATT and ATET are found to be significantly higher for cancer patients (2.69 times) across different measures of mental burden. The treatment effects are significantly lower for the cancer group in case of their self-rated health. The analysis were repeated with treatment effect estimators to ensure the sensitivity of our findings. In the next section of the paper with multivalued treatment categories, I measured burden across gender and cancer sites. Cervical cancer was found to not only being the most widely prevalent cancer, but a cervical cancer patient incurred a significantly higher magnitude of mental burden of 1.83, 2.63, and 3.31 times greater than all other female cancer patients, male cancer patients, and control patients respectively. This calls for counseling services as a part of cancer treatment process in the hospitals. Also the study throws light to specific cancers with severe side-effects that needs special attention.

Finally, in Chapter 4, I estimated the economic burden as a measure of the number of life years (YLL) and productive life years lost (YPLL) to cancer due to premature cancer related deaths. Where, YLL was calculated based on life expectancy, YPLL was calculated based on the expected working life expectancy of 65 years. YLL was found higher for females compared to males and it varies by cancer sites. The amount of lost productivity due to premature cancer deaths measured under current market wage rate and labor force participation rate can be as high as \$149 million and \$121 million for males and females respectively. Lung cancer among males and cervical cancer among females contributed mostly to the total burden. The magnitude of financial burden project the severity of loss to cancer. Appropriate preventative policies may not be able to offset the entire loss but will be instrumental in mitigating it.

Overall, the findings of the three chapters lead to similar policy implications which complement each other. The dissertation broadly aims to inform the policymakers about the severity of cancer and the need to have a national cancer control measure in form of screening services. Also, a successful implementation of the policy implies a higher uptake rate of services. This increase in uptake can be achieved if individuals understand the true value and associated benefits of screening. I believe that a direct account and stated preferences of cancer patients is effective in advising the general individual on better health choices.

5.2 Future research

Based on the potential and need of cancer research in Nepal, The American Cancer Society has funded two additional rounds of funding to extend the current research.

5.2.1 Cancer Research: Phase 2

1. One of the primary aims of Phase-2 survey is to compile and digitize all the past records of cancer patients as well as initiate tracking of future cancer patients. Super-specialty cancer hospitals across Nepal submit their annual patient records to B.P Koirala Memorial Hospital. B.P Koirala Memorial is the biggest cancer super-specialty hospital in Nepal, which will be used as a base institution for compiling the national cancer registry records.

2. With the preliminary analysis on the gender differences in the intensity of mental burden, I found that cervical cancer patients face significantly higher burden compared to all other patients. This is an important finding specially because cervical cancer is the widely prevalent one in Nepal. It is an unique gynecological cancer that intrudes in a marital relationship through disruptions in their sexual relationships. In the next phase of our project, through collaboration with other research partners, we aim to study specific side effects of cancer such as marital disruptions beyond physical disabilities of cancer.

3. We will extend our study on mental burden by undertaking an in-depth estimation of quality of life among the cancer patients using EURO-QoL living stan-

dards instruments. Through discrete choice experiments and different attributes, we will analyze patient's mobility, self-care, and ability to undertake usual activities, pain/discomfort, and anxiety/depression of the patients.

5.2.2 Cancer Research: Phase 3

The extension of our current research will include dissemination of information about the need of cancer preventative measures among the general individuals. We would use cancer patients' perspective as informational intervention to predict an increase in the uptake rate of screening or cancer immunizations. To this end, we will focus on controlling measures aimed at cervical cancer. Cervical cancer being the most popular cancer among women in Nepal will be the focus of our study in Phase-3 of our research. Medical graduates and UNM researchers together will introduce informational interventions on HPV vaccination to a treatment group of population through randomized control trial. We will track if the informational intervention led to an increase in immunization uptake through a follow-up survey.

Appendices

A Structural Equation Modeling Manual

(Note: The manual is compiled from the published literature on SEM)

The SEM model consists of measurement equations and latent equations. I am following MacKinnon et al. (2007) to show the equations of mediation analysis done under SEM.

$$Y = i_1 + cX + e_1 \tag{1}$$

$$Y = i_2 + c^{'}X + bM + e_2 \tag{2}$$

$$M = i_3 + aX + e_3 \tag{3}$$

Y is the dependent variables, X represents all the independent variables. M is the mediator variable. 'c' is the direct effect that relates independent variable and dependent variables and $c^{'}$ is the coefficient that relates independent variable to the dependent variable after adjusting for the mediator. 'b' is the coefficient that shows the effect of the mediator on the dependent variable after adjusting for the independent variables, and e_1, e_2, e_3 are residuals. Following the sequential ignorability assumption, the errors are assumed to be uncorrelated for a recursive SEM model.

Steps to establish mediation (Baron and Kenny, 1986)

First, X should be significantly related to Y. Second, X should also be significantly related to the hypothesized mediator variable (M). Third, the mediating variable must be significantly related to the dependent variable after controlling for X in the equation. The coefficient relating independent variable and the dependent variable should be greater in absolute value than the coefficient relating independent to dependent variable after controlling for the mediator and other controls.

Assumptions of Single mediator model (MacKinnon et al., 2007)

The model assumes that the residuals in Equation 2 and Equation 3 are independent.

The mediator ‘M’ and the residual in Equation 2 are also independent.

There is no XM interaction in Equation 3.

The causal order of the model is not misspecified with no confounding variables between the mediator and outcome variable.

No reciprocal causation between the mediator and outcome variable.

No misspecification due to imperfect measurement.

Empirical conditions for Mediation (Baron and Kenny, 1986; MacKinnon et al., 2002; Bolger, 1998; Crandall et al., 2012)

1. X is significantly related to M
2. M is significantly related to Y
3. The relationship of X to Y diminishes when M is accounted for in the model.

Different types of mediation (Crandall et al., 2012)

Full Mediation: X no longer influences Y after accounting for the mediator.

Partial Mediation: The relationship between X to Y is significant but is reduced to half in absolute size after accounting for the mediator.

Inconsistent mediation: Also called mediation with suppression is when the relationship between X and Y changes in sign but remains significant after controlling for the mediator.

No mediation: Mediator (M) is not significantly related to Y but X and Y remains significant after including the mediating factor in the model.

Recursive and Non Recursive SEM (Kline, 2012)

Given the structural model is correctly specified, in most of the SEM models, the disturbances between the endogenous variables are assumed to be uncorrelated. However correctly specifying the variance-covariance matrix needs understanding of the recursive and non-recursive nature of the data. Both the recursive and non-recursive model assumes that there is no endogeneity in the model. In recursive models, all the causal effects are unidirectional. There is no reverse causality between variables and hence the disturbances between endogenous variables are uncorrelated. If we allow for correlated disturbances, it should only be between pairs of variables without direct effects between them. Non-Recursive models on the other hand allows feedback loops, i.e., the two endogenous variables are both causes and effects of each other. In these models, we can allow for correlated errors even between the pairs of variables with direct effect between them.

SEM vs OLS (Baron and Kenny, 1986; Gunzler et al., 2013)

In a structural model we are estimating a system of equations where variables identified can be both causes and effects of the model. This temporal ordering and *a priori* assignment of the variables makes OLS an unsuitable estimation procedure. Even in hypothesized SEM models, where we do not assume simultaneity in the disturbances, SEM remains advantageous to standard regression analysis (OLS). First, The ability of a variable to be both the predictor and response in the same model is an advantage of SEM over OLS. Second, SEM allows for unobserved latent factors from a group of correlated observed factors. This allows for the ease of interpretation of latent/unobserved variables. Third, SEM can be extended to mediation analysis where direct and indirect effects of variables can individually be calculated. This cannot be achieved in a standard regression. Forth, SEM has the ability to deal with time series data and longitudinal data and can easily be extended to multiple mediator and multilevel mediation analysis.

Limitations of SEM (Hox and Bechger, 1998)

The assumptions needed to estimate a SEM model are stringent and difficult to test statistically. It is therefore important for the applied researchers to have a well-established theoretical understanding of the hypothesized relationships. The causal interpretation of the regression results has also been criticized in the literature. If the nature of the data is not longitudinal, then it is improper to give a causal inference of our results. Other empirical limitations include the normality assumptions of variables, required sample size for estimation, inability to estimate interaction hypothesis, convergence problems, and complex model specifications.

Cited papers on SEM

Baron, R. M. and Kenny, D. A. (1986). The moderator mediator variable distinction in social psychological-research - conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51(6):1173–1182.

Bolger, N. (1998). Data analysis in social psychology. *Handbook of social psychology*, 1:233–265.

Crandall, C. S., Preacher, K. J., Bovaird, J. A., Card, N. A., and Little, T. D. (2012). Structural equation modeling of mediation and moderation with contextual factors. In *Modeling contextual effects in longitudinal studies*, pages 211–234. Routledge.

Gunzler, D., Chen, T., Wu, P., and Zhang, H. (2013). Introduction to mediation analysis with structural equation modeling. *Shanghai archives of psychiatry*, 25(6):390.

Hox, J. J. and Bechger, T. M. (1998). An introduction to structural equation modeling.

Kline, R. B. (2012). Assumptions in structural equation modeling.

MacKinnon, D. P., Fairchild, A. J., and Fritz, M. S. (2007). Mediation analysis. *Annu. Rev. Psychol.*, 58:593–614.

MacKinnon, D. P., Lockwood, C. M., Hoffman, J. M., West, S. G., and Sheets, V. (2002). A comparison of methods to test mediation and other intervening variable effects. *Psychological methods*, 7(1):83.

Appendices

B Stata Codes associated with the chapters [1]

The files included in Appendix B are :

1. Stata files used in Chapter 1

2. State files used in Chapter 2

3. Stata files used in Chapter 3

4. Stata files used in Chapter 4

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[1] For brevity, I only provided selected codes specific to the figures and tables of the chapters.

Stata files used in Chapter 1

Data files used in this Chapter:

1. OriginalRawCancerFile
2. Final_ControlFilenew.dta

Do files used in the chapter

1. DefinitionFileCancerPhase1_2015
2. BasicStatDoFileCancerPhase1_2015
3. RecodedFileCancerPhase1_2015
4. DefinitionFileCancerPhase1_2015
5. BasicStatDoFileCancerPhase1_2015
6. Control_Cleaningdofile
7. Appending the two data sets

Creation of the do files

1. **DefinitionFileCancerPhase1_2015**

```
clear all
set more off
local FinalCancerData "C:\Users\Soumi\Google Drive\UNM Coursework_Sep12017\PhD_4th Year\Chronic Illness_Cancer study\Data\Data_Nepal\FinalCancerData\Chapter-1 Descriptive\Chapter1"
cd "`FinalCancerFolder'"
use OriginalRawCancerFile.dta,clear
```

2. **RecodedFileCancerPhase1_2015**

```
clear all
set more off
local FinalCancerData "C:\Users\Soumi\Google Drive\UNM Coursework_Sep12017\PhD_4th Year\Chronic Illness_Cancer study\Data\Data_Nepal\FinalCancerData\Chapter-1 Descriptive\Chapter1"
cd "`FinalCancerFolder2'"
include "DefinitionFileCancerPhase1_2015"
```

3. **BasicStatDoFileCancerPhase1_2015**

```
clear all
set more off
local FinalCancerData "C:\Users\Soumi\Google Drive\UNM Coursework_Sep12017\PhD_4th Year\Chronic Illness_Cancer study\Data\Data_Nepal\FinalCancerData\Chapter-1 Descriptive\Chapter1"
cd "`Chapter1'"
```

```
include "RecodedFileCancerPhase1_2015"
```

4. Creating the appended data [Cancer and Control data]

```
clear all
set more off
local tmpf1 "C:\Users\Soumi\Google Drive\UNM Coursework_Sep12017\PhD_4th
Year\Chronic Illness_Cancer study\Data\Data_Nepal\FinalCancerData\Chapter-1
Descriptive\Chapter1"
cd "`tmpfl1'"
** Calling the cancer cleaning do file
include "BasicStatDoFileCancerPhase1_2015"
**Creating the cancer vs control patients. Generating 1 for cancer and 0 for control
gen cancerorco=.
replace cancerorco =1

** Appending cancer and control data sets
** I am renaming some of the variables that have the same information but are named
differently in two data sets.
rename type_cancer type_disease
rename  cancer_others disease_others
rename routine_check screeningfor_cancer
rename reasons_noscreen whynot_screening
rename cancer_treated Cancer_treated
rename cancer_survive Cancer_survive
rename no_stigma Cancer_stigma
rename prevent_cancer Cancer_prevent
rename low_awareness Cancer_awareness
rename from_someone Cancer_contagious
rename specialised_30days speciiased_treatment
rename under under_18

 ** Saving the tempfile of cancer
tempfile append_cancer
save "`append_cancer'.dta",replace

 ** Calling the control do file
set more off
local tmpf2 "C:\Users\Soumi\Google Drive\UNM Coursework_Sep12017\PhD_4th
Year\Chronic Illness_Cancer study\Data\Data_Nepal\FinalCancerData\Chapter-1
Descriptive\Chapter1"
cd "`tmpfl2'"
include "Control_Cleaningdofile"

** Saving the tempfile of control
```

```
tempfile append_control
save "`append_control'.dta",replace

 **Appending the two data sets
append using "`append_cancer'.dta"
```

Stata codes

** Figure 1.1 – Figure 1.2 **

In ArcGIS

** Figure 1.3 **

```
graph bar (mean) totalexpenses , over(cancerorco, relabel(1 "Control" 2 "Cancer"))
blabel(total, format(%9.2f)) b1title (" Groups", size (small) )  ytitle("Amount in NRs",
size(small)) saving(Expense, replace) title("Per month treatment expenses", size(medium))
///
ttest totalexpenses, by(cancerorco)
graph bar (mean) quit_job , over(cancerorco, relabel(1 "Control" 2 "Cancer"))  ///
b1title("Groups") blabel(total, format(%9.3f) size(small)) ytitle("Percentage (x100)" ,
size(small)) yscale(range( 0 .2)) saving(Quitjob, replace) title(" Loss of Employment by
groups", size(medium))  ttest quit_job, by(cancerorco)


graph bar (mean) aggresive_payment , over(cancerorco, relabel(1 "Control" 2 "Cancer"))
b1title("Groups") blabel(total, format(%9.3f) size(small)) ytitle("Percentage (x100)" ,
size(small)) yscale(range( 0 .2)) saving(Aggressivepayment, replace) title("Aggressive means
of financing", size(medium)) ttest aggresive_payment, by(cancerorco)

graph bar (mean) healthinsurance , over(cancerorco, relabel(1 "Control" 2 "Cancer"))
b1title("Groups") blabel(total, format(%9.3f) size(small)) ytitle("Percentage (x100)" ,
size(small)) yscale(range( 0 .2)) saving(Insurance, replace) title("Insurance", size(medium))

gr combine Expense.gph Quitjob.gph Aggressivepayment.gph Insurance.gph, xsize(15)
ysize(15) title("Economic Burden") subtitle("(Cancer & Control patients)")    ///
          row(2) note("Source: Nepal Study Center, December 2015")
```

** Figure 1.4 **

Creating mental burden graph [This is the general definition of mental burden]

```
gen g_mentalburden = little_interest+ depressed + needs_family + energetic_recode+
heart_pound + vomiting + chestpain + feeling_bad + hurting_oneself + QOL_recode+
depressed_earthquake + economic_situation
rename g_mentalburden MentalBurden_General
kdensity MentalBurden_General, nograph generate(x fx)
```

```
kdensity MentalBurden_General if cancerorco==0, nograph generate(fx0) at(x)
kdensity MentalBurden_General if cancerorco==1, nograph generate(fx1) at(x)
label var fx0 "Control"
label var fx1 "Cancer"
line fx0 fx1 x, sort ytitle(Density)
**Two smaple Wilcoxon rank-sum (Mann Whitney) test
ranksum MentalBurden_General,by (cancerorco)
```

**** Figure 1.5****

```
graph bar (mean) knowledge_tests , over(cancerorco, label(labsize(small)) relabel (1
"Control" 2 "Cancer" )) blabel(total, format(%9.2f)) bargap (50000)  b1title("Groups",
size(small)) ytitle("percentage", size(small)) saving(Screening, replace) title(" Any screening
test", size (medium))

graph bar (mean) BSF Mammography if Female==1, over(cancerorco, relabel (1 "Control" 2
"Cancer")) blabel(total, format(%9.2f) size(small)) ytitle("Percentage (x100)") yscale(range( 0
.2)) saving(tests1, replace) title(" Breast cancer", size (medium))  legend (label (1 "BSF") label
(2 "Mammography ") size(vsmall))

graph bar (mean) PAP HPV if Female==1, over(cancerorco, relabel (1 "Control" 2
"Cancer")) blabel(total, format(%9.3f) size(small)) ytitle("Percentage (x100)") yscale(range(
0.05)) saving(tests2, replace) title(" Cervical cancer", size (medium)) legend (label (1 "PAP")
label (2 "HPV") size(vsmall))

graph bar (mean) colonsocopy FOBT, over(cancerorco, relabel (1 "Control" 2 "Cancer"))
blabel(total, format(%9.3f) size(small))  ytitle("Percentage (x100)") yscale(range( 0 .1))
saving(tests3, replace) title(" Colon cancer", size (medium)) legend (label (3 "Colonsocopy")
label (4 "FOBT") size(vsmall))

graph bar (mean) PSAT if Female==0, over(cancerorco, relabel (1 "Control" 2 "Cancer"))
blabel(total, format(%9.3f) size(small))  ytitle("Percentage (x100)") yscale(range( 0 .005))
saving(tests4, replace) title(" Prostate cancer", size (medium)) legend (label (3 "PSAT")
size(vsmall))


** Combining all the above graphs together
gr combine tests1.gph tests2.gph tests3.gph tests4.gph, xsize(20) ysize(15) title("Knowledge
different cancer screening test") subtitle("(Cancer & Control patients)") row(2) note("Source:
Nepal Study Center, December 2015")
```

Stata files used in Chapter 2

Data files used in this Chapeter

1. OriginalRawCancerFile
2. IncomeWTPdata
3. IncomeWTProbustdata

Do files used in this chapter

1. BasicStatDoFileCancerPhase1_2015
2. CreatingIncomeWTPdata
3. DefinitionFileCancerPhase1_2015
4. RecodedFileCancerPhase1_2015
5. Robustnesscheckfile_2015
6. WTP_IntervalRegressionFile
7. WTP_SEMRegressionFile

Creation of the do files

1. WTP_IntervalRegressionFile

```
clear all
set more off
local FinalCancerData "C:\Users\Soumi\Google Drive\UNM
Coursework_4thJan2017\PhD_4th Year\Chronic Illness_Cancer
study\Data\Data_Nepal\FinalCancerData\WTP_Paper\WorkingDofiles\FinalCancerFold
er2"
cd "`FinalCancerFolder2'"
include "BasicStatDoFileCancerPhase1_2015"
```

2. CreatingIncomeWTPdata

```
clear all
set more off
local FinalCancerData "C:\Users\Soumi\Google Drive\UNM
Coursework_4thJan2017\PhD_4th Year\Chronic Illness_Cancer
study\Data\Data_Nepal\FinalCancerData\WTP_Paper\WorkingDofiles\FinalCancerFold
er2"
cd "`FinalCancerFolder2'"
include "BasicStatDoFileCancerPhase1_2015"
```

3. WTP_SEMRegressionFile

```
cd "C:\Users\Soumi\Google Drive\UNM Coursework_Sep12017\PhD_4th
Year\Chronic Illness_Cancer study\Data\Data_Nepal\FinalCancerData\Chapter2-
WTP_Paper\WorkingDofiles\FinalCancerFolder2"
use IncomeWTPdata.dta,clear
```

Stata codes

```
**Figure 2.1**

In ArcGIS

**Figure 2.2**
In ArcGIS


**Figure 2.3**

clear all
set more off
local tmpfl1 "C:\Users\Soumi\Google Drive\UNM Coursework_4thJan2017\PhD_4th
Year\Chronic Illness_Cancer
study\Data\Data_Nepal\FinalCancerData\WTP_Paper\Original Do files"
cd "`tmpfl1'"
include "Cancer_Cleaningdofile"

**Willingness to pay questions
** Total number of respondents that were asked the WTP questions =599
** Total number_respondents in version A = 298, Total number of respondents in version B
= 301

The bids are 500, 1000,3000, 6000, 10000
Screening-  Merging of version A and Version B [ Orginal amount]

egen Screening1 = rowtotal(scA_amount scB_amount)
gen Actual_recode1 = Screening1
recode Actual_recode1 (500=500) (1000=1000) (1500=1000) (3000=3000) (5000=3000)
(6000=6000) (10000=10000) (10001=10000)
tab Actual_recode1

** Getting the unique amount of double amount that was asked
gen Screening_doubleA1 = scA_doubleamount if scA_paid==1
gen Screening_doubleB1 = scB_doubleamount if scB_paid==1
egen Screening_double1 = rowtotal(Screening_doubleA1 Screening_doubleB1)
gen Amount_doublerecode1 = Screening_double1
recode Amount_doublerecode1 (1000=1000) (2000=2000) (5000=2000) (6000=6000)
(10000=6000) (12000=12000) (20000=20000) (20001=20000) (60000=20000)
```

```
tab Amount_doublerecode1

** Getting the unique amount of half bids that were asked
gen Screening_halfA1 = scA_halfamount if scA_paid==0
gen Screening_halfB1 = scB_halfamount if scB_paid==0
egen Screening_half1 = rowtotal(Screening_halfA1 Screening_halfB1)
gen Amount_halfrecode1 = Screening_half1
recode Amount_halfrecode1(250=250) (500=500) (1500=1500) (2000=1500) (3000=3000)
(5000=5000) (6000=5000) (12000=5000) (15000=5000)
tab Amount_halfrecode1
save "`CancerFile_version2'.dta",replace


use "`CancerFile_version2'.dta",clear
egen Screening_Paid1 = rowtotal ( scA_paid scB_paid)
tab Screening_Paid1
tabstat Screening_Paid1, by (Actual_recode1)
gen one_11=1 // this is assigning the value one to all the observations done to create a
proportion of saying yes to screening recode
collapse (sum) Screening_Paid1 one_11 , by(Actual_recode1) // this is summing respectively
those categories who have been asked about the screening recode and also those categories
who have said yes to respective categories of screening recode.
gen proportion_screening =Screening_Paid1 /one_11
drop if proportion_screening==0

** Creating graph
twoway line proportion_screening Actual_recode1, title (WTP - Cancer Screening) xlabels( 0
1000 3000 6000 10000)
tempfile Screening_actual
save "`Screening_actual'.dta",replace
```

Figure 2.4

Please see the codes for Table 2.6
The figure is made is latex

Figure 2.5

Please see the codes for Table 2.6
The figure is made is latex

***** Table 2.1 ****

Descriptive statistics using tab

** Table 2.2 ***

```
gen nn=.
replace nn =1 if (Screening_Paid==0) & (Screeninghalf_Paid==0)
replace nn=0 if missing(nn)

gen ny=.
replace ny =1 if (Screening_Paid==0) & (Screeninghalf_Paid==1)
replace ny=0 if missing(ny)

gen yn=.
replace yn =1 if (Screening_Paid==1) & (Screeningdouble_Paid==0)
replace yn=0 if missing(yn)

gen yy=.
replace yy =1 if (Screening_Paid==1) & (Screeningdouble_Paid==1)
replace yy=0 if missing(yy)
```

** Table 2.3 and Table 2.4 **

Descriptive statistics table using tab

** Table 2.5 **

```
clear all
set more off
local FinalCancerData "C:\Users\Soumi\Google Drive\UNM
Coursework_4thJan2017\PhD_4th Year\Chronic Illness_Cancer
study\Data\Data_Nepal\FinalCancerData\WTP_Paper\WorkingDofiles\FinalCancerFold
er2"
cd "`FinalCancerFolder2'"
include "BasicStatDoFileCancerPhase1_2015"
```

**Generating the interval WTP variables.

```
replace Screeningdouble_Paid=. if Screening_Paid==0
 replace Screeninghalf_Paid=. if Screening_Paid==1

gen FinalWTP_min =.
 replace FinalWTP_min=250 if (Actual_recode==500) & (Screening_Paid==0) & (
Screeninghalf_Paid==1)
 replace FinalWTP_min=500 if (Actual_recode==500) & (Screening_Paid==1) & (
Screeningdouble_Paid==0) & missing(FinalWTP_min)
 replace FinalWTP_min=1000 if (Actual_recode==500) & (Screening_Paid==1) &
(Screeningdouble_Paid==1) & missing(FinalWTP_min)
 replace FinalWTP_min=500 if (Actual_recode==1000) & (Screening_Paid==0) & (
Screeninghalf_Paid==1) & missing(FinalWTP_min)
```

```
replace FinalWTP_min=1000 if (Actual_recode==1000) & (Screening_Paid==1) & (
Screeningdouble_Paid==0) & missing(FinalWTP_min)
replace FinalWTP_min=2000 if (Actual_recode==1000) & (Screening_Paid==1) & (
Screeningdouble_Paid==1) & missing(FinalWTP_min)
replace FinalWTP_min=1500 if (Actual_recode==3000) & (Screening_Paid==0) & (
Screeninghalf_Paid==1) & missing(FinalWTP_min)
replace FinalWTP_min=3000 if (Actual_recode==3000) & (Screening_Paid==1) &
(Screeningdouble_Paid==0) & missing(FinalWTP_min)
replace FinalWTP_min=6000 if (Actual_recode==3000) & (Screening_Paid==1) &
(Screeningdouble_Paid==1) & missing(FinalWTP_min)
replace FinalWTP_min=3000 if (Actual_recode==6000) & (Screening_Paid==0) &
(Screeninghalf_Paid==1) & missing(FinalWTP_min)
replace FinalWTP_min=6000 if (Actual_recode==6000) & (Screening_Paid==1) &
(Screeningdouble_Paid==0) & missing(FinalWTP_min)
replace FinalWTP_min=12000 if (Actual_recode==6000) & (Screening_Paid==1) &
(Screeningdouble_Paid==1) & missing(FinalWTP_min)
replace FinalWTP_min=10000 if (Actual_recode==10000) & (Screening_Paid==1) &
(Screeningdouble_Paid==0) & missing(FinalWTP_min)
replace FinalWTP_min=20000 if (Actual_recode==10000) & (Screening_Paid==1) &
(Screeningdouble_Paid==1) & missing(FinalWTP_min)
replace FinalWTP_min=5000 if (Actual_recode==10000) & (Screening_Paid==0) &
(Screeninghalf_Paid==1) & missing(FinalWTP_min)
replace FinalWTP_min=0 if (Screening_Paid==0) & ( Screeninghalf_Paid==0) &
missing(FinalWTP_min)


gen FinalWTP_max =.
replace FinalWTP_max=499 if (Actual_recode==500) & (Screening_Paid==0) & (
Screeninghalf_Paid==1) & missing(FinalWTP_max)
replace FinalWTP_max=249 if (Actual_recode==500) & (Screening_Paid==0) & (
Screeninghalf_Paid==0) & missing(FinalWTP_max)
replace FinalWTP_max=999 if (Actual_recode==500) & (Screening_Paid==1) & (
Screeningdouble_Paid==0) & missing(FinalWTP_max)
replace FinalWTP_max=999 if (Actual_recode==1000) & (Screening_Paid==0) & (
Screeninghalf_Paid==1) & missing(FinalWTP_max)
replace FinalWTP_max=499 if (Actual_recode==1000) & (Screening_Paid==0) & (
Screeninghalf_Paid==0) & missing(FinalWTP_max)
replace FinalWTP_max= 1999 if (Actual_recode==1000) & (Screening_Paid==1) & (
Screeningdouble_Paid==0) & missing(FinalWTP_max)
replace FinalWTP_max= 2999 if (Actual_recode==3000) & (Screening_Paid==0) & (
Screeninghalf_Paid==1) & missing(FinalWTP_max)
replace FinalWTP_max= 1499 if (Actual_recode==3000) & (Screening_Paid==0) & (
Screeninghalf_Paid==0) & missing(FinalWTP_max)
replace FinalWTP_max= 5999 if (Actual_recode==3000) & (Screening_Paid==1) &
(Screeningdouble_Paid==0) & missing(FinalWTP_max)
replace FinalWTP_max= 5999 if (Actual_recode==6000) & (Screening_Paid==0) &
(Screeninghalf_Paid==1) & missing(FinalWTP_max)
```

```
 replace FinalWTP_max= 2999 if (Actual_recode==6000) & (Screening_Paid==0)  &
(Screeninghalf_Paid==0) & missing(FinalWTP_max)
 replace FinalWTP_max= 11999 if (Actual_recode==6000) & (Screening_Paid==1) &
(Screeningdouble_Paid==0) & missing(FinalWTP_max)
 replace FinalWTP_max=19999 if (Actual_recode==10000) & (Screening_Paid==1) &
(Screeningdouble_Paid==0) & missing(FinalWTP_max)
 replace FinalWTP_max=9999 if (Actual_recode==10000) & (Screening_Paid==0) &
(Screeninghalf_Paid==1) & missing(FinalWTP_max)
 replace FinalWTP_max=4999 if (Actual_recode==10000) & (Screening_Paid==0) &
(Screeninghalf_Paid==0) & missing(FinalWTP_max)
 replace FinalWTP_max= . if  (Screening_Paid==1) & ( Screeningdouble_Paid==1) &
missing(FinalWTP_max)
 gen ln_minwtp = ln(FinalWTP_min+1)
 gen ln_maxwtp = ln(FinalWTP_max+1)


** Interval regression codes **

set more off
intreg ln_minwtp ln_maxwtp  energetic content_QOL feeling_bad lose_hope hurting_oneself
chances_cure relativechances_cure cancer_survive cancer_treated Distance
aggresive_payment information_hospitals knowledge_tests stigmatized_recode
hide_cancer_recode attitude_changed_recode comm_family perceive_risk risk_recoccurence
screen_help, vce (robust)
estimate store m1

** Calculating the mean WTP from interval regression
predict xb2
gen mwtp2 = exp(xb2)
bootstrap mwtp2a = r(mean) ,reps (1000) : sum mwtp2


** Probit regressions**

probit Screening_Paid Actual_recode energetic content_QOL feeling_bad lose_hope
hurting_oneself chances_cure  relativechances_cure cancer_survive cancer_treated Distance
aggresive_payment information_hospitals knowledge_tests stigmatized_recode
hide_cancer_recode attitude_changed_recode comm_family perceive_risk risk_recoccurence
screen_help i.Education i.Income_HH ln_expenses age_patient Madhesi_Dalit
estimate store pr1

** Calculating the mean WTP from probit regression

wtpcikr Actual_recode energetic content_QOL feeling_bad lose_hope hurting_oneself
chances_cure relativechances_cure cancer_survive cancer_treated Distance
aggresive_payment information_hospitals knowledge_tests stigmatized_recode
hide_cancer_recode attitude_changed_recode comm_family perceive_risk risk_recoccurence
screen_help , reps (1000) saving (C:\Users\Soumi\Google Drive\UNM
```

```
Coursework_Sep12017\PhD_4th Year\Chronic Illness_Cancer study\Data\Data_Nepal\FinalCancerData\WTP_Paper\WorkingDofiles\FinalCancerFolder2\WTPPrbit1)


**Doubleb - Alejandro- Lopez model [ doubleb command]**
** Some of the bids were inconsistent so I am recoding them to make consistent.
Note: bid1 should be lower than bid2

gen bid1=Actual_recode
gen bidh = Screening_doublerecode
gen bidl=  Screening_halfrecode

gen nn=.
replace nn =1 if (Screening_Paid==0) & (Screeninghalf_Paid==0)
replace nn=0 if missing(nn)

gen ny=.
replace ny =1 if (Screening_Paid==0) & (Screeninghalf_Paid==1)
replace ny=0 if missing(ny)

gen yn=.
replace yn =1 if (Screening_Paid==1) & (Screeningdouble_Paid==0)
replace yn=0 if missing(yn)

gen yy=.
replace yy =1 if (Screening_Paid==1) & (Screeningdouble_Paid==1)
replace yy=0 if missing(yy)

gen depvar =1 if nn==1
replace depvar =2 if ny==1
replace depvar =3 if yn==1
replace depvar =4 if yy==1

gen answer1 =0
replace answer1=1 if depvar==3|depvar==4
label define dummy 0 "NO" 1 "YES"
label values answer1 dummy
gen answer2 =0
replace answer2=1 if depvar==2|depvar==4
gen bid2=.
replace bid2 = bidh if answer1==1
replace bid2=bidl if answer1==0

summarize energetic, meanonly
scalar ener_1 = r(mean)
summarize content_QOL, meanonly
scalar QOL_1 = r(mean)
```

```
summarize feeling_bad, meanonly
scalar bad_1 = r(mean)
summarize lose_hope, meanonly
scalar hope_1 = r(mean)
summarize hurting_oneself, meanonly
scalar hurting_1 = r(mean)
summarize chances_cure, meanonly
scalar chances_1 = r(mean)
summarize relativechances_cure, meanonly
scalar relative_1 = r(mean)
summarize cancer_survive, meanonly
scalar survive_1 = r(mean)
summarize cancer_treated, meanonly
scalar treated_1 = r(mean)
summarize Distance, meanonly
scalar Distance_1 = r(mean)
summarize aggresive_payment, meanonly
scalar aggresive_1 = r(mean)
summarize information_hospitals, meanonly
scalar information_1 = r(mean)
summarize knowledge_tests, meanonly
scalar knowledge_1 = r(mean)
summarize stigmatized_recode, meanonly
scalar stigmatized_1 = r(mean)
summarize hide_cancer_recode, meanonly
scalar hide_1 = r(mean)
summarize attitude_changed_recode, meanonly
scalar attitude_1 = r(mean)
summarize comm_family, meanonly
scalar comm_1 = r(mean)
summarize perceive_risk, meanonly
scalar perceive_1 = r(mean)
summarize risk_recoccurence, meanonly
scalar risk_1 = r(mean)
summarize screen_help, meanonly
scalar screen_1 = r(mean)

** Recoding bid2 to make it consistent
recode bid2 (2000=20000) if _n==67
recode bid2 (1500=500) if _n==84
recode bid2 (5000=1500) if _n==104
recode bid2 (5000=1500) if _n==261
recode bid2 (5000=1500) if _n==279
recode bid2 (5000=1500) if _n==397
recode bid2 (2000=20000) if _n==454
recode bid2 (2000=20000) if _n==492
recode bid2 (.=500) if _n==499
recode bid2 (1500=500) if _n==499
```

```
recode bid2 (5000=1500) if _n==260
recode bid2 (5000=1500) if _n==278
recode bid2 (5000=1500) if _n==396
recode bid2 (2000=20000) if _n==452
recode bid2 (2000=20000) if _n==490
recode bid2 (5000=3000) if _n==491
recode bid2 (.=500) if _n==497
```

```
doubleb bid1 bid2 answer1 answer2 energetic content_QOL feeling_bad lose_hope
hurting_oneself chances_cure  relativechances_cure cancer_survive cancer_treated Distance
aggresive_payment information_hospitals knowledge_tests stigmatized_recode
hide_cancer_recode attitude_changed_recode comm_family perceive_risk risk_recoccurence
screen_help
estimate store pr2

** Calculating the mean WTP from doubleb regression
nlcom (WTP: (_b[_cons] +ener_1*_b[energetic]+QOL_1*_b[content_QOL] +
bad_1*_b[feeling_bad] + hope_1*_b[lose_hope] + hurting_1*_b[hurting_oneself] +
chances_1*_b[chances_cure] + relative_1*_b[relativechances_cure] +
survive_1*_b[cancer_survive] + treated_1*_b[cancer_treated]  + Distance_1*_b[Distance] +
aggresive_1*_b[aggresive_payment] + information_1*_b[information_hospitals] +
knowledge_1*_b[knowledge_tests] + stigmatized_1*_b[stigmatized_recode] +
hide_1*_b[hide_cancer_recode] + attitude_1*_b[attitude_changed_recode]  +
comm_1*_b[comm_family] + perceive_1*_b[perceive_risk] + risk_1*_b[risk_recoccurence]
+ screen_1*_b[screen_help])), noheader
```

***Preparing the data to run a Structural Equation Model ***

SEM need a continuous dependent variable

Now those who have said Yes and Yes to both the initial and the follow up bid amounts, the infinite value of yearly WTP is trimmed according to their monthly income [which comes up to 8% of their monthly income]

```
** I replaced the maximum WTP with the monthly income
gen ln_maxwtp = ln(FinalWTP_max+1)
** save IncomeWTPdata.dta

** Also ran robustness of results when WTP is trimmed to 5% of the income or 2.5% of the
income.

clear all
set more off

cd "C:\Users\Soumi\Google Drive\UNM Coursework_Sep12017\PhD_4th Year\Chronic
Illness_Cancer study\Data\Data_Nepal\FinalCancerData\Chapter2-
WTP_Paper\WorkingDofiles\FinalCancerFolder2"
```

```
use IncomeWTPdata.dta,clear
```

```
gen Others=1 if ! missing(others)
replace Others=0 if missing(others)
gen Comorbidities =1 if
(diabetic==1)|(blood_pressure==1)|(mental_disorder==1)|(epilepsy
==1)|(asthma==1)|(heart_disease==1)|(copd==1)|(Alzheimers==1)|(otherreasons==1)
|(Others==1)
replace Comorbidities =0 if missing(Comorbidities)

gen Noedu =1 if Education==1
replace Noedu =0 if missing(Noedu)

gen Income =1 if Income_HH>1
replace Income =0 if missing(Income)

gen RiskReoccurence =1 if (risk_recoccurence ==3) | (risk_recoccurence==4)
replace RiskReoccurence =0 if missing(RiskReoccurence)

gen DistanceDummy =1 if (Distance>1)
replace DistanceDummy =0 if missing(DistanceDummy)
```

**** The Structural Equation Model [Recursive Framework] ****

```
set more off
 sem (Optimism -> cancer_treated, ) (Optimism -> cancer_survive, ) (Optimism ->
ln_maxwtp, ) (Optimism -> Chances, ) (Chances -> chances_cure, ) (Chances ->
relativechances_cure, ) (Chances -> ln_maxwtp, ) (Information -> Optimism, ) (Information
-> Chances, ) (Information -> knowledge_tests, ) (Information -> information_hospitals, )
(Information -> Pessimism, ) (Information -> ln_maxwtp, ) (Pessimism -> feeling_bad, )
(Pessimism -> lose_hope, ) (Pessimism -> hurting_oneself, ) (Pessimism -> ln_maxwtp, )
(Optimism -> SelfRated) (Stigma -> attitude_changed_recode, ) (Stigma ->
stigmatized_recode, ) (Stigma -> hide_cancer_recode, ) (Stigma -> ln_maxwtp, ) (SelfRated -
> content_QOL, ) (SelfRated -> energetic, ) (SelfRated -> ln_maxwtp, ) (comm_family ->
ln_maxwtp Chances) (DistanceDummy -> Optimism ln_maxwtp,) (Income -> Optimism, )
(Income -> Chances, ) (Income -> ln_maxwtp, ) (Madhesi_Dalit -> ln_maxwtp Information
SelfRated, ) (age_patient -> Information, (age_patient -> ln_maxwtp, ) (relative_cancer ->
Optimism, ) (ln_expenses -> ln_maxwtp) (relative_cancer -> Pessimism, ) (screen_help ->
Optimism ln_maxwtp, ) (RiskReoccurence -> ln_maxwtp Pessimism Chances )
(aggresive_payment ->ln_maxwtp) (perceive_risk -> Information, ) (perceive_risk ->
ln_maxwtp, ) (Pessimism ->Chances,) (Stigma aggresive_payment -> Pessimism ,
covstruct(_lexogenous, diagonal) cov(_lexogenous*_oexogenous@0) vce(robust)
standardized latent(Optimism Chances Information Pessimism Stigma SelfRated)
nocapslatent
```

```
** Table 2.6 **
** Decomposition of the total effects into direct and indirect effects**

set more off
estat teffects, compact standardized


** Calculating the mean WTP from the structural model**
predict WTPHAT , xb(ln_maxwtp)
gen MeanSEMWTP = (exp(WTPHAT))
bootstrap MeanSEMWTP1 = r(mean) ,reps (1000) : sum MeanSEMWTP

** Checking the variance-covariance matrix
estat framework, standardized

** Diagnostic checking
estat gof, stats(all)
```

The Stata codes on Non-Recursive nature SEM with correlated errors, unstructured covariance structure, and other variations of SEM models are not included here.

Stata files used in Chapter 3

Data files used in this Chapter:

1. FinalCancerFile
2. Final_ControlFilenew.dta

Do files used in the chapter

1. Cancer_Cleaningdofile
2. Control_Cleaningdofile
3. Appending_Control_Cancer

Creation of do files

1. **Creating appended do file**

```
gen cancerorco=.   // Creating the cancer vs control patients. Generating 1 for cancer and 0 for control
replace cancerorco =1

rename type_cancer type_disease
rename  cancer_others disease_others
```

```
rename routine_check screeningfor_cancer
rename reasons_noscreen whynot_screening
rename cancer_treated Cancer_treated
rename cancer_survive Cancer_survive
rename no_stigma Cancer_stigma
rename prevent_cancer Cancer_prevent
rename low_awareness Cancer_awareness
rename from_someone Cancer_contagious
rename specialised_30days type_treatment
rename under under_18

 **Saving the tempfile of cancer
tempfile append_cancer
save "`append_cancer'.dta",replace

** Calling the control do file
set more off
local tmpf2 "C:\Users\Soumi\Google Drive\UNM Coursework_Sep12017\PhD_4th
Year\Chronic Illness_Cancer
study\Data\Data_Nepal\FinalCancerData\Chapter3MentalBurdenPaperr"
cd "`tmpfl2'"
include "Control_Cleaningdofile"


**Saving the tempfile of control
tempfile append_control
save "`append_control'.dta",replace

 **Appending the two data sets
append using "`append_cancer'.dta"
gen question_no =_n
```

2. Treatmenteffects_Binary

```
clear all
set more off
local tmpf1 "C:\Users\Soumi\Google Drive\UNM Coursework_Sep12017\PhD_4th
Year\Chronic Illness_Cancer
study\Data\Data_Nepal\FinalCancerData\Chapter3MentalBurdenPaper"
cd "`tmpfl2'"
include "Appending_Control_Cancer"
```

3. Treatmenteffects_Multinomial

```
clear all
```

```
local tmpf1 "C:\Users\sroychowdhury\Google Drive\UNM Coursework_Sep12017\PhD_4th Year\Chronic Illness_Cancer study\Data\Data_Nepal\FinalCancerData\MentalBurdenPaper"
cd "`tmpfl2'"
include "Appending_Control_Cancer"
```

Stata Codes

**** Creating Mental Burden Variables****

MentalBurdenDisease-1

```
a. gen c_mentalburden = worried_finance + family_distress + awkward_appearance + lose_hope + personal_care
   rename c_mentalburden MentalBurden_Disease
```

MentalBurdenDisease-2

```
b. gen emo_burden = worried_finance + family_distress + awkward_appearance + lose_hope + personal_care + little_interest + depressed + hurting_oneself
```

MentalBurdenDisease-3

```
c. gen emo_burden2 = worried_finance + family_distress + awkward_appearance + lose_hope + little_interest +  depressed + hurting_oneself + personal_care + heart_pound  + vomiting + chestpain
```

Self-Assessed Health Status

```
d. gen Self_Assessed = content_QOL + general_life
```

**** Creating Treatment Categories****

Separating out the type of cancer based on gender, i.e of all the female cancer patients what percentage got cervical, breast or other types of cancer

```
gen Cancer_male = Cancer_recode if gender==1
gen Cancer_female = Cancer_recode if gender==2

recode Cancer_male  (1=1) (2=10) (3=2) (4=3) (5=10) (6=4) (7=5) (8=6) (9=7) (10=8) (11=9) (12=10)

recode Cancer_female  (1=1) (2=2) (3=3) (4=4) (5=5) (6=6) (7=11) (8=7) (9=8) (10=9) (11=10) (12=11)
```

**** With cervical cancer as the base category**

```
** Cervical cancer
gen Treatment_categories = 1 if Cancer_female==5
```

```
** All other female cancer
replace Treatment_categories = 2 if  (Cancer_female==2) | (Cancer_female==1) |
(Cancer_female==3) | (Cancer_female==4) | (Cancer_female==6) | (Cancer_female==7)
| (Cancer_female==8) | (Cancer_female==9) | (Cancer_female==10)

** All other male cancer
replace Treatment_categories = 3 if (Cancer_male==1) | (Cancer_male==2) |
(Cancer_male==3) | (Cancer_male==4) | (Cancer_male==5) ///
| (Cancer_male==6) | (Cancer_male==7) | (Cancer_male==8) | (Cancer_male==9) |
(Cancer_male==10) // all other male cancers

** Control patients
replace Treatment_categories = 4 if (cancerorco==0)
```

```
** Figure 3.1**
```

```
kdensity MentalBurden_Disease, nograph generate(y fy)
kdensity MentalBurden_Disease if cancerorco==0, nograph generate(fy0) at(y)
kdensity MentalBurden_Disease if cancerorco==1, nograph generate(fy1) at(y)
label var fy0 "Control"
label var fy1 "Cancer"
line fy0 fy1 y, sort ytitle(Density) saving(KdensityMB, replace) title("Distribution of Mental
Burden", size(medium)) subtitle("(Cancer and Control patients)" , size (small)) note("Source:
Nepal Study Center, December 2015")
```

Kolmogorov–Smirnov test

```
ksmirnov MentalBurden_Disease, by(cancerorco)
```

Normality of the distribution

```
swilk MentalBurden_Disease
```

Two sample Wilcoxon rank-sum

```
ranksum MentalBurden_Disease,by (cancerorco)
median MentalBurden_Disease,by (cancerorco)
```

```
** Figure 3.2 **
```

Common support region by treatment groups

```
psgraph, treated (cancerorco) pscore (myscore)
```

```
** Figure 3.3 **
```

```
tebalance density
```

```
** Table 3.1 **
```

Distribution of cancer patients across cancer hospitals - tabulate

```
** Table 3.2 **
```

Descriptive Statistics of Treatment and Control groups - tabulate

**** Table 3.3****
**** Propensity Scores ****

```
set more off
*** Define treatment, outcome, and independent variables
global treatment cancerorco
global ylist Self_Assessed [MentalBurden_Disease  emo_burden emo_burden2 Self_Assessed
]

global x1list age_patient Inc10_20 Inc20_30 Inc30 Edu1_8 Edu9_12 Edu12 Agriculture
Selfemployed Ad_ExJobs Laborers Housewife Chherti Newar Janajati Madhesi_Dalit Alcohol
Smoke relative_cancer Exercise kitchen_inside wooden_fuel live_mainroad Married
screeningfor_cancer

global breps 1000 [Boorstrap replications]
drop if MentalBurden_Disease==.
drop if age_patient ==.
drop if Moderatesupport==.
drop if Lowsupport==.
drop if  Absence==.
drop if Quit_job ==.
drop if Inc10_20 ==.
drop if Inc20_30 ==.
drop if Inc30==.
drop if Edu1_8==.
drop if Edu9_12==.
drop if Edu12 ==.
drop if ln_expenses==.
drop if aggresive_payment==.
drop if Chherti==.
drop if Newar==.
drop if Janajati==.
drop if Madhesi_Dalit==.

describe $treatment $ylist $xlist
summarize  $treatment $ylist $xlist

bysort $treatment: summarize $ylist $xlist
reg $ylist $treatment
reg $ylist $treatment $xlist
 pscore $treatment $xlist, pscore (myscore) comsup detail
```

***Matching methods**

```
** Nearest neighbor matching
```

```
attnd $ylist $treatment $xlist, pscore(myscore) comsup boot reps ($breps) dots

** Radius matching
attr $ylist $treatment $xlist, pscore(myscore) comsup boot reps ($breps) dots radius (0.01) //
Matching within a very conbservative radius.

** Kernel Matching
attk  $ylist $treatment $xlist, pscore(myscore) comsup boot reps ($breps) dots

** Stratification matching
atts $ylist $treatment $xlist, pscore(myscore) comsup blockid(myblock) boot reps ($breps)
```

**** Table 3.4** [All the regressions have been ran individually for Mental Burden Disease-1, Mental Burden Disease-2, Mental Burden Disease-3, SelfAssessed Health]**

```
set more off
quietly: psmatch2 cancerorco age_patient i.Income_HH i.Education i.Occupation Chherti
Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Married Exercise
kitchen_inside wooden_fuel live_mainroad screeningfor_cancer, out(MentalBurden_Disease)
logit noreplacement

reg MentalBurden_Disease /*emo_burden emo_burden2*/ cancerorco age_patient
i.Lacksupport ln_expenses  i.Income_HH i.Education i.Occupation Chherti Newar Janajati
Madhesi_Dalit Alcohol Smoke relative_cancer Married Exercise kitchen_inside wooden_fuel
live_mainroad screeningfor_cancer [fweight=_weight]

estimate store Norepl1


quietly: psmatch2 cancerorco age_patient i.Income_HH i.Education i.Occupation Chherti
Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Married Exercise
kitchen_inside wooden_fuel live_mainroad screeningfor_cancer, out(MentalBurden_Disease)
logit
reg MentalBurden_Disease /*emo_burden emo_burden2*/ cancerorco age_patient
i.Lacksupport ln_expenses i.Income_HH i.Education i.Occupation Chherti Newar Janajati
Madhesi_Dalit Alcohol Smoke relative_cancer Married Exercise kitchen_inside wooden_fuel
live_mainroad screeningfor_cancer [fweight=_weight]

estimate store Repl1


quietly:psmatch2 cancerorco age_patient i.Income_HH i.Education i.Occupation Chherti
Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Married Exercise
kitchen_inside wooden_fuel live_mainroad screeningfor_cancer, out(emo_burden) logit
noreplacement
```

```
reg emo_burden /*emo_burden emo_burden2*/ cancerorco age_patient i.Lacksupport
ln_expenses i.Income_HH i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit
Alcohol Smoke relative_cancer Married Exercise kitchen_inside wooden_fuel live_mainroad
screeningfor_cancer [fweight=_weight]
estimate store Norepl2


quietly:psmatch2 cancerorco age_patient  i.Income_HH i.Education i.Occupation Chherti
Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Married Exercise
kitchen_inside wooden_fuel live_mainroad screeningfor_cancer, out(emo_burden) logit

reg emo_burden /*emo_burden emo_burden2*/ cancerorco age_patient i.Lacksupport
ln_expenses i.Income_HH i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit
Alcohol Smoke relative_cancer Married Exercise kitchen_inside wooden_fuel live_mainroad
screeningfor_cancer [fweight=_weight]
estimate store Repl2


quietly: psmatch2 cancerorco age_patient  i.Income_HH i.Education i.Occupation Chherti
Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Married Exercise
kitchen_inside wooden_fuel live_mainroad screeningfor_cancer, out(emo_burden2) logit
noreplacement

reg emo_burden2 /*emo_burden emo_burden2*/ cancerorco age_patient i.Lacksupport
ln_expenses  i.Income_HH i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit
Alcohol Smoke relative_cancer Married Exercise kitchen_inside wooden_fuel live_mainroad
screeningfor_cancer [fweight=_weight]
estimate store Norepl3


quietly: psmatch2 cancerorco age_patient i.Income_HH i.Education i.Occupation Chherti
Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Married Exercise
kitchen_inside wooden_fuel live_mainroad screeningfor_cancer, out(emo_burden2) logit
reg emo_burden2 /*emo_burden emo_burden2*/ cancerorco age_patient i.Lacksupport
ln_expenses i.Income_HH i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit
Alcohol Smoke relative_cancer Married Exercise kitchen_inside wooden_fuel live_mainroad
screeningfor_cancer [fweight=_weight]
estimate store Repl3


quietly: psmatch2 cancerorco age_patient i.Income_HH i.Education i.Occupation Chherti
Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Married Exercise
kitchen_inside wooden_fuel live_mainroad screeningfor_cancer, out(Self_Assessed) logit
noreplacement

reg Self_Assessed /*emo_burden emo_burden2*/ cancerorco age_patient i.Lacksupport
ln_expenses i.Income_HH i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit
```

```
Alcohol Smoke relative_cancer Married Exercise kitchen_inside wooden_fuel live_mainroad
screeningfor_cancer [fweight=_weight]
estimate store Norepl4


quietly: psmatch2 cancerorco age_patient i.Income_HH i.Education i.Occupation Chherti
Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Married Exercise
kitchen_inside wooden_fuel live_mainroad screeningfor_cancer, out(Self_Assessed) logit

reg Self_Assessed /*emo_burden emo_burden2*/ cancerorco age_patient i.Lacksupport
ln_expenses i.Income_HH i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit
Alcohol Smoke relative_cancer Married Exercise kitchen_inside wooden_fuel live_mainroad
screeningfor_cancer [fweight=_weight]
estimate store Repl4

esttab Norepl1 Repl1 Norepl2 Repl2 Norepl3 Repl3 Norepl4 Repl4 using
ReplaceNoreplacenew.csv,nogap star(* 0.1 ** 0.05 *** 0.01)scalars( "ll log_likelihood" "chi2
chi-squared" "aic AIC" "bic BIC" )replace
```

**** Table 3.5****

Regression Adjustments (RA)

```
teffects ra (Self_Assessed  /* MentalBurden_Disease Self_Assessed  emo_burden
emo_burden2 */ age_patient i.Lacksupport ln_expenses i.Income_HH i.Education
i.Occupation Chherti Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Exercise
kitchen_inside wooden_fuel live_mainroad Married screeningfor_cancer) (cancerorco), vce
(robust)

teffects ra (Self_Assessed /* MentalBurden_Disease Self_Assessed emo_burden
emo_burden2 */ age_patient i.Lacksupport ln_expenses i.Income_HH i.Education
i.Occupation Chherti Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Exercise
kitchen_inside wooden_fuel live_mainroad Married screeningfor_cancer) (cancerorco), atet
vce (robust)
```

Inverse Probability Weighting Estimator (IPW)

```
teffects ipw ( Self_Assessed   /* Self_Assessed emo_burden2  */) (cancerorco age_patient
i.Income_HH i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit Alcohol
Smoke relative_cancer Exercise kitchen_inside wooden_fuel live_mainroad Married
screeningfor_cancer), vce (robust)

teffects ipw (   Self_Assessed /* Self_Assessed emo_burden2 */ )  (cancerorco age_patient
i.Income_HH i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit Alcohol
Smoke relative_cancer Exercise kitchen_inside wooden_fuel live_mainroad Married
screeningfor_cancer), atet vce (robust)
```

Inverse Probability Weighting Regression Adjustments (IPWRA)

```
teffects ipwra ( Self_Assessed /* Self_Assessed Self_Assessed emo_burden2  emo_burden */
age_patient i.Lacksupport ln_expenses i.Income_HH i.Education i.Occupation Chherti
Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Exercise kitchen_inside
wooden_fuel live_mainroad Married screeningfor_cancer) (cancerorco age_patient
i.Income_HH i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit Alcohol
Smoke relative_cancer Exercise kitchen_inside wooden_fuel live_mainroad Married
screeningfor_cancer), vce (robust)
```

```
teffects ipwra ( Self_Assessed  /* Self_Assessed Self_Assessed emo_burden2  emo_burden
*/ age_patient i.Lacksupport ln_expenses i.Income_HH i.Education i.Occupation Chherti
Newar Janajati Madhesi_Dalit Alcohol Smoke relative_cancer Exercise kitchen_inside
wooden_fuel live_mainroad Married screeningfor_cancer) (cancerorco age_patient
.Income_HH i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit Alcohol Smoke
relative_cancer Exercise kitchen_inside wooden_fuel live_mainroad Married
screeningfor_cancer), atet vce (robust)
```

Augmented inverse-probability weighting

```
teffects aipw ( Self_Assessed   /* Self_Assessed emo_burden2  emo_burden */ age_patient
i.Lacksupport ln_expenses  i.Income_HH i.Education i.Occupation Chherti Newar Janajati
Madhesi_Dalit Alcohol Smoke relative_cancer Exercise kitchen_inside wooden_fuel
live_mainroad Married screeningfor_cancer) (cancerorco age_patient i.Income_HH
i.Education i.Occupation Chherti Newar Janajati Madhesi_Dalit Alcohol Smoke
relative_cancer Exercise kitchen_inside wooden_fuel live_mainroad Married
screeningfor_cancer), vce (robust)
```

** Table 3.6**

Regression Adjustments (RA)

```
set more off
teffects ra   (/*MentalBurden_Disease emo_burden emo_burden2 */ Self_Assessed
age_patient Lowsupport Moderatesupport  ln_expenses Alcohol Smoke relative_cancer
Exercise kitchen_inside wooden_fuel live_mainroad Married screeningfor_cancer Inc10_20
Inc20_30 Inc30 Chherti Newar Janajati Madhesi_Dalit Agriculture Selfemployed Ad_ExJobs
Laborers Housewife) (Treatment_categories),  vce(robust)
```

```
teffects ra   (/*emo_burden emo_burden2 MentalBurden_Disease */ Self_Assessed
age_patient Lowsupport Moderatesupport ln_expenses Alcohol Smoke relative_cancer
Exercise kitchen_inside wooden_fuel live_mainroad Married screeningfor_cancer Inc10_20
Inc20_30 Inc30 Chherti Newar Janajati Madhesi_Dalit Agriculture Selfemployed Ad_ExJobs
Laborers Housewife) (Treatment_categories), atet  vce(robust)
```

Inverse Probability Weighting Estimator (IPW)

```
teffects ipw ( /*emo_burden2 emo_burden MentalBurden_Disease*/ Self_Assessed)
(Treatment_categories age_patient Alcohol Smoke relative_cancer Exercise kitchen_inside
wooden_fuel live_mainroad Married screeningfor_cancer Inc10_20 Inc20_30 Inc30 Chherti
Newar Janajati Madhesi_Dalit Agriculture Selfemployed Ad_ExJobs Laborers Housewife),
vce(robust)
```

```
teffects ipw (/*emo_burden2 Self_Assessed emo_burden MentalBurden_Disease */
Self_Assessed ) (Treatment_categories age_patient  Alcohol Smoke relative_cancer Exercise
kitchen_inside wooden_fuel live_mainroad Married screeningfor_cancer Inc10_20 Inc20_30
Inc30 Chherti Newar Janajati Madhesi_Dalit Agriculture Selfemployed Ad_ExJobs Laborers
Housewife) , atet vce(robust)
```

Inverse Probability Weighting Regression Adjustments (IPWRA)

```
teffects ipwra (Self_Assessed /*MentalBurden_Disease Self_Assessed emo_burden
emo_burden2*/  age_patient Lowsupport Moderatesupport ln_expenses Alcohol Smoke
relative_cancer Exercise kitchen_inside wooden_fuel live_mainroad Married
screeningfor_cancer Inc10_20 Inc20_30 Inc30 Chherti Newar Janajati Madhesi_Dalit
Agriculture Selfemployed Ad_ExJobs Laborers Housewife) (Treatment_categories
age_patient Alcohol Smoke relative_cancer Exercise kitchen_inside wooden_fuel
live_mainroad Married screeningfor_cancer Inc10_20 Inc20_30 Inc30 Chherti Newar Janajati
Madhesi_Dalit Agriculture Selfemployed Ad_ExJobs Laborers Housewife), vce(robust)
```

```
teffects ipwra (  Self_Assessed /* MentalBurden_Disease emo_burden emo_burden2*/
age_patient Lowsupport Moderatesupport ln_expenses Alcohol Smoke relative_cancer
Exercise kitchen_inside wooden_fuel live_mainroad Married screeningfor_cancer Inc10_20
Inc20_30 Inc30 Chherti Newar Janajati Madhesi_Dalit Agriculture Selfemployed Ad_ExJobs
Laborers Housewife) (Treatment_categories age_patient Alcohol Smoke relative_cancer
Exercise kitchen_inside wooden_fuel live_mainroad Married screeningfor_cancer Inc10_20
Inc20_30 Inc30 Chherti Newar Janajati Madhesi_Dalit Agriculture Selfemployed Ad_ExJobs
Laborers Housewife) , atet vce(robust)
```

Augmented inverse-probability weighting

```
teffects aipw ( Self_Assessed /* MentalBurden_Disease Self_Assessed emo_burden
emo_burden2*/  age_patient Lowsupport Moderatesupport ln_expenses Alcohol Smoke
relative_cancer Exercise kitchen_inside wooden_fuel live_mainroad Married
screeningfor_cancer Inc10_20 Inc20_30 Inc30 Chherti Newar Janajati Madhesi_Dalit
Agriculture Selfemployed Ad_ExJobs Laborers Housewife) (Treatment_categories
age_patient Alcohol Smoke relative_cancer Exercise kitchen_inside wooden_fuel
live_mainroad Married screeningfor_cancer Inc10_20 Inc20_30 Inc30 Chherti Newar Janajati
Madhesi_Dalit Agriculture Selfemployed Ad_ExJobs Laborers Housewife) , nls vce(robust)
```

```
** Table 3.7**
gen cervical =.
replace cervical =1 if Treatment_categories==1
replace cervical =0 if missing(cervical) & (Treatment_categories < 4)
set more off
global x2list worried_finance family_distress awkward_appearance lose_hope personal_care little_interest depressed hurting_oneself heart_pound vomiting chestpain content_QOL general_life
foreach x in $x2list {
 esize twosample `x', by(cervical) all
     }
```

```
**Appendix 3.1**
Weighted Regressions
set more off
foreach weight in "dose_w" {
regress age_patient i. cancerorco [pweight = `weight'] , vce(robust)
oprobit Lacksupport i. cancerorco [pweight = `weight'] , vce(robust)
logit live_mainroad i. cancerorco [pweight = `weight'] , vce(robust)
logit relative_cancer i. cancerorco [pweight = `weight'] , vce(robust)
regress ln_expenses i. cancerorco [pweight = `weight'] , vce(robust)
logit aggresive_payment i. cancerorco [pweight = `weight'] , vce(robust)
oprobit Income_HH i. cancerorco [pweight = `weight'] , vce(robust)
oprobit Education i. cancerorco [pweight = `weight'] , vce(robust)
probit Edu1_8 i. cancerorco [pweight = `weight'] , vce(robust)
probit No_Edu  i. cancerorco [pweight = `weight'] , vce(robust)
logit Exercise i. cancerorco [pweight = `weight'] , vce(robust)
logit kitchen_inside i. cancerorco [pweight = `weight'] , vce(robust)
logit Alcohol i. cancerorco [pweight = `weight'] , vce(robust)
logit Smoke i. cancerorco [pweight = `weight'] , vce(robust)
logit wooden_fuel i. cancerorco [pweight = `weight'] , vce(robust)
logit live_mainroad i. cancerorco [pweight = `weight'] , vce(robust)
logit Married i. cancerorco [pweight = `weight'] , vce(robust)
logit screeningfor_cancer i. cancerorco [pweight = `weight'] , vce(robust)
logit Newar i. cancerorco [pweight = `weight'] , vce(robust)
logit Chherti i. cancerorco [pweight = `weight'] , vce(robust)
logit Janajati i. cancerorco [pweight = `weight'] , vce(robust)
logit Madhesi_Dalit i. cancerorco [pweight = `weight'] , vce(robust)
logit Brahmin i. cancerorco [pweight = `weight'] , vce(robust)
logit Unemployed i. cancerorco  , vce(robust)
logit Agriculture i. cancerorco [pweight = `weight'] , vce(robust)
logit Selfemployed i. cancerorco [pweight = `weight'] , vce(robust)
logit Ad_ExJobs i. cancerorco [pweight = `weight'] , vce(robust)
logit Laborers i. cancerorco [pweight = `weight'] , vce(robust)
logit Housewife i. cancerorco [pweight = `weight'] , vce(robust)
}
```

Unweighted Regressions

```
regress age_patient i. Treatment_categories, vce(robust)
oprobit Lacksupport i. Treatment_categories , vce(robust)
logit live_mainroad i. Treatment_categories  , vce(robust)
logit relative_cancer i. Treatment_categories , vce(robust)
regress ln_expenses i. Treatment_categories  , vce(robust)
logit aggresive_payment i. Treatment_categories  , vce(robust)
oprobit Income_HH i. Treatment_categories  , vce(robust)
oprobit Education i. Treatment_categories  , vce(robust)
logit Exercise i. Treatment_categories , vce(robust)
logit kitchen_inside i. Treatment_categories  , vce(robust)
logit Alcohol i. Treatment_categories  , vce(robust)
logit Smoke i. Treatment_categories , vce(robust)
logit wooden_fuel i. Treatment_categories , vce(robust)
logit Married i. Treatment_categories , vce(robust)
logit screeningfor_cancer i. Treatment_categories  , vce(robust)
logit Newar i. Treatment_categories  , vce(robust)
logit Chherti i. Treatment_categories , vce(robust)
logit Janajati i. Treatment_categories  , vce(robust)
logit Madhesi_Dalit i. Treatment_categories  , vce(robust)
logit Brahmin i. Treatment_categories  , vce(robust)
logit Unemployed i. Treatment_categories  , vce(robust)
logit Agriculture i. Treatment_categories  , vce(robust)
logit Selfemployed i. Treatment_categories  , vce(robust)
logit Ad_ExJobs i. Treatment_categories  , vce(robust)
logit Laborers i. Treatment_categories , vce(robust)
logit Housewife i. Treatment_categories  , vce(robust)
```

Stata files used in Chapter 4

Data files used in this Chapter:

3. FinalCancerFile.dta
4. Final_ControlFilenew

Do files used in the chapter

4. Cancer_Cleaningdofile
5. Control_Cleaningdofile
6. Appending_Control_Cancer

Creation of do file

1. **Creating appended do file**

```
clear all

set more off
```

```
local tmpf1 "C:\Users\sroychowdhury\Google Drive\UNM
Coursework_Sep12017\PhD_4th Year\Chronic Illness_Cancer
study\Data\Data_Nepal\FinalCancerData\Chapter4-Employment_Paper"

cd "`tmpfl1'"

include "Cancer_Cleaningdofile"

gen cancerorco= .

replace cancerorco =1

**Appending cancer and control data sets

** I am renaming some of the variables that have the same information but are named
differently in two data sets.

rename routine_check screeningfor_cancer
rename reasons_noscreen whynot_screening
rename cancer_treated Cancer_treated
rename cancer_survive Cancer_survive
rename no_stigma Cancer_stigma
rename prevent_cancer Cancer_prevent
rename low_awareness Cancer_awareness
rename from_someone Cancer_contagious
rename specialised_30days type_treatment
rename under under_18

** Saving the tempfile of cancer
tempfile append_cancer
save "`append_cancer'.dta",replace


** Calling the control do file
set more off
local tmpf2 "C:\Users\sroychowdhury\Google Drive\UNM
Coursework_Sep12017\PhD_4th Year\Chronic Illness_Cancer
study\Data\Data_Nepal\FinalCancerData\Chapter4-Employment_Paper"
cd "`tmpfl2'"
include "Control_Cleaningdofile"

**Saving the tempfile of control
tempfile append_control
save "`append_control'.dta",replace

** Appending the two data sets
append using "`append_cancer'.dta"
gen question_no =_n
```

** For those who have undergone all types of treatment**

```
gen Treatment_Types=.
replace Treatment_Types=1 if  (type_treatment==1) |(type_treatment==2) |
(type_treatment==3)
replace Treatment_Types=2 if  (type_treatment==4) |(type_treatment==5)
|(type_treatment==6)
replace Treatment_Types=3 if  (type_treatment==7)

gen Treat3=1 if Treatment_Types==3
replace Treat3=0 if missing(Treat3) & (cancerorco==1)
```

** Quit working if they were working before**

```
tab nowork_30days
tab nowork_30days if  Absence==1
tab nowork_30days if  working_before==1
tab working_before if gender==2

tab working_before
tab quit_job if working_before==1

tab working_before  if cancerorco==1
tab quit_job  if (cancerorco==1) & (working_before==1)
sum quit_job  if (working_before==1) & (Treat3==1)

tab working_before  if cancerorco==0
tab quit_job  if (cancerorco==0) & (working_before==1)
```

** Figure 4.1 & Figure 4.2**

In Excel

** Table 4.5**

```
recode cancerorco (0=1) (1=0), gen(Control)
probit quit_job Control i.Education Chherti Newar Janajati Madhesi_Dalit Married
age_patient Agri if (working_before==1)  /*& (gender==2)*/, vce(robust)
margins, dydx(*) post
estimate store emp_cmp1

probit quit_job Control i.Education Chherti Newar Janajati Madhesi_Dalit Married
age_patient Agri if (working_before==1)  & (gender==1), vce(robust)
margins, dydx(*) post
estimate store emp_cmp2


probit quit_job Control i.Education Chherti Newar Janajati Madhesi_Dalit Married
age_patient Agri if (working_before==1)  & (gender==2), vce(robust)
margins, dydx(*) post
```

```
estimate store emp_cmp3

probit quit_job Treat3 i.Education Chherti Newar Janajati Madhesi_Dalit Married
age_patient Agri  if (working_before==1) /*& (gender==1)*/, vce(robust)
margins, dydx(*) post
estimate store emp_cmp4

esttab emp_cmp1 emp_cmp2 emp_cmp3 emp_cmp4 using cancercontrol.csv,nogap star(*
0.1 ** 0.05 *** 0.01)scalars( "ll log_likelihood" "chi2 chi-squared" "aic AIC" "bic BIC"
)replace
```

Table 4.1-4.4 and Table 4.6 are productivity loss and Opportunity cost calculations not done in Stata.

Appendices

C IRB Documents

The Institutional Review Board Requirement (IRB) protocols of the University of New Mexico-USA, Kathmandu University-Nepal, and National Health Research Council-Nepal are attached herewith.

[Please note that the attached IRB documents should only be considered as sample IRB examples because IRB requirements can change periodically. Also, all the attached documents are initial submissions and have gone through various modifications based on the requirements of the project and are not necessarily the final ones.]

UNM IRB PROTOCOL

TITLE:	**Socio-economic Consequences of Cancer in Nepal**
VERSION DATE:	**21st February 2015**
INVESTIGATOR/RESPONSIBLE FACULTY:	**Prof. Alok Bohora**
STUDENT INVESTIGATOR:	**Soumi Roy Chowdhury**
FUNDING AGENCY:	**American Cancer Society**

BACKGROUND/SCIENTIFIC RATIONALE

In the context of developing countries, chronic illness is one of the dominant health burdens, and cancer alone is responsible for 70% of the total deaths. The cost associated with the chronic illness is estimated to increase to $84 billion by 2015 (Nuget, 2008). Cancer care is expensive, time consuming and is life altering for the entire family, which includes not only the cancer patients but also the family members who care for them(Nelson, 2010). In a country like Nepal, such burdens can be quite significant and devastating especially for the poor. Although cancer develops slowly, the impact on financial and non-financial stress can be speedy, deep, and irreversible for the patient as well as for the family members (caregivers). Even in a system where care falls under the public funding envelope, burden of the out-of-pocket cost can also be significantly high (16.5%) (Longo et al., 2006).This study will attempt to measure and quantify such *costs,* which could be direct as well as indirect in the context of Nepal.

My involvement with this particular research topic started last year when Nepal Study Centre (NSC), a research wing located at the Economics Department of University of New Mexico received the funding from American Cancer Society to undertake a project on Nepal about the incidence and socio-economic consequences of cancer. I was involved in the process since the preparation of the grant for research. Currently I am in the process of organizing all the ground details necessary for the study. I will be responsible to reach out to Nepal for data collection process.

Literature Review:

Given below is the brief description of three literatures which are equally important and pertinent to the main objective of our research agenda. The first paper 'Burden of Illness in Cancer Survivors: Findings From a Population-Based National Sample' is a USA based study aims at measuring the economic cost of cancer , the second paper 'Multi-institution Hospital-based Cancer Incidence Data for Nepal - An Initial Report' is one of the very first attempts to quantify the cancer incidents in Nepal. The third paper 'Economic burden of cancer across the European Union: a population-based cost analysis' portrays the impact of cancer on the countries of European Union.

'Burden of Illness in Cancer Survivors: Findings from a Population-Based National Sample'
K. Robin Yabroff, William F. Lawrence, Steven Clauser, William W. Davis, Martin L. Brown
Journal of the National Cancer Institute, Vol. 96, No. 17, September 1, 2004

The major objective of the paper is to measure the burden of Illness among cancer survivors in a population based sample. It stands out from the contemporary literature in its attempt to push the envelope of measuring cost in capturing not only the direct hospitalization cost but also other components such as intangible cost and productivity loss. Through using a large national survey data they could delineate specifically the burden of cancer illness by comparing patients of a similar demographic background without cancer.

The authors used 2000 National Health Interview survey data to identify the potential cancer survivors and the corresponding control group. The control group was formed on the basis of age, educational attainment and sex. The final sample consisted of 1823 cancer survivors and 5469 matched controlled subjects. Health related utility which captures the overall state of health across multiple domains of quality of life is measured using Health Activities and Limitation Index (HALex). Loss in productivity is captured by asking them the number of days lost due to the illness, limitations in the ability to work due to health problems. Moreover the survivors were asked specific question on types of cancer, age of diagnosis and time since it got diagnosed.

The highest percentage of cancer survivors were diagnosed from that of prostate cancer followed by colorectal cancer. As compared to that of the controlled subject, cancer survivor reports lower health utility status across all measures of health and productivity. Burden is measured by the HALex utility value, lost productivity (e.g. jobs in past 12 months, unable to work due to health reasons, limitation in the kind and amount of work, days lost, etc), general health status, number of bed days, and through measuring other limitations. Co-morbid situations are also taken into account like heart problems, stroke, lung/breath problem so as to see how the burden of cancer gets increased with additional morbidity issues. All these measures have been separately analyzed across cancer survivors and controlled subjects. The analysis results in every single measure significantly different and results in worst outcomes for the cancer patients.

Thus the paper concludes that apart from the direct cost, the productivity cost due to morbidity and the intangible burden associated with cancer are substantial that it leaves an impact even in the long run. For cancer survivors with 11 years and above have still substantial different burden as compared to their matched controlled. The next set of results includes in studying the burden associated with respective types of cancer survivors. Survival of lung cancer reported greater burden as compared to those breast, colorectal and prostate cancer.

Multi-institution Hospital-based Cancer Incidence Data for Nepal - An Initial Report
Kishore K Pradhananga, Mina Baral, Bhakta Man Shrestha
Asian Pacific Journal of Cancer Prevention, Vol 10, 2009

A very short paper but important in the context of giving an overview on the cancer registration system of some of the developing countries like Nepal. This paper is very important in giving a credible reason that why cancer related research should be promoted and undertaken in such countries. Prior to this study, there was only one publication available with cancer incidents of one cancer specialty hospital in Nepal. This paper collects data from seven major hospitals to study the rate of incidence of the disease.

These hospitals which form the basis of the study are BP Koirala Memorial Cancer Hospital, Bharatpur; Bir, Tribuhvan Kanti Children's and Bhaktapur Hospitals in Kathmandu; BP Koirala Institute of Health Sciences in Dharan; and Manipal Teaching Hospital in Pokhara. The data has been collected over a period of one year from 1st Jan 2005- 31st December 2005. Given below in Table 1 is a description of number of cases being diagnosed with cancer in one year across different institutional setting.

Table 1: Distribution of cancer patients according to hospitals

Institution	Females		Males		Total	
BP Koirala	1,197	51.2	957	46.5	2,154	49
Bhaktapur	522	22.3	486	23.6	1008	22.9
Bir	87	3.7	119	5.8	206	4.7
Tribuhvan	80	3.4	54	2.6	134	3
BP Koirala	354	15.1	348	16.9	702	16
Manipal	87	3.7	75	3.6	162	3.7
Kanti	13	0.6	18	0.9	31	0.7
Total	2,340	100	2,057	100	4,397	100

The paper then finds the incidents based on the different cancer sites. A gender wise declassification of a detailed list of 19 types of cancer sites across all these cancer institutions have been presented, of which the most common cancer sites were found to be lung, oral cavity and stomach in males, and cervix, breast and lung in females. The Nepal cancer incidents figures have as well been compared against India and Pakistan.

A crude age wise distribution of cancer incidents across the gender of male and female states that female of age below 60 years are much more likely to be diagnosed with cancer as compared to their male counterpart. For males, they are more likely to be diagnosed with cancer at their later ages with lung cancer standing out alone as the major player of all the types. For female, the variation of diagnosis varies significantly across time. From an early age as close to 20 years, there are symptoms of breast, cervix, and ovary and lung cancer.

Owing to the figures, the paper indicates an immediate urgency and commitment is needed in the process of compiling data to understand the various risk factors associated with the study. The paper limits itself in studying the impacts such disease which becomes the rationale for our proposed study.

Economic burden of cancer across the European Union: a population-based cost analysis

Ramon Luengo-Fernandez, Jose Leal, Alastair Gray, Richard Sullivan, Lancet Oncology,2013

This paper is done in the context of assessing the economic burden imposed by cancer on the European Union in 2008.
The study indicates the inadequacy of cancer statistics which prompts them to use various sources of information like country-specific aggregate data from international and national sources like WHO, the Organization for Economic Co-operation and Development, EUROSTAT, national ministries of health, and statistical institutes. This shows registering and documenting cancer incidence is the need of the hour.

They evaluated the cost of all cancers and also those associated with breast, colorectal, lung, and prostate cancers. With their country specific morbidity , mortality data, they estimated health-care costs from expenditure on care in the primary, outpatient, emergency, and inpatient settings, and also drugs. The significant contribution of the paper rests in their estimating the costs of unpaid care provided by relatives or friends of patients (ie, informal care), lost earnings after premature death, and costs associated with individuals who temporarily or permanently left employment because of illness.

The analysis is done using OLS through the following set of dependant and independent variables:
Independent variables: national income, crude cancer incidence, crude cancer mortality, case fatality (mortality divided by incidence), 5-year cancer relative survival, and cancer specific disability-adjusted life-years as explanatory variables. Dependant variables: Cancer related health care expenditure across various types of cancer

Cancer cost is as high in EU as €126 billion in 2009, with health care accounting for €51·0 billion (40%). The two major component bearing the cost is productivity losses because of early death cost €42·6 billion and lost working days €9·43 billion. Informal care is the unpaid services of the family and it accounts for €23·2 billion of the total cost. The results of the ordinary least-squares regression showed a strong positive relation between cancer-related health-care expenditure and national income ($p<0·0001$) and cancer incidence ($p=0·003$). Lung cancer had the highest economic cost (€18·8 billion, 15% of overall cancer costs), followed by breast cancer (€15·0 billion, 12%), colorectal cancer (€13·1 billion, 10%), and prostate cancer (€8·43 billion, 7%). Highest productivity lost is associated with lung cancer followed by colorectal cancer then breast cancer and prostate cancer. Highest morbidity is for breast cancer. Hospital inpatient accounted for more than half of the cancer related cost followed by drug, outpatient, primary and emergency care. Cancer related health care expenditure decrease the deaths but they are not significant. 60% of the cancer related cost is in the non health areas with majority is due to productivity lost because of early death.

OBJECTIVES/AIMS/HYPOTHESES

The purpose of the study is threefold. The first objective is to build a valuable cancer care dataset that may be used as a follow-up cohort study in the future. The second objective is to assess the impact cancer demand care has on the entire family unit in terms of both financial and non-financial burdens. The third objective is methodological where we will explore new approaches to analyze the multi-dimensional complex linkages between health and other socio-economic and behavioral factors.

A set of tentative research questions is outlined as follows:

- Estimation of financial burden (direct and indirect –care related, loss of employment, debt burden)
- Assessing the impact of cancer on financial stress, emotional stress, physical stress, and quality of life.
- Identification of risk factors (environmental and behavioral –smoking).
- Assessing the disparity in quality of care for poor versus the rich.
- Identifying coping strategies (e.g., support network) and examining its effect on the cost of care (e.g., providing hospital ride, time sharing), quality of care, and the emotional state.

STUDY DESIGN AND PROCEDURES

I. *Study Design*

The research will mainly be a survey based study administered through questionnaire. The questionnaire will contain the socio demographic profile, questions on economic and mental burden that the patient and the family have to go through during the process of diagnosis and treatment of cancer. After the data is collected, the analysis part of it will be conducted using the econometric software STATA.

II. *Study Procedures*

The study will be on cancer patients and will be administered through a formatted questionnaire. The interview will be a verbal communication between the interviewer and the participants and will NOT include any kind of clinical trials, neither the participants will be asked to show any lab reports. There will NOT be any recordings or photography of the participants, the entry in the questionnaire is entirely based on the verbal answers given by the participants.

The questionnaire will be divided in sections such as participants' self reported health status, diagnosis and the treatment processes of the disease, cost of treatment (economic burden), palliative care options available, mental burden caused to the participant and family on account of the disease.

A wide and varied literature review on the socio-economic consequences on cancer gives us the idea as to what variables are particularly important to our study The questionnaire is prepared with the help of some existing surveys and as well as incorporating our own project agenda. Some pre existing cancer patient questionnaires are: SCCS Cancer Survivor Navigation Questionnaire, NHIS questionnaire - Sample Adult, Behavioral Risk Factor Surveillance System Questionnaire of CDC, NHS patient survey and PHQ 9 questionnaires.

The survey area for this study is Nepal, where Nepali is the popular spoken language. Both English and Nepali questionnaires will be with me throughout the survey. I believe most of the participants will be able to read the questionnaire on their own, if some participants want me to read it out to them; I will do that as well. Both the English and Nepali versions of the questionnaire are attached.

A pre testing or a pilot survey will be done in Nepal with some patients of Dhulikhel hospital to start with.

The testing will be done to assure about the time and to feel the level of comfortability of the participants regarding answering the questions related to their disease. As I will survey them, if it is seen that there are missing observation related to the main research questions then the participants will be dropped from the analysis.

To have any follow up regarding the present study and more importantly to keep the opportunity open for extending the study into a Panel data of Cancer patients, we may have to contact those patients again who will give us the consent of providing personal information. If the follow up study happens to be possible, it is going to open up a very unique and significant contribution in filling up the data gaps of cancer patients in Nepal. The consent procedures are detailed below.

III. *Consent Procedures*

We are requesting to have two different consent processes, first for those who agrees to share their personal information and second for those who don't consent to give any personal information for any follow up. All the participants will be asked whether they agree to provide us information about their personal details like name, contact details and address. They can agree or disagree with that.

If they agree to share the information, they are asked to document it by signing the consent form. For those participants who disagree to provide the necessary details, the data will be completely anonymous and no identifiable information will be collected. Hence, to respect the demand of those participants who don't want to share their personal information, we request IRB to have a waiver of consent documentation for them only whereas for those who will share their personal information with us will document it by signing the consent form.

The consent procedures will solely involve the member of the study. A scripted consent is given below in English. The translated Nepali version with be attached to the protocol. The research will not involve minors. All the participants in the research will be 18 years or older.

Script

Namaste (Hello),

You are requested to participate in a research study that is done by Professor Alok Bohara , who is the principal investigator and Soumi Roy Chowdhury, the student investigator from the Department of Economics, University of New Mexico, USA. The research is studying the Socio-economic consequences of cancer in Nepal and is funded by Amercian Cancer Society. This is a consent form that describes the purpose of the study, your role and the possible risks and benefits that are associated with the study. After knowing all the details, if you feel comfortable, you are very welcome to participate in the survey.

If you agree to participate, I will ask you some questions on how cancer impacts your life and the life of your family. In answering these questions, you will have to describe about the type of cancer you have, your awareness regarding the causes and consequences of cancer, what is your current treatment methods and the amount of cost it incurs in treating cancer. We would also like to know how it is impacting your life and life of your family members' .This discussion will not take more than 30 minutes.

I should however mention that there are some risks of participating in this research. You may feel awkward, uncomfortable and upset. If you do feel so, you don't have to answer the questions. Your participation in the study is entirely voluntary. There are no direct benefits that you will get from this project, but the information will be helpful in building knowledge about the impact of cancer from a societal perspective.

In future, if I need to contact you for any follow up regarding this study or for any new study, do you give your consent to collect some of your personal information like your name, phone number, address or any other alternative contact id (you will be given a separate sheet to be filled out). If you are not comfortable with sharing your personal information, you don't have to do so.

Yes ☐ No ☐

It is however important to mention that we will take all measures to protect the security of all your personal information. Participants providing personal details can withdraw anytime within 1- 3 months of the survey (if you decide to withdraw within 1 month, you can get the paper copy back , otherwise we will delete your responses from the soft version of the data) whereas others need to make the decision of withdrawal before I leave from the interview venue. No names will be entered while data gets transferred in a soft version as your responses will be coded by an id number and not by your name. Only the student investigator and personal investigator will have your name and id links and will de-identify that at the close of the project. The University of New Mexico Institutional Review Board (IRB) that oversees human subject research and/or other entities may be permitted to access your records. There may be times when we are required by law to share your information. Your name will not be used in any published reports about this study.

If you don't want to give the interview in the hospital, you can give us any appointment place and time where I can go and meet you. If you have any questions or concerns about this study, you may contact the student investigator through the following contact details (…………………….. (Nepal) / 505-358-1564 (USA) / sroychowdhury@unm.edu). If you would like to speak with someone other than the research team, you may call the UNM Office of the IRB at (505) 277-2644. If you have questions regarding your rights as a research participant, you may call the UNM Office of the IRB (OIRB) at (505) 277-2644. The IRB is a group of people from UNM and the community who provide independent oversight of safety and ethical issues related to research involving human participants. For more information, you may also access the OIRB website at http://irb.unm.edu.

Only if you have given consent above regarding disclosing your personal information, you need to sign in the following. If you disagree to provide personal details, then you don't need to sign the consent form. Do you have any questions at this time?

………………………………..
…
…………
(Date)
(Participant signature)
………………………………..
…
…………
(Dat
e)
(Investigators signature)

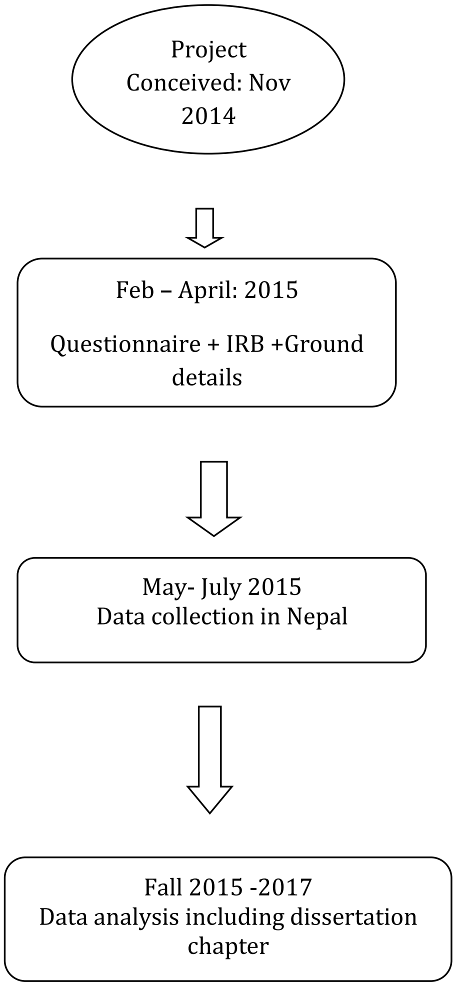
Privacy of Consent process

The consent process will hold at any place deemed private by the participants. It will mainly be in any health facility like hospitals where participants come for check-ups. Inpatients admitted for cancer are given separate room facilities which will thus ensure their privacy during the interview process. Outpatients will also be approached for interview, if they don't feel comfortable in giving interview in the hospital and wanted me to meet in a private place (e.g home etc), I will also do that. Most of the outpatients will likely be from Kathmandu Valley close to the hospital, so reaching out to their comfortable place will not be a problem. All the participants will be approached with due permission of their physician who are treating them. Physicians will be provided IRB approved letters to be given to the patients and if the patients agree to join the survey, then the project researchers will meet the patients.

The enumerator will give enough time to the respondent regarding their decision to participate in the survey, so that if they need time, enumerators will approach them at later date within a week. The consent form will be read out to them and proper attention will be given to ensure that the participants understand the context of the consent script. As has been mentioned in the protocol, the personal information will only be asked from patients who will agree to do that. For the participants who will not give any consent of collecting personal information, the data will be absolutely anonymous with no single identifiable information attached to them. The request of identifying information is only to open up the possibility of any follow up on the present study or future study that may take place. Such a measure will be completely unique and innovative in this area of research. A separate sheet is attached to highlight the specific information that will be requested for. Since in Nepal, Nepali is the most widely spoken language, we will use both English and Nepali consent form and questionnaire throughout the process of survey. I will carry both the English and Nepali versions with me as I expect that the young adults will feel comfortable with the English version whereas the old people will go with Nepali.

The translated version of the questionnaire and the consent form is attached.

IV. *Study Timelines*



V. *Study Location(s)*

The research will be in Katmandu, the capital city of Nepal. The reason we choose the site is because:

We needed to have the study on developing country.

Cancer incidences are growing in Nepal.

Nepal Study Centre-UNM and KU's Memorandum of understanding facilitate the successful completion of the study.

The NSC, through its offices at UNM and a branch in Nepal's Kathmandu University, strives to foster collaboration between the University of New Mexico, Kathmandu University, and the International Centre for Integrated Mountain Development (ICIMOD). Kathmandu University and Nepal Study Centre of UNM has a Memorandum of Understanding which helps in undertaking many projects of NSC-UNM in Nepal. Following link will help in understanding the collaborative work that Kathmandu University is doing with NSC over years.
http://nepalstudycenter.unm.edu/KUVC_UNMVisit.htm

Kathmandu University provides a separate locked office and cabinet for ensuring the safety of the investigator as well as for the data. All the paper works and the collected questionnaire will be kept in the safety lock and will not be made accessible to any other persons except for me. The paper form of the questionnaire will be transferred, entered and saved in an electronic format before bringing that to USA for analysis. Once the data is securely stored in electronic format, the paper form of the questionnaire will be destroyed.

We have a letter of support from Kathmandu University which shows their commitment towards the project. The permission is hereby attached.

VI. *Participant Compensation*

As a part of compensation, the respondents will be given showpieces as a mark of thanking them for their time and energy. We have set aside 80,000 Nepali rupees as a part of the compensation which means 160 NRs. per showpiece which should be a good amount.

VII. *Study Resources*

Staffs:
1) Prof. Alok Bohora, University of New Mexico
2) Soumi Roy Chowdhury, Graduate Student- University of New Mexico

May – July 2015 will be used for data collection.
University of Kathmandu will provide an office space to the investigator and will give a locked cabinet for the preservation of the data.

The major medical support facility will be Dhulikkhel hospital which is the school of medical science under Katmandu University. I will stay and operate closely to this hospital so in any kind of medical emergency this will be my first reference point. Except for that, general hospitals and medical stores are in close proximity of the university where investigator can avail for any medical help.

VIII. *Unanticipated Problems*

Unanticipated problems will be reported to the IRB of UNM and the doctors of the patients apart from reporting to the Principal Investigator of the project.

EXPECTED RISKS/BENEFITS

I. *Risks*

The potential risk though remains how much time they will be willing to allot towards the study as most likely there is certainly going to be time constraint. The challenge to the enumerator remains in creating a reasonable informal environment where participants feel comfortable in discussing about their personal health information as we can absolutely understand that discussing personal issues like health to any stranger is not always an easy job to do. They may feel uncomfortable and awkward on some questions. If at any point of the dialogue, I feel that the patients are psychologically getting stressed, there will be no compulsion imposed on them to continue with the study. There is no economic burden being imposed on the participants of the study, nor did they have to go through any political or social stigmatization. We understand that the relative risks are higher for those patients that agree to disclose their personal information, but sincere efforts will be done to protect the confidentiality. The right of accessibility of individual name and their corresponding id will only be limited to the Principal Investigator and student investigator otherwise required by law.

As a step towards minimizing the risk, all the researchers associated with the project have gone through the Human Research Protection Training to be aware of the guidelines needed for such research. The student investigator will be extremely cordial and respectful while talking to the participants as she understands that the participants are cancer patients and must be in a very delicate state of their minds.

II. *Benefits*

There will be no immediate benefit from the study to the participants but there will be long term benefits through knowledge gathering and information. This particular research is meant to identify the consequences (financial and emotional) a patient and the family goes through throughout the treatment process. It mainly studies the impact that it leaves on the patients and the family members. We believe such a research will be beneficial from the perspective of society in developing appropriate safety nets to mitigate such burden.

Human Subjects Interactions

I. *Target Population*

The target population for our study are the cancer patients. They can be either male or female. Since the research is about the socio economic consequences on cancer, we have to track down the cancer patients for this research. They are our sole targeted sample of study.

II. *Inclusion and Exclusion Criteria*

Exclusion:
All the patients under 18 years of age are excluded from the analysis.
Patients who are severely disabled are also exempted from the study.

Inclusion:
All patients above 18 years will be a part of the study.

III. *Participant Enrollment*

Surveying 500 cancer patients will be our targeted agenda.

IV. *Recruitment and Screening Procedures*

As mentioned earlier, Dhulikhel hospital which is a School of Medical Science affiliated under Katmandu University work closely with NSC-UNM in any kinds of health related research. Dhulikkhel also gets cancer patients on a regular basis, the physicians of Dhulikkhel will be our primary contact person regarding patients. Physicians will be provided IRB approved letters to be given to the patients and if the patients agree to join the survey, then the project researchers will meet them in hospital itself or wherever the patients are comfortable meeting with. We can get information regarding other oncologists operating in different other hospitals using the contact of Dhulikkel physicians. That is how we can repeat the survey procedure onto other hospitals as well.

In case of any screening failures, the paper work will be immediately destroyed and no information about the interviewee will be sustained anymore.

The PI will draft the following letter and will give to the physicians who will then communicate with their respective patients.

> Dear Friends,
> My name is Soumi and I am a graduate student of University of New Mexico from the United States of America. I am conducting a research study to examine socio economic consequences of cancer in Nepal. Our research has been funded by American Cancer Society where our objective is to understand what financial and mental consequences that a cancer patient and his family go through.
> In this context, we need your 30 minutes to understand the suffering, hear from you the plight that you and your family go through. What has changed in your life because of cancer and how it has affected you and your family? What do you think should be and can be if possible being done to lower the sufferings of cancer patients? We want to hear all of your experience regarding this disease to the point you are comfortable with. We will not force you to show us or disclose any minute details. We will just hear and

note your experience. Your identity will be kept anonymous throughout the research period.

We have talked to your physician, if you are interested in joining the project; please let your physician know so that we can communicate with you. Please see the enclosed IRB approved form of University of New Mexico which proves that the research will be done maintaining all the health ethics and codes.

This is not your consent form, you can talk to us and we will give you a formal consent form detailing the purpose, your role in the project, types of questions being asked and all our necessary contact information. After reading the consent form, if you think you are comfortable with the whole procedure then you are welcome to participate but incase you are not comfortable, you can withdraw from participation.

Treating physician signature
…………………………………………

V. *Privacy of Participants*

Investigators will give the patients the flexibility of meeting anywhere wherever the patients will feel comfortable. If the patients would like to meet in hospital they can be interviewed there with prior permission from the treating physician since mostly patients will have their own rooms for treatment. Whereas if they would like the researchers to come to their home or in other meeting place for conducting the survey, that too will be welcomed.

Physicians help will be needed during the process of recruitment, where there is no possibility that any outsider will know about the communication. After screening, there will be a one to one dialogue between the researcher and participants in participant's preferred location where he will feel the privacy. Once the information is collected, it will be kept safely locked in Katmandu University's locked cabinet which will be only accessible to me. The data will be entered and stored in personal hard drive and then will be brought to USA in an electronic format. All the paper documents will be destroyed before coming to USA. In the Nepal Study Centre of Economic Department UNM, we have a security coded gate which is only accessible to few. The data will be stored in a password protected computer accessible to the primary investigator Prof. Bohara.

STUDY DATA

I. *Data Management Procedures*

At this point in the project, no secondary sources of data will be used. The main data that we will have is from the primary investigation.

After having the signed consent forms of the participants, I will scan them and keep the soft copy in a password protected hard drive within 1 month of the survey. All the paper documents will be destroyed back in Nepal after scanning.

A link will be created for those participants that have agreed to give the personal information. I will have their names and the contact details entered in an excel soft copy and then I will create an individual id corresponding to each of their names. This process will go on continuously as I survey throughout the two months. After each entry, I will go on destroying the paper copy of the contact details. The individual id will be noted down in that particular participant's survey questionnaire which will be the base of entering the data later.

I will give myself one month to convert the paper responses of survey questionnaire in soft copy. The responses of the individual for whom we don't have the data will be entered anonymously. If we have the data for participants, we enter the data under the id created.

So at the end of the process, the PI and the Student Investigator (myself) will have a soft excel copy of the link, soft copy of the survey data with the individual ids and the scanned consent forms. Once it gets into an electronic version, it is not possible for anyone other than the Principal Investigator and the Student Investigator to identify any individual participant by their survey responses. The electronic form of the data will be brought back to USA through a protected hard drive and will be stored in password protected computer of NSC-UNM office which has a security gate code accessible only to a few. The data will be looked through and analyzed by PI and me. The final de- identification of the data will happen at the time of the close of the study.

II. *Data Analysis/Statistical Considerations*

Sampling Technique

Of the seven hospitals as identified by Kumar et.al 2009 in their study which mainly cater to cancer patients in Nepal , at least three hospitals are situated in Kathmandu valley. These three hospitals will be included as a target population for survey sampling. The hospitals respectively are Bhaktapur, Dhulikhel and Bir. Teaching hospitals situated in Kathmandu will also be considered for sampling purposes. Tentatively, a sample of 500 cancer patients will be included in our survey.

Statistical Technique

Given our increasing involvement in field research work in Nepal, and the multi-disciplinary nature of our collaboration, we feel that there is a need for methods that can detect and unravel complex socio-economic and health linkages. We will explore three possible methods: Structural Equation Model (SEM), Partial Least Squares (PLS), and directed acyclic graphs (DAG), a graphical algorithm developed by Greenland (1999). These methods are generally suitable for survey research with extensive set of variables that are generally collinear and are hard to write as a causally well-defined regression equation. For example, a financial stress variable may have to be entered into the model as a latent factor rather than a well-define observable variable. Likewise, the whole structural linkages between the health status (e.g., cancer), risk factors, demographics, financial and emotional stress may have to be treated as a multidirectional network (e.g., Bayesian network) instead of a bi-directional causal regression model.

III. *Quality Control and Quality Assurance*

---------------------NA------------------------------

IV. *Participant Confidentiality*

Throughout the survey in Nepal, I will be given a locked office space in Kathmandu University to be used for keeping and storing the required and important documents. The accessibility of the office space will be restricted only to me. I will have a separate computer and hard drive apart from my laptop which are password protected for storing the data files.

As the data gets into a soft version and after I bring it to USA, we will keep the data in the administrative server of Nepal Study Centre of Economics Department, UNM which is protected by administrative password accessible only to the director of NSC and Principal Investigator of this study. The office of NSC in the Economics Department, UNM is security locked with the accessibility available only to few of us in the department.

V. *Participant Withdrawal*

I have kept the timeline of withdrawal for those who provided personal information to 1-3 months. If they contact me within 1 month, I will give them their paper copy back and if they contact me within 3 months, I will drop them from the version of the soft copy and no analysis will be run based on their data. The reason I have limited the withdrawal to three months is because, the analysis of the data will likely to start by then and once it starts , withdrawal can hamper the process of analysis.

But for those patients of whom we don't have any identifiable information, they will need to decide on their withdrawal before I leave the interview venue, since there will not be any other ways of identifying their survey questionnaire.

If the participants want to participate but are not comfortable to certain sections of the questionnaire, we will still keep the participation and put the undisclosed information as missing. Depending on the extent of the missing information, we will decide whether to drop the participant from the analysis. Irrespective of which category of participants they are, they have the right to withdraw during the survey if they are not comfortable and don't want to go ahead with it.

PRIOR APPROVALS/REVIEWED AT OTHER IRBS

No, this is not reviewed by any other IRB

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Application for Approval of Research Proposal – Amendment
Kathmandu University School of Medical Sciences Institutional Review Committee
(KUSMS/IRC)
Dhulikhel, P.O. Box: 11008, Nepal
Tel: 977-11-490497
Fax: 977-11-490707
e-mail: kusmsirc@dhulikhelhospital.org

NOTE: Please type all entries in English and submit on IRC office & email address for further process.

Research Proposal Description Sheet

1 Title

Socio-economic Consequences of Cancer in Nepal

A study on socio- psychological- economic consequences of cancer in Kathmandu valley and Bharatpur of Nepal: Understanding the risk factors, coping strategies and willingness to pay of the cancer and non-cancerous patients.

2. Objectives

General

The main purpose to the study is to fill the void of necessary and required information about cancer incidents in Nepal and how such incidents do leave a burden on the patients and their families. The study will seek to understand the extent of such burden and how such burdens can be minimized which will lead us to significant policy implications.

Specific

The purpose of the study is threefold. The first objective is to build a valuable cancer care dataset that may be used as a follow-up cohort study in the future. The second objective is to assess the impact cancer demand care has on the entire family unit in terms of both financial and non-financial burdens. The third objective is methodological where we will explore new approaches to analyze the multi-dimensional complex linkages between health and other socio-economic and behavioral factors.

3. Summary (Up to 200 words)

In the context of developing countries, chronic illness is one of the dominant health burdens, and cancer alone is responsible for 70% of the total deaths. The cost associated with the chronic illness is estimated to increase which leads us to the important question that what will be the economic , social and psychological consequences of the disease to the patient and to the family as well. The purpose of the study is threefold. The first objective is to build a valuable cancer care dataset that may be used as a follow-up cohort study in the future. The second objective is to assess the impact cancer demand care has on

the entire family unit in terms of both financial and non-financial burdens. The third objective is methodological where we will explore new approaches to analyze the multi-dimensional complex linkages between health and other socio-economic and behavioral factors. The study will mainly be undertaken through administered questionnaire. The questionnaire will contain the socio demographic profile, questions on economic and mental burden that the family has to go through during the process of diagnosis and treatment of a cancer patient in their family. After the data is collected, the analysis part of it will be conducted using the econometric software STATA. Structural Equation Model (SEM), Partial Least Squares (PLS), and directed acyclic graphs (DAG) methods will also be used to analyse the data.

4. Introduction

In the context of developing countries, chronic illness is one of the dominant health burdens, and cancer alone is responsible for 70% of the total deaths. The cost associated with the chronic illness is estimated to increase to $84 billion by 2015 (Nuget, 2008). Cancer care is expensive, time consuming and is life altering for the entire family, which includes not only the cancer patients but also the family members who care for them(Nelson, 2010). In a country like Nepal, such burdens can be quite significant and devastating especially for the poor. Although cancer develops slowly, the impact on financial and non-financial stress can be speedy, deep, and irreversible for the patient as well as for the family members (caregivers). Even in a system where care falls under the public funding envelope, burden of the out-of-pocket cost can also be significantly high (16.5%) (Longo et al., 2006).This study will attempt to measure and quantify such *costs,* which could be direct as well as indirect in the context of Nepal.

5. Statement of the Problem

The importance of the study emerges from the fact that there is no organized cancer registry in Nepal that can lead to further research in cancer. Given the significance of the disease and the burden it may create, the study aims to understand the socio-economic consequences, quality of life of cancer patients and measure the willingness to pay to avoid the pain and suffering associated with cancer.

6. Literature Review

Given below is the brief description of three literatures which are equally important and pertinent to the main objective of our research agenda. The first paper 'Burden of Illness in Cancer Survivors: Findings From a Population-Based National Sample' is a USA based study aims at measuring the economic cost of cancer , the second paper 'Multi-institution Hospital-based Cancer Incidence Data for Nepal - An Initial Report' is one of the very first attempts to quantify the cancer incidents in Nepal. The third paper 'Economic burden of cancer across the European Union: a population-based cost analysis' portrays the impact of cancer on the countries of European Union.

'Burden of Illness in Cancer Survivors: Findings from a Population-Based National Sample'
K. Robin Yabroff, William F. Lawrence, Steven Clauser, William W. Davis, Martin L. Brown
Journal of the National Cancer Institute, Vol. 96, No. 17, September 1, 2004

The major objective of the paper is to measure the burden of Illness among cancer survivors in a population based sample. It stands out from the contemporary literature in its attempt to push the envelope of measuring cost in capturing not only the direct hospitalization cost but also other components such as intangible cost and productivity loss. Through using a large national survey data they could delineate specifically the burden of cancer illness by comparing patients of a similar demographic background without cancer.

The authors used 2000 National Health Interview survey data to identify the potential cancer survivors and the corresponding control group. The control group was formed on the basis of age, educational attainment and sex. The final sample consisted of 1823 cancer survivors and 5469 matched controlled subjects. Health related utility which captures the overall state of health across multiple domains of quality of life is measured using Health Activities and Limitation Index (HALex). Loss in productivity is captured by asking them the number of days lost due to the illness, limitations in the ability to work due to health problems. Moreover the survivors were asked specific question on types of cancer, age of diagnosis and time since it got diagnosed.

The highest percentage of cancer survivors were diagnosed from that of prostate cancer followed by colorectal cancer. As compared to that of the controlled subject, cancer survivor reports lower health utility status across all measures of health and productivity. Burden is measured by the HALex utility value, lost productivity (e.g. jobs in past 12 months, unable to work due to health reasons, limitation in the kind and amount of work, days lost, etc), general health status, number of bed days, and through measuring other limitations. Co-morbid situations are also taken into account like heart problems, stroke, lung/breath problem so as to see how the burden of cancer gets increased with additional morbidity issues. All these measures have been separately analyzed across cancer survivors and controlled subjects. The analysis results in every single measure significantly different and results in worst outcomes for the cancer patients.

Thus the paper concludes that apart from the direct cost, the productivity cost due to morbidity and the intangible burden associated with cancer are substantial that it leaves an impact even in the long run. For cancer survivors with 11 years and above have still substantial different burden as compared to their matched controlled. The next set of results includes in studying the burden associated with respective types of cancer survivors. Survival of lung cancer reported greater burden as compared to those breast, colorectal and prostate cancer.

Multi-institution Hospital-based Cancer Incidence Data for Nepal - An Initial Report
Kishore K Pradhananga, Mina Baral, Bhakta Man Shrestha
Asian Pacific Journal of Cancer Prevention, Vol 10, 2009

A very short paper but important in the context of giving an overview on the cancer registration system of some of the developing countries like Nepal. This paper is very important in giving a credible reason that why cancer related research should be promoted and undertaken in such countries. Prior to this study, there was only one publication available with cancer incidents of one cancer specialty hospital in Nepal. This paper collects data from seven major hospitals to study the rate of incidence of the disease.

These hospitals which form the basis of the study are BP Koirala Memorial Cancer Hospital, Bharatpur; Bir, Tribuhvan Kanti Children's and Bhaktapur Hospitals in Kathmandu; BP Koirala Institute of Health Sciences in Dharan; and Manipal Teaching Hospital in Pokhara. The data has been collected over a period of one year from 1st Jan 2005- 31st December 2005. Given below in

Table 1 is a description of number of cases being diagnosed with cancer in one year across different institutional setting.

Table 1: Distribution of cancer patients according to hospitals

Institution	Females		Males		Total	
BP Koirala	1,197	51.2	957	46.5	2,154	49
Bhaktapur	522	22.3	486	23.6	1008	22.9
Bir	87	3.7	119	5.8	206	4.7
Tribuhvan	80	3.4	54	2.6	134	3
BP Koirala	354	15.1	348	16.9	702	16
Manipal	87	3.7	75	3.6	162	3.7
Kanti	13	0.6	18	0.9	31	0.7
Total	2,340	100	2,057	100	4,397	100

The paper then finds the incidents based on the different cancer sites. A gender wise declassification of a detailed list of 19 types of cancer sites across all these cancer institutions have been presented, of which the most common cancer sites were found to be lung, oral cavity and stomach in males, and cervix, breast and lung in females. The Nepal cancer incidents figures have as well been compared against India and Pakistan.

A crude age wise distribution of cancer incidents across the gender of male and female states that female of age below 60 years are much more likely to be diagnosed with cancer as compared to their male counterpart. For males, they are more likely to be diagnosed with cancer at their later ages with lung cancer standing out alone as the major player of all the types. For female, the variation of diagnosis varies significantly across time. From an early age as close to 20 years, there are symptoms of breast, cervix, and ovary and lung cancer.

Owing to the figures, the paper indicates an immediate urgency and commitment is needed in the process of compiling data to understand the various risk factors associated with the study. The paper limits itself in studying the impacts such disease which becomes the rationale for our proposed study.

Economic burden of cancer across the European Union: a population-based cost analysis

Ramon Luengo-Fernandez, Jose Leal, Alastair Gray, Richard Sullivan, Lancet Oncology,2013

This paper is done in the context of assessing the economic burden imposed by cancer on the European Union in 2008.
The study indicates the inadequacy of cancer statistics which prompts them to use various sources of information like country-specific aggregate data from international and national sources like WHO, the Organization for Economic Co-operation and Development, EUROSTAT, national ministries of health, and statistical institutes. This shows registering and documenting cancer incidence is the need of the hour.

They evaluated the cost of all cancers and also those associated with breast, colorectal, lung, and prostate cancers. With their country specific morbidity , mortality data, they estimated health-care costs from expenditure on care in the primary, outpatient, emergency, and inpatient settings, and also drugs. The significant contribution of the paper rests in their estimating the costs of unpaid care provided by relatives or friends of patients (ie, informal care), lost earnings after premature death, and costs associated with individuals who temporarily or permanently left employment because of illness.

The analysis is done using OLS through the following set of dependant and independent variables:
Independent variables: national income, crude cancer incidence, crude cancer mortality, case fatality (mortality divided by incidence), 5-year cancer relative survival, and cancer specific disability-adjusted life-years as explanatory variables. Dependant variables: Cancer related health care expenditure across various types of cancer

Cancer cost is as high in EU as €126 billion in 2009, with health care accounting for €51·0 billion (40%). The two major component bearing the cost is productivity losses because of early death cost €42·6 billion and lost working days €9·43 billion. Informal care is the unpaid services of the family and it accounts for €23·2 billion of the total cost. The results of the ordinary least-squares regression showed a strong positive relation between cancer-related health-care expenditure and national income ($p<0·0001$) and cancer incidence ($p=0·003$). Lung cancer had the highest economic cost (€18·8 billion, 15% of overall cancer costs), followed by breast cancer (€15·0 billion, 12%), colorectal cancer (€13·1 billion, 10%), and prostate cancer (€8·43 billion, 7%). Highest productivity lost is associated with lung cancer followed by colorectal cancer then breast cancer and prostate cancer. Highest morbidity is for breast cancer. Hospital inpatient accounted for more than half of the cancer related cost followed by drug, outpatient, primary and emergency care. Cancer related health care expenditure decrease the deaths but they are not significant. 60% of the cancer related cost is in the non health areas with majority is due to productivity lost because of early death.

7. Rationale / Justification

Cancer as chronic disease can impact the life of not only the patients but also the life of the immediate family member. The facets of impact on account of cancer can be multiple; the burdens can be direct as well as indirect. The direct burden is the medical cost associated with cancer and the indirect burden can be of various forms: the loss of employment of the patient and the immediate care taker, overall quality of life and mental distress. In the face of such existing dimensions of cancer, it is important to know the burden and more importantly what are the necessary steps that can be done to mitigate it. The ultimate goal of the project is to recommend some policies to the government so that the necessary actions can be taken to address such issues.

8. Research Questions (if relevant)

The importance of the study emerges from the fact that there is no organized cancer registry in Nepal that can lead to further research in cancer. Given the significance of the disease and the burden it may create, the study aims to understand the socio-economic consequences, quality of life of cancer patients and measure the willingness to pay to avoid the pain and suffering associated with cancer.

A set of tentative research questions is outlined as follows:

- What is the financial burden (direct and indirect care related, loss of employment, debt burden) associated with cancer?
- How does cancer impact on financial stress, emotional stress, physical stress, and quality of life?
- Can we identify some risk factors (environmental and behavioral –smoking) that instigate cancer incidents?
- How can we assess the disparities in quality of care for poor versus the rich? Does gender plays a role in the self report of quality of life due to social desirability issues?
- Can we identify coping strategies (e.g., support network) and examining its effect on the cost of care (e.g., providing hospital ride, time sharing), quality of care, and the emotional state for cancer patients?

- What are the stated willingness to pay for cancer treatment versus cancer pain and other important side effects of cancer?

Other objectives are

- Primary data set development of five hospitals.
- Analyzing the relationship between different nodes of cancer using an new and improved methodology such as directed acyclic graph
- One chapter of doctoral dissertation.

9. Research Design and Methodology

Research Method

Qualitative ( ), Quantitative ( ), Combined (X)

Study Variables

Cancer incidents, type and stages of cancer, direct medical cost, indirect medical cost

(missed working days, job loss) to both patients and immediate care , WTP for better screening, risk perceptions and social desirability issues. Generic and cancer specific Quality of Life among other socio demographic questions etc are also being asked in the questionnaire.

Type of Study

Descriptive Study ( )

(Specify ……………………………………………………………….)

Analytical Study (X)

(Specify …………...…………………………………………………….)

Experimental Study ( )

The research will mainly be a survey based study administered through questionnaire. The questionnaire will contain the socio demographic profile, questions on economic and mental burden that the patient and the family have to go through during the process of diagnosis and treatment of cancer. After the data is collected, the analysis part of it will be conducted using the econometric software STATA.

Cross sectional study (X)

In this study, by qualitative part, we address the verbal responses of the patients on their state of health. Individuals responding on the mental burden questions and interpersonal communication with family comes under the purview of qualitative responses. Whereas, analyzing the economic burden by quantifying the cost associated with the treatment are considered as quantitative responses.

Study Site and its Justification:

Study Site-

The research will be in Katmandu, the capital city of Nepal. The reason we choose the site is because: We needed to have the study on developing country. Cancer incidences are growing in Nepal. Nepal Study Centre-UNM and KU's Memorandum of understanding facilitate the successful completion of the study. The NSC, through its offices at UNM and a branch in Nepal's Kathmandu University, strives to foster collaboration between the University of New Mexico, Kathmandu University, and the International Centre for Integrated Mountain Development (ICIMOD). Kathmandu University and Nepal Study Centre of UNM has a Memorandum of Understanding which helps in undertaking many projects of NSC-UNM in Nepal. Following link will help in understanding the collaborative work that Kathmandu University is doing with NSC over years.
http://nepalstudycenter.unm.edu/KUVC_UNMVisit.htm
Kathmandu University provides a separate locked office and cabinet for ensuring the safety of the investigator as well as for the data. All the paper works and the collected questionnaire will be kept in the safety lock and will not be made accessible to any other persons except for me. The paper form of the questionnaire will be transferred, entered and saved in an electronic format before bringing that to USA for analysis. Once the data is securely stored in electronic format, the paper form of the questionnaire will be destroyed.
We have a letter of support from Kathmandu University which shows their commitment towards the project. The permission is hereby attached.

Selected hospitals of Kathmandu Valley like Bir, Bhaktapur , Bharatpur , Dhulikhel, and Army.

Justification of Site

Kathmandu valley being the capital of Nepal, we expected to have been able to survey at more than one hospitals so that we can increase our sample size. Quality of care in the Kathmandu Valley is expected to be high; hence more patients are likely to be driven towards these hospitals.

Target Population

500 Treatment group (Cancer patients)

100-200 Control group

Sampling Methods

Of the seven hospitals as identified by Kumar et.al 2009 in their study which mainly cater to cancer patients in Nepal, at least four hospitals are situated in Kathmandu valley. These hospitals will be included as a target population for survey sampling. The hospitals respectively are Bhaktapur, Dhulikhel, Bir , Teaching and Army hospitals. Teaching hospitals situated in Kathmandu will also be considered for sampling purposes. Tentatively, a sample of 500 cancer patients will be included in our survey. The sampling will be done randomly among the cancer patients. The patients are going to get tracked in the hospital. Since the study will encompass all the different types of cancer at all various stages so the sampling will ultimately depend on the availability of the cancer patients as inpatient, in day care or outpatients. For selecting the control group, another patient from the same hospital on the same day will be interviewed who are suffering from chronic diseases.

Kathmandu , being the capital city of Nepal with the availability of proper health care facilities, all the major hospitals of the capital city were needed to be sampled in. That is the reason why the highest proportion of hospitals in the sample are from Kathmandu. B.P Koirala Cancer hospital is the biggest cancer hospital in Nepal. Apart from hospitals in the Kathmandu valley, in order to be able to get a proper representation of cancer patients in Nepal, Chitwan's B.P Koirala Cancer hospital is taken into account. This is a purposive sampling method.

Of the seven hospitals as identified by Kumar et.al 2009 in their study which mainly cater to cancer patients in Nepal, at least five hospitals of Nepal will be included as a target population for survey sampling. The hospitals respectively are Bhaktapur, Dhulikhel, Bir , Bharatpur and Army hospitals.

Sampling Frame (if relevant) and Sampling Process including Criteria for Sample

Selection Criteria

In this section, I include the consent procedures and the selection criteria of the participants of the study. The consent process will hold at any place deemed private by the participants. It will mainly be in any health facility like hospitals where participants come for check-ups. Inpatients admitted for cancer are given separate room facilities which will thus ensure their privacy during the interview process. Outpatients will also be approached for interview depending on their feasibility. All the participants will be approached with due permission of the hospital authority. Hospital authority will be provided IRB approved letters of University of New Mexico, USA and Dhulikhel Hospital, Nepal to be given to the patients and if the patients agree to join the survey, then the project researchers will meet the patients.

The enumerator will give enough time to the respondent regarding their decision to participate in the survey, so that if they need time, enumerators will approach them at later date within a week.

The research demands for a verbal concern. All the participants will be told the serial number of their questionnaire, so that they can use it later for claiming withdrawal in 3 months if they want. The study doesn't necessarily require any name but the address. All the participants will be given a serial number so that they can claim their withdrawal if wanted to do so. Proper attention will be given to the fact that participants understand the content of the consent script. Enumerator at the starting of the survey will explain verbally about the research and the content of the script, participants will be asked thoroughly if they need the enumerator to go over the consent script again. If the participants think that they need time before giving their consent, then they will be given my contact information (Soumi – Student Investigator of University of New Mexico) so that they can approach me at a later date.

The consent will be obtained verbally from the participants solely by the members of the study. A scripted consent is given below in English. The translated Nepali version with be attached to the protocol. The research will not involve minors. All the participants in the research will be 18 years or older.

Of the seven hospitals as identified by Kumar et.al 2009 in their study which mainly cater to cancer patients in Nepal, at least five hospitals of Nepal. These hospitals will be included as a target population for survey sampling. The hospitals respectively are Bhaktapur, Dhulikhel, Bir , Bharatpur and Army hospitals. Tentatively, a sample of 400 cancer patients will be included in our survey. This is supplemented with 200 control patients which are non cancerous.

Only two of the five hospitals included into our survey such as Bhaktapur and B.P Koirala hospital are specialized cancer hospitals of Nepal. Rest of the hospitals only had one inpatient cancer ward and a day care. Considering the fact that if the enumerators spend two weeks in each hospital, then they would be able to get 30x3=90 patients from Bir, Dhulikhel and Army. Similarly from Bhaktapur alone, we are expecting around 100 patients in total in those two weeks. In addition from Bharatpur, given it has the highest flow of cancer patients, we are expecting to collect 200 patients in two weeks. This gives us an approximate number of 400 cancer patients.

On the other hand, for selecting the control group, another patient from the same hospital on the same day will be interviewed who are suffering from acute disease and not from any chronic disease. For those hospitals that are specialized cancer hospitals, we wouldn't take any control patient interview. Bhaktapur and B.P Koirala hospital will come under this purview. The control groups are selected so that we can have a comparable group of non-cancerous patients who are suffering from some other serious diseases. So that we can have a comparably fair control group, these non-cancerous patient need to be an in-patient with >3 days of admission to the hospital. We would not take into account any patients under control group who are outpatient or inpatient with <3 days of admission because we didn't want to make the results bias to start with. Since cancer patients will have a significantly higher burden than the outpatient non-cancerous patient, in order to match up with their level of burden, we need control group with serious health problem that needs hospital admissions for a longer length.

We aim to collect 200 control patients since we do have mainly Bir, Dhulikhel and Army to choose for. Our criteria is 2:1 where two cancer patients will be matched with one control patients.

The consent script:

Hi, my name is Soumi and I am a graduate student of University of New Mexico, United States of America. I am conducting a research study to examine socio economic consequences of cancer in Nepal. I know you must be busy but your involvement will just require 30 minutes and your contribution can significantly enhance the knowledge, future diagnosis and treatment procedures of cancer.

You will be asked a series of questions, designed to understand the prognosis of the disease, the kinds of treatment available in Nepal and the cost of such treatments. We will be asking you about the effects cancer had in your and your family's daily life. Through this, we can analyze the extent of economic and mental burden cancer can impose on the society. This will help us in developing or recommending policies of how to mitigate the extent of burden. If you feel uncomfortable to any of the questions of the survey, you may always refuse to answer the question or withdraw from the survey.

All of your responses will be anonymous and your participation is entirely voluntary. Only the researchers involved in this study will have access to the information you provide. The data will be de-indentified within 3 months, so that no information will be linked to you. Once the data gets de-identified it will not be possible even for us to know which response belongs to you. You can also withdraw at any time within 3 months of your survey from the study. We will hand you over your questionnaire and will not record or keep any details of yours with us.

Would you want to give the interview here in hospital? If No then you can give us any appointment place and time where I can go and meet you. If you have any questions or concerns about this study, you may contact me through this number ……
Do you have any questions at this time? Do you want to participate in the study?

Tools and Techniques for Data Collection

The study will be on cancer patients and will be administered through a formatted questionnaire. The interview will be a verbal communication between the interviewer and the participants and will NOT include any kind of clinical trials, neither the participants will be asked to show any lab reports. There will NOT be any recordings or photography of the participants, the entry in the questionnaire is entirely based on the verbal answers given by the participants.
The questionnaire will be divided in sections such as participants' self reported health status, diagnosis and the treatment processes of the disease, cost of treatment (economic burden), palliative care options available, mental burden caused to the participant and family on account of the disease.
A wide and varied literature review on the socio-economic consequences on cancer gives us the idea as to what variables are particularly important to our study The questionnaire is getting framed with the help of some existing surveys and as well as incorporating our own project agenda. Some pre existing cancer patient questionnaires are: SCCS Cancer Survivor Navigation Questionnaire, NHIS questionnaire - Sample Adult, Behavioral Risk Factor Surveillance System Questionnaire of CDC, NHS patient survey and PHQ 9 questionnaires.

Pre-testing the Data Collection Tools (if relevant)

A pre testing or a pilot survey will be done in Nepal with some patients of Dhulikhel hospital to start with.

The testing will be done to assure about the time and to feel the level of comfortability of the participants regarding answering the questions related to their disease

It is expected that the length of the interview would range for about 20-30 minutes.

Limitation of the Study (if relevant)

The major limitation of the study is in the form of the length of the questionnaire especially given the interviewees are cancer patients. We understand that the patients waiting for their treatment will be under burden and we are anticipating that it will be difficult to capture the responses of the outpatients.

The potential risk though remains how much time they will be willing to allot towards the study as there is certainly going to be time constraint. The challenge to the enumerator remains in creating a reasonable informal environment where participants feel comfortable in discussing about their personal health information as we can absolutely understand that discussing personal issues like health to any stranger is not always an easy job to do. They may feel uncomfortable and awkward on some questions. If at any point of the dialogue, I feel that the patients are psychologically getting stressed, there will be no compulsion imposed on them to continue with the study. There is no economic burden being imposed on the participants of the study, nor did they have to go through any political or social stigmatization.

10. Plan for Supervision and Monitoring

The project team consists of four enumerators who will be collecting the data onto the field. There will be a field supervisor who will be supervising all the enumerators and will keep a note of the progress of survey in terms of everyday data collection. A translator will not only accompany the student investigator of UNM but both the supervisor and the translator will also involve in the data collection process.

11. Plan for Data Management

At this point in the project, no secondary sources of data will be used. The main data that we will have is from the primary investigation. The data will be de-identified and decoded in such a manner that it will not be possible to associate any data points with any corresponding participants. So if the participants wish to withdraw, they should do it within a period of 3 months. Once it gets into an electronic version, it is not possible to identify any participants. The electronic form of the data will be brought back to USA through a protected hard drive and will be stored in password protected computer of NSC-UNM office which has a security gate code accessible only to a few. The data will be looked through and analyzed by Principal Investigator and Student Investigator responsible for the project. The data will be analyzed over the span of couple of years. Only the Principal investigator, Prof. Alok Bohara and the Student Investigator Soumi Roy Chowdhury will be responsible for analyzing the data.

12. Plan for Data Analysis

The data will be analyzed over the span of couple of years. Only the Principal investigator , Prof. Alok Bohara and the Student Investigator Soumi Roy Chowdhury will be responsible for analyzing the data.

The data will be analyzed by the student investigator over the course of her dissertation. The analysis will include running econometric technique based on the nature of the data. Since the data will be stored in the NSC UNM office computer under a personalized account, only the student investigator will have the access for it. Three possible methods will be explored: Structural Equation Model (SEM), Partial Least Squares (PLS), and directed acyclic graphs (DAG). These are the methods generally suitable for survey research with extensive set of variables that are generally collinear. The student investigator under the supervision of PI – Prof . Bohara will only have the data accessibility and are only responsible for the data analysis.

13. Expected Outcome of the Research

This will be a first of kind scientific study to assess, among other things, the socio-economic and behavioral impact of cancer in the context of Nepal. We will be developing a sound data base for a sample of 400 household level data covering both the cancer patients as well as their caregivers. In the future, this baseline survey will provide an opportunity to do a follow-up study. Results from the study will be written up and presented at conferences and will be submitted for publication. The findings of the study will help develop strategies to mitigate the financial shocks created due to cancer in Nepalese households. This pioneering work in Nepal will also help develop analytical and predictive models for informing future health financing policies in relation to cancer in Nepal.

14. Plan for Dissemination of Research Results

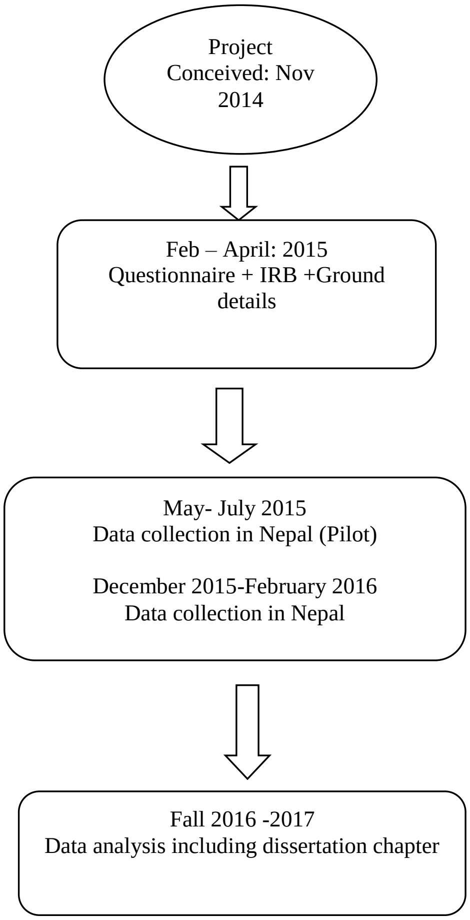
The results of the survey will be presented in various conferences and sincere attempts will be done to publish the findings through publication in peer reviewed journal. The doctoral dissertation is an important outcome for the project.

15. Work Plan (should include duration of study, tentative date of starting the project and work schedule)

Tasks

The following are the anticipated tasks necessary to achieve the above objective.

Task 1: Preparing a survey questionnaire for the project
Task 2: Travelling to Nepal and undertaking related managements of project.
Task 3: Meeting with the hospitals authorities, Expert group and Focus group
Task 4: Training and briefing of the project to the enumerators
Task 5: Identifying cancer patients through the help of hospital authority.
Task 6: Household survey with the help of enumerators in the hospitals of Kathmandu mentioned above (For 2 months).
Task 7: Data entry (2 persons for 1 month)
Task 8: Final deliverable data


Project Conceived: Nov 2014
Feb – April: 2015
Questionnaire + IRB +Ground details
May- July 2015
Data collection in Nepal (Pilot)
December 2015-February 2016
Data collection in Nepal
Fall 2016 -2017
Data analysis including dissertation chapter

Ethical Consideration

16. Regarding the human participants:

Are human participants required in this research? If yes, offer justification.

Yes, the project will have human participants since the research is about the socio economic consequences of cancer patients and their quality of life which justifies their participation.

Clearly indicate the participants responsibilities in the research. What is expected of the research participants during the research?

The participants will only be asked about their experience with cancer, the stage they are currently in, the economic cost and the opportunity cost of the patients and their families. Questions pertaining to their quality of life and willingness to pay for additional treatments options and alleviation from pain are also asked. The participants will not be asked to show or reveal any lab reports or prescriptions. They will just be expected to self report their answers.

Are vulnerable members of the population required for this research? If yes, offer justification.

All the participants will be 18 years or older and patients severely ill of cancer and are unable to respond will not be included in the survey.

Are there any risks involved for the participants? If yes, identify clearly what are the expected risks for the human participants in the research and provide a justification for these risks.

There will not be any clinical risk associated with the survey. The potential risk though remains how much time they will be willing to allot towards the study as there is certainly going to be time constraint. The challenge to the enumerator remains in creating a reasonable informal environment where participants feel comfortable in discussing about their personal health information as we can absolutely understand that discussing personal issues like health to any stranger is not always an easy job to do. They may feel uncomfortable and awkward on some questions. If at any point of the dialogue, I feel that the patients are psychologically getting stressed, there will be no compulsion imposed on them to continue with the study. There is no economic burden being imposed on the participants of the study, nor did they have to go through any political or social stigmatization.

The enumerators will be trained to be extremely cordial and respectful while talking to the participants as I understand that the participants are cancer patients and must be in a very delicate state of their minds. Necessary arrangements like decoding the data within 3 months of survey will be done. The data will be brought in USA in an electronic format using a password coded safe hard drive. None of the paper works will be disclosed in public and will be kept in safe cabinet to assure confidentiality before de identifying or decoding. The paper works will be immediately destroyed at each process of decoding.

Are there any benefits involved for the participants? If yes, identify clearly what are the expected benefits for the participants.

There will be no immediate benefit from the study to the participants but there will be long term benefits through knowledge gathering and information. Most of the research from the context of social science perspective is policy focused. This particular research is meant to identify the consequences (financial and emotional) a patient and the family goes through throughout the treatment process. So the deliverables from this research will include a policy recommendation to the government about the possible pathways in mitigating this burden.

17. Informed Consent Form / Ethical Issues:

Statements required in the Informed Consent Form include:

Hi, my name is Soumi and I am a graduate student of University of New Mexico, United States of America. I am conducting a research study to examine socio economic consequences of cancer in Nepal. I know you must be busy but your involvement will just require 30 minutes and your contribution can significantly enhance the knowledge, future diagnosis and treatment procedures of cancer.

You will be asked a series of questions, designed to understand the prognosis of the disease, the kinds of treatment available in Nepal and the cost of such treatments. We will be asking you about the effects cancer had in your and your family's daily life. Through this, we can analyze the extent of economic and mental burden cancer can impose on the society. This will help us in developing or recommending policies of how to mitigate the extent of burden. If you feel uncomfortable to any of the questions of the survey, you may always refuse to answer the question or withdraw from the survey.

All of your responses will be anonymous and your participation is entirely voluntary. Only the researchers involved in this study will have access to the information you provide. The data will be de-indentified within 3 months, so that no information will be linked to you. Once the data gets de-identified it will not be possible even for us to know which response belongs to you. You can also withdraw at any time within 3 months of your survey from the study. We will hand you over your questionnaire and will not record or keep any details of yours with us.
Would you want to give the interview here in hospital? If No then you can give us any appointment place and time where I can go and meet you. If you have any questions or concerns about this study, you may contact me through this number ……

Do you have any questions at this time? If you want me to go through the questionnaire or if you want to take time before replying, then you can contact us later. Do you want to participate in the study?

Obtaining the Consent

How is informed consent obtained from the research participants ?

The consent process will hold at any place deemed private by the participants. It will mainly be in any health facility like hospitals where participants come for check-ups. Inpatients admitted for cancer are given separate room facilities which will thus ensure their privacy during the interview process. Outpatients will also be approached for interview, if they don't feel comfortable in giving interview in the hospital and wanted me to meet in a private place (e.g home etc), I will also do that. All the participants will be approached with due permission of their physician who are treating them. Physicians will be provided IRB approved letters to be given to the patients and if the patients agree to join the survey, then the project researchers will meet the patients.
The enumerator will give enough time to the respondent regarding their decision to participate in the survey, so that if they need time, enumerators will approach them at later date within a week.
The research demands for a verbal concern. All the participants will be told the serial number of their questionnaire, so that they can use it later for claiming withdrawal in 3 months if they want. The study doesn't necessarily require any name but only address. All the participants will be given a serial number so that they can claim their withdrawal if wanted to do so. Proper attention will be

given to the fact that participants understand the content of the consent script. Enumerator at the starting of the survey will explain verbally about the research and the content of the script, participants will be asked thoroughly if they need the enumerator to go over the consent script again. If the participants think that they need time before giving their consent, then they will be given my contact information so that they can approach me at a later date.

Please indicate who is responsible for obtaining informed consent from the participants in this research study?

The four enumerators, the supervisor and translator apart from the Student Investigator from UNM will be mainly responsible for data collection and getting consent from the participants.

Is there anything being withheld from the research participants at the time the informed consent is being sought?

No (X) Yes ( )

If yes, explain ………………………………………………………………………………
………………………………………………………………………………
……………………..

Annexes

18. Annexes should include

a. References

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b. **Data Collection Instruments including questionnaires**
Questionnaire is attached

c. **Information Sheet and Informed consent form (if relevant),**
The consent form is also enclosed in the text before.
Hi, my name is Soumi and I am a graduate student of University of New Mexico, United States of America. I am conducting a research study to examine socio economic consequences of cancer in Nepal. I know you must be busy but your involvement will just require 30 minutes and your contribution can significantly enhance the knowledge, future diagnosis and treatment procedures of cancer.

You will be asked a series of questions, designed to understand the prognosis of the disease, the kinds of treatment available in Nepal and the cost of such treatments. We will be asking you about the effects cancer had in your and your family's daily life. Through this, we can analyze the extent of economic and mental burden cancer can impose on the society. This will help us in developing or recommending policies of how to mitigate the extent of burden. If you feel uncomfortable to any of the questions of the survey, you may always refuse to answer the question or withdraw from the survey.

All of your responses will be anonymous and your participation is entirely voluntary. Only the researchers involved in this study will have access to the information you provide. The data will be de-indentified within 3 months, so that no information will be linked to you. Once the data gets de-identified it will not be possible even for us to know which response belongs to you. You can also withdraw at any time within 3 months of your survey from the study. We will hand you over your questionnaire and will not record or keep any details of yours with us.
Would you want to give the interview here in hospital? If No then you can

give us any appointment place and time where I can go and meet you. If you have any questions or concerns about this study, you may contact me through this number ……

Do you have any questions at this time? Do you want to participate in the study?

d. **List of abbreviations**
Not applicable

e. **Recently updated Curriculum Vitae of Principal Investigator**
CV is attached

f. **For Students**
Approval letter from Academic Supervisor
The letter is attached.

Research Proposal Approval Format

Research Title: A study on socio- psychological- economic consequences of cancer in Kathmandu valley and Bharatpur of Nepal: Understanding the risk factors, coping strategies and willingness to pay of the cancer and non-cancerous patients.

Nepal Health Research Council (NHRC)

P.O. Box: 7626, Ramshah Path, Kathmandu, Nepal
Tel: +977-1-4254220, 4227460, Fax: +977-1-4262469
E-mail: nhrc@nhrc.org.np, Website: http://www.nhrc.org.np

For Official Use Only

(Please see the check list before Registration of the application form)

Registration No.:
Registration Date:
Approved Date:
Name of PI:
Total Budget of the Project:
NHRC Processing Fee:
Research Site:
Tentative Date of Initiating the Project:
Duration of the Research Project:
Name of Internal Reviewer:
Name of External Reviewer:

NHRC/RES/PROP/Approval

Signature & Seal of NHRC:

Passport size photograph

Part – I

Administrative Information

1. Research Title: A study on socio- psychological- economic consequences of cancer in Kathmandu valley and Bharatpur of Nepal: Understanding the risk factors, coping strategies and willingness to pay of the cancer and non-cancerous patients.

2. Name and Title of Principal Investigator responsible for the proposed research:

Bohara		Alok
Last (Surname)	Middle (if any)	First name

Nationality: American

Citizenship Number with district name from where it was obtained (only for Nepali)

Passport Number (only for non Nepali citizen): 453700562

Signature: ABohara Date: March 1 , 2016

Postal Address: **Physical Address: 1915 Roma Ave. NE**
1019

Telephone No.: **505-277-5304**

Mobile No.: **505 5733660**

Fax No.:

bohara@unm.edu

e-mail:

Alternate e-mail:

3. Full name of the Institution associated with the Principal Investigator (if applicable) : **University of New Mexico**

Designation: **Professor and Director of Nepal Study Center, University of New Mexico**

Postal Address (if different from the address given above):

Same as above

Telephone No.:

Fax No.:

e-mail:

Website:

4. Declaration of the head of the Institution (if applicable)

If the proposed research is approved, we will allow him/her to conduct the research in this institution.

Signature: Date:

Last (Surname)	Middle (if any)	First name

Designation:

Name of the Institution

Contact/Postal Address:

Telephone No.:

Fax No.:

Institutional e-mail:

Website:

5. Name and Title of Co-investigators responsible for the proposed research (Use the similar format if more than one):

Passport size photograph

Last (Surname) Middle (if any) First name

Nationality: ☐

Citizenship Number with district name from where it was obtained (only for Nepali) ☐

Passport Number (only for non Nepali citizen): ☐

Affiliated Institution (if applicable): ☐

Designation: ☐

Signature: ☐ Date: ☐

Postal Address (if different from the address given above):

☐

Telephone No.: ☐

Fax No.: ☐

e-mail: ☐

(Use additional sheet if necessary)

6. List the name(s) and institutional affiliation to the researcher(s) (other than co-investigator) to assist your project in Nepal and abroad (if any)

	Name	*Institution and Address*
(a)	Suraj Makaju	Kathmandu University
(b)	Bikram	Kathmandu University
	Neelam Shah	Kathmandu University
	Madhavi Bhandari	Kathmandu University
	Jeena Manandhar	Kathmandu University

(Use additional sheet if necessary)

7. List the name(s) of Nepali researcher(s) (other than co-investigator) or Nepalese Institution/hospital/NGO(s) etc. from whom you may seek co-operation (if any) - N/A

(a)

(b)

(Use additional sheet if necessary)

8. List major equipment(s) in relation to your research project you plan to bring/import to Nepal (If applicable)

(a) None

(b)

(Use additional sheet if necessary)

8.1 List details of all specimen(s) (if any) that you may transport from Nepal in relation to your research.

(a) None

(b)

(c)

(d)

8.2 Country of Destination:

Name of Institution:

8.3 Mode of Transportation of Specimen

8.4 How will you ensure duplicate specimens remain in the country?

(If necessary use additional sheet)

9. Is this research part of your Thesis?

Yes ☒ No ☐

If yes,

PhD, Economics

For what degree and in which subject?

From which university?	Univesity of New Mexico
From which country?	United States of America

Part – II

Financial Information

10.Research Title:

Socio-economic Consequences of Cancer in Nepal [1]

11.Name of the funding organization:

American Cancer Society

Contact information of funding organization or agency:

Postal Address:
250 Williams St.
Atlanta, GA 30303

Telephone No.: 404.329.7618

Fax No.: 404.565.3215

e-mail: jeffrey.drope@cancer.org

Contact person at the funding organization or agency:

Drope		Jeffrey
Last (Surname)	Middle (if any)	First name

Designation: Vice President, Economic and Health Policy Research

---

[1] The title used while writing the grant and the fund number of the university identifies the grant with this title of the project: Hence the title is kept intact here.

Total amount of funds (in NRs / US $) allocated for the proposed research project: USD 10,000

Itemized budget (in detail) and justify the resources required for the proposed research work (*use additional sheet*)

Part – III

Research Proposal Description

12.Research Title:

A study on socio- psychological- economic consequences of cancer in Kathmandu valley and Bharatpur of Nepal: Understanding the risk factors, coping strategies and willingness to pay of the cancer and non-cancerous patients.

13.Proposal Summary (maximum 500 words):

In the context of developing countries, chronic illness is one of the dominant health burdens, and cancer alone is responsible for 70% of the total deaths. The cost associated with the chronic illness is estimated to increase which leads us to the important question that what will be the economic , social and psychological consequences of the disease to the patient and to the family as well. The purpose of the study is threefold. The first objective is to build a valuable cancer care dataset that may be used as a follow-up cohort study in the future. The second objective is to assess the impact cancer demand care has on the entire family unit in terms of both financial and non-financial burdens. The third objective is methodological where we will explore new approaches to analyze the multi-dimensional

complex linkages between health and other socio-economic and behavioral factors. The study will mainly be undertaken through administered questionnaire. The questionnaire will contain the socio demographic profile, questions on economic and mental burden that the family has to go through during the process of diagnosis and treatment of a cancer patient in their family. After the data is collected, the analysis part of it will be conducted using the econometric software STATA. Structural Equation Model (SEM), Partial Least Squares (PLS), and directed acyclic graphs (DAG) methods will also be used to analyse the data.

14. Introduction:

14.1 Background of Study (maximum 500 words):

In the context of developing countries, chronic illness is one of the dominant health burdens, and cancer alone is responsible for 70% of the total deaths. The cost associated with the chronic illness is estimated to increase to $84 billion by 2015 (Nuget, 2008). Cancer care is expensive, time consuming and is life altering for the entire family, which includes not only the cancer patients but also the family members who care for them(Nelson, 2010). In a country like Nepal, such burdens can be quite significant and devastating especially for the poor. Although cancer develops slowly, the impact on financial and non-financial stress can be speedy, deep, and irreversible for the patient as well as for the family members (caregivers). Even in a system where care falls under the public funding envelope, burden of the out-of-pocket cost can also be significantly high (16.5%) (Longo et al., 2006).This study will attempt to measure and quantify such *costs,* which could be direct as well as indirect in the context of Nepal.

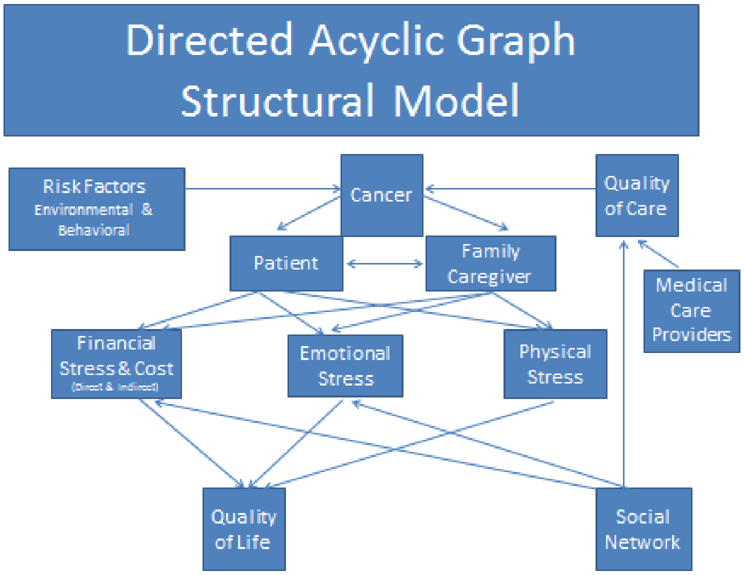
14.2 Statement of the Problem and Rationale / Justification (maximum 500 words)

The importance of the study emerges from the fact that there is no organized cancer registry in Nepal that can lead to further research in cancer. Given the significance of the disease and the burden it may create, the study aims to understand the socio-economic consequences, quality of life of cancer patients and measure the willingness to pay to avoid the pain and suffering associated with cancer.

Cancer as chronic disease can impact the life of not only the patients but also the life of the immediate family member. The facets of impact on account of cancer can be multiple; the burdens can be direct as well as indirect. The direct burden (direct cost) is the medical cost associated with cancer and the indirect burden (indirect cost) can be of various forms: the loss of employment of the patient and the immediate care taker, overall quality of life and mental distress. Quality of life (QOL) is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life. It measures the general wellbeing of the individuals. In the face of such existing dimensions of cancer, it is important to know the burden and more importantly what are the necessary steps that can be done to mitigate it. The ultimate goal of the project is to recommend some policies to the government so that the necessary actions can be taken to address such issues.

14.3 Conceptual framework

The Nepal Study Center at UNM is developing a field experimental methods lab where we hope to develop cutting edge research methods. So far, our approach has been in estimating parametric models for well-defined problem. Given our increasing involvement in field research work in Nepal, and the multi-disciplinary nature of our collaboration, we feel that there is a need for methods that can detect and unravel complex socio-economic and health linkages. We will explore three possible methods: Structural Equation Model (SEM), Partial Least Squares (PLS), and directed acyclic graphs (DAG), a graphical algorithm developed by Greenland (1999). These methods are generally suitable for survey research with extensive set of variables that are generally collinear and are hard to write as a causally well-defined regression equation. For example, a financial stress variable may have to be entered into the model as a latent factor rather than a well-define observable variable. Likewise, the whole structural linkages between the health status (e.g., cancer), risk factors, demographics, financial and emotional stress may have to be treated as a multidirectional network (e.g., *Bayesian* *network*) instead of a bi-directional causal regression model. A structural model in a DAG format may look like the following:



14.4 Research Objectives / purpose / aim of the study:

General

The importance of the study emerges from the fact that there is no organized cancer registry in Nepal that can lead to further research in cancer. Given the significance of the disease and the burden it may create, the study aims to understand the socio-economic consequences, quality of life of cancer patients and measure the willingness to pay to avoid the pain and suffering associated with cancer.

Specific

A set of tentative research questions is outlined as follow:

- What is the financial burden (direct and indirect care related, loss of employment, debt burden) associated with cancer?
- How does cancer impact on financial stress, emotional stress, physical stress, and quality of life?
- Can we identify some risk factors (environmental and behavioral –smoking) that instigate cancer incidents?
- How can we assess the disparities in quality of care for poor versus the rich? Does gender plays a role in the self report of quality of life due to social desirability issues?
- Can we identify coping strategies (e.g., support network) and examining its effect on the cost of care (e.g., providing hospital ride, time sharing), quality of care, and the emotional state for cancer patients?
- What are the stated willingness to pay for cancer treatment versus cancer pain and other important side effects of cancer?

Other objectives are

- Primary data set development of five hospitals.
- Analyzing the relationship between different nodes of cancer using an new and improved methodology such as directed acyclic graph
- One chapter of doctoral dissertation.

15. Research Design and Methodology

Research Method

Qualitative ☐ Quantitative ☐ Combined ☒

Study Variables:

Cancer incidents, type and stages of cancer, direct medical cost, indirect medical cost (missed working days, job loss) to both patients and immediate care , WTP for better screening, risk perceptions and social desirability issues. Generic and cancer specific Quality of Life among other socio demographic questions etc are also being asked in the questionnaire.

Type of Study (Specify):

Cross sectional study (X)

In this study, by qualitative part, we address the verbal responses of the patients on their state of health. Individuals responding on the mental burden questions and interpersonal communication with family comes under the purview of qualitative responses. Whereas, analyzing the economic burden by quantifying the cost associated with the treatment are considered as quantitative responses.

Study Site and Its Justification:

Selected hospitals of Kathmandu Valley like Bir, Bhaktapur , Bharatpur , Dhulikhel, and Army.

Kathmandu valley being the capital of Nepal, we expected to have been able to survey at more than one hospitals so that we can increase our sample size. Quality of care in the Kathmandu Valley is expected to be high; hence more patients are likely to be driven towards these hospitals.

Study Population (Specify):

400 Treatment group (Cancer patients)

100-200 Control group (Patients with acute but not chronic disease, especially control patients should be non-cancerous)

Inclusion Criteria:

All patients above 18 years will be a part of the study.

Control group: Non-cancerous patients admitted in the hospital for >3 days.

Treatment group: Outpatients who are diagnosed with cancer + Inpatients who are admitted to the hospitals will be included.

Exclusion Criteria:

All the patients under 18 years of age are excluded from the analysis.
Patients who are severely disabled are also exempted from the study.

Control group: No outpatients will be included in the survey and no inpatients with <3 days of admission to the hospital will be considered for interview.

Patients that has not been diagnosed with cancer will not be included in the sample.

Study Unit:

Cancer patients in Bir, Bhaktapur , Bharatpur , Dhulikhel, and Army.

Sampling Methods / Techniques (Specify):

Kathmandu , being the capital city of Nepal with the availability of proper health care facilities, all the major hospitals of the capital city were needed to be sampled in. That is the reason why the highest proportion of hospitals in the sample are from Kathmandu. B.P Koirala Cancer hospital is the biggest cancer hospital in Nepal. Apart from hospitals in the Kathmandu valley, in order to be able to get a proper representation of cancer patients in Nepal, Chitwan’s B.P Koirala Cancer hospital is taken into account. This is a purposive sampling method.

Of the seven hospitals as identified by Kumar et.al 2009 in their study which mainly cater to cancer patients in Nepal, at least five hospitals of Nepal will be included as a target population for survey sampling. The hospitals respectively are Bhaktapur, Dhulikhel, Bir , Bharatpur and Army hospitals.

Sample size (with justification):

Criteria for Sample Selection:

Of the seven hospitals as identified by Kumar et.al 2009 in their study which mainly cater to cancer patients in Nepal, at least five hospitals of Nepal. These hospitals will be included as a target population for survey sampling. The hospitals respectively are Bhaktapur, Dhulikhel, Bir , Bharatpur and Army hospitals. Tentatively, a sample of 400 cancer patients will be included in our survey. This is supplemented with 200 control patients which are non cancerous.

Only two of the five hospitals included into our survey such as Bhaktapur and B.P Koirala hospital are specialized cancer hospitals of Nepal. Rest of the hospitals only had one inpatient cancer ward and a day care. Considering the fact that if the enumerators spend two weeks in each hospital, then they would be able to get 30x3=90 patients from Bir, Dhulikhel and Army. Similarly from Bhaktapur alone, we are expecting around 100 patients in total in those two weeks. In addition from Bharatpur, given it has the highest flow of cancer patients, we are expecting to collect 200 patients in two weeks. This gives us an approximate number of 400 cancer patients.

On the other hand, for selecting the control group, another patient from the same hospital on the same day will be interviewed who are suffering from acute disease and not from any chronic disease. For those hospitals that are specialized cancer hospitals, we wouldn't take any control patient interview. Bhaktapur and B.P Koirala hospital will come under this purview. The control groups are selected so that we can have a comparable group of non-cancerous patients who are suffering from some other serious diseases. So that we can have a comparably fair control group, these non-cancerous patient need to be an in-patient with >3 days of admission to the hospital. We would not take into account any patients under control group who are outpatient or inpatient with <3 days of admission because we didn't want to make the results bias to start with. Since cancer patients will have a significantly higher burden than the outpatient non-cancerous patient, in order to match up with their level of burden, we need control group with serious health problem that needs hospital admissions for a longer length.

We aim to collect 200 control patients since we do have mainly Bir, Dhulikhel and Army to choose for. Our criteria is 2:1 where two cancer patients will be matched with one control patients.

Data Collection Technique / Methods (Specify):

The study will be on cancer patients and will be administered through a formatted questionnaire. The interview will be a verbal communication between the interviewer and the participants and will NOT include any kind of clinical trials, neither the participants will be asked to show any lab reports. There will NOT be any recordings or photography of the participants, the entry in the questionnaire is entirely based on the verbal answers given by the participants.

The questionnaire will be divided in sections such as participants' self reported health status, diagnosis and the treatment processes of the disease, cost of treatment (economic burden), palliative care options available, mental burden caused to the participant and family on account of the disease.

A wide and varied literature review on the socio-economic consequences on cancer gives us the idea as to what variables are particularly important to our study The questionnaire is getting framed with the help of some existing surveys and as well as incorporating our own project agenda. Some pre existing cancer patient questionnaires are: SCCS Cancer Survivor Navigation Questionnaire, NHIS questionnaire - Sample Adult, Behavioral Risk Factor Surveillance System Questionnaire of CDC, NHS patient survey and PHQ 9 questionnaires.

Data Collection Tools: (please attached in annex)

Pre-testing the Data Collection Tools (if applicable):

A pre testing or a pilot survey will be done in Nepal with some patients of Dhulikhel hospital to start with.

The testing will be done to assure about the time and to feel the level of comfortability of the participants regarding answering the questions related to their disease.

It is expected that the length of the interview would range for about 20-30 minutes.

Validity and Reliability of the Study Tools:

The questionnaire has been made out of the pre-approved questionnaire of National Health Service (NHS), Patient Health Questionnaire (PHQ) guidelines.

Potential Biases (if applicable):

Limitation of the Study:

The potential risk though remains how much time they will be willing to allot towards the study as there is certainly going to be time constraint. The challenge to the enumerator remains in creating a reasonable informal environment where participants feel comfortable in discussing about their personal health information as we can absolutely understand that discussing personal issues like health to any stranger is not always an easy job to do. They may feel uncomfortable and awkward on some questions. If at any point of the dialogue, I feel that the patients are psychologically getting stressed, there will be no compulsion imposed on them to continue with the study. There is no economic burden being imposed on the participants of the study, nor did they have to go through any political or social stigmatization.

16. Plan for Supervision and Monitoring:

The project team consists of four enumerators who will be collecting the data onto the field. There will be a field supervisor who will be supervising all the enumerators and will keep a note of the progress of survey in terms of everyday data collection. A translator will not only accompany the student investigator of UNM but both the supervisor and the translator will also involve in the data collection process.

17.Plan for Data Management and Analysis:

Data Management:

At this point in the project, no secondary sources of data will be used. The main data that we will have is from the primary investigation. The data will be de-identified and decoded in such a manner that it will not be possible to associate any data points with any corresponding participants. So if the participants wish to withdraw, they should do it within a period of 3 months. Once it gets into an electronic version, it is not possible to identify any participants. The electronic form of the data will be brought back to USA through a protected hard drive and will be stored in password protected computer of NSC-UNM office which has a security gate code accessible only to a few. The data will be looked through and analyzed by Principal Investigator and Student Investigator responsible for the project. The data will be analyzed over the span of couple of years. Only the Principal investigator, Prof. Alok Bohara and the Student Investigator Soumi Roy Chowdhury will be responsible for analyzing the data.

Data analysis

The data will be analyzed by the student investigator over the course of her dissertation. The analysis will include running econometric technique based on the nature of the data. Since the data will be stored in the NSC UNM office computer under a personalized account, only the student investigator will have the access for it. Three possible methods will be explored: Structural Equation Model (SEM), Partial Least Squares (PLS), and directed acyclic graphs (DAG). These are the methods generally suitable for survey research with extensive set of variables that are generally collinear. The student investigator under the supervision of PI – Prof . Bohara will only have the data accessibility and are only responsible for the data analysis.

18.Expected Outcome of the Research:

This will be a first of kind scientific study to assess, among other things, the socio-economic and behavioral impact of cancer in the context of Nepal. We will be developing a sound data base for a sample of 400 household level data covering both the cancer patients as well as their caregivers. In the future, this baseline survey will provide an opportunity to do a follow-up study. Results from the study will be written up and presented at conferences and will be submitted for publication. The findings of the study will help develop strategies to mitigate the financial shocks created due to cancer in Nepalese households. This pioneering work in Nepal will also help develop analytical and predictive models for informing future health financing policies in relation to cancer in Nepal.

19.Plan for Dissemination of Research Results:

The results of the survey will be presented in various conferences and sincere attempts will be done to publish the findings through publication in peer reviewed journal. The doctoral dissertation is an important outcome for the project.

20.Plan for Utilization of the Research Findings (optional):

How is the research project going to strengthen the research capability of the host institution: Nepali Researcher (if submitted from abroad):

21. Work Plan *(should include duration of study, tentative date of starting the project and work schedule / Gantt chart):*
    22. *<u>Tasks</u>*
    23. The following are the anticipated tasks necessary to achieve the above objective.
    24. Task 1: Preparing a survey questionnaire for the project
    25. Task 2: Travelling to Nepal and undertaking related managements of project.
    26. Task 3: Meeting with the hospitals authorities, Expert group and Focus group
    27. Task 4: Training and briefing of the project to the enumerators
    28. Task 5: Identifying cancer patients through the help of hospital authority.
    29. Task 6: Household survey with the help of enumerators in the hospitals of Kathmandu mentioned above (For 2 months).
    30. Task 7: Data entry (2 persons for 1 month)
    31. Task 8: Final deliverable data

Part – IV

<u>Ethical Consideration</u>

22. Regarding the human participants:

Are human participants required in this research? If yes, provide justification.

☒ Yes (*provide justification*) No ☐

Yes, the project will have human participants since the research is about the socio economic consequences of cancer patients and their quality of life which justifies their participation.

How many participants are required for the research? Explain.

400 Cancer patients
200 Control Patients

What is the frequency of the participant's involvement in the research? Explain.

Once

Clearly indicate the participant's responsibilities in the research. What is expected of the research participants during the research?

The participants will only be asked about their experience with cancer, the stage they are currently in, the economic cost and the opportunity cost of the patients and their families. Questions pertaining to their quality of life and willingness to pay for additional treatments options and alleviation from pain are also asked. The participants will not be asked to show or reveal any lab reports or prescriptions. They will just be expected to self report their answers.

Are vulnerable members of the population required for this research? If yes, provide justification.

All the participants will be 18 years or older and patients severely ill of cancer and are unable to respond will not be included in the survey.

Are there any risks involved for the participants? If yes, identify clearly what are the expected risks for the human participants in the research and provide a justification for these risks.

There will not be any clinical risk associated with the survey. The potential risk though remains how much time they will be willing to allot towards the study as there is certainly going to be time constraint. The challenge to the enumerator remains in creating a reasonable informal environment where participants feel comfortable in discussing about their personal health information as we can absolutely understand that discussing personal issues like health to any stranger is not always an easy job to do. They may feel uncomfortable and awkward on some questions. If at any point of the dialogue, I feel that the patients are psychologically getting stressed, there will be no compulsion imposed on them to continue with the study. There is no economic burden being imposed on the participants of the study, nor did they have to go through any political or social stigmatization.

The enumerators will be trained to be extremely cordial and respectful while talking to the participants as I understand that the participants are cancer patients and must be in a very delicate state of their minds. Necessary arrangements like decoding the data within 3 months of survey will be done. The data will be brought in USA in an electronic format using a password coded safe hard drive. None of the paper works will be disclosed in public and will be kept in safe cabinet to assure confidentiality before de identifying or decoding. The paper works will be immediately destroyed at each process of decoding.

Are there any benefits involved for the participants? If yes, identify clearly what are the expected benefits for the participants.

There will be no immediate benefit from the study to the participants but there will be long term benefits through knowledge gathering and information. Most of the research from the context of social science perspective is policy focused. This particular research is meant to identify the consequences (financial and emotional) a patient and the family goes through throughout the treatment process. So the deliverables from this research will include a policy recommendation to the government about the possible pathways in mitigating this burden.

23. Informed Consent Form / Ethical Issues:

Statements required in the Informed Consent Form include:

A statement that the human participants can withdraw from the study at any time without giving reason and without fear. State clearly how the participants can opt out the study.

A statement guaranteeing the confidentiality of the research participants.

If required, a statement on any compensation that might be given to the research participant and or their community.

A statement indicating that the participants has understood all the information in the consent form and is willing to volunteer / participate in the research.

Signature space for the research participants, a witness, and the date.

(Informed Consent form should be submitted in English and in the language appropriate to the research participants)

Obtaining the Consent

How informed consent is obtained from the research participants?

☐ Verbal ☒ Written

Please indicate who is responsible for obtaining informed consent from the participants in this research study?

…… The four enumerators, the supervisor and translator, investigators (PI and CO PI) will be mainly responsible for data collection and getting consent from the participants

…………………………………..………………………………

Is there anything being withheld from the research participants at the time the informed consent is being sought? NO

If yes, explain

………………………………………………………………………………

Is the research sensitive to the Nepali culture and the social values?

Yes ☐ No ☒ Explain.

………………………………………………………………………………

Is health insurance *(if applicable)* being made available to the research participants? If yes, please provide the necessary insurance data.
………………………………………………………………………………

(Include in consent form)

24. Regarding Clinical Trial:

In case of a clinical trial address the following:
The trial treatment
………………………………………………………………………………
A detailed explanation of the trial procedures including all invasive procedures.
………………………………………………………………………………
The potential or direct benefits (if any) for the research participants.
………………………………………………………………………………

Alternative procedure(s) or treatment(s) that may be available.
………………………………………………………………………………
The risks, discomforts, and inconveniences associated with the study
………………………………………………………………………………
Provisions for management of any adverse reactions
………………………………………………………………………………
The provisions of insurance coverage for any permanent disability or death caused directly by the investigational treatment or procedure.
………………………………………………………………………………
The provision of including the name and address, including telephone numbers of person to be contacted in case of adverse events or for any information related to the trial.
………………………………………………………………………………
Is there going to be a transfer of any biological materials from the country? Explain.
………………………………………………………………………………
Is there a Data Safety Monitoring Board?
If Yes, Mention
………………………………………………………………………………
Is this trail internationally registered?
……………………………………..

Part – V

ACCEPTANCE OF GENERAL CONDITIONS AND DECLARATION BY THE PRINCIPAL INVESTIGATOR

I hereby certify that the above mentioned statements are true, I have read and understood the regulation of the Nepal Health Research Council (NHRC) on the approval of research proposal and will act in conformity with the said regulation in all respects.

If the research is terminated, for any reason, I will notify NHRC of this decision and provide the reasons for such actions. I will provide NHRC with a written notice upon the completion of the research as well as a final summary/full report of the research study. If I publish the results in a journal, I shall acknowledge the NHRC and shall provide the Council with three copies of any such articles.

Abohara

…………………………

Signature of Applicant **Date:March 1,2016**………………

INFORMED CONSENT:

- Describe the manner in which informed consent will be obtained.

The consent process will hold at any place deemed private by the participants. It will mainly be in any health facility like hospitals where participants come for check-ups. Inpatients admitted for cancer are given separate room facilities which will thus ensure their privacy during the interview process. If patients doesn't have individual rooms for their treatment, then the interview will be in wards sitting close to their individual beds. In that way, levels of privacy can be maintained. If the patients are in the state of walking and want to sit in the hospital lobby while giving responses, that can also be done. If the patient's condition is critical and they are not in the state of answering any questions, they won't be approached. Further, patients won't be approached during their lunch-snacks time, neither would we try to collect any data during the rounds of the doctors. Outpatients will also be approached for interview, if they don't feel comfortable in giving interview in the hospital and wanted me to meet in a private place (e.g home etc), I will also do that. All the participants will be approached with due permission of their physician who are treating them. Physicians will be provided IRB approved letters to be given to the patients and if the patients agree to join the survey, then the project researchers will meet the patients. If the physicians or the nurses around the hospital warns us about any criticality of the patients or of the wards, the enumerators will obey that.

The enumerator will give enough time to the respondent regarding their decision to participate in the survey, so that if they need time, enumerators will approach them at later date within a week.

The research demands for a verbal concern. All the participants will be told the serial number of their questionnaire, so that they can use it later for claiming withdrawal in 3 months if they want. The study doesn't necessarily require any name but only address. Proper attention will be given to the fact that participants understand the content of the consent script. Enumerator at the starting of the survey will explain verbally about the research and the content of the script, participants will be asked thoroughly if they need the enumerator to go over the consent script again. If the participants think that they need time before giving their consent, then they will be given my contact information so that they can approach me at a later date.

- Indicate what kind of consent (e.g. parental, child, adult, etc) will be used.

Adult

- If the subjects are children/adolescents ages 7-18 years, an Assent Form must be included with the IRB application. The signed Assent Form along with the Parental/Guardian Consent Form must be retained on file for at least three years after completion of the research project.

NA

- If prisoners / pregnant women, or fetuses are to be included in the research sample, it is likely that a full IRB review will be required and additional human subjects' protections will be expected.

NA

- If the subjects do not read or comprehend English, you must provide a consent form in their language as well as in English for IRB review and approval.

- If you are requesting a waiver of written consent (i.e. a signature on an informed consent form) from the subjects, you MUST justify this request by providing an explanation of why obtaining written consent would add additional risk to the subjects and your alternative provisions for informing them about the study.

- If consent documents from another site will be used, you will have to indicate this and provide a copy of the authorized consent document and IRB approval with your application.

- You will have to provide any other relevant information if necessary. Please be aware that the PI is legally required to retain all signed Informed Consent forms for at least three years after the project terminates

- The Informed Consent form must be written at a level that the subjects will understand. Please use simple language, and avoid clinical jargon.

- Attach a copy of the written informed consent form (assent or parental consent where applicable). Consent documents MUST be in format requested. See examples on line.

- If the study uses database or archival data the use of informed consent is not applicable.

CONFIDENTIALITY OF DATA: ***Confidentiality of data MUST be address for all studies.***

- Indicate the extent to which confidentiality of records identifying subjects will be maintained.

- Describe the storage and disposal of information where applicable.

Check List

For all applicants

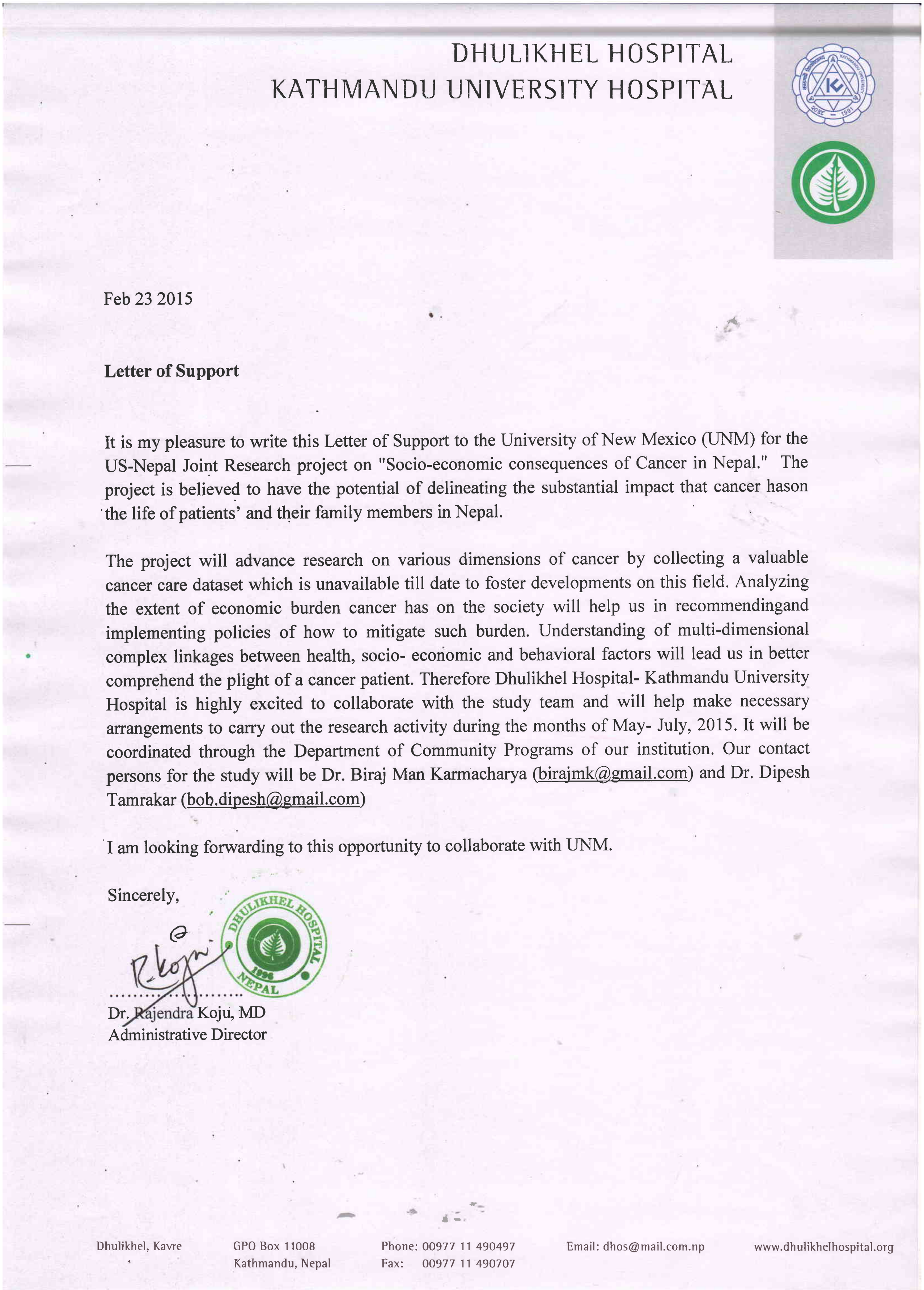
1. Covering letter addressed to the Member secretary indicating the submission of the approval of proposal.
2. Proposal will only be accepted if submitted in NHRC format.
3. Both printed and electronic version of the proposal should be submitted.
4. Curriculum Vitae of the Principal Investigator & Co-Principal Investigator of the study team should be submitted.
5. If the Principal Investigator is a non Nepali citizen, at least one Co-investigator should be a Nepali citizen.
6. Submission of the application processing fee to NHRC.(According to NHRC rules and regulations)
7. Source of funding for the proposed project.
8. The proposal should have institutional ethical clearance from his/her own country if submitted from academic and related institution.
9. If the research study is to be conducted in any hospitals/organization or institution/community, a letter of approval from the related hospital/organization or institution/district authority should be provided.
10. Consent form should be in Nepali & local language (if necessary).
11. Data collection tools should be in Nepali & local language (if necessary) including interview guideline, observation checklist, questionnaires etc.
12. Style of referencing should be in Harvard style.
13. List of abbreviations / acronyms should be provided.

For students' applicants

1. Approval letter from concern Institute/University.
2. Recommendation letter from Academic Supervisor.

Processing Fee

Researcher has to pay the processing fee as per the rules and regulations of NHRC.



DHULIKHEL HOSPITAL
KATHMANDU UNIVERSITY HOSPITAL

Feb 23 2015

Letter of Support

It is my pleasure to write this Letter of Support to the University of New Mexico (UNM) for the US-Nepal Joint Research project on "Socio-economic consequences of Cancer in Nepal." The project is believed to have the potential of delineating the substantial impact that cancer hason the life of patients' and their family members in Nepal.

The project will advance research on various dimensions of cancer by collecting a valuable cancer care dataset which is unavailable till date to foster developments on this field. Analyzing the extent of economic burden cancer has on the society will help us in recommendingand implementing policies of how to mitigate such burden. Understanding of multi-dimensional complex linkages between health, socio- economic and behavioral factors will lead us in better comprehend the plight of a cancer patient. Therefore Dhulikhel Hospital- Kathmandu University Hospital is highly excited to collaborate with the study team and will help make necessary arrangements to carry out the research activity during the months of May- July, 2015. It will be coordinated through the Department of Community Programs of our institution. Our contact persons for the study will be Dr. Biraj Man Karmacharya (birajmk@gmail.com) and Dr. Dipesh Tamrakar (bob.dipesh@gmail.com)

I am looking forwarding to this opportunity to collaborate with UNM.

Sincerely,

1996

R. Koju

……………………
Dr. Rajendra Koju, MD
Administrative Director

Dhulikhel, Kavre
GPO Box 11008
Kathmandu, Nepal
Phone: 00977 11 490497
Fax: 00977 11 490707
Email: dhos@mail.com.np
www.dhulikhelhospital.org

Appendices

D Questionnaires

I include two sets of questionnaires

1. Questionnaire used to the cancer patients

2. Questionnaire used to the control patients

Version -Bhaktapur	311
Version – Others	111

Socio- Economic Consequences of Cancer in Nepal

Namaskar, my name is Soumi Roy Chowdhury and I am a graduate student of University of New Mexico, United States of America. I am conducting a research study on behalf of Nepal Study Centre to examine socio economic consequences of cancer in Nepal. I know you must be busy but your involvement will just require 30 minutes and your contribution can significantly enhance the knowledge, future diagnosis and treatment procedures of cancer.

You will be asked a series of questions, designed to understand the prognosis of the disease, the kinds of treatment available in Nepal and the cost of such treatments. We will be asking you about the effects cancer had in your and your family's daily life. Through this, we can analyze the extent of economic and mental burden cancer can impose on the society. This will help us in developing or recommending policies of how to mitigate the extent of burden. If you feel uncomfortable to any of the questions of the survey, you may always refuse to answer the question or withdraw from the survey.

All of your responses will be anonymous and your participation is entirely voluntary. Only the researchers involved in this study will have access to the information you provide. The data will be de-indentified within 3 months, so that no information will be linked to you. Once the data gets de-identified it will not be possible even for us to know which response belongs to you. You can also withdraw at any time within 3 months of your survey from the study. We will hand you over your questionnaire and will not record or keep any details of yours with us.
Would you want to give the interview here in hospital? If No then you can give us any appointment place and time where I can go and meet you. If you have any questions or concerns about this study, you may contact me through this number ……

Do you have any questions at this time? Do you want to participate in the study?
Thank you very much for your kind cooperation.

Hospitals	Bhaktapur	1	Bir	2	Dhulikhel	3	Army	4	Teaching	5	Bharatpur	6

I. Are you 18 years or older?? *(Ask if respondent looks very young)*

18 years or older	1 (start the survey)
Less than 18 years old	2 Can't include in the survey

Note to enumerators: Please write number in english

PSU Code:	Date of Interview: (day/month/year) eg. 19 August 2014

Respondent's Name:	Enumerator's name:
Phone Number:	Enumerator's code:
Address:	Signature:
Ward Number:	
Name of the place:	Supervisor's Name:
City/VDC/District	Supervisor's code:
Landmark:	Signature:
Nearest Bus Stand:	
Interview start time:	Data entry operator's name:
Interview end time:	Signature:
Back Checked : 1 Accompanied : 2 Scrutinized : 3	

General Health Questions

A.1 What type of cancer do you have?	Lung	1
	Breast	2
	Stomach & Oesophageal	3
	Head and Neck & Brain	4
	Cervix Uteri	5
	Trachea	6
	Colon and rectal	7
	Prostate	8
	Bladder cancer	9
	Oral & nasopharynx	10
	Other (Specify)	11
A.2 Why did you think cancer must have caused to you? (Tick all that apply) [Beliefs] ***To enumerator: Ask for every single options, if they say yes, then tick it. But all the options should be presented to them.***	Genetics	1
	Tobacco / Smoking	2
	Diet and Physical activity	3
	Sun and UV exposure	4
	Cancer is due to bad karma	5
	Because of my wrongdoings	6
	Contagious –I got it from someone	7
	Causes are unknown	8
	Other reasons	9
	Don't know	10
A.3 Before diagnosis, did you realize something is wrong with you? How?	Seizures	1
	Weight Loss	2
	Lump in breast	3

A. Yes B. No	Change: Bowel habit	4
	Sores	5
	I didn't realize	6
	Diagnosed while testing for c comorbidities	7
	Others(Specify)	8
A.4 Do you know about all the diagnostic tests the hospital did to you?	Yes	1
	No	0
A.5 What was your age when you first got diagnosed with Cancer?	18-25 years	1
	25-40 years	2
	40-60 years	3
	60-80 years	4
	Other	5
A.6 What are the other major health disease do you have apart from cancer? (Tick all that apply)	Diabetic	1
	Blood pressure	2
	Mental disorder	3
	Epilepsy	4
	Asthma	5
	Heart Disease	6
	COPD	7
	Alzheimer	8
	Others	9
	None	10
A.7 Before you are finally diagnosed with cancer, do you use to do routine screening check - ups for cancer? If yes, go to A.8 otherwise A.9	Yes No	1 0
A.8 If Yes, how many times in a year	1-2 2-4 4-6 >6	1 2 3 4
A.9 If No, why do you didn't screen?	Didn't feel the need Didn't know about screening Other …………………	1 2 3
A.10 Do you think if you had screened it would have helped?	Yes No	1 0
A.11 Do you believe (Tick all that apply) ***To enumerator: Ask for every single options, if they say yes, then tick it. But all the options should be presented to them.***	Cancer can be treatable	1
	People with cancer generally survive	2
	People can talk freely without any stigma about cancer	3
	I know what to do to prevent cancer	4
	Awareness on causes and available causes of cancer is very	5

	low.	
	I know that I got it from someone	6
A.12 Before you had cancer, have you been given any information from hospitals (any posters or through educational campaign) regarding cancer, how to prevent it or about symptoms?	Yes	1
	No	0
A.13 What kind of information due you think will be helpful?	Symptoms of cancer Screening practices Preventive mechanisms None Others (if specify)	1 2 3 4 5
A.14 Did the hospital inform you about the stage of cancer that you were diagnosed with?	Grade 1	1
	Grade 2	2
	Grade 3	3
	Grade 4	4
	I don't know /They didn't say anything	5
A.15 Did you ever perceive the risk of getting cancer?	Yes No	1 0
A.16 What are the most important coping strategies do you follow or believe in?	Communication with physician	1
	Communication with family	2
	Desire to fight back disease	3
	Belief in God	4
	Maintaining a prescribed lifestyle	5
	Talk with other people with cancer	6
	Fight Stigmas	7
	Others…. (specify)	8
	None of the above	9
A.17 Have you heard about the following screening practices?	Breast Self-examination Test	1
	Mammography	2
	Colonoscopy	3
	Fecal Occult Blood test	4
	Prostate specific antigen test	5
	Pap test	6
	HPV test	7
	No test	8

B. Specialized treatment versus Hospice care[1]

B.1 Were you interested in specialized treatment of cancer in hospital? If yes, go to B.2 If No, go to B.5	Yes	1
	No	0
B.2 Have you had any of the specialized treatments in last 30 days?	Surgery only	1
	Chemotherapy	2
	Radiation therapy	3
	Surgery and Chemotherapy	4
	Surgery and Radiotherapy	5
	Chemotherapy and Radiotherapy	6
	All three	7
B.3 What are the potential side effects that they are facing during treatment? ***To enumerators: Ask what are the side effects that they are facing while getting treatment***	Nausea and vomiting	1
	Hair loss	2
	Weight loss	3
	Urination	4
	Blood clots	5
	Bowel Movements	6
	Memory Loss	7
	Others …………………	8
	They have not mentioned any effects	9
B.4 Do you know what hospice care is? ***To enumerators: Hospice care is a home-based care at the final stages of life where patients are not taking any chemo, radiation or surgical treatments but are just living on care of family and drugs to minimize the pain.***	Yes, focus on caring not curing	1
	No	0
B.5 Presently are you in a hospice care? ***To enumerators: Applicable to only those who are not getting treated with chemo /surgery/radiation and are only surviving on medicines.*** ***If yes go to B.6, If No go to Section C***	Yes	1
	No	0
B.6 Why do you wanted hospice care and not treatment? Tick all that apply To the enumerators: Read out to them all the options and then tick on those choices they have said yes to.	Economically viable	1
	No availability of treatment processes	2
	Untreated stage of cancer	3
	Too old for availing treatments	4
	Wanted to stay with family for the remaining days	5
	Treatment costs are high	6
	I didn't think that treatment would help me	7

---

[1] Need to make the difference clear: Specialized treatments mean those who are getting surgery/chemotherapy/ radiation therapy or such kinds of specialized treatments. But hospice care is when patients are fully living on medicines and are not availing any of this specialized care.

	No side effects	9
	Others	10
B.7 Who was your primary care giver during hospice care?	Family Member: Specify the relation ………………………………	1
	Hospital Nurse	2
	Neighbors	3
	Mental health worker	4
	Religious counselor (Priest)	5
	Friends	6
	Others………….. Specify	7

Measuring Economic Burden

C.1 When you were diagnosed with your cancer, were you working for pay? If Yes, go to C.2 , otherwise go to C.3	Yes	1
	No	2
C.2 Are you working now? ***Note to enumerators: Irrespective of their responses, you should ask them question C.3***	Yes	1
	No	2
C.3 Core Direct cost borne by any cancer patients in last 30 days .(Please specify the amount)		NRS
a. Screening [In total]		
b. Hospitalization		
c. Surgery		
d. Chemotherapy		
e. Radiation therapy		
f. Physician visit		
g. Prescription of drugs		
h. Medical Devices (walkers/wheel chairs) [In total]		
i. Hospice care ***To enumerators: Ask the hospice care patients, information about 'a', f'', 'g', 'h' and 'i' .***		
j. Total Expenses		
C.4 Other Related Direct cost		
a. Transportation to health care providers		

b. Child care related to obtaining health care cost		
c. Lodging for remote treatment facilities		
C.5 (Core Indirect cost) After the diagnosis of cancer, have any of the following happened to you? Tick all that apply	Changed jobs or employers	1
	Taken a leave of absence	2
	Quit your job	3
	Been let go or fired	4
	Missed work	5
	Worked fewer hours	6
	Turned down a job or demotion	7
	Felt that your work suffered	8
	Felt your co-workers treated you badly	9
	Felt your supervisor treated you badly	10
C.6 If you had taken leave for treatment, how many days you didn't go to work in last 30 days?	<5 days	1
	5-10 days	2
	11-20 days	3
	>20 days	4
	Comments (specify)…………	5
C.7 Before you diagnosed with cancer, did your primary care giver working for pay? ***To enumerators: Primary care giver is the family person who was with the patient throughout to take care of her.***	Yes	1
	No	0
C.8 After you have been diagnosed with cancer, did your primary care giver working for pay? (Related Indirect cost)	Yes	1
	No	0

Mental Burden

C.9 Generic Measures Of Quality of Life in last 7 days	Not at all (1)	Several Days (2)	More than half the days (3)	Nearly Every day (4)
a. Little interest or pleasure in doing things				
b. Feeling down, depressed, or hopeless				
c. Because of my physical condition, I have				

trouble meeting the needs of my family				
d. Feeling very energetic				
e. Did your heart race, pound, or skip?				
f. Feeling like vomiting most of the time				
g. Did you have chest pain or pressure?				
h. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down				
i. How good is your general life?				
j. Thoughts that you would be better off dead or of hurting yourself in some way				
k. I am content with the quality of my life right now				
l. You feel very depressed about the earthquake even now				
m. You are worried about country's current situation				
C.10 Cancer Specific Measures of Quality of Life				
a. Feel worried about your financial problems due to cancer?				
b. Family related Distress				
c. Do you feel concerned/ awkward regarding your appearances?				
d. Do you feel that you lose hope in the fight against illness?				
e. I have accepted my illness				
f. Do you need personal care for everyday things (eating, bathing, dressing and so on?)				

D. Willingness to Pay / Risks and Perceptions

Please answer this question taking into account your age, stage of cancer, the pain and suffering that you are going through the entire process of cancer treatment.

[Note to the enumerators: Please refer to the narration and the description of the good before you ask the WTP questions]

D.1 Assume that *hospitals are* undertaking screening program once a year to facilitate the screening practices of all the patients irrespective of the fact that they have cancer or not. This will screen the patients at the earlier stages so that they can be treated at their earliest and their chances of survival will significantly increase. But patients need to pay for each of the time they will take the screening test in addition to their annual medical expenditure. Patients may have to go on doing the test for their entire life given they never diagnose with cancer or they may get their cancer diagnosed at early stages and significantly increase the chances of survival.

Note to the enumerators. This is the willingness to pay for introducing innovative screening procedures so that general population can get screened of cancer early in their life and can get necessary treatments which can increase the probability of survival.

Now assume that such a screening program existed before you got diagnosed with cancer. Under such circumstances, if you are asked a yearly fee of …………………….(select from the bids) for the rest of your life to pay for the screening.
Would you have paid for it ? A) Yes
B) No

D .2 If the respondents indicates Yes to the first offered amount ……………… , then they are asked the follow up question that:

Whether you want to pay the double of it? Yes ………..(a)………………….

No …………..(b)………………..

D.3 If the respondents say No to the first amount ……….., then they are asked the follow up question:

Whether you want to pay the half of it ? Yes ………..(a)……………

No ………….(b)…………..

Note to the enumerators: Irrespective of the fact that they have said Yes / Yes , Yes / NO, No/Yes or No/No to the first two questions, everyone will be asked the following open ended question.

D.4 How certain you are about your answer above in a scale of 1-10? Circle the following number

1 2 3 4 5 6 7 8 9 10

(1 : Not Certain, 10 : Very Certain)

D.5 Now suppose that the screening program did not take off , so you don't need to pay for it any more. Assume that *hospitals are* undertaking a research activity and/or bringing in high technology machines and introducing world's best infrastructures which can free you from cancer and all the related pains and it lets you regain your health again without side effects. Introducing these machines will increase your cost of treatment, but on the other hand significantly increases the chances of your survival.
Under such circumstances, if you are asked an extra monthly fee in addition to your monthly medical expenditure of …………………….for the rest of your treatment period. Will you pay for it? A) Yes …………..
B) No

Note to the enumerators: This is the willingness to pay for introducing more cutting edge cancer treatment equipments

D .6 If the respondents indicates Yes to the first offered amount ……………… , then they are asked the follow up question that:

Whether you want to pay the double of it?	Yes ………..(a)………………….
	No ……………(b)………………..

D.7 If the respondents say No to the first amount ………….., then they are asked the follow up question:

Whether you want to pay the half of it ?	Yes ………..(a)……………
	No ………….(b)…………..

Note to the enumerators: Irrespective of the fact that they have said Yes / Yes , Yes / NO, No/Yes or No/No to the first two questions, everyone will be asked the following open ended question.

D.8 How certain you are about your answer above in a scale of 1-10? Circle the following number

1 2 3 4 5 6 7 8 9 10

(1 : Not Certain, 10 : Very Certain)

Informational interventions

D.9 Now I want to introduce before you two informational interventions:

The first one is a Screening Guidelines for early cancer detection published by American Cancer Society. This is a guideline which says irrespective of whether anyone has any symptoms of cancer, they should practice screening at different stages of life. It shows at what stage of life they should be screening for what type of cancer. Early detection significantly increases the survival rate. Upto 35% of the premature deaths could be avoided through screening [National Cancer Institute]

The Second one is a set of pictures on modern equipments and technologies used by the top 30 cancer hospitals of the world. These hospitals have significantly higher cancer survival rate in the world. Introducing these techniques in the cancer treatment may increase your rate of survival too.

According to U.S. News & World Report for 2014-15, top 30 US hospitals on cancer has a survival rate that ranges from 80% to 100%.

Now after knowing about the two alternatives that may be available to you and the respective merits that are associated with each of them, how does your earlier stated willingness to pay has changed?

a) They will remain same

[Yes/ No]

b) Now I want to pay more for Screening procedures relative to modern technology

[Yes /No]

c) Now I want to pay more for Modern technology relative to Screening procedures

[Yes /No]

d) Now I want to pay less for both the screening and Modern Technology

[Yes /No]

e) Now I want to pay more for both the screening and Modern Technology [Yes /No]

I am assuming that you must have seen other cancer patients across you either in your family or neighborhood. You have seen some of your friends or contacts or extended family with cancer. Usually the cancer cases you have seen across, in general what will you say that you have a relatively higher chance of getting cure than the cancer patients around you? Depending on the cancer patients you have seen across you in your family or neighborhood		
D.9 Do you think, you have comparatively higher chances of getting cure relatively to the other cancer patients you see around you?	Yes No	1 0
D.10 Now that you have this information, how certain do you think you will get completely cured of cancer? [Figures are in percentages] [0-completely uncertain ,100-completely certain]	0-10 10-20 20-30 30-40 40-50 50-60 60-70 70-80 80-90 90-100 I Don't know	1 2 3 4 5 6 7 8 9 10 11
D.11 Do you believe that cancer can come back even after you get completely cured of it? Rate your response from a scale of 1-10. 1- Not at all. 10- Definitely believe that cancer can come back	1 2 3 4 5 6 7 8 9 10	

E. Socio- Demographic Profile

E.1 What is the composition of your household (people living under the same roof)?	No. of men…………………… No. of women…………………… No of children under18 ………..	1 2 3
E.2 What is your current age?	Years	

E.3 What is your height and weight? To enumerators: Consider taking heights in foot as well.	In inch ……………………… In kg	1 2
E.4 Indicate the gender	Male Female Don't want to disclose	1 2 3
E.5 Do you smoke?	Yes, regularly Yes, sometimes No	1 2 3
E.6 Do you drink alcohol?	Yes, regularly Yes, sometimes No	1 2 3
E.7 What is your current marital status?	Never Married Currently Married Divorced Separated Widowed	1 2 3 4 5
E.8 What is the highest level of education that you have completed?	No formal schooling Grades (1-5) Grades(6-8) Grades (9-12) Bachelors Masters or other professional degrees	1 2 3 4 5 6

E.9 What is your primary occupation?	Unemployed In school Agriculture Shop keeper/ Self Employed Executive jobs/ Lecturer /Teacher Administrative Job (ex.Government, NGO) Not working outside the house Housewife Other / Working Labourers	1 2 3 4 5 6 7 8 9
E.10 How long does it take for you to reach the cancer treatment hospital?	Close to 1 day (>15 hours) 10- 15 hours 5-10 hours 3-5 hours 1-3 hours <1 hour	1 2 3 4 5 6
E.11 What is your primary religion?	Hindu Buddhist Muslim Christian Other	1 2 3 4 5
E.12 What is your caste/ethnicity?	Brahmin Chherti Newar Janajati	1 2 3 4

	Madhesi, Thaurs, Musalman Pahadi Dalit MadhesiDalit Other	5 6 7 8
E.13 What is your income level?(Permonth) E.131 What is your family income ?(Permonth) E.132 Is family income equal to patient's income? (Yes 1 , No :0)	<10,000 10,000-20,000` 20,000-30,000 30,000-50,000 >50,000	1 2 3 4 5
E.14 Do you do physical exercise?	Yes Less than 1 hour/week 1-3 hours per week 3-7 hours per week >7 hours per week 2. No	1. a. b. c. d. 2.
E.15 How are you paying for the treatment?	Health Insurance From savings Family paying Out of pocket Borrowing from others Selling properties or valuables Government Relief fund Others ………………….	1 2 3 4 5 6 7

E.16 Do you live under the following circumstances (To enumerators ask every single options to them)	Near or close to main road Use wooden fuel for cooking Kitchen is inside your house HH member smoke inside the house	1 2 3 4
E.17 Do any of your immediate relative had cancer before? (Mother, Father, Siblings, Grandparents, Aunt, Uncle, Cousins, maternal family, any other close family members)	Yes No	1 0

F. Social network : (INTERPERSONAL SUPPORT EVALUATION LIST (ISEL)

F.1 When I feel lonely, there are several people I can talk to.	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.2 There are several people that I trust to help solve my problems	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.3 I meet with family or friends on a daily basis (Ask: Do you live with your family)	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.4 As I feel very sick, I easily find someone to help me with my daily works.	definitely true	(a)
	probably true	(b)
	probably false	(c)

	definitely false	(d)
F.5 I feel that there is no one I can share my most private worries and fears with	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.6 Attitudes of the close family members have changed towards me since I had cancer?	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.7 I feel embarrassed in public / stigmatized because of cancer?	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.8 I want to hide the fact that I have cancer disease from others?	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)

WTP Elicitation Script

In recent years, there has been a major increase in the number of cancer cases in Nepal. Cancer is a disease that develops from abnormal cell growth in a body. This abnormal growth does not happen overnight, it is a steady process, which develops over years. At the onset, an individual may not realize that any abnormality exists because symptoms of cancer develop after the cell growth has matured and has taken the shape of a tumor. However, with all the preventative measures in the health sector today, it is not difficult to track any abnormality in the growth of cells. This does not need a monthly tracking, but can be done on an annual basis. If any irregularities show up during the tracking period, they can be treated immediately before developing into cancer. Detection at initial stages can result in significant increase in survival rates of patients. A hospital can initiate an annual comprehensive cancer screening program where individuals can get screened for the most widespread cancers. Through our study, we are trying to see if cancer patients put a retrospective value on early screening facilities. We also reminded them that accessing these services would involve opportunity costs and benefits. On one hand, they may have to spend time and money to visit the hospitals, wait to be screened, take leave from work, manage domestic chores, or adjust their total monthly expenditures. On the other hand, they are valuing a good that may lead to a greater benefit to the society. If such a service is provided, it may help future generations with improved cancer detection, higher survival outcomes, and reduced amount of economic and mental burden. Given they are already diagnosed with cancer and are currently facing the perils of the disease, they are in a better position to understand what a preventative measure can do. The stated value will indicate the importance they place on having such a program prior diagnosis. Their perspective on the good will then be used to inform the asymptomatic individuals about the importance of screening and the need for it. Specifically we asked that: Individuals will need to pay each time they take the screening test in addition to their annual medical expenditure. They may have to go on doing the test for their entire life given they are never diagnosed with cancer or they may get their cancer diagnosed at early stages and significantly increase the chances of survival. Now assume that such a screening program existed before they were diagnosed with cancer. Under such circumstances, if they are asked a yearly fee (Select from the bids). Would they have paid for it? [Yes, No]

Control Patients

Version	211

Socio- Economic Consequences of Cancer in Nepal

Namaskar, my name is Soumi Roy Chowdhury and I am a graduate student of University of New Mexico, United States of America. I am conducting a research study on behalf of Nepal Study Centre to examine socio economic consequences of cancer in Nepal. I know you must be busy but your involvement will just require 30 minutes and your contribution can significantly enhance the knowledge, future diagnosis and treatment procedures of cancer.

You will be asked a series of questions, designed to understand the prognosis of the disease, the kinds of treatment available in Nepal and the cost of such treatments. We will be asking you about the effects cancer had in your and your family's daily life. Through this, we can analyze the extent of economic and mental burden cancer can impose on the society. This will help us in developing or recommending policies of how to mitigate the extent of burden. If you feel uncomfortable to any of the questions of the survey, you may always refuse to answer the question or withdraw from the survey.

All of your responses will be anonymous and your participation is entirely voluntary. Only the researchers involved in this study will have access to the information you provide. The data will be de-indentified within 3 months, so that no information will be linked to you. Once the data gets de-identified it will not be possible even for us to know which response belongs to you. You can also withdraw at any time within 3 months of your survey from the study. We will hand you over your questionnaire and will not record or keep any details of yours with us.
Would you want to give the interview here in hospital? If No then you can give us any appointment place and time where I can go and meet you. If you have any questions or concerns about this study, you may contact me through this number ……

Do you have any questions at this time? Do you want to participate in the study?
Thank you very much for your kind cooperation.

Hospitals	Bhaktapur	1	Bir	2	Dhulikhel	3	Army	4	Teaching	5	Bharatpur	6

I. Are you 18 years or older?? *(Ask if respondent looks very young)*

18 years or older	1	(start the survey)
Less than 18 years old	2	Can't include in the survey
Inpatient (>3 days)	1	(start the survey)
Inpatient (<3 days)	2	Can't include in the survey
Done Diagnostic test (>2)	1	(start the survey)
Diagnostic test (<2)	2	Can't include in the survey

Note to enumerators: Please write number in english

PSU Code:	Date of Interview: (day/month/year) eg. 14 July 2012
Respondent's Name:	Enumerator's name:
Phone Number:	Enumerator's code:
Address:	Signature:
Ward Number:	
Name of the place:	Supervisor's Name:
City/VDC/District	Supervisor's code:
Landmark:	Signature:
Nearest Bus Stand:	
Interview start time:	Data entry operator's name:
Interview end time:	Signature:

Back Checked : 1 Accompanied : 2 Scrutinized : 3

General Health Questions

A.1 What type of disease do you have?	Chronic Disease (Specify)	1
	Others/Acute (Specify)	2
A.2 Why did you think must have caused to you?	Dirty water	1
	Absence of mosquito nets	2
	Lack of proper diet and physical activity	3
	Unhygienic food	4
	Normal cold	5
	Others	6
A. 3 Do you do regular screening checkups for any possible detection of any medical conditions like	Cancer	1
	Heart Diseases	2

	Kidney disease	3
	Diabetes	4
	Asthma	5
	Alzheimer	6
	Epilepsy	7
	Other ………..(specify)	8
A.4 If Yes, how many times in a year	1-2 2-4 4-6 >6	1 2 3 4
A.5 If No, why do you didn't screen?	Didn't feel the need Didn't know about screening Other …………………	1 2 3
A.6 Do you think if you screen it will help you in future?	Yes No	1 2
A.7 If I ask you specifically about one disease, say cancer: Do you believe (Tick all that apply) ***To enumerator: Ask for every single options, if they say yes, then tick it. But all the options should be presented to them.***	Cancer can be treated	1
	People with cancer survive	2
	People can talk freely without any stigma about cancer	3
	I know what to do to prevent cancer	4
	Awareness on causes and available causes of cancer is very low.	5
	People get it from someone	6
A.8 What do you think are the causes of cancer? (Tick all that apply) [Beliefs] ***To enumerator: Ask for every single options, if they say yes, then tick it. But all the options should be presented to them.***	Genetics	1
	Tobacco / Smoking	2
	Diet and Physical activity	3
	Sun and UV exposure	4
	Cancer is due to bad karma	5
	Because of wrongdoings	6
	Contagious	7
	Causes are unknown	8
	Other reasons	9

	Don't know	10
A.9 Have you heard about the following cancer screening practices?	Breast Self-examination Test	1
	Mammography	2
	Colonoscopy	3
	Fecal Occult Blood test	4
	Prostate specific antigen test	5
	Pap test	6
	HPV test	7

B. Disease Treatment and Management

B.1 Do you always come to hospital to treat your health illness or you first take some pre-medication on your own?	Yes	1
	No	2
B.2 How bad is your acute illness?	Very Bad	1
	Not so bad	2
	Fair	3
	It will be fine soon	4
B.3 What are the potential side effects that you experience throughout the treatment?	Nausea and vomiting	1
	Extreme Pain	2
	Insomnia	3
	Weak	4
	Appetite Loss	5
	Others ……….Specify	6
B.4 What are the general problems are you facing throughout the treatment process? (Tick all that apply)	Economical/ Financial Problems /No insurance	1
	No availability of treatment processes	2
	Geographically very far	3
	Lack of family support	4
	I wanted to see herbalist/ acupuncturist	5
	Other reasons (Specify)	6
B.5 Have you had any specialized treatment in last 30 days? ***To enumerators: Ask if doctors did any surgery , xrays, or any such treatments apart from only prescribing medicines.***	Yes	1
	No	2
	If Yes, Specify ……………….	a
B.6 Do you know what hospice care is?	Yes, focus on caring not curing	1
	No	2
B.7 Did you want to receive hospice care and not hospital treatment? If Yes, go to B.8 otherwise go to Section C .	Yes	1
	No	2
	Can't say	3

B.8 Why do you wanted hospice care? Tick all that apply	Economically viable	1
	No availability of treatment processes	2
	Geographically very far	3
	Treatment costs are high	4
	Full family support	5
	Others	6
B.9 Who would be your primary care giver during hospice care?	Family Member: Specify the relation ………………………………	1
	Hospital Nurse	2
	Neighbors	3
	Mental health worker	4
	Religious counselor (Priest)	5
	Friends	6
	Others ……………………………… Specify	7

C. Measuring Economic Burden

C.1 Were you working for pay before the acute illness got diagnosed? If Yes, go to C.2 , otherwise go to C.3	Yes	1
	No	2
C.2 Are you working now?	Yes	1
	No	2
C.3 Core Direct cost borne by patients in last 30 days .(Please specify the amount)		NRS
a. Xrays/ Screening (in total)		
b. Hospitalization		
c. Outpatient clinical care		
d. Physician visit		
e. Prescription of drugs		
f. Medical Devices (walkers/wheel chairs)		
g. Nursing / Long term care		
h. Hospice care		
i. Total Expenses		
C.4 Other Related Direct cost		
a. Transportation to health care providers		
b. Child care related to obtaining health care cost		
c. Lodging for remote treatment facilities		
C.5 (Core Indirect cost)	Changed jobs or employers	1

As a result of your illness, have any of the following happened to you within 12 months? Tick all that apply	Taken a leave of absence	2
	Quit your job	3
	Been let go or fired	4
	Missed work	5
	Worked fewer hours	6
	Turned down a job or demotion	7
	Felt that your work suffered	8
	Felt your co-workers treated you badly	9
	Felt your supervisor treated you badly	10
C.6 If you had taken leave for treatment, how many days you didn't go to work ?	1-10 days	1
	10-30 days	2
	30-60 days	3
	>60 days	4
	Other (specify)……………	5
C.7 Before your illness did your primary care giver working for pay?	Yes	1
	No	2
C.8 Did your primary caregiver go to work after you were diagnosed with illness? (Related Indirect cost)	Yes	1
	No	2

Mental Burden

C.9 Generic Measures Of Quality of Life	Not at all (1)	Several Days (2)	More than half the days (3)	Nearly Every day (4)
a. Little interest or pleasure in doing things				
b. Feeling down, depressed, or hopeless				
c. Because of my physical condition, I have trouble meeting the needs of my family				
d. Feeling very energetic				
e. Did your heart race, pound, or skip?				
f. Feeling like vomiting most of the time				
g. Did you have chest pain or pressure?				

h. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down				
i. How is your general life?				
j. Thoughts that you would be better off dead or of hurting yourself in some way				
k. I am content with the quality of my life right now				
l. You feel very depressed about the earthquake even now				
m. You are worried about country's current situation				
C.10 Disease Specific Measures of Quality of Life				
a. Feel worried about your financial problems due to your health illness?				
b. Family related Distress				
c. Do you feel concerned/ awkward regarding your appearances?				
d. Do you feel that you lose hope in the fight against my illness				
e. I have accepted my illness				
f. Do you need personal care for everyday things (eating, bathing, dressing and so on?)				

D. Willingness to Pay and Risks and Perceptions

The current situation in Nepal is such that the incidence of cancer has increased among the general population and is spreading very rapidly throughout. It is the most widespread non communicable disease. Almost 7% of the total deaths in the country is due to cancer. That is the reason why we focused on cancer of all other acute diseases. Now I will be presenting before you some hypothetical scenario for you to state some willingness to pay for certain of those things based on the level of importance. (Taken from Lang, et. al 2010)

Bid amount need to be confirmed from pre test. Extra monthly out of medical expenditure was used as the payment method.

D.1 Assume that *hospitals are* undertaking screening program once a year to facilitate the screening practices of all the patients irrespective of the fact that they have cancer or not. This will screen the patients at the earlier stages so that they can be treated at their earliest and their chances of survival will significantly increase. But patients need to pay for each of the time they will take the screening test. Patients may have to go on doing the test for their entire life given they never diagnose with cancer or they may get the cancer diagnosed and significantly increase the risk of your survival. This is the willingness to pay for introducing innovative screening procedures so that general population can get screened of cancer early in their life and can get necessary treatments which can increase the probability of survival.

Under such circumstances, if you are asked a yearly fee of …………………….(select from the bids) for the rest of your life to pay for the screening.
Will you pay for it ? A) Yes
B) No

D .2 If the respondents indicates Yes to the first offered amount ……………… , then they are asked the follow up question that:

Whether you want to pay the double of it? Yes …………(a)………………….

No ……………(b)………………..

D.3 If the respondents say No to the first amount ………., then they are asked the follow up question:

Whether you want to pay the half of it ? Yes …………(a)……………

No ………….(b)…………..

Note to the enumerators: Irrespective of the fact that they have said Yes / Yes , Yes / NO, No/Yes or No/No to the first two questions, everyone will be asked the following open ended question.

D.4 How certain you are about your answer above in a scale of 1-10? Circle the following number

1 2 3 4 5 6 7 8 9 10

(1 : Not Certain, 10 : Very Certain)

D.5 Now suppose that the screening program did not take off , so you don't need to pay for it any more. Assume that *hospitals are* undertaking a research activity and/or bringing in high technology machines and introducing world's best infrastructures which can free you from cancer and all the related pains and it lets you regain your health again without side effects. Introducing these machines will increase your cost of treatment, but on the other hand significantly increases the chances of your survival.
Under such circumstances, if you are asked an extra monthly fee of …………………….for the rest of your treatment period. Will you pay for it? A) Yes …………..
B) No

Note to the enumerators: This is the willingness to pay for introducing more cutting edge cancer treatment equipments

D .6 If the respondents indicates Yes to the first offered amount ……………… , then they are asked the follow up question that:

Whether you want to pay the double of it? Yes ………..(a)………………….

No ……………(b)………………..

D.7 If the respondents say No to the first amount ………….., then they are asked the follow up question:

Whether you want to pay the half of it ? Yes ………..(a)……………

No ………….(b)…………..

Note to the enumerators: Irrespective of the fact that they have said Yes / Yes , Yes / NO, No/Yes or No/No to the first two questions, everyone will be asked the following open ended question.

D.8 How certain you are about your answer above in a scale of 1-10? Circle the following number

1 2 3 4 5 6 7 8 9 10

(1 : Not Certain, 10 : Very Certain)

Informational interventions

D.9 Now I want to introduce before you two informational interventions:

The first one is a Screening Guidelines for early cancer detection published by American Cancer Society. This is a guideline which says irrespective of whether anyone has any symptoms of cancer, they should practice screening at different stages of life. It shows at what stage of life they should be screening for what type of cancer. Early detection significantly increases the survival rate. Upto 35% of the premature deaths could be avoided through screening [National Cancer Institute]

The Second one is a set of pictures on modern equipments and technologies used by the top 30 cancer hospitals of the world. These hospitals have significantly higher cancer survival rate in the world. Introducing these techniques in the cancer treatment may increase your rate of survival too. According to U.S. News & World Report for 2014-15, top 30 US hospitals on cancer has a survival rate that ranges from 80% to 100%.

Now after knowing about the two alternatives that may be available to you and the respective merits that are associated with each of them, how does your earlier stated willingness to pay has changed?

a) They will remain same

[Yes/ No]

b) Now I want to pay more for Screening procedures relative to modern technology

[Yes /No]

c) Now I want to pay more for Modern technology relative to Screening procedures

[Yes /No]

d) Now I want to pay less for both the screening and Modern Technology

[Yes /No]

I am assuming that you must have seen some cancer patients across you either in your family or neighborhood. You have seen some of your friends or contacts or extended family with cancer. You probably have an idea of some of the risk factors associated with the likelihood of getting cancer. The reasons cancer occurs, the treatment process and the likelihood of getting cure if someone has cancer. With whatever amount of knowledge you have regarding cancer, can you respond to the following questions?

(Note: The questions are particularly related to cancer disease)

D.9 Compared to most others your age, what do you think your chances are of getting any types of cancer?	A lot lower	1
	Lower	2
	Higher	3
	A lot higher	4
D.10 How likely do they think that performing prevention behavior reduces their likelihood of occurring cancer? Like doing exercise, routine diet, quit smoking, alcohol, and avoiding other potential risk factors	Very unlikely	1
	Unlikely	2
	Likely	3
	Very Likely	4

E. Socio- Demographic Profile

E.1 What is the composition of your household (people living under the same roof)?	No. of men……………………… No. of women…………………… No of children <18………	1 2 3
E.2 What is your current age?	Years …………………………………………	
E.3 What is your height and weight? To enumerators: Consider taking heights in foot as well.	In inch ……………………… In kg ……………………………………	1 2
E.4 Indicate the gender	Male Female Don't want to disclose	1 2 3
E.5 Do you smoke?	Yes, regularly Yes, sometimes No	1 2 3
E.6 Do you drink alcohol?	Yes, regularly Yes, sometimes No	1 2 3
E.7 What is your current marital status?	Never Married Currently Married Divorced Separated Widowed	1 2 3 4 5

E.8 What is the highest level of education that you have completed?	No formal schooling Grades (1-5) Grades(6-8) Grades (9-12) Bachelors Masters or other professional degrees	1 2 3 4 5 6
E.9 What is your primary occupation?	Unemployed In school Agriculture Shop keeper/ Self Employed Executive jobs/ Lecturer /Teacher Administrative Job (ex.Government, NGO) Not working outside the house Housewife Other	1 2 3 4 5 6 7 8 9
E.10 How long does it take for you to reach the nearest treatment hospital?	Close to 1 day (>15 hours) 10- 15 hours 5-10 hours 3-5 hours 1-3 hours <1 hour	1 2 3 4 5 6

E.11 What is your primary religion?	Hindu	1
	Buddhist	2
	Muslim	3
	Christian	4
	Other	5
E.12 What is your caste/ethnicity?	Brahmin	1
	Chherti	2
	Newar	3
	Janajati	4
	Madhesi, Thaurs, Musalman	5
	Pahadi Dalit	6
	MadhesiDalit	7
	Other	8
E.13 What is your income level?(Permonth)	<10,000	1
	10,000-20,000`	2
	20,000-30,000	3
	30,000-50,000	4
	>50,000	5
E.14 Do you do physical exercise?	Yes	1.
	Less than 1 hour/week	a.
	1-3 hours per week	b.
	3-7 hours per week	c.
	>7 hours per week	d.
	2. No	2.

E.15 How are you paying for the treatment?	Health Insurance From savings Family paying Out of pocket Borrowing from others Selling properties or valuables Government Relief fund Others …………………	1 2 3 4 5 6 7
E.16 Do you live under the following circumstances (To enumerators ask every single options to them)	Near or close to main road Use wooden fuel for cooking Kitchen is inside your house HH member smoke inside the house	1 2 3 4
E.17 Do any of your immediate relative had cancer before? (Mother, Father, Siblings, Grandparents, Aunt, Uncle, Cousins, maternal family, any other close family members)	Yes No	1 2

F. Social network : (INTERPERSONAL SUPPORT EVALUATION LIST (ISEL)

F.1 When I feel lonely, there are several people I can talk to.	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.2 There are several people that I trust to help solve my problems	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.3 I meet with family or friends on a daily basis (Ask: Do you live with your family)	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.4 As I feel very sick, I easily find someone to help me with my daily works.	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.5 I feel that there is no one I can share my most private worries and fears with	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.6 Attitudes of the close family members have changed towards me since I had this acute disease?	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)
F.7 I feel embarrassed in public / stigmatized because of my disease?	definitely true	(a)
	probably true	(b)

	probably false	(c)
	definitely false	(d)
F.8 I want to hide the fact that I have this acute problem from others?	definitely true	(a)
	probably true	(b)
	probably false	(c)
	definitely false	(d)

References

The cited references specific to the chapters are provided here.

I include the references separately for the chapters such as:

1. References cited in Chapter 1
2. References cited in Chapter 2
3. References cited in Chapter 3
4. References cited in Chapter 4

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