ECONOMIC BURDEN ON HOUSEHOLDS WITH PEOPLE WITH NON-COMMUNICABLE DISEASES, WITH SPECIAL REFERENCE TO CANCER: PRIORITIES FOR POLICY OPTIONS PERTAINING TO THE SRI LANKAN CONTEXT

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ABSTRACT

Title of Dissertation	Economic Burden on Households with People with Non-Communicable Diseases, with Special Reference to Cancer: Priorities for Policy Options Pertaining to the Sri Lankan Context
Author	Rajapaksha Pathirathnage Chamarie Kanchana Jayasinghe
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Non-communicable diseases have become a major threat to Sri Lanka as well as all developing and developed countries. Though the government provides all health facilities free of charge at public hospitals, people have to bear the out-of-pocket expenditure. The expenditure compared to other diseases is double the burden from non-communicable diseases.

Based on a literature review, it was found that there is a lack of studies on the economic burden on households with individuals with non-communicable diseases, with specific reference to cancer in Sri Lanka. This study has focused on assessing the economic burden on households. In addition it has tried to identify the determinants effect of the economic burden on households. This study focuses on the demographic, economic, and disease characteristics of patients. Identifying the major effects of cancer is helpful for prioritizing policy options in order to reduce the burden on households. Furthermore, the analysis is concerned with the challenges faced by patients in order to provide better policy options. Finally, based on the findings it prioritizes policy options.

Primary data were collected from a semi-structured questionnaire. After the pilot study, 400 respondents were selected using the stratified sampling method. The mixed method mainly, focused on the quantitative method, was adopted for the study. Qualitative analysis was used to triangulate the quantitative findings.

Both bivariate and multivariate analyses confirmed the same findings; some null hypotheses were rejected and some were not. Gender, distance, income, types of cancer, severity of disease, and period of suffering are significant effects in terms of the economic burden on households with cancer patients. Further, sources of financing are significant regarding the economic burden and in terms of direct cost and indirect costs as well.

It was found that there are many challenges faced by the respondents, and high opportunity costs in obtaining government allowances led the respondents not to apply or use the allowance. Some people have lack of information about sources of financing and health issues. The findings of the study provide priorities that can helpful for decision-makers in creating policy options to reduce the economic burden on households. Since direct costs have become higher compared to other types of costs, and it is necessary to focus on direct medical costs, travel costs, and the cost of special foods in order to reduce the burden. Both direct medical costs and travel costs can be reduced by a more fair distribution of resources to the nearest hospital and by facilitating easy accessibility for patients. One option is to reform the present system of allowing medical or sick leaves for patients. The introduction of special insurance schemes for the self-employed sector would be useful for self-employed patients that would suffer from non-communicable diseases. Beginning the treatment process at the earliest possible stage could reduce a huge burden at later stages for both affected households and the government. Therefore, it is necessary to have continuous awareness campaigns in all corners of Sri Lanka, reaching all the people. In addition, free periodical cancer screening tests could help early detection and treatment, which could either eliminate or reduce the burden on households in the country as a whole.

This study contributes both theoretically and practically, and as well as shows some of the unchartered areas for future research. The study shows the relationship between the determinants and economic burden on households. The practical contribution is comprised of suggestions regarding policy options to the government, highlighting priorities to be considered and the selection of cost-effective policy options amongst them. There are some other aspects that have not come under the scope of the study. The social costs for the households could affect them, and this is a very important area for future research. Proper qualitative analysis also can be carried out in future research.

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ABBREVIATIONS

Abbreviations	Equivalence
CBSL	Central Bank of Sri Lanka
CTB	Ceylon Transport Board
MOFAP	Ministry of Finance and Planning
MOHMSU	Ministry of Health, Medical Statistic Unit
MOHNCCP	Ministry of Health, National Cancer Control Programme
MOHIMNCCP	Ministry of Health and Indigeneous Medicine, National Cancer Control Programme
MOHNIMNCCP	Ministry of Health Nutrition and Indigeneous Medicine, National Cancer Control Programme
MOHNNCDU	Ministry of Healthcare and Nurition, Non- Communicable Diseases Unit
NCDs	Non-Communicable Diseases
UN	United Nations
VIF	Variance Inflation Factor
WB	World Bank
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

1.1 Introduction

Non-communicable diseases (NCDs) have become the major health problem in Sri Lanka. The introductory chapter of this report provides an overview of NCDs, special aspects of cancer, and how presently this has become a serious threat to the country. It discusses many of the problems gradually escalated in the country, which are due to the increase of NCDs, and shows the necessity to study the economic burden of NCDs, with particular reference to cancer. Furthermore, purpose of the study and the research questions on which the research was based are also been discussed in detail in this chapter. While discussing the significance of the study, the chapter also endeavors to identify the beneficiaries and types of benefits that could be achieved. This chapter concludes by discussing the assumptions that have been made in the conduct of this research study.

1.2 Background

1.2.1 Health Situation in Sri Lanka

Public health is universally free in Sri Lanka although the private and public healthcare systems function side by side. It has become free at health care delivery stage and has been a policy since 1951 (Perera & Gunatilleke, 2006). The country has a well-organized and appropriately-managed healthcare system from the grassroots level to the top national hospitals. At the time of independence in 1948, Sri Lanka had provided free healthcare, but it was limited to major cities. From 1948 to 1977, however the government increased health expenditure by obtaining foreign assistance. Health conditions were improved and life expectancy started to increase. In addition, other health indicators showed similar improvement (CBSL, 1998). Furthermore after

1977, Sri Lanka has provided access to private sector participation in the healthcare sector and this has led to further improvement of the health sector. The literacy rate of Sri Lanka is commendably high due to universally free education up to the first university degree, so that people's awareness about general health and dietary practices is high. Special attention has been given to the health and hygienic components of the school curriculum since the introduction of the free education system nearly six decades ago. Moreover, the high health indicators which rank on par with developed countries are due to many factors such as government intervention in both the health and education sectors, free education and a free health system, the training of employees in the health sector, expanding health sector facilities to rural areas, and the improvement of immunization coverage, sanitation and nutrition (Karunathilaka, 2012). Many of the millennium development goals have been achieved at the county level due to the investment in the social sector (Attanayake, 2005). However, presently the country is facing challenges with new diseases. Sri Lanka also is facing the problem of an aging population and due to demographic changes, and it is suffering from NCDs. There is a demographic transition which refers to the trend of diseases having changed from communicable to non-communicable (MOFAP, 2009).The Sri Lankan government declared the year 2013 officially as the year of NCD prevention (MOHNCCP, 2013). Since one of the major NCDs is cancer, there is a necessity to work on the cancer control activities in Sri Lanka (MOHNCCP, 2013). In addition, the controlling of NCDs has been made a top priority in Sri Lanka. Though free public health exists, there are direct and indirect costs of ill health that have created a problem of the affordability of healthcare (Perera & Gunatilleke, 2006). The burden on households for the cost of healthcare leads to medical poverty traps (Perera & Gunatilleke, 2006). Epidemiological and demographic evolution causes a double burden on households with diseases and aging people, creating new ways of healthcare deliveries and financing essential to address the changing pattern (Attanayake, 2005).

1.2.2 Cancer Situation in Sri Lanka

The cancer situation in Sri Lanka has also had a severe impact on NCDs. These cancers can be divided based on gender. It has been found that most of the

cancers in males are lip, oral cavity, and pharynx cancers, while for females breast cancer is most common. (MOHIMNCCP, 2014). There were 16,511 new cases of cancer in the year 2008 in Sri Lanka and out of that, 7695 were males and 8816 were females (MOHIMNCCP, 2014). Furthermore, compared to year 2007, a 20% increase in cancer was found in 2008 in Sri Lanka. (MOHIMNCCP, 2014). Moreover an overall crude cancer rate of 81.6 per population of 100,000 has been cited in Sri Lanka (MOHIMNCCP, 2015). In addition breast cancer became the leading type of cancer in the 2008. The five leading cancers among males were the lips, oral cavity and pharynx, trachea, bronchus and lungs, oesophagus, colon and rectum, and lymphoma. On the other hand for females the five main cancers are of the breast, cervix uteri, thyroid gland, and ovary and oesophagus (MOHIMNCCP, 2014). Moreover it has found one in every ten males and females will develop cancer during their life time of age 0 to 74 years (MOHIMNCCP, 2014).

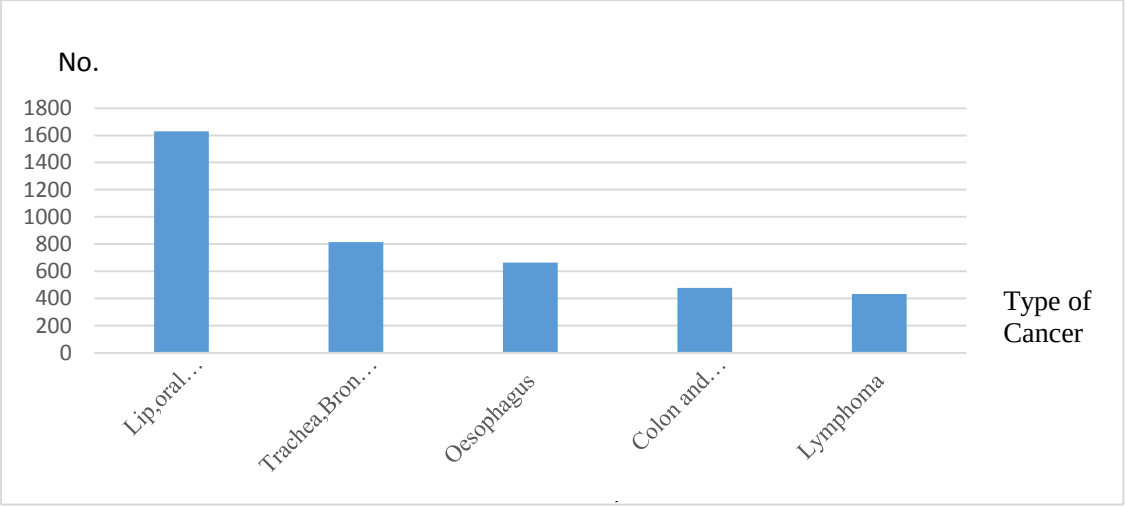

Figure 1.1 Main Types of Cancer - Male

Source: MOHIMNCCP, 2014**.**

Figure 1.1 provides the five main types of cancer that are suffered by males in Sri Lanka. According to the statistics, lip, oral cavity, and pharynx have become the leading cancers for males in Sri Lanka.

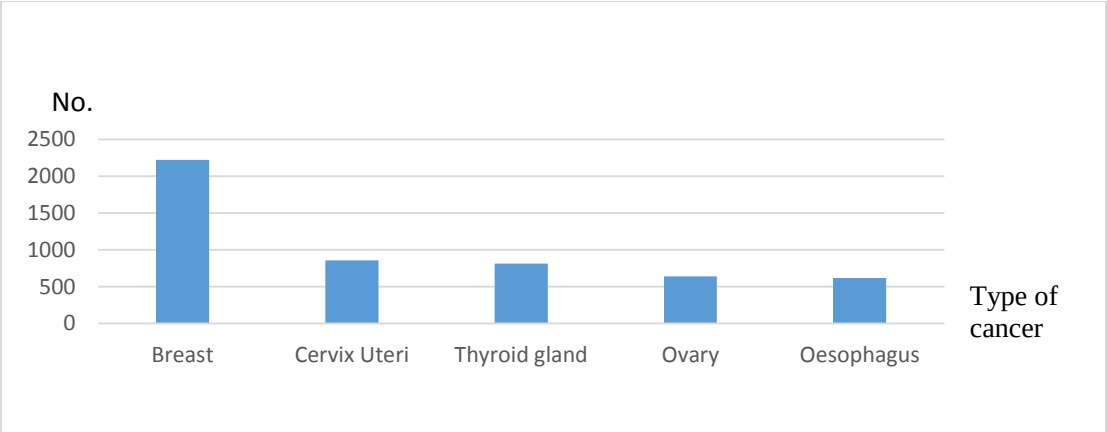

Figure 1.2 Main Types of Cancer - Female

Source: MOHIMNCCP, 2014.

Figure 1.2 depicts the situation of the main types of cancer in females. Breast cancer has become the main cancer for females in Sri Lanka. Moreover, the number of patients is nearly three times higher compared to other main types of cancer patients.

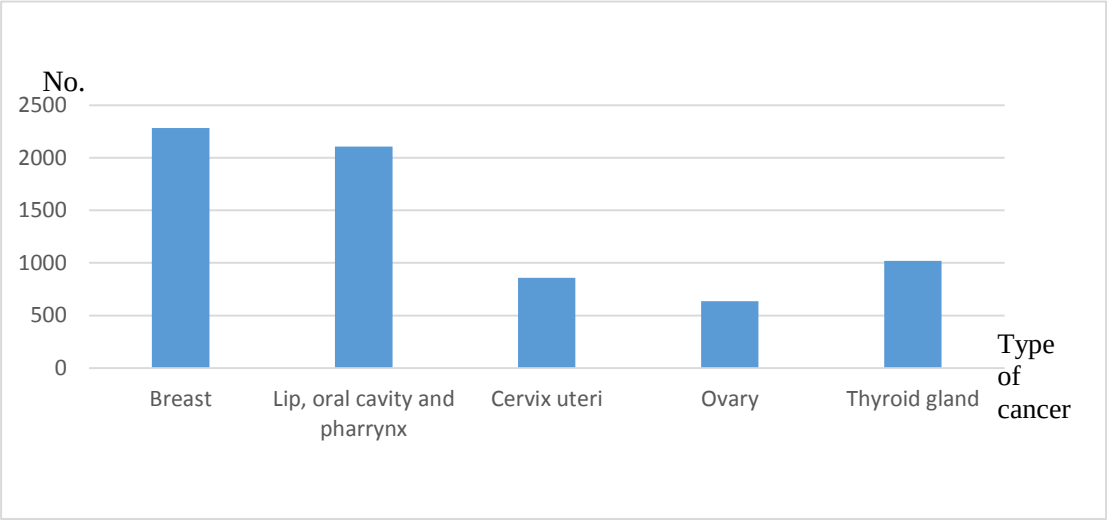

Figure 1.3 Main Types of Cancer – General Situation in Sri Lanka

Source: MOHIMNCCP, 2014.

The overall cancer situation in Sri Lanka mainly includes five cancers; namely, breast; lip, oral cavity, and pharynx; cervix uteri; ovary; and thyroid gland (Figure 1.3). Cancer of the oesophagus has become the main cancer common for both females and males (figure 1.1 and 1.2). However, it has not become one of the leading five types of cancer for the general situation in Sri Lanka.

1.3 Statement of the Problem

An overwhelming majority of people are still engaged in blue collar jobs in Sri Lanka, even though Sri Lanka has reached lower middle income status recently. Poverty has not been eradicated yet and it is markedly visible in the remote areas of the country. Still the country is reporting comparatively high NCDs, such as cancer, diabetes, cardiovascular diseases, chronic kidney diseases, hypertension, and chronic respiratory diseases.

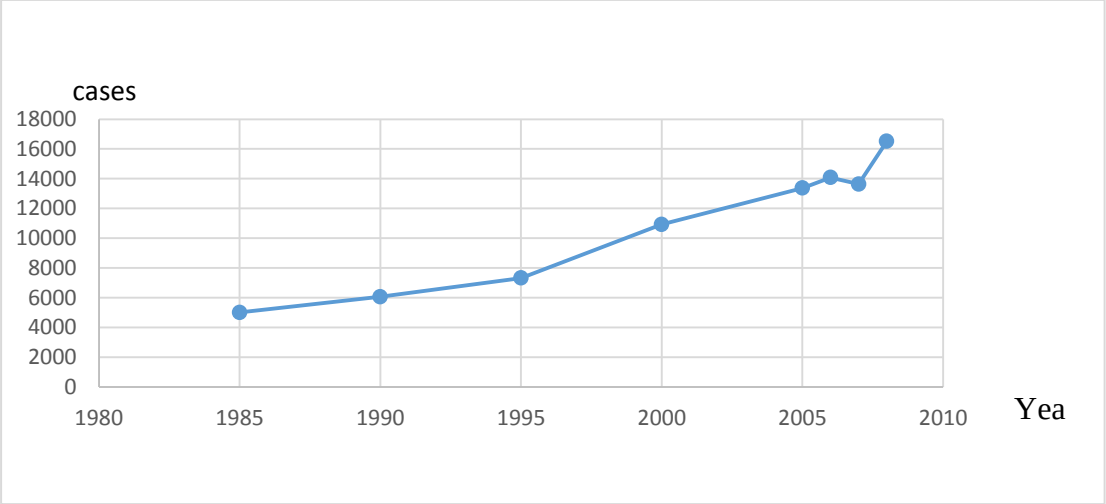

Figure 1.4 Pattern of Cancer Incidence in Sri Lanka
Source: Adopt from Different Sources by Author

A huge increase in cancer patients has been seen annually, except for 2007 (Figure 1.4). Therefore there is a necessity to identify the burden on cancer patients.

A communicable disease can spread from person to person, whereas those that cannot spread from person to person are called NCDs (MOFAP, 2009). As per the World Health Organization (WHO), 39 million people die from NCDs per year everywhere in the world. Furthermore, it has been found that 80% of the deaths in low-income developing countries are due to NCDs (Bloom et al., 2011). There is an upward trend in deaths from NCDs (Population Council, 2011). Sri Lanka has also demonstrated a high risk situation by having 71% out of the total deaths in the year 2001 due to NCDs (MOHNNCOU, 2015). Smoking, alcohol consumption, and unhealthy dietary patterns and behaviour are considered as the major causes for NCDs.

The cost of NCDs spreads from the individual level through the household, regional and national level, and the gravity of the cost varies from short term through medium and long terms. NCDs are a major problem for all countries because they lead to societies with more disabled persons with long life spans (MOFAP, 2009).

The cost of NCDs has swollen the public health costs in Sri Lanka. There is a necessity to study the economic burden of NCDs of patients due to the prevalent situation in Sri Lanka. Health expenditure for 2012 was Rs. 89,291 million and out of that 83.08% was for recurrent expenditure and a major portion of the expenditure was for patient care services (MOHMSU, 2012). Moreover 95% of the inpatient care provided by the health public sector (MOHMSU, 2012).

Since NCDs are a fairly new and challenging phenomenon in Sri Lanka, and there are no comprehensive studies in the field of the economic aspects of patients, it is very much essential to investigate this area. There is a marked vacuum in the literature in the proposed study area. There was a one study about three NCDs in Sri Lanka (Attanayake, 2005) but it was not focused on the disease of cancer. Another study was conducted on the affordability and accessibility of healthcare for NCDs in Sri Lanka in 2006 in Sri Lanka (Perera & Gunatilleka, 2006). There are many studies about the economic burden caused by NCDs (Sharma, 2013; Taylor, 2010) referring to India and developing countries and nations (Chan et al., 2012; Engelgau et al., 2011), one study referring to the global economic costs of cancer (American Cancer Society, 2010), and only one study referring to cancer based on data for the year 2004 in India (Mahal et al., 2013) and it was not focused on the determinants. Moreover there are many studies referring to the risk factors (Thankappan et al., 2010) of NCDs.

However there has been no study conducted referring to the economic burden of households specifically with patients with cancer in Sri Lanka. Therefore there is a gap in the literature in this regard, as well as a lack of discussion of policy options based on priorities.

NCDs have created serious economic issues in the global economy (Bloom et al., 2011). Moreover 63% of the deaths in the world are from NCDs; namely, cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes (Bloom et al., 2011). NCDs can impose large health, financial, and economic costs on countries (Anderson, 2012). Assessing the burden of NCDs is a challenging task in the resource scarce setting. Insufficient and inaccurate data, inconsistency in case definitions, differences in reporting of results, insufficient funds for research work and poor infrastructural facilities are some of the integral parts of this type of environment (chan et al., 2012). The virtual doubling of healthcare for patients suffering from NCDs against that of other illnesses, the chronic nature of NCDs, the high cost of some medications and financial vulnerability are some of the distress financing of care (Sharma, 2013). Another study also found that the cost of NCDs is much higher than that of communicable diseases (Annigeri & Nayanatara, 2008). It was found that people that are suffering from chronic diseases work fewer hours compared to others in the USA (Bloom et al., 2011). Poverty and ill health together carry negative implications across the generations. Therefore there is a necessity to measure the economic burden on households in order to arrive at proper control measures. It has been found (Mahal et al., 2010) that the economic burden of NCDs has created a situation where different income groups have been forced to depend on different sources of financing of their treatments.

"Out-of-pocket payments" exclude Rs.1.3 billion poor people from gaining access to health services; and they consistently encourage health service overuse by people that can pay and underuse by those that cannot (Chand, 2012). Moreover, NCDs cost more regarding out-of-pocket expenditure in financing health (Engelgau et al., 2011). Therefore, NCDs have created problems for both households and for the country and it is necessary to address these issues in a more sustainable way.

1.4 Significance of the Study

Since the majority of hospital deaths are due to NCDs in Sri Lanka (MOFAP, 2009), this problem creates a direct uncomfortable socio-economic environment for the affected households while there are cumulative implications at the national level. Sri Lanka is also facing similar problems, especially regarding cancer. This research focuses on the economic burden on households with people with NCDs with special reference to cancer. Cancer has become the second most common cause of hospital death in Sri Lanka in 2007 (MOHNIMNCCP, 2015). On the other hand, a higher portion of the health costs for NCDs is borne by out-of-pocket expenditure (Engelgau et al., 2011). Therefore burden has severely affected for households. It has affected for poor and vulnerable people significantly in developing countries (Engelgau et al., 2011). It will affect for national economic growth, poverty in developing countries (Engelgau et al., 2011). Though Sri Lanka has an increasing rate of life expectancy compared to other developing countries, due to these illnesses there is a significance withdrawal from the labour market and reduction of productivity (WB, 2008, as cited in Engelgau et al., 2011). Therefore by identifying the main determinants affecting the economic burden of NCDs with particular reference to cancer and the recommendations based on scientific study will be helpful to policymakers in reducing the burden on households.

1.5 Research Questions

The main research question concerns what determines the burden of cancer for a household and what strategies are currently being used in bearing the burden on households and how to prioritize policy options that can be adopted to reduce the burden of cancer on households.

1) What is the economic burden of cancer on households?
2) What are the determinants affecting the economic burden of NCDs of cancer on households?
3) What is the relationship between the economic burden of illness in the case of NCDs, with special reference to cancer, and the sources of financing the burden?

4) What are the challenges for financing the burden of cancer on households?

5) Finally, what are the priorities for policy options that could be adopted to reduce the burden of cancer on households?

1.6 Expected Benefits of the Study

The benefits of the study can be useful for many sectors such as interested individuals, and private sector and public sector institutions. The benefits for the individual consist of both present households and future households that have cancer patients. Identifying the major factors affecting the economic burden on households due to cancer can reduce the burden through the support of different stakeholders. In addition the allocation of resources by the government will be very productive. It will be helpful for future patients to assess the potential burden of cancer they are forced to bear, and it will be helpful in creating a mechanism so that people can bear the economic burden of cancer in the future.

There are some benefits for the private sector as well. Private public partnerships can be helpful in reducing the economic burden on households in many ways. Private insurance companies can also arrange insurance schemes based on the significant factors affecting on households which can be helpful for both the private sector as well as for citizens. Moreover, based on the determinants affecting the economic burden on households with people with cancer, the private sector can arrange corporate social responsibility projects focusing on reducing the economic burden on households with people with cancer.

There can be a considerable change in allocating public resources if the determinants affecting the economic burden on households due to cancer are properly calculated. Those policy interventions to reduce the economic burden on households can be done by linking many government institutions, such as the Ceylon Transport Board, the Ministry of Health, the import and export sectors, as well as changing budgets depending on the significant determinants. Providing and linking infrastructure facilities will properly address the reduction of the economic burden on households with people with NCDs referring to cancer and will assist in creating efficient resource allocation based on priorities.

Moreover, findings of the study can be used by doctors in hospitals to create awareness of the burden of this disease. In addition, the findings of the research will also aid the government in the allocation of resources, since "Non- Communicable Diseases are a big threat to health care in Sri Lanka" (MOFAP, 2009). In addition study will be helpful to utilize resources and awareness based on the type of cancer depending on the gender. Additionally, the policymakers of the government can review the present policies and use redistributive policies, especially referring to cancer where necessary. Further, this information can be used for primary and secondary healthcare programs. The non-communicable disease unit and cancer control unit under the Ministry of Health in Sri Lanka can use the advocacy tool for policy implementation. By using the information regarding the challenges faced by cancer patients, the government can also help the patients in rearranging ways and means of financing. Finally the study would, to some measure, contribute in bridging the existing gap in the literature where there is a lack of studies on the economic burden of cancer affecting the households in Sri Lanka.

1.7 Scope of the Study

The scope of the study is limited to only cancer patients in Sri Lanka. Only cancer patients have been selected for many reasons, since other studies have been conducted on the economic costs of three other NCDs (Attanayake, 2005) but not cancer in Sri Lanka. In addition, cancer is the one of the NCDs in Sri Lanka having the second common reason for hospital deaths in there (MOHIMNCCP, 2015). Data were collected from the respondents (patients) that visited the clinics.

New cancer patients in Sri Lanka for the year 2008 were at 16,511 (MOHIMNCCP, 2015). The age standardized crude cancer incidence rate was 86.4 per 100,000 people (MOHIMNCCP, 2015).The economic burden, which has been considered for the study, is comprised of the direct medical costs, direct non-medical costs, and indirect costs to the patients and households due to suffering from the disease. This study has not considered the aspects of psychological costs or direct costs to the government.

1.8 Limitations and Delimitations

This study has focused mainly on five types of cancers contracted by females and five types of cancers contracted by males. However, there are many types of cancers that were not considered for this study that were not significant in terms of the number of recorded patients. In some other cases the patients opted to resort only to traditional treatment based on either herbal treatment and/or spiritual treatment.

1.9 Organization of the Study

This paper consists of six chapters. namely, 1) Introduction, 2) Literature Review, 3) Research Methodology, 4) Data Analysis 5) Qualitative Analysis, and 6) Conclusions and Recommendations. Finally it acknowledges the bibliography for the study. Chapter one provides an overview of the NCDs and the situation of cancer in Sri Lanka. In addition, it explains the problem statement, the significance of the problem, the objectives of the study, the research questions, and scope of the study. The second chapter is a review of the literature and discusses related theories, approaches and how the hypotheses are presented. Chapter three depicts the methodology of the research. It explains the research design, the unit of analysis, the population, sample size, sampling method, data collection methods, and analysis. The fourth chapter provides the quantitative data analysis of the study in reaching the research questions as a qualitative support quantitative method. Chapter five consists of the qualitative data analysis in order to triangulate the quantitative findings. Chapter six provides the conclusion and recommendations. It described the policy options that can be prioritized to reduce the economic burden on households with people with cancer.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter provides an overview of the different aspects of the economic burden of NCDs, published by different scholars and institutions. It provides a foundation to develop the conceptual framework that could deal with the problem. This chapter covers a comprehensive review of related theories, research activities in related areas, a literature on the definition of NCDs and cancer, the risk factors of NCDs and cancer, and why NCDs and cancer have become significant in the present context. It goes on to various sources dealing with the overall impact of NCDs in developing countries, the situation in the developed countries and in particular, how this has affected Sri Lanka, since this study is mainly about the economic impact of NCDs, referring to the cancer patients on Sri Lanka. This chapter also looks at the economic cost of NCDs to the world in general, its impact on the private sector and also the impact on the health sector. Then the literature is explored in order to identify the demographic and economic determinants of burden of cancer as well as the disease characteristics. Based on the literature, this chapter has identified various sources of financing in terms of people with NCDs bearing the economic burden on households. Finally, this chapter highlights the potential solutions to this problem, based on the various literature reviewed in the course of the study, and also, by summing up literature, it has identified the gaps in the literature.

2.2 Concepts on Non-Communicable Diseases

Many definitions and concepts of NCDs have been offered, and these definitions are helpful in identify the situation of NCDs as well as especially the cancer disease.

The term “non-communicable disease” is defined as “diseases of long duration, generally slow progression and they are the major cause of adult mortality and morbidity worldwide” (WHO, 2005, as cited at Bloom et al., 2011). NCDs have also been defined as “diseases of long duration, and are generally slow in progression” (Sharma, 2013).

Cardiovascular diseases (CVD) are “group of diseases involving the heart, blood vessels, or the sequelae of poor blood supply due to a diseased vascular supply” (Bloom et al., 2011).

> Cancer refers to the rapid growth and division of abnormal cells in a part of the body. These cells outlive normal cells and have the ability to metastasize, or invade parts of the body and spread to other organs. There are more than 100 types of cancers, and different risk factors contribute to the development of cancers in different sites. Cancer is the second largest cause of death worldwide, representing about 13% of all deaths (7.5 million deaths) (Bloom et al., 2011).

Chronic respiratory diseases means “chronic diseases of the airways and other structures of the lung. Some of the most common are asthma, chronic obstructive pulmonary disease (COPD), respiratory allergies, occupational lung diseases and pulmonary hypertension” (Bloom et al., 2011).

These diseases do not spread from person to person but they have a chronic nature which adversely affects for people’s life span.

2.3 Theories on the Field

The economic burden of NCDs can be examined either at the individual/ household level or the national level**.** The theoretical aspects of the burden on NCDs are not sufficiently developed to a great extent yet**.** This branch of economics is still growing and its importance is highlighted in major studies carried out in the past**.** Economic theories in the literature can either be used or adapted to examine the burden of NCDs**.** In addition to economic theories, public policy theories are also

used to suggest policy options that will address the priority areas related to the economic burden on households**.**

Economic theories can be adapted for a micro-level analysis as well as a macro-level analysis**.** Health has considered as a merit good under the Musgravian approach **(**Musgrave, 1973, as cited in Annigeri & Nayanatara, 2008**)** and recently it has been treated as a durable good (Grossman, 1992, as cited in Annigeri & Nayanatara, 2008)**.** The cost of NCDs affects the individual level, the household level, the community level, the regional level and the national level**.**

There are macro-economic theories applicable to the economic burden of NCDs. The economic growth model is one of the theories applied to the economic burden of cancer disease. The economic growth model provides the "macro-economic consequences of premature mortality" of the disease for countries (Abegunde & Stanciole, 2006). The economic growth theory mainly refers to the macro-economic aspects of a burden.

Diseases definitely create a challenge and burden regarding "individual or household income and savings and for investment activities" (Abegunde & Stanciole, 2006). In addition to the individual it has an impact on the country in terms of issues such as the reduction of life expectancy, economic productivity, reduction of the quality and quantity of the labor force of the country, and finally will lead to the reduction of gross domestic production (Abegunde & Stanciole, 2006). Moreover it affects some other social issues such as the reduction of intergenerational skills, wealth transfer, the impact of the schooling of children and a spiral effect of ill health and poverty (Abegunde & Stanciole, 2006).

Solow growth model can also be applied to the discussion of the economic burden of diseases. Further, the Cobb Douglas function and capital accumulation function can be used to estimate the long-term economic impact due to NCDs on the economic growth of countries (Abegunde & Stanciole, 2006). There can be an impact on the economy through changes in "labour supply, or opportunity cost of one unit of labour, and the impact of cost of treating chronic disease on savings" (Abegunde & Stanciole, 2006).

Some scholars have stated there is a two-way relationship between health and economic growth (Suhrcke et al., 2007). In one aspect, economic development can

influence the better health of the population, and it will lead to economic growth as a cycle. At the micro level, increase in wealth creates better health and it will lead to economic development (Suhrcke et al., 2007). The economic growth model and solow growth model address the macro-economic aspects of an economy.

The financing of the cost of diseases is normally borne by households out of their current earnings, which will in-turn affects the households' savings and the accumulation of capital assets (Abegunde & Stanciole, 2006). The stepwise approach has been used to identify the risk factors regarding NCDs within and across countries (Thankappan et al., 2010). The substitution effect and income effect have an impact on the labour supply and will finally create a burden for the economy (Suhrcke et al., 2007).

Human capital theory explains that when labour is more educated productivity is higher. In addition good health has a link with life expectancy (Suhrcke et al., 2007). Good health contributes to raising productivity as well as the age limit of voluntary retirement. Moreover, people that are healthier have a higher savings ratio than others (Suhrcke et al., 2007).

There are other economic concepts such as adverse selection and the moral hazard principal are applied to the economic burden on healthcare. Once insurers calculate risks differently for their customers and it differs from the actual situation, it affects insurers due to the high risk nature of NCDs. On the other hand, patients that have insurance may be less concerned about health since they have a safety net to make health payments through insurance. It creates a moral hazard for the economy unless insurers adhere to certain limits for their healthcare payments.

Insufficient and incomplete information leads to create an asymmetric environment in the society. Lack of information about the healthcare burden will create the issue of asymmetry of information. Patients and suppliers do not have complete information about the healthcare market, and this can create will create excess supply or demand in the market. The cost due to market mismatches between suppliers and buyers finally falls on disease-affected households.

Measuring the burden for NCDs becomes difficult because of many factors, such as lack of available data, inconsistency of definitions in measuring diseases, differences in results, etc. (Chan et al., 2012). Moreover (Abegunde & Stanciole,

2006) have explained that there are three methods of estimating illness; namely, the cost of illness method, the economic growth model, and the full income method. Bloom and others have explained three approaches to calculating economic burden; namely, the standard cost of illness method, macroeconomic simulation, and the value of a statistical life (Bloom et al., 2011). Economic burden can be analyzed by using two approaches; namely, the cost perspective and the benefit perspective (Abegunde & Stanciole, 2006).

The cost of illness is also called in health economics "cost consequence analysis." It calculates the cost involved with a disease or health condition and includes direct costs, indirect costs, and intangible costs. The World Health Organization (WHO) has introduced the DALY analysis to measure the loss of healthy life. DALY Analysis is "a time based measure that combines years of life lost due to premature mortality and years of life lost due to time lived in states of less than full health" (WHO as cited in Taylor, 2010).

The economics theories relevant to NCDs are not widely visible in the literature and still are being developed and adapted. Adapted versions of microeconomic theories, welfare economic theories, growth theories, health economics, as well as cost benefits analysis are used as theoretical foundations for NCDs analyses. Field findings on NCD-related issues can be elaborated in the light of such theories to improve the quality of analysis.

In addition to the economic theories, public policy theories have also been used to provide policy options for priority areas identified in the study. Public policy is simply "whatever governments choose to do or not to do" (Dye, 2008). Policy problems can be defined as "social problems dealt with by the public authorities" (Hill, 2014), whereas the social problem identified in this study is the economic burden on households caused by cancer as an NCD. Policy options would engage many different public authorities in the process of public policymaking. The economic burden on households with patients with NCDs affects many sectors such as the labour market, the health sector, as well as taxation. These researches should address human problems and this study is focused on households with people with NCDs, especially referring to cancer. In addition the study uses multiple perspectives, such as those of different branches of economics and public policy. Therefore the

characteristic of policy research, namely human created, pluralistic, the multi-perspective, systematic, decision-relevant, and creative (Putt & Springer, 1989), can be seen in this study.

2.4 Economic Burden

The economic burden of diseases is mostly explained as "direct medical cost and productivity losses on account of illness using the so-called 'cost of illness' method to arrive at an aggregate measure of the economic cost of the disease" (Rice, 1966, as cited in Mahal et al., 2010). Based on the literature, the economic burden of disease can be defined as the direct and indirect cost for patients and households due to a specific illness.

When people are suffering from chronic diseases they have to bear the out-of-pocket expenditure on health. Out-of-pocket health payments refer to the payments made by households at the point at which they receive health services (Van Minh & Tran, 2012).

Catastrophic expenditure occurs when a household's total out-of-pocket health payments equals or exceeds 40% of the household's capacity to pay (Van Minh & Tran, 2012). Engelgau and others have explained that "[c]atastrophic spending on NCD related hospitalization, which was defined as occurring when health expenses on hospitalization for a given household exceeded 40% of the ability to pay" (Engelgau et al., 2012). In addition, catastrophic health expenditure has been defined as "when health expenditures exceeds 40% of a household's non-food expenditures or capacity to pay for services" (Xu et al., 2003, as cited in Le et al., 2012). Therefore catastrophic expenditure explains how far it has become a major component of household expenditure, which can lead to medical poverty. A household's consumption expenditure comprises both monetary and in-kind payment on all goods and services, and the money value of the consumption of homemade products.

Human capital methodology can be explained as when "the lost income for each dead/disabled/sick individual is calculated as the present value of their expected future stream of income" (Mahal et al., 2010).

NCDs create damage not only due to premature death but also because of the negative economic impact of their illness on many others (Van Minh & Tran, 2012). The negative economic implications of NCDs affect households, local communities, regions as well as at the national level. Chan and others have discussed the size of the burden for NCDs in low- and middle-income countries (Chan et al., 2012).

2.4.1 Components of Economic Burden

The components of economic burden consist of direct costs, indirect costs, and the impact on households. According to Van Minh and Tran (2012), out of pocket expenditure for households consists of purchasing drugs, payments for hospital fees, fees for diagnostics and other indirect expenditure and self-medication. The types of costs involved in the burden of diseases include direct costs and indirect costs (Annigeri & Nayanatara, 2008).

2.4.1.1 Direct Costs

Direct costs for the most part can be divided into direct medical costs and direct non-medical costs. Direct medical costs consist of health expenditures for the cost for drugs and hospital fees (Le et al., 2012). However, in Sri Lanka all public hospitals provide medicine for free and it is totally free for everyone for clinic visits, but all medicines may not be available on time. The cost of drugs has become above half of the total cost of diabetes (Abdulkadri et al., 2009) and almost half for hypertension (Abdulkadri et al., 2009).

Direct non-medical costs include those for example for transportation, accommodations, the cost of hiring caregivers, etc. (Le et al., 2012). Travel costs have become a major problem for vulnerable patients that need a secondary level of medical support (Attanayake, 2005). Direct costs to the user consist of transport costs, informal treatment, and the cost of special foods (Attanayake, 2005).

In Sri Lanka most patients use the public health sector for the treatment of NCDs since public healthcare is totally free for all patients there. Still some of the high-income patients go to the private sector to avoid the inconvenience of using health care incontinences in the public sector. Though there are many public hospitals, few specific hospitals provide facilities for patients with NCDs in Sri Lanka (Perera & Gunatilleka, 2006), and there can be shortages of drugs and some drugs have to be obtained from outside, which is costly.

2.4.1.2 Indirect Costs

Direct costs are not the only costs that provide an economic burden on households since other parties also pay for the cost of healthcare (Mahal et al., 2010). Indirect costs have been calculated by using the human capital methodology approach. They include loss of income/productivity due to the disease; these costs have become nearly half of the total costs of illness (Abdulkadri et al., 2009).

Time costs for treatment have an economic burden in two ways. First they have an impact on households' economic activity and on the other hand patients have to recruit or hire replacements. Indirect costs have a direct link with the loss of income for both patients and households (Attanayake, 2005).

2.4.1.3 Impact on Other Households

In addition, the loss of income to other households was also taken for study in order to ascertain opportunity costs. Indirect costs mostly consist of morbidity costs and mortality costs and are calculated using human capital methodology (Le et al., 2012).

Table 2.1 Summary of Literature Referring to Types of Cost

Author (Year)	**Types of Cost**
Mahal et al. (2010)	Annual income loss
Abdulkadri et al. (2009)	Direct and indirect costs; cost of medications, cost of diagnostics. Value of loss of productive life.
Le et al. (2012)	Direct costs, indirect costs, intangible costs
Van Minh and Tran (2012)	Types of cost
Attanayaka (2005)	Types of direct costs, direct costs, indirect costs, household costs
Perera & Gunatilleka (2006)	Household cost for outpatient care
Annigeri and Nayanatara (2008)	Direct Cost, Indirect Cost

2.5 Types of Non-Communicable Diseases

There are mainly four diseases that lead NCDs in terms of mortality and mobility; namely, "cardiovascular diseases (including heart disease and stroke), diabetes, and cancer and chronic respiratory diseases (including chronic obstructive pulmonary diseases and asthma)" (Bloom et al., 2011). In addition cardiovascular disease, diabetes, cancer and chronic respiratory diseases have shown a rising trend compared to other diseases (Population Council, 2011). It has been found that NCDs have contributed to 60% of the deaths in the world and this figure is rising in developing countries (Binder & Laing, 2009).

NCDs include cancers, cardiovascular diseases (CVD), chronic obstructive pulmonary disease (COPD), diabetes, diseases of the digestive system, eye conditions, genitourinary conditions, neuro-psychiatric conditions, skin and musculoskeletal conditions, and skin diseases, according to the WHO definitions (Taylor, 2010).

2.6 Risk Factors in Relation to Non-Communicable Diseases

The risk factors of NCDs cover all aspects of human society. The effects are social, environmental, behavioral, and biological. Behavioral factors such as excessive use of alcohol, tobacco use, indulging in unhealthy diet such as junks and fast foods or physical inactivity can influence biological processes such as blood glucose level, lung function or brain chemistry. These conditions in turn could affect social and environmental factors such as urbanization, air pollution; and consumption trends may influence behavior and biology (Chand, 2012).

Moreover though people believe that NCDs are increasing in developed countries, in developing countries NCDs have begun to increase due to behavioural factors such as smoking and obesity (Population Council, 2011). Many of the risk factors for NCDs are manmade such as the abuse use of alcohol, tobacco, junk food, and lack of exercise (Mayer-Foulkes & Villouta, 2012).

There will be a preventive effect due to the reduction of factors such as tobacco control, improved diet, exercise, and the reduction of the use of alcohol (Beaglehole et. al., 2011, as cited in Chan et al., 2012). People's awareness of NCDs

is making positive implications in terms of reducing NCDs as there is a global trend for controlling tobacco and excessive alcohol consumption, and improved diet and engagement in exercise. Smoking is not the only factor that presents the risk of cancer, but also the high consumption of alcohol, too little physical activity, poor diet, as well as obesity can lead to the increase of a cancer situation (Chandler, 2006). Furthermore, issues such as population ageing, urbanization, and globalization have made a negative contribution to the rising trend of NCDs (Population Council, 2011).

It has been found that migrants from South Asia to Europe are more vulnerable to NCDs (Davies, Blake, & Dhavan, 2011). Although there are high risk factors such as high blood pressure, high blood glucose, obesity, tobacco use, and physical inactivity, there are some variations among the population groups regarding risk factors (Davies et al., 2011). Moreover, South Asians have unique factors in terms of the high risk of presenting NCDs (Davies et al., 2011). Social characteristics, such as nationality and gender, are also high risk factors for NCDs (Davies et al., 2011). One study found that men experience higher risks of contracting NCDs compared to women since men have a higher exposure to risk factors (Population Council, 2011).

2.7 Situation of Cancer Disease

It has been found more than two third of deaths of cancer deaths occur in low-income and middle-income countries (Population Council, 2011). Moreover the second largest number of deaths due to NCD is from cancer at 27% (Population Council, 2011), while fifty-three percent of deaths are due to NCDs in India. (Reddy et al., 2005, as cited in Thankappan et al., 2010). Figure 2.1 shows the total deaths due to diseases, according to the World Bank (WB) income group and in terms of sex for the year 2008.

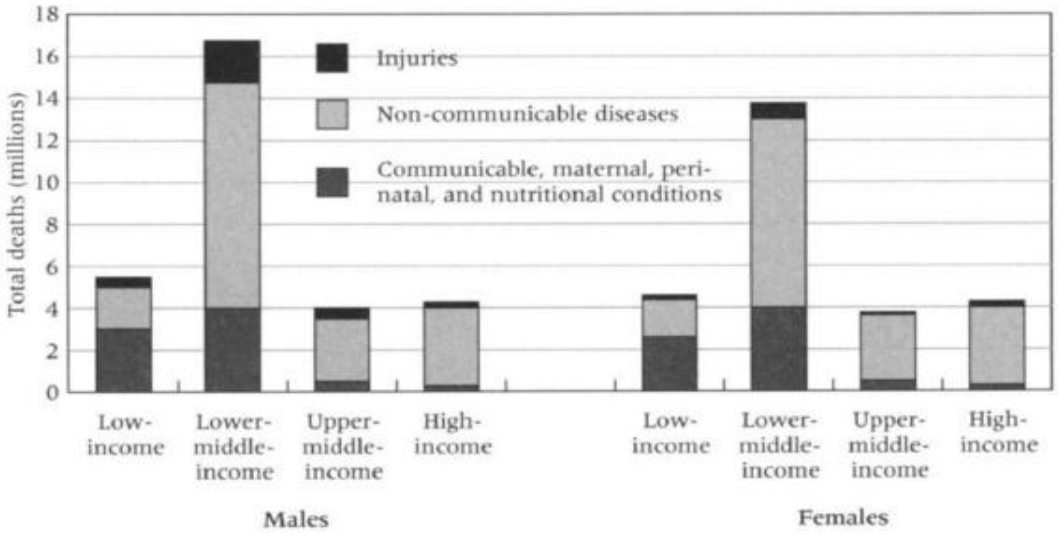

Figure 2.1 Total Deaths Due to Diseases, According to World Bank Income Group and in Terms of Sex for the Year 2008

Source: Population Council, 2011.

2.8 Health Situation in Low- and Middle-Income Countries

When countries become richer the higher share of mortality from disease shifts from communicable diseases to NCDs (Taylor, 2010). High-income countries and middle-income countries have the highest rate of mortality from NCDs while low-income countries have the highest rate of mortality due to other diseases.

Vietnam is a middle-income country having both public and private provider system (Van Minh & Tran, 2012). The public healthcare system consists of levels: the Ministry of Health, Provincial Health Services, and District Health Facilities and Commune Health Centers (Van Minh & Tran, 2012). Government hospitals charge user fees to recover costs. It has become a burden to people since it has been found that out of pocket payment is from nearly 50 % to 70% of total health expenditure (Van Minh & Tran, 2012). Direct out-of pocket-payment includes direct costs such as the purchasing cost for drugs, user fees for the hospital, fees for diagnostic services, and indirect costs, including pursuing medical care (Van Minh & Tran, 2012).

In India clinical activities and treatment costs are from out-of pocket expenditure. This creates a burden for poor people and can lead to increasing poverty and catastrophic spending (Sharma, 2013). Indian people have been seen to spend 3.3% of the gross domestic production from out-of-pocket expenditure for tests, treatments, and medical services for NCDs (Taylor, 2010). Moreover the government funds only 26% out of the total health expenditure (Taylor, 2010).

Early diagnosis of the cancer and proper treatment can reduce the mortality by 30-80%. (Taylor, 2010). The burden of NCDs has a larger impact on the economy, including loss of productivity, aggravated presenters, loss of employment, etc. (Taylor, 2010).

There is a traditional belief that NCDs are a problem for developed countries, but now it has become a real problem for low- and middle-income countries (Abdulkadri et al., 2009; Population Council, 2011). Moreover it has become a major challenge for poor countries (The Economist, 2007, as cited in Abdulkadri et al., 2009).

NCDs were the four main reasons for the cause of death from 1985 to 2000 in the Caribbean region. (Abdulkadri et al., 2009). Diseases such as heart disease, cancer, stroke, and diabetes represented 51% of all deaths in 2000 (Abdulkadri et al., 2009). This disease situation can create a huge economic burden for patients as well as for the economy (Narayan et al., 2006, as cited in Abdulkadri et al., 2009).

2.9 Health Policy in Sri Lanka

Free public health services for both preventive and curative healthcare have made a vast development in the health sector in Sri Lanka. During the pre-independence period of Sri Lanka, free medical treatments have been provided at hospitals for some level of income groups in Sri Lanka (CBSL, 1998). During the period from independence until the 1970s, free health services have been strengthen and improved (CBSL, 1998). Government expenditure on health services also increased. During the period from 1970 to 1977, there were severe changes in all policies, including health policy in Sri Lanka. The allocation of resources were reduced and government expenditure on health also declined during this period

(CBSL, 1998). Since the economic liberalization in 1977 after policy changes for economic liberalization, private sector participation in the health sector continuously expanded rapidly in the health sector in Sri Lanka (CBSL, 1998). In 1992, national health policy revitalized and made it as a multi sector effort (CBSL, 1998).

Presently Sri Lanka has introduced a national policy for NCDs; namely, "the national policy and strategic framework for prevention and control of non-communicable diseases" (MOHNNCDU, 2009). Since some risk factors such as unhealthy diet, physical inactivity, alcohol consumption, and stress (MOHNNCDU, 2009). can be controlled by individuals themselves, while risk factors such as air pollution are unable to be controlled at the household level. This National Policy and Strategic Framework for the Prevention and Control of Non-Communicable Diseases has not addressed the disease of cancer (MOHNNCDU, 2009). while cancer has been addressed in a separate policy framework called the "National Policy and Strategic Framework on Cancer Prevention and Control of Sri Lanka" (MOHNIMNCCP, 2015; MOHNNCDU, 2009). The National Policy and Strategic Framework for the Prevention and Control of Non-Communicable Diseases has a link with other policies, such as national mental health policy, national agriculture policy, national transport policy, and national environmental policy, wherever necessary (MOHNNCDU, 2009).

The present National Policy and Strategic Framework on Cancer Prevention and Control of Sri Lanka has prioritized working on the causes of preventable cancers in Sri Lanka and it has focused on strategies to reduce the burden of those cancers (MOHNIMNCCP, 2015). Therefore this study is under the scope of the public policy of the government of Sri Lanka. Moreover "affordability, sustainable, and equitable accessibility to individuals and the community" is one guiding principle (MOHNIMNCCP, 2015). Therefore the policy options suggested by this study can be useful under the guiding principles.

There are seven policy objectives in this policy and strategies are based on these policy objectives (MOHNIMNCCP, 2015). These seven policy objectives are the following:

1) Policy Objective 1: Ensure primary prevention of cancers by addressing risk factors and determinants by improved public awareness and empowerment.

2) Policy Objective 2: To advocate for early detection of cancers by improved public awareness and relevant service providers, particularly primary care providers, through opportunistic screening

3) Policy Objective 3: Ensure equitable and continuous accessibility to diagnosis and treatment facilities for cancers

4) Policy Objective 4: Expand rehabilitation, survivorship care and palliative care facilities for cancer patients and support to their caregivers at institutional and community levels

5) Policy Objective 5: Strengthen cancer information systems and surveillance to monitor the progress and to evaluate the outcomes of cancer control actions

6) Policy Objective 6: To promote professional education of doctors, nurses, technicians and health workers to argument trained human resources

7) Policy Objective 7: Promote research and utilization of its findings for prevention and control of cancers" (MOHNIM, 2015).

These objectives attempt to be achieved through strategies that have been formulated. There are different institutions and under different levels for the implementation of policy (MOHNIMNCCP, 2015).

According to the National Policy and Strategic Framework on Cancer Prevention and Control of Sri Lanka, cancer control includes all activities referring to reducing the burden in Sri Lanka (MOHNIMNCCP, 2015). Therefore the research findings will help to create priorities. In addition there are fourteen guiding principles, and out of them, some guiding principles are focused on "equity and social justice," and "affordability, sustainable, and equitable accessibility to individuals and the community." Therefore identifying the economic burden and based on the determinants affects for the burden will be helpful to policymakers to address these guiding principles.

2.10 Economic Burden of Diseases

It has been estimated that the majority of deaths due to NCD will arise among the most productive age groups, and 80% of the deaths will occur in low- and middle-

income countries (Abegunde & Stanciole, 2006). In addition to economic losses due to morbidity and mortality, NCDs have created a huge economic burden, such as the loss of productivity, absenteeism and loss of employment (Taylor, 2010).

Cancer care consists of three phases: prevention, detection, and treatment (Walsh, 2014). It is essential to intervene through policies during these three phases in order to reduce the burden of cancer (Walsh, 2014). Prevention "is to limit the incidence of cancer by controlling exposure to risk factors or increasing individuals' resistance to them" (Silva, 1999, as cited in Walsh, 2014). Prevention is an easier way to reduce the burden of cancer than detection or treatment (Walsh, 2014). The detection of cancer can be divided into two areas, screening and diagnostic; screening finds out the potentiality for cancer but diagnostic will be helpful in diagnosing the cancer (Walsh, 2014). Treatment for cancer can be curative treatment or palliative care (Walsh, 2014). Curative treatment reduces the mortality while palliative care is to manage the symptoms and treatments according to the type of cancer, stage, and attributes and access (Walsh, 2014).

In Sri Lanka there are mainly two methods of treatment; one is public funded through government hospitals and the other is privately funded by private hospitals. Many people go to government hospitals since it is free for them while some diagnostic tests and medication are received from the outside if they are not available in the hospital. For some patients some private medical care can be covered through insurance but for the majority it is paid by out-of-pocket expenditure.

There are socioeconomic inequalities that can be perceived in the curative care used by people due to a lack of health insurance and peoples' preferences (Bradley et al., 2002, as cited in Walsh, 2014). There are out-of-pocket expenses, and opportunity costs involving the suffering from the disease, and this economic burden can be reduced through income and health insurance (Walsh, 2014).

Low- and middle-income countries have limited resources, and the economic burdens has become a double burden regarding these diseases (Abegunde & Stanciole, 2006). The proportion of the burden from NCDs remains stable in high-income countries, while low- and middle-income countries have proven to have an increasing burden due to NCDs (Pinheiro et al., 2011). There are fewer costs of illness studies that deal with chronic diseases (Abegunde & Stanciole, 2006).

Chronic illnesses make patients spend more on health services, which leads to spending more on health from out-of-pocket expenditure and family members also have to contribute to patients' health expenditure (Van Minh & Tran, 2012). Moreover some studies in Vietnam have found that due to the issue of diabetes, rural people have had to sell their assets, use their savings, or borrow from neighbors to finance health costs (Van Minh & Tran, 2012).

The treatment costs for NCD are high and doubled compared to other diseases due to the nature of NCDs and the higher costs of medical expenditure and financial vulnerability (Sharma, 2013). NCDs have a severe impact on development as well as poverty reduction efforts. They reduce the working-age population, reduce productivity, and reduce per capita gross domestic production (Engelgau et al., 2011). Similarly, NCDs have an impact on the expenditure side due to a rising demand for treatments on the part of affected people (Engelgau et al., 2011). In addition to that, NCDs reduce the savings and investment capacity of the government since the government has to spend its limited revenue on pensions and healthcare expenditure (Engelgau et al., 2011). Moreover, NCDs increase the higher dependency ratio and lowers economic growth (Engelgau et al., 2011). Finally, NCDs result in widening poverty and inequality (Engelgau et al., 2011).

There are micro- as well as macro-economic impacts of diseases that create a crowding out effect regarding household consumption and this leads to the standard of living of people. In addition there is an economic impact concerning the reduction of labour supply; labour productivity will reduce and this finally will lead to an impact at the macro level through a decline in economic growth (Schrcke et al., 2006, as cited in Abdulkadri et al., 2009).

It has been found that though the people of Sri Lanka have a high life expectancy compared to other developing countries, chronic illnesses have reduced the potential for productivity because the people that are suffering from NCDs are leaving the labor market prematurely (WB, 2008, as cited in Engelgau et al., 2011). A huge cost of absenteeism due to illness can be seen (Suhrcke et al., 2007). Moreover, absence of labour has an impact on labour productivity within a given period of time but not much of an impact on labour supply (Suhrcke et al., 2007).

2.11 Determinant Effects of the Burden on Cancer Patients

The demographic and socio-economic characteristics of households have an impact on healthcare expenditures and sources of financing with regard to illness (Mahal et al., 2013). The characteristics of the cancer patients in this study are mainly focused on demographic and economic characteristics as well as disease characteristics. Demographic and economic characteristics such as gender, education, age, type of employment, distance to hospital, income of patient, and the number of dependents of patients have been used in this study. The disease characteristics discussed in the study are comprised of the type of the cancer, severity of the disease and the period of suffering of the patients. Social and demographic changes have created an epidemic of NCDs in Latin America and the Caribbean (Litvak et al., 1987, as cited in Abdulkadri et al., 2009). Demographic characteristics have a link with the risk factors of NCDs and it is useful to make an inference about the economic impact of NCDs on demographic characteristics (Mahal et al., 2010). Since there is a lack of comprehensive studies about the determinants of the economic burden of cancer, the literature on NCDs has been reviewed in order to identify these determinants for the study.

2.11.1 Demographic and Economic Characteristics

There are non-modifiable risk factors such as age, gender, and genetic factors that can affect NCDs. The socio-economic and demographic characteristics of households can affect health expenditure and sources of financing (Mahal et al., 2013).

2.11.1.1 Gender

Gender as an impact on diseases can be analyzed in two ways; in terms of being a domestic burden and as a public burden (Quah, 2011). There is a belief that the overall burden of disease is much higher for women than for men (Quah, 2011). Public burden refers to diseases is mainly on morbidity and mortality of the affected individual due to disease (Quah, 2011). The gender differences among illnesses can be analyzed through a few hypotheses; namely, the social patterns hypothesis, the sex role hypothesis, the role set hypothesis, and the stress hypothesis

(Quah, 2011). The public burden of disease varies from country to country and gender has a more significant impact on the domestic burden of disease than the public burden of disease (Quah, 2011). Males have a higher burden compared to females when the disease is related to hypertension (Le et al., 2012).

2.11.1.2 Education

There are a number of contributory factors that affect the healthcare expenditure among households. The differences in the socio-economic and demographic characteristics of households can impact healthcare expenditure (Mahal et al., 2013). It has been found there are variations of spending on medical costs and other expenses based on educational level (Mahal et al., 2013).

2.11.1.3 Age

NCD studies provide interesting findings related to cost and age. The age impact on cost varies in the case of hypertension. Indirect costs and intangible costs have decreased with age, while direct costs have increased with age (Le et al., 2012).

2.11.1.4 Type of Employment

The employment of the patient and his or her employment status differently affect diseases (Bloom et al., 2013). The type of employment has an impact on the indirect costs of the illness due to early retirement or loss of productivity because of the disease (Bloom et al., 2013). Another study found that economic consequences become higher once a patient has become employed (Mahal et al., 2010). In addition there is a huge impact on health spending in informal sectors due to a lack of paid medical leave and loss of employment (Mahal et al., 2010). Moreover, the labour market adjusts much more easily to low-skilled workers (Mahal et al., 2010).

2.11.1.5 Distance

The inequitable distribution of healthcare facilities creates problems for patients (Perera & Gunatilleka, 2006). Travel costs are one of the direct costs in terms of economic burden, and travel costs can be determined according to the distance to the hospital. Since healthcare for NCDs is from tertiary hospitals, patients have to travel long distances and this makes for higher travel costs (Attanayake, 2005).

2.11.1.6 Income

Income has a direct impact on economic burden since it has an impact on the capacity to pay for preventive and curative care (Davies et al., 2011). The economic effect of a disease badly and disproportionately affects the poor (Engelgau et al., 2011, as cited in Le et al., 2012). Moreover it has been found that a household's willingness to pay for a disease depends on the income. People with a high income are willing to pay more for treatments than poor people (Le et al., 2012). People from poor households have greater relative economic burden than their richer household counterparts (Van Minh & Tran, 2012) and this is similar to other countries' studies, such as those in India in 2008 and China in 2009 (Van Minh & Tran, 2012).

2.11.2 Disease Characteristics

The characteristics of disease vary from disease to disease and they affect the economic burden. There are many types of cancers but the present study will be focused only on the five main types of cancer based on gender. Therefore it is concerned with the types of cancer, the severity of the disease, and the period of suffering as the main characteristics of the disease for study.

2.11.2.1 Type of Cancer

It was found that socio-economic inequalities can be seen in cancer screening and it varies across cancers, countries, etc. (Walsh, 2014).

2.11.2.2 Severity of the Disease

Disease conditions affect the type of medical costs (Abdulkadri et al., 2009). Moreover treatment also varies depending on the stage of the cancer (Walsh, 2014).

Table 2.2 Summary of the Literature on the Characteristics of Patients

Author (Year)	Characteristics
Attanayaka (2005)	Living standard of outpatients: type of house, availability of water and sanitary facilities, energy source, other facilities, monthly income Gender, age, education, occupation

Table 2.2 (Continued)

Author (Year)	Characteristics
Mahal et al. (2013)	Matching variable: educational status, house type, land ownership, water source, sanitation type, major source of livelihood, demographic structure (number of children, young adults and elderly, number of household members that are female) caste, religion, rural urban status, covered social or private insurance

2.12 Sources of Financing

Many studies (Attanayaka, 2005; Mahal et al., 2010; Engelgau et al., 2011; Engelgau et al., 2012; Van Minh & Tran, 2012). have discussed different sources of financing for NCDs. Health insurance has been seen to contribute less and it has a modest effect on the economic burden of disease (Van Minh & Tran, 2012). In addition rural people sometimes sell their assets, savings, and borrow from neighbors as a way of financing their diabetics healthcare in Vietnam (Hien et al., 2004, as cited in Van Minh & Tran, 2012). Women have become vulnerable in terms of financing since they are mostly not employed in paid work and have less savings, so there is no employer to pay for health insurance for them. In India the liquidation of wealth and assets and borrowing is the way of financing for NCD costs (Engelgau et al., 2011).

Table 2.3 Summary of the Literature on Sources of Financing

Author (Year)	Ways of Financing
Attanayaka (2005)	Future studies must work on exploring alternative ways of financing
Mahal et al. (2010)	One's savings & income, finances from friends & family, community insurance, borrowing, sale of assets
Van Minh and Tran (2012)	Selling assets, using savings, or borrowing from neighbors to finance health costs

Table 2.3 (Continued)

Author (Year)	Ways of Financing
Engelgau et al. (2012)	Household income, savings, support from family and friends, selling assets
Engelgau et al. (2011)	Borrowing and sale of assets
Hien et al. (2004), as cited in Van Minh and Tran (2012)	Sale of assets, savings, borrow from neighbors

2.13 Methods of Evaluating the Economic Burden

A study conducted by Attanayaka (2005) focused on five common diseases and it used the output-related method (Goldschmidt-Clermont, 1987; Fox-Rushby & Mills, 2000, as cited in Attanayake, 2005). The socio-economic characteristics have been identified as living standards, gender, age, and education and occupation (Attanayake, 2005). The economic impact at the national level arises with many issues. A decrease in the working age population reduces productivity, and there will be a demand for social security systems and an increase in the dependency ratio (Engelgau et al., 2011). In addition the reduction of savings and investment by households will impact national-level investment (Engelgau et al., 2011). A final increase in the dependency ratio, the reduction of labour productivity, and the reduction of the factors of production will lead to a lower GDP growth rate and a widening of poverty and inequality (Engelgau et al., 2011).

The direct costs to the patient can be the cost of travelling for the patient and other accompanying persons, formal and informal treatment, and complementary cost items (Attanayake, 2005).

Indirect costs are for example loss of production or income to the patient and other household members. This loss depends on their occupation and its nature (Attanayake, 2005). Indirect costs can be the loss of income for the patient, for household members, and other costs (Attanayake, 2005).

Table 2.4 Summary of the Literature on the Methods of the Calculation of Costs

Authors (Year)	Costing Method
Attanayaka (2005)	Method: direct costs to the provider, direct and indirect costs to the user. Valuing the loss of time. Output-related method (Goldschmidt-Clermont, 1987; Fox-Rushby and Millls, 2000; Attanayaka , 2002)
Mahal et al. (2010)	Cost of illness, human capital methodology, value of statistical lives lost, Solow type production function.
Abdulkadri et al. (2009)	Cost of illness approach, human capital approach
Health Canada (2002); Barcelo et al. (2003), as cited in Abdulkadri et al. (2009)	Cost of illness approach
Mahal et al. (2013)	Propensity score matching
Le et al. (2012)	Cost of illness method, human capital methodology, contingent valuation willingness to pay approach

2.14 Conceptual Framework

Conceptualization can be defined as **"**the process through which we specify what we mean when we use particular terms in research**" (**Babbie, 2008**).** Based on the literature review and its relevance to Sri Lanka, this study has adopted the following conceptual framework. It was found from the literature that there are various types of costs involved in the economic impact of NCDs (Anderson, 2012). It was also found that there are various types of costs involved due to NCDs. However, since this study is based on the households' aspects, it has not focused on the macro level or the opportunity costs involved in the country as a whole. The independent variables/causes of the economic burden of NCDs provide the "necessary causal" (Babbie, 2008) relation with economic burden. Furthermore, much of the literature has discussed direct medical costs, direct non-medical costs, and indirect costs as a "sufficient cause" of the economic burden on households with people with NCDs**.**

Two models are used in this research to answer the research questions**.** Figure 2**.**2 was conceptualized in order to find the answer to the research question two; namely, to identify the determinants affecting the economic burden of NCDs of cancer on households**.** Further, Figure 2**.**3 was conceptualized in order to find the answer to the research question three; namely, to identify the relationship between the economic burden of illness in the case of NCDs with special reference to cancer and the sources of financing to deal with the burden**.**

The determinants identified for research question two are demographic, economic, and disease characteristics**.** These characteristics are significant in terms of economic burden and the significant factors of the burden have been used in this study to provide policy options**.**

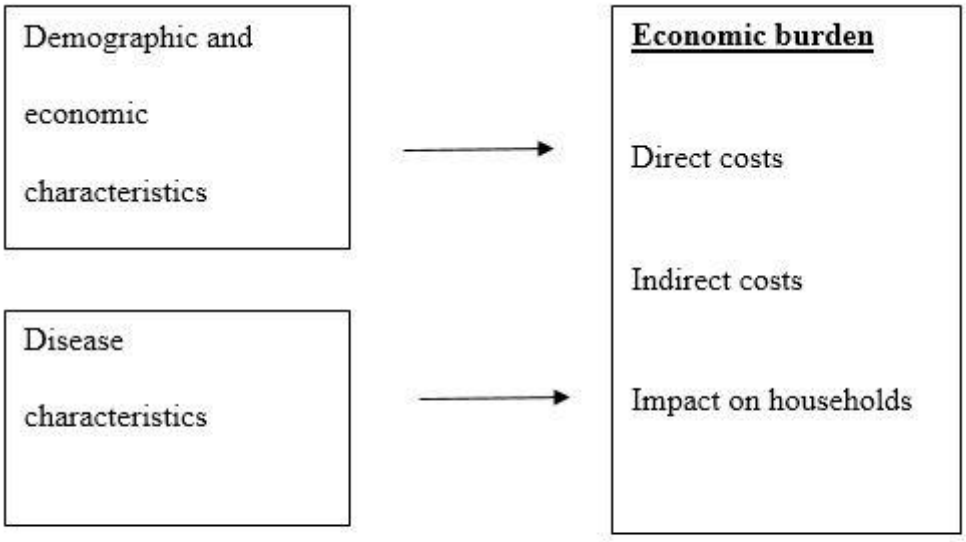

Figure 2.2 Conceptual Framework for Determinants Affecting Economic Burden

The dependent variable of the study is economic burden. Economic burden can be measured in three ways (Bloom et al., 2011): using the cost of illness approach; the value of lost output: the economic growth approach; and the value of statistical life (VSL) approach. The cost of illness approach is the commonly used method (Bloom et al., 2011) in identifying the economic impact of diseases on households. The cost of illness, microeconomic, and macro-economic analyses are the major three methods of estimating the economic burden and the methodology depends

on the purpose of the study and the availability of the data (Suhrcke et al., 2006, as cited in Abdulkadri et al., 2009).

The cost of illness approach has been used in this analysis.

The value of lost output: the economic growth approach, estimates the projected impact of cancer on aggregate economic output. This has not been used since this research is based on the households' aspects rather than the macroeconomic level. The value of statistical life approach includes the peoples' willingness to pay for the reduction of their disability or death due to cancer. It was also not used in this analysis since it is beyond the impact of cancer on patients.

When using the cost of illness approach, the human capital methodology approach also has been used to calculate the loss of income owing to ill health The human capital methodology approach provides the loss of income due to disability and it "is calculated by the present value of their expected future stream of income" (Mahal et al., 2010).

Therefore, based on cost of illness method, the dependent variables of the study consist of three variables: direct costs, indirect costs, and the impact on households. Since this study is limited to households it has not considered costs such as costs at the macro level.

The direct costs involve personal medical care costs for diagnosis, procedures, drugs, and inpatient and outpatient care. In addition there are some other direct costs, such as the costs of transportation for treatment and care for patients, as well as accompanying persons, special food that has to be used, and these costs will be analyzed in this research. Indirect costs consist of changes in employment status due to illness, loss of income for the patient, and the cost of hiring labour. In addition the impact on other households also been calculated under indirect costs and these are the dependent variables regarding economic implications. The human capital approach has been used for the calculating indirect costs. This approach calculates the "forgone earnings over an economically productive life-time in estimating indirect costs of premature mortality and morbidity" (Health Canada, 2002, as cited in Abdulkadri et al., 2009).

The independent variables for this study mainly consist of demographic, economic, and disease characteristics. It was found in the literature that the

demographic characteristics of other NCDs have an impact on economic burden. Therefore this study identifies the demographic and economic determinants such as gender, education, age, type of employment, distance, and dependents and income. In addition to that, disease characteristics such as the type of disease, the severity of the disease, and the period of suffering have been taken as the independent variables for the study.

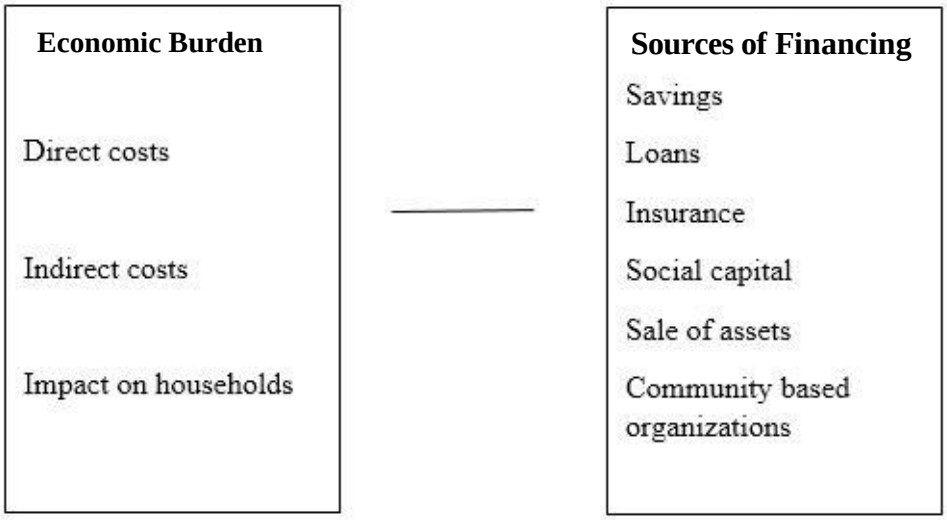

Figure 2.3 Conceptual Framework for the Correlation between Economic Burden and Sources of Financing

Furthermore the relationship between economic burden and sources of financing is analyzed in order to answer the third research question of the study**.** Sources of financing were measured by the questionnaire**.** It is also focused on in order to provide proper policy options to finance the economic burden on households**.**

2.15 Research Hypotheses

Research hypotheses "are the predictions the researcher makes about the expected relationships among the variables" (Cresswell, 2009). It is a statistical procedure where the researcher makes inferences about the population based on the sample. The hypotheses in this study were based on other studies referring mainly to NCDs and that made inferences concerning cancer.

2.15.1 Demographic and Economic Characteristics

Based on the literature it was found that there is a relationship between the economic burden of NCDs and demographic and economic characteristics. It was found that gender (Quah, 2011; Le et al., 2012), education (Mahal et al., 2013), age (Le et al., 2012), type of employment (Mahal et al., 2010; Bloom et al., 2013), distance (Attanayake, 2005; Perera & Gunatilleka, 2006), income (Davies et al., 2011; Le et al., 2012; Van Minh & Tran, 2012) are different in terms of economic burden. Therefore the following hypotheses were based on the literature and the conceptual framework.

H1: There is a difference in the economic burden of cancer between genders.

H2: There is a difference in the economic burden of cancer among levels of education.

H3: There is a difference in the economic burden of cancer among age groups.

H4: There is a difference in the economic burden on cancer among types of employment.

H5: There is a difference between the economic burden of cancer and the distance to the hospital.

H6: There is a difference between the economic burden of cancer and the number of dependents.

H7: There is a difference between the economic burden of cancer and level of income.

2.15.2 Disease Characteristics

Literature has indicated that there is a difference between the economic burden of illness and disease characteristics such as type of cancer and disease condition (Abdulkadri et al., 2009; Walsh, 2014).

H8: There is a difference between the economic burden of cancer and type of cancer.

H9: There is a difference between the economic burden of cancer and the severity of the disease.

H10: There is a difference between the economic burden of cancer and the period of suffering.

2.15.3 Sources of Financing

A vast literature has found that there are different sources of financing for NCDs (Mahal et al., 2010; Engelgau et al., 2011; Engelgau et al., 2012; Van Minh & Tran, 2012). In addition sources of financing vary from household to household. Therefore this study has focused on identifying how sources of financing and economic burden vary among households. The following hypotheses have been based on the literature and the conceptual framework.

H11: There is a difference between sources of financing for cancer and economic burden.

H12: There is a difference between sources of financing for cancer and direct costs.

H13: There is a difference between sources of financing for cancer and indirect costs.

H14: There is a difference between sources of financing for cancer and the impact on households.

2.16 Chapter Summary

This chapter provides a wide analysis of the literature on the economic burden on households due to NCDs. Since there is a lack of comprehensive studies with reference to cancer, the literature on NCDs has been reviewed. In addition this chapter has examined the demographic and economic characteristics that affect the economic burden on households with people with NCDs. In addition, this chapter has explained the methodologies used by different authors for the calculation of economic burden both at macro and micro levels. Moreover the chapter has analyzed different sources of financing for bearing the economic burden on households. This chapter has also provided an analysis of the literature on the economic burden on households due to NCDs and the gaps in the literature that must be studied.

CHAPTER 3

METHODOLOGY

3.1 Introduction

The objective of this chapter is to provide the research design and methodology related to the study. It explains the research process such as the research design, unit of analysis, population, sample size, sampling method, operational definitions of the terms, measurements and instruments, data collection methods, and the method of the data analysis. This study is based on both data collection through questionnaire as well as through available secondary data. The information through the interviews with the patients has been used for the detailed analysis of the study. It begins by explaining the chosen research design, and the selected scope of the study. This chapter also gives details on the target population and sampling techniques employed. While the number of patients has been taken as the unit of analysis, the rationale of the sample size and the method of sampling has been constructed. It has justified the choice of research instruments and how the questionnaire has been constructed. This chapter explains the use of pretesting, and the validity and reliability of the data and the research instrument established. Furthermore, it provides the methods of the data collection and the analytical framework.

3.2 Quantitative Research Design

This research is based on mixed methods, but mainly the quantitative method. This involved the conduction of a large field survey of cancer patients. Since the main objective of the research was to identify economic burden on households with people suffering from cancer, it was necessary to quantify the numerical analysis for economic the aspects.

3.2.1 Study Area

There are only a few cancer treatment centers in Sri Lanka-one specialized hospital for cancer, teaching hospitals, and provincial general hospitals (MOHAIMNCCP, 2014). In addition it has been recorded that the highest cancer incidence based on geographical area is in the western province for both females and males (MOHNCCP, 2013). This study is based on patients who visited clinics for the treatment of cancer. They are treated mostly as outpatients but most of them have to get inpatient care in the hospital from time to time, depending on their treatment requirements. The sample has been selected from the outpatients visiting clinics.

3.2.2 Target Population

The target population for the study is cancer patients. The number of new registration of cancer patients for the year 2008 was 16511 (MOHAIMNCCP, 2015). In addition, it was found that 26300 new cancer patients registered for treatment in 2014 (Waidyasekara, 2015). The age standardized crude cancer incidence rate was 86.4 per 100 000 people (MOHAIMNCCP, 2015).

3.2.3 Sampling Techniques

The unit of analysis was the patients that have cancer in Sri Lanka. This study was based on stratified sampling method. The sample size calculator, the Yamane formula, was used in order to identify the sample size. Out of the population, the sample size was near to 400 by using different statistical measurements. Therefore, it was increased to four hundred samples for better stratification (Appendix A). Data were collected from cancer patients that were still visiting the clinics. Each specialized clinic is held on a specific date conducted by specialized doctors and the respondents were selected from the specific clinics, as scheduled on week days. The clinics were not held during weekends. Based on Ministry of Health and hospital statistics, the selected study sample was categorized according to the gender of cancer patients. One hundred and seventy-five males and 225 females were selected for study proportionately based on the type of cancer and gender.

The presence of the majority of the respondents was predictable in the clinic on a given date, as it was compulsory for them to attend the clinics on specific dates,

run by hospitals for these patients. Therefore they were available for the study purpose. Furthermore, no objections or interruptions to the interview process were experienced as prior permission for the study was obtained from the hospitals administration, including each consultant heading each clinic. In addition, ethical clearance for the study from an ethics review board in Sri Lanka was also obtained in advance, which is a prerequisite for conducting research of this nature. Therefore there were no unwarranted interruptions to the study from any authority.

The questionnaire was filled out by the researcher through interviews with the patients and the patients expressed their willingness to provide this information. The consent of both the patient and the accompanying person was always obtained before filling out the questionnaire with the information gathered from them. On the other hand, the patients that were not attending the clinic on given dates regularly were automatically excluded from the survey since they were not seeking further medical treatments. Further, the respondents were not asked to fill in the form themselves, but the researcher herself filled in the questionnaire since the majority of the respondents were not in a position, physically and/or mentally, to do so. It was also necessary to make sure that no data were missing and that there was no ambiguity or misunderstanding regarding the questionnaire. They were mostly ready to provide, to the best of their ability, the information sought in the questionnaire.

3.2.4 Research Instruments

A semi-structured questionnaire was used as the main instrument for the research. Some questions in the questionnaire were structured since the answers were specified and measurable. However, the questions referring to the challenges of financing the treatment of the patients' cancer were open ended due to the non-availability of structured measurements. Nominal and ratio level measurements were used throughout the questionnaire. The questionnaire was helpful in terms of addressing the main research question about the economic burden on households with people suffering from cancer than other research instruments.

The research instrument was prepared on the basis of the literature and information obtained from studies conducted in other countries about economic burden on households. The questions were based on the conceptual framework.

Moreover, some of the questions in the questionnaire were prepared based on previous research questionnaire (Liyanage, Jayatilaka, De Silva, 2012). In addition, the relevant parts of the questionnaire from the national household consumption survey were keenly studied and used as a guide where applicable in drafting the questionnaire in order to achieve better categorization of some of the demographic characteristics. The answers for some of the questions were modified after the pilot survey based on the answers of the respondents.

The questionnaire was filled out by the interviewer during the face-to-face interviews with the respondents. Further, the questionnaire was mainly focused on key variables such as direct medical costs, direct non-medical costs, and indirect medical costs and demographic and economic characteristics, disease characteristics of households, and sources of financing. In addition, in-depth discussions with the patients were helpful in preparing policy options.

3.2.5 Pre-Testing

A pilot study was conducted with forty respondents (10% of the sample) in order to test the suitability of the questionnaire. Then their understanding of the questions was discussed. Since the researcher filled out the questionnaire, it was easy to conduct a discussion about the questions. After filling out the questionnaire, the researcher had a discussion with each respondent about his or her understanding of the questions. The respondents' difficulty in understanding the question was revealed when they explained how they understood certain question and how they found certain questions difficult to answer. Identifying the problems in the questions was helpful for ascertaining the validity of the questions. After the pilot survey, a few suggested that the answers for a few of the questions should be modified and after that the study continued. The findings of the pilot study were helpful for the reliability of the research. Accuracy and consistency related to the objectives of the study were ensured.

3.2.6 Validity and Reliability

The validity and reliability of the numerical questionnaire items were analyzed. The term reliability has been defined as "[t]hat quality of measurement

method that suggests that the same data would have been collected each time in repeated observations of the same phenomenon" (Babbie, 2008). The independent variables for the study were precise measurements and there were no subjective measurements. Generally, precise measurements are greater compared to imprecise measurements (Babbie, 2008). The dependent variable of the study is a direct measurement that does not include scales. The test-retest method was used for some questions as a reliability measure. As stated in Babbie (2008), validity refers to the extent to which an empirical measure adequately reflects the real meaning of the concept under consideration. The content validity of the study was measured with reference to the extant literature. Other literature and studies were made use of in order to construct and prepare the questionnaire in the study. In addition, the measurements of the variables that were selected for the study were taken from the literature. Demographic characteristics that were precise were studied through face validity. In addition, some questions were prepared based on the national household survey conducted by the Department of Census and Statistics and revisions made according to the respondents. Moreover, the questionnaire was evaluated by experts (no less than 12 members of the ethics review committee) within the field that have been involved with before starting the data collection work. After their expert comments and suggestions, the questionnaire was revised and the data collection was begun.

3.2.7 Data Collection Techniques

Data were collected from both primary and secondary sources. Primary data were collected from interviews using a semi-structured questionnaire. Primary data were from the respondents that had gone to the clinics on the specific cancer clinic dates.

The survey method was used for the collection of the primary data. The population was the total number of patients seeking treatment for cancer in Sri Lanka. Further secondary data were used from various available sources such as the Central Bank of Sri Lanka, World Bank Reports, and the Ministry of Health, etc. until year 2016 in Sri Lanka. These data were analyzed using descriptive and inferential statistics. These secondary data were very helpful for finding the clinics, identifying

the patients, categorizing the sample, and using the human capital methodology for the study.

3.2.8 Data Analysis

The primary data collected from the questionnaire were coded and analyzed by using the Statistical Package for Social Science (SPSS). Both descriptive and inferential statistical techniques were used for the analysis of study. The descriptive statistics included demographic information and the challenges faced by the participants regarding ways of financing to cope with their economic burden. Inferential statistics included simple regressions. Economic burden was analyzed using the cost of illness approach (Bloom et al., 2011). Furthermore, human capital methodology (Mahal et al., 2010) was used in order to analyze the total income loss due to cancer. This research did not consider the value of lost output-the economic growth approach or the value of statistical life (VSL) approach (Bloom et al., 2011).Therefore the cost of illness approach was used for the calculation of the economic burden related to households. Sources of financing were analyzed by ranking those alternatives.

3.2.9 Logical and Ethical Considerations

This research was carried out with logical and ethical considerations. Prior approval and ethical clearance for the study was obtained from an ethical review committee in Sri Lanka. After receiving their valuable comments, the questionnaire was revised accordingly and resubmitted to the committee, which then granted ethical clearance for the study. After obtaining ethical clearance, the research began the data collection from the respondents. Moreover, a survey was conducted with the consent of the patients and participation was voluntary. Once the researcher received verbal consent from the respondents, she explained three documents to the respondents: a letter of introduction, an information sheet, and a consent form. The letter of introduction explained the details about the researcher, the purpose of the research, the necessity of valid and correct information, and contact information concerning the research. The information sheet was explained, as well as the security of the information, and that the respondents' identity would not be revealed. Additionally,

the method of the analysis and the presentation of the data were explained. In addition to that, the information sheet clearly outlined what was expected from the respondents regarding the face-to-face interview, the approximate time duration for the interview, freedom to leave the interview process if the respondents wished to do so, and flexibility and freedom to ask questions of the researcher during and after the interview. After reading those documents by the respondents, their written consent was obtained and it clearly mentioned that participation was voluntary. Moreover, if the respondents had visited to clinic with a companion, and in almost all the cases this was the case, the researcher explained all of this information to the accompanying person and received verbal consent from that person as well. The letter of introduction, information sheet, consent form, and questionnaire were prepared in three languages, English, Sinhala, and Tamil. This information conveyed via the three languages would not create any misapprehension concerning the real meaning and understanding or participating in the interview since Sri Lanka uses all three languages as official languages. Moreover, it was made clear to the participants that the data collected were to be exclusively used only for the analysis of the research and not for other purposes.

3.2.10 Operational Definitions

Table 3.1 Operational Definitions

Variable	Definition	Measurement
Economic burden on households due to disease	Burden of disease can be defined as direct and indirect costs which include opportunity costs for the patients and households due to a specific illness.	Ratio
	Direct costs include costs for diagnosis, costs for procedure, drugs, inpatient care, outpatient care, informal treatment, travel costs, travel costs for the accompanying	Ratio

Table 3.1 (Continued)

Variable	Definition	Measurement
	person, the cost of special foods and other household costs.	
	Indirect costs consist of loss of income for patients due to disease.	Ratio
	Impact on the households consists of loss of income for households due to the disease of the patient.	
Demographic and economic characteristics	Demographic characteristics refers to gender, education, age, type of employment, distance, and dependents refer to the patients.	
	Economic characteristics refer to the income of the patient.	
Disease characteristics	Characteristics of the diseases refer to type of cancer, the severity of the disease and, duration of the suffering of the patient.	
	Type of cancer, severity of disease	Nominal
	Period of suffering	Scale
Sources of financing	Sources of financing are the ways of bearing the economic burden by households due to illness.	Interval

3.2.11 Methods of Data Analysis

The analysis of the study mainly consisted of three stages. First, the analysis assessed the economic burden on households with people suffering from cancer. Data were used as descriptive statistics to analyze the economic burden on households. Moreover the cost of illness method and human capital methodology approach were used for finding out the economic burden on these households. First the study

analyzed the demographic characteristics of the selected respondents that participated in the study.

The determinants affecting economic burden on households with people suffering from cancer were analyzed using bivariate analysis. Data were analyzed pertaining to the relationship of each independent variable with the dependent variable. This relationship was examined using independent sample t-test, ANOVA, and Pearson's correlation analysis. When the findings revealed that some variables were significant, further analyses were carried out with the Tukey test to find out how these variables had become significant and different necessitating further explanation. When the findings of the ANOVA tables showed that some variables had become significant, further analysis was carried out using eta squared to find out the effect size.

Multivariate inferential analysis was used in order to identify the determinants affecting the economic burden on households with people suffering from cancer. Multiple regression was the instrument used to identify the significant factors affecting the economic burden on households.

In order to identify the relationship between economic burden and sources of financing, the study analysed the relationship using confidence intervals among direct cost, indirect cost with sources of financing. Univariate and bivariate analysis were used to identify the significant variables of sources of financing regarding the economic burden on households.

Primary data were recorded and entered in the statistical Package for Social Science (SPSS). After entering the data they were checked as to whether the statistical assumptions for the multiple regression were violated.

3.2.11.1 Assumptions of Multiple Regression

There are some assumptions that should not violate a study when using multiple regression. In addition there are some solutions when assumptions are violated. Therefore, the analysis in the study checked the assumptions of multiple regression and found solutions where necessary.

1) Sample Size

The size of the sample is essential for generalizing the findings of the study for the target population. A smaller sample size creates less

scientific value for the research regarding generalization (Pallant, 2007). Different scholars have provided different methods for using the sample size for a multiple regression. The research has not violated those criteria given by those scholars. The sample size calculator, the Yamane formula, was used to check the sample size. On the other hand, other scholars (Tabachnick & Fidell, 2007, as cited in Pallant 2007) have provided a formula for calculating a sample by considering the number of independent variables. Therefore the sample of 400 respondents did not violate having a smaller sample in this study.

2) Handling of Missing Data

Missing data refers to information that is essential for the study and that is not available. Missing data can happen when a respondent has no answer for one or more questions in the survey (Hair et al., 2010) However, in this study, the researcher filled out the questionnaire during a face-to-face interview, and therefore there were no missing data for this study. If there were any errors or issues with the data during the face-to-face interview they were solved with discussion with the respondent. However, in order to check for procedural errors a frequency distribution table was studied. The procedural errors found through the frequency tables were corrected again by using the same data from the survey questionnaire.

3) Issues with Outliers

Outliers can be defined as "observations with a unique combination of characteristics identifiable as distinctly different from other observations" (Hair et al., 2010). The study used box plots in order to determine whether there were any outliers. When any outliers were found, the study also checked whether this occurrence was due to procedural outliers. Once it was determined that the occurrence was due to procedure, the data were rechecked and corrected. It was found that some of the observations were not due to procedural outliers. These outliers were studied case by case and the researcher investigated how those cases had become outliers. These outliers were due to extraordinary spending patterns of the relevant household with cancer patients. There were only two outliers that had standardized residual less than-3.3. Therefore these outliers were not removed.

4) Multicollinearity

The term multicollinearity refers whether there is a relationship among the independent variables. Multicollinearity issues arise "when any single independent variable is highly correlated with a set of other independent variables" (Hair et al., 2010). The study has focused on multicollinearity. Data were analyzed by using SPSS. Two values, namely tolerance and VIF value, were used for the analysis. If the tolerance value was less than .10, it suggested multicollinearity. The data were analyzed the tolerance value and no multicollinearity was found. In addition to that data were analyzed using VIF value (Variance Inflation Factor). VIF has been described as an "indicator of the effect that the other independent variables have on the standard error of a regression coefficient" (Hair et al., 2010). If the VIF value is above 10 it is considered a problem of multicollinearity. However, in this study all variables have below 2 of VIF. Therefore it was statistically proven again that there was no multicollinearity.

5) Normality and Linearity of the Distribution

The research was carried out in order to find out whether the data were normally distributed as one of the assumptions of multiple regression. Once the research found that data were not distributed normally, the dependent variable, namely, economic burden on households with cancer patients, was transferred to the square root of the value.

3.3 Qualitative Research Design

This research was mainly based on the qualitative support quantitative method. Qualitative analysis was used to triangulate the quantitative findings for better data analysis.

Qualitative research "begins with assumptions and the use of interpretive/theoretical frameworks that inform the study of research problems addressing the meaning individuals or groups ascribe to a social or human problem" (Cresswell, 2013, p. 44). In this research the qualitative analysis comprised stories, and lived experiences of cancer patients that were the subjects of the quantitative study.

3.3.1 Participants of the Study

This study was based on cancer patients, who were outpatients visiting clinics. The participants were identified for the interview during the data collection for the quantitative study based on a few factors. One of the factors was whether they were willing to continue with the research interview. In addition to that, availability for the interview is also essential. Some of the participants had some difficulties with speaking and therefore they were excluded from the qualitative study because the interviews required long discussions. Moreover it was necessary to have enough time for the discussion. Therefore only the participants that had time to participate in the interviews were included in the study.

3.3.2 Sample Size

This research was conducted with 400 respondents for quantitative study and the researcher filled out all of the questionnaires during the interviews. For this study, thirteen cases were purposefully selected for the qualitative analysis. Therefore this study entails information obtained from the thirteen participants that participated in the interviews.

The information derived from the interview was used to develop case studies referring to the demographic, economic, and disease characteristics of the patients. Ten cases are presented in this study. The first case is about a male cancer patient that has to bear the huge burden as the bread winner of the family. The second case is about another male cancer patient that had to face a huge economic burden from being a male and the breadwinner. The third case is about a woman suffering from cancer and had less economic burden. The first, second, and third cases are useful for identifying how gender affects economic burden of cancer patients. The fourth case is about a male cancer patient that has a high level of education and has faced fewer problems due to his advanced knowledge about cancer prior to suffering from the disease. The fifth respondent in this case study was a pensioner, had a high level of education, and faced less of a burden compared to others. The sixth case depicts how income has become more powerful in getting things done. The seventh story also proves how different income groups differently affect the economic burden on households with people suffering from cancer. A patient with dependents explained

how far households face a burden due to the disease in the eighth case. The ninth case provides an example of how the burden of cancer is faced when there are no dependents. The tenth case depicts how a woman respondent had to bear the economic burden because she lived far from the clinic. The eleventh case is about a male respondent that was also affected by his distance from the hospital. The twelfth and thirteenth cases prove how different cancers can lead to differently burden effects.

3.3.3 Reliability and Validity of Qualitative Data

The information received from one respondent was supported by another respondent in the study. The participants who were patients provided information based on their lived experiences. Therefore information was received from the target source. In addition common patterns or themes were identified during the interview. Data were cross checked in order to ensure that the themes were supported by evidence. A theme is qualified as a theme because it is supported by multiple sources. In case a theme is not supported by multiple events, that theme is explained as a unique phenomenon.

3.3.4 Qualitative Data Analysis

Data were collected by note taking. These notes were transcribed to memos. Transcribing the memos comprised the process of reading the transcript and editing memos, generating themes from the memo, using them to write case studies and linking case studies to the theme in the quantitative data.

3.4 Chapter Summary

This chapter has provided the methodology of the research used in this study. It has explained both the quantitative and qualitative methods used in the study. In the quantitative method population, sample size, operational definitions, and data analysis techniques have been explained. In addition, the qualitative method, the data-collection method, and the methodology of the data analysis were described.

CHAPTER 4

DATA ANALYSIS

This chapter mainly focuses on the data analysis and presentation of the data. The data were collected from the primary data by using a semi-structured questionnaire. It is focused on the main objectives of the study. This chapter explains the economic burden on households with people suffering from cancer and the main determinants affecting this economic burden regarding cancer patients. In addition the research has analyzed how the sources of financing vary based on the economic burden and challenges faced by households in terms of financing. The primary data collected from the questionnaire were analyzed using descriptive statistics, and bivariate and multivariate statistics.

4.1 Economic Burden of Cancer on Households

The economic burden of cancer has been analyzed here by using the cost of illness method. It was analyzed under three categories: direct costs, indirect costs, and impact on the household. Direct medical costs consist of the cost of diagnosis, the cost of procedures, the cost of medicine, and inpatient costs. As a long-standing policy of universal free health facilities, the government clinics provide necessary medication free of charge for their registered patients. There are mismatches at times between the supply and demand for medicine in those clinics. Some patients depend on the market to replenish their medicine requirements in such circumstances. In addition some patients take some diagnostic tests outside the hospital and in the private sector since opportunity costs for visiting the hospital and the waiting time for diagnostic tests are much greater for them.

Therefore, the following table 4.1 provides the descriptive analysis of the economic burden of households due to cancer.

Table 4.1 Economic Burden on Households with Cancer Patients

	N	Minimum	Maximum	Mean	Std. Deviation
Direct cost (58%)	400	200	1197968	113973	161627
Indirect cost (35%)	400	0	540924	69399	121445.2
Impact on household (7%)	400	0	445212	13715	47969.8
Economic burden	400	200	1237950	197088	204365.6
N	400				

It was found that direct costs are the major economic costs compared to other types of cost (Table 4.1). They represent nearly 58% of the average economic burden on households. Though the government provides medicine and other facilities free in hospital clinics, based on the average cost, direct costs have become more of a burden to households with people with cancer compared to other costs. However, for some respondents there were no indirect costs or impacts on the household. Therefore the minimum cost has become zero for indirect costs and the cost of the impact on households.

4.1.1 Descriptive Analysis of Direct Costs

Direct costs consist of many sub-cost variables. Those are direct medical costs, informal costs, transportation costs, additional travel costs, travel costs for accompanying persons, the cost for special foods and other household costs. Since direct costs is the highest portion of the economic burden, it is necessary to study how these sub-variables have been affected as a share of direct costs.

Table 4.2 Detailed Analysis of Direct Costs

	N	Minimum	Maximum	Mean	Std. Deviation
Direct medical cost amount (43%)	400	0	725000.00	48562.59	103957.24
Informal cost per year (6%)	400	0	175000.00	6791.50	21695.00
Travel cost per year for patient (18%)	400	0	547500.00	20541.38	52064.28

Table 4.2 (Continued)

	N	Minimum	Maximum	Mean	Std. Deviation
Additional travel costs per year (2%)	400	0	25000.00	1751.91	2543.64
Travel cost for accompanying person (23%)	400	0	638350.00	26217.08	84453.03
Cost of special food per year (4%)	400	0	75000.00	5086.27	10036.34
Other household costs per year (4%)	400	0	285168.00	5023.08	28232.86
Direct costs	400	200	1197968.00	113973.82	161627.08
N	400				

Table 4.2 shows that the highest contribution to the mean direct cost is direct medical costs. It is nearly 43% of the average direct costs. Though the hospital clinics provide everything for free, the respondents had some diagnostic tests done outside the hospital clinics in order to reduce waiting time. The cost of diagnostic tests is very high in the private sector, but people that can afford them like to do all diagnosis tests outside the hospital due to the long waiting lists in hospitals. Moreover, when some medical treatments are provided to in-patients though in-patient care and treatment is free, patients have to seek support care and treatment by hiring labour services of attendants whenever needed, which is more costly for them.

Informal costs have become 6% of the average direct costs. However, they are mainly due to some unusual cases of respondents who would spend more on getting informal treatments based on their beliefs. Nevertheless, the median value for informal treatments is far less and is Rs.800 per year only. Most of the respondents spent their money on religious offerings (poojas) such as flowers, oil, and incense for a very cheaper price. Other respondents following a different denomination get blessings from their respective churches free of charge, but some people believe in extreme expensive poojas and spend their money on such offerings. Moreover some respondents believe in natural aurvedic treatment and carry out those treatments in parallel with hospital treatments, but these respondents are extreme outliers compared to the majority of patients.

Traveling costs for patients have become a burden for people who are coming far from the clinic and they represent 18% of the average direct cost. It has become the third highest cost in the direct cost category. In addition to the people that are coming from far to the clinic, there are other people that do not live far from the clinic, but they prefer to take private modes of transportation such as hiring taxis to public modes of transportation. Then their travelling cost also becomes high. Moreover they have to take private transportation due to their poor health and are unable to travel using the public transport system.

Additional travel costs consist of expenses related to refreshments purchased from restaurants while people travel between home and clinics, and the accommodation cost. Accommodation costs include rented accommodations during the visit. At times, some respondents sought accommodation at either friends' or relatives' homes. Payments is not given in this situation, however token gifts are given as a courtesy. The cost of these gifts are counted as a part of the accommodation cost. Additional travel costs though do not involve much (2% of the average direct cost) for the respondents, and some respondents who are extremely poor and unable to afford to pay accommodations received accommodation facilities maintained by different charity organizations.

Travel costs for the accompanying person from the time of leaving home to attending the clinic until the respondent reaches home are the second highest (23%) cost from the average direct cost and the travel cost for the accompanying person consists of travel costs for the accompanying person, other additional costs, and loss of income per visit of the employed accompanying person. Most of the accompanying persons try to manage their leave or loss per day by having mutual arrangements. Transportation costs for the accompanying person will become zero when taking private transportation, but when taking public transportation the cost for traveling for the accompanying person is always included. Sometimes patients take more than one accompanying person and this will create more burden on households.

When considering the overall travel costs which consist of travel costs for the patient, additional travel costs, and the travel cost for the accompanying person, it is exactly 43%, which is equal to the direct medical costs. Then travel costs become the major cost on par with the direct medical cost.

The cost for special foods (4% of the average cost) are different with different types of respondents. It was found that the respondents had five types of answers for the cost of special foods. Some respondents (25%) buy those special foods which make them better and give proper nutrition. However, 54% of the respondents do not buy such special foods. Moreover, 12% of the respondents who were buying special foods also stated that the cost of such special food is difficult to be borne by the households. Only a few people (less than 1%) get those special foods free of charge through their social network. On the other hand, few patients (less than 1%) buy special foods since they are unable to afford these foods by themselves.

The other household cost (4% of the average direct cost) consists of the cost of household activities such as domestic helpers to attend to the respondents' health condition. Some respondents stated that they get support from neighbors and relatives from time to time free of charge. Therefore they do not have to pay for the support of household activities. However, some households take some support from time to time when it is really needed. Only a few respondents have taken the support of a helper since they live an affluent life.

4.1.2 Impact of Household Health Expenditure on Medical Poverty

In addition to assessing the economic burden, it has been studied how far the health expenditure of these households has been affected due to being impoverished by health expenditure. There is no significant difference between the median expenses of the people who are in the category of medical poverty and others (p=.912) at the 5% error level.

4.2 Determinants Affecting Economic Burden

The study has determined the demographic and economic characteristics as well as the disease characteristics of the cancer patients of the study. The study has investigated the demographic and economic characteristics; namely, gender, education, age, type of employment, distance, income, and the number of dependents. The disease characteristics consist of type of cancer, the severity of the disease, and the period of suffering.

4.2.1 Gender

Cancer has become a problem for both males and females, but it was found that there is a higher probability of women having cancer than men (MOHNIMNCCP, 2015). The stratified sampling was also based on the ratio of gender to the population. Fifty-six percent of the sample were females and 44% were males.

Table 4.3 shows that there is a difference between the male and female cancer patient groups in households and economic burden. Therefore, based on the study, there is enough evidence to reject null hypothesis 1 (H1) and it was concluded that there is a difference in the economic burden of households with cancer patients between gender at the 5% error level.

Table 4.3 Relationship between Gender and Economic Burden

	Levene's test for equality of variances		**T-test for equality of Mean difference**				
	F	**sig**	**t**	**df**	**Sig (2-tailed)**	**Mean Difference '000**	**Std. error Difference '000**
Economic burden	33.216	<.001	-5.253	272.512	<.001	-110.465	21.03

According to the Levene's test of variance between the two gender groups it is evident that the variance of economic burden was not equal between males and females ($P < 0.001$) at the 5% level of significance. Therefore the t-test was performed under the assumption that the variances between the two groups were not equal. Moreover the extremely small p-value of the t-test for the equality of the mean difference ($p<0.001$) provides evidence for a statistically-significant difference in the average economic burden between gender groups. Due to the negative confidence interval of the mean difference it was evident that the economic burdens of males as greater than that of the females.

4.2.2 Education

The education of the respondents consisted of many ordinal categories. The study found that only a few respondents had no schooling (2.5%) whilst a similar percentage had achieved the degree level (3.8%). On the other hand the majority of the respondents (34%) had a secondary level of education. Moreover, only 1.5% of the males and 1% of the females had not gone to school. All of the other patients had completed different levels of education in Sri Lanka. Since the country has free education the majority (97.5%) have had some school education. On the other hand the people that have a degree and above have become fewer (3.75%) and out of that 1.5% were females. The completion of primary education was at 18% and out of that the majority were females (10%).

The study has aimed to identify whether there is a difference in the level of education and the economic burden on households with cancer patients and different levels of education groups have been studied.

Table 4.4 Relationship between Level of Education and Economic Burden

Economic Burden	**Sum of Squares '000**	**df**	**Mean Square '000**	**F**	**Sig.**
Between groups	235768.28	5	47153.65	1.13	.343
Within groups	16428594.48	394	41696.94		
Total	16664362.76	399			

The average economic burden across the different educational groups was approximately equal according to table 4.4. According to the one way ANOVA (p =.343) the average economic burden as not significantly different across the level of education groups at the 5% level. Therefore based on the study, there was not enough evidence to reject null hypothesis 2 (H2) and it was concluded that there was no difference in the economic burden of households with cancer patients and level of education.

4.2.3 Age

Age was another demographic characteristics that was used to identify the economic burden on households. The study found that a majority of the respondents were from the age group of the 51- 60.

Table 4.5 Relationship between Age and Economic Burden

Economic Burden	Sum of Squares '000	Df	Mean Square '000	F	Sig.
Between groups	65056.22	5	13011.24	.309	.908
Within groups	16599306.54	394	42130.22		
Total	16664362.76	399			

The economic burden across different age groups was approximately equal (Table 4.5). According to the one way ANOVA (p=.908), the average economic burden was not significantly different across the age groups. Therefore, there was not enough evidence to reject null hypothesis 3 (H3) and it was concluded that there was no difference in the economic burden on households with cancer patients and across age groups.

4.2.4 Type of Employment

The study has focused on identifying whether there is a difference in different types of employment (occupation) and the economic burden of cancer. According to table 4.6 the average economic burden across different occupation groups was approximately equal. According to the one way ANOVA (p=.609) the average economic burden was not significantly different across the age groups at the 5% level.

Table 4.6 Relationship between Types of Employment and Economic Burden

	Sum of Squares '000	**Df**	**Mean Square '000**	**F**	**Sig**
Between Groups	76683.99	3	25561.33	.610	.609
Within Groups	16587678.76	396	41888.07		
Total	16664362.76	399			

There was no enough evidence to reject the null hypothesis 4 (H4) and it was concluded that there was no difference between the type of employment and the economic burden of cancer at the 5% error level.

4.2.5 Distance

The relationship between distance and economic burden (Pearson correlation = .123) was significant (p = 0.014) at the 5% error level. The correlation value was positive.

Table 4.7 Correlations between Distance and Economic Burden

		Economic burden	**Distance**
Distance	Pearson Correlation	1	.123*
	Sig. (2-tailed)		.014
	N	400	400

Note: * Correlation was significant at the 0.05 level (2-tailed).

Distance has become a significant factor in the economic burden of households with cancer patients. Therefore based on the study, there was enough evidence to reject null Hypothesis 5 (H5) and it was conclude that there was a difference between distance and economic burden at the 5% error level.

4.2.6 Dependents

The relationship between dependents and economic burden (Pearson correlation =.025) was not significant (p= .621) at the 5% error level. The correlation value was positive.

Table 4.8 Correlations between Dependents and Economic Burden

		Economic burden	**Dependents**
Economic Burden	Pearson Correlation	1	.025
	Sig. (2-tailed)		.621
	N	400	400

Table 4.8 shows there was not enough evidence to reject null hypothesis 6 (H6) and it could be concluded that there was no relationship between the number of dependents and the economic burden of cancer.

4.2.7 Income

This research has focused on identifying whether there is a relationship between the levels of income and the economic burden of cancer. It was found that there was a different between level of income and the economic burden of cancer. According to the ANOVA, economic burden was different among levels of income (p =.015) at the 5% level of significance.

Table 4.9 Relationship between Income and Economic Burden

	Sum of Squares ‘000	**df**	**Mean Square ‘000**	**F**	**Sig**
Between groups	579627.884	4	144906.971	3.154	.015
Within groups	12726403.12	277	45943.694		
Total	13306031	281			

Furthermore, among the levels of income concern there were significant differences in the economic burden between the income group of 10000_19999 and 40000 and above (p = 0.039) according to Tukey's multiple comparison. In addition to the statistical significance, the actual difference in the mean scores between groups was near a medium effect (the effect size calculated using eta squared was .043). Therefore it could reject null hypothesis 7 (H7) and it was concluded that there was a difference between level of income and economic burden of cancer at the 5% error level.

4.2.8 Type of Cancer

According to the ANOVA the economic burden was different according to the types of cancer (p-value <0.001) at the 5% level of significance.

Table 4.10 Relationship between Type of Cancer and Economic Burden

	Sum of Squares '000	**df**	**Mean Square '000**	**F**	**Sig**
Between Groups	2297894.6	8	287236.828	7.817	<.001
Within Groups	14366468.1	391	36742.885		
Total	16664362.7				

In addition to the statistical significance, the actual difference in the mean burden between the groups was quite high (the effect size calculated using eta squared was .13). Furthermore, among the types of cancers there were significant differences in economic burden between the following types according to Tukey's multiple comparison.

Table 4.11 Significance of the Type of Cancer

Type of Cancers	**P-value**
Lip, oral cavity and pharynx and lymphoma	.003
Breast and trachea, bronchus, and lungs	.009
Breast and lymphoma	<.001
Trachea, bronchus, and lungs and oesophagus	.024
Trachea, bronchus, and lungs and ovary	.005
Cervix uteri and lymphoma	<.001
Oesophagus and lymphoma	<.001
Thyroid gland and lymphoma	<.001
Ovary and lymphoma	<.001

It was proven that there is a relationship between the type of cancer and the economic burden of cancer. Based on Tukey's multiple comparison it was found that some types of cancers (Table 4.11) are significantly different from others by comparison of pairs. There was enough evidence to reject null hypothesis 8 (H8) and it could-be concluded that the type of cancer has a significant impact on the economic burden of cancer.

4.2.9 Severity of the Disease

According to the ANOVA the economic burden was different according to the severity of the disease ($p<.001$) at the 5% level of significance.

Table 4.12 Relationship between Severity of Disease and Economic Burden

	Sum of Squares '000	**df**	**Mean Square '000**	**F**	**Sig**
Between groups	667819.6	2	333909.8	8.287	<.001
Within groups	15996543.1	397	40293.5		
Total	16664362.7				

In addition to the statistical difference the actual difference in economic burden between the groups was near to a medium effect (the effect size calculated using eta squared was .04). Furthermore, among the severity of the disease there were significant differences in the economic burden between different levels according to Tukey's multiple comparison.

Table 4.13 Significance of Severity of the Disease

Severity of the Disease	**P-value**
Recovered but follow up and not recovered but spreading and taking treatments	<.001
Not recovered and not spreading, but taking treatments and not recovered but spreading and taking treatments	.007

The data analysis revealed that the severity of the disease has become significant with the economic burden on households. There was a significant difference among the groups (Table 4.13) according to Tukey's comparison. There was enough evidence to reject null hypothesis 9 (H9) and it can be concluded that the severity of the disease had a significant impact on the economic burden of cancer at the 5% error level.

4.2.10 Period of Suffering

Furthermore, another disease characteristic was studied: how far the duration of suffering affects the economic burden of cancer on households. Some patients were suffering from the disease for a long time, but mostly they have recovered fully from the disease and are taking follow-up treatments. However, some people did not suffer for a long time but have not recovered and are taking treatments.

Table 4.14 Relationship between Periods of Suffering and Economic Burden

		Economic Burden	Period of Suffering
Economic burden	Pearson Correlation	1	-.192**
	Sig. (2-tailed)		<.001
	N	400	400

Note: **. Correlation was significant at the 0.01 level (2-tailed).

The relationship between period of suffering and economic burden (Pearson correlation = -.192) was significant (p = 0.001) at the 5% level. The correlation value was negative. There was enough evidence to reject null hypothesis 10 (H10) and it can concluded that the period of suffering had a significant impact on Economic burden of cancer at the 5% error level.

4.3 Multivariate Analysis of the Determinants Affecting Economic Burden

The study used bivariate as well as multivariate analysis for identifying the determinants affecting for the economic burden on households of cancer patients. Multivariate analysis was used to analyze the data, which involved more than one variable. Multiple regression can be defined as a "general statistical technique used to analyze the relationship between a single dependent variable and several independent variable" (Hair et al., 2010). Multiple regression was used to analyze the determinant effects of the economic burden on households with cancer patients. The multiple regression used in this study did not violate the basic assumptions. Both bivariate analysis as well as multiple regression proved that the same independent variables are significant in relation to the economic burden on households.

Table 4.15 Relationship between the Determinants and Economic Burden

Independent variable	B	β	T	P
Constant	336.804		19.15	<.001
Gender male	90.141	.215	4.532	<.001
Distance	.351	.119	2.551	.011
Income 40000 above	111.419	.143	3.105	.002
Types of cancer -	118.943	.123	2.584	.010
lymphoma	-67.096	-	-2.385	.018
Type of cancer -		.111		
oesophagus				
Severity of disease	124.369	.129	2.684	.008
Period of suffering	-.690	-	-3.827	<.001
		.178		

Note: R^2= .192, Adj R^2 = .177, F(7,389)=13.188, p <.001

The hypotheses were tested at 5% level of significance in this study. The economic burden on households with cancer patients was the dependent variable of the study. The independent variables consisted of demographic characteristics, economic characteristics, and disease characteristics. These determinants explained 18% of the total variance of economic burden on households with cancer patients (R^2 = .192, Adjusted R^2 = .177 F =13.188, p<.001).

When considering all of the determinants, the regression model showed that males had the strongest positive impact on economic burden (β = .215, t =4.532, p<0.001). Cancer creates more opportunity costs for taking treatments for males compared to female cancer patients.

The other demographic characteristic that affected the economic burden was distance (β = .119, t=2.551, p =.011). When distance increases the economic burden on households will increase at the 5% error level.

The economic characteristic of income (β = .143, t=3.105, p =.002) was also different regarding the economic burden on households. When considering all of the

income levels, the income of above Rs.40 000 created more economic burden for households compared to the income level below Rs.10000.

The model has identified that the types of cancer, the severity of the disease and the period of suffering will create a greater burden for patients under the disease characteristics. Patients with lymphoma cancer experienced a greater burden (β = .123, t = 2.584, p = .010) compared with patients with lip, oral cavity, and pharynx cancer. In addition the patients that were suffering from oesophagus cancer has created negative impact (β = - .111, t = -2.385, p = .018) compared with the patients suffering from lip, oral cavity and pharynx cancer.

Patients that had not recovered but in whom the disease was spreading had greater burden (β =.129, t=2.684, p = .008) compared to the people that had fully recovered and were taking follow-up treatments. The period of suffering (β = -.178, t= -3.827 , p =<.001) had a negative relationship with economic burden. This is due to the fact that when patients take treatments for a long period of time and recovered from the disease, they sometimes take follow-up treatments from time to time. However, the economic burden during this convalescent period is less than the severe period of the disease.

4.4 Relationship between the Economic Burden of the Illness in the Case of Non-Communicable Diseases, with Special Reference to Cancer and the Sources of Financing the Burden

This study has analyzed how sources of financing can have a significant influence on the economic burden on households with people suffering from cancer. The following means (coping strategy) of financing—savings, loans, insurance, social capital, sale of assets, and community-based organizations—were selected based on the extant literature. The category of savings consisted of the previous month's salary, the savings of the patient, and the savings of the family members. Mortgage included the mortgage of jewelry and other productive assets. The sale of assets consisted of the sale of livestock and the sale of productive assets. Loans were mainly from friends and relatives and money lenders. One of the main items that the respondents have used was social capital, which consisted of support from children and received in kind from friends and relatives. Finally the study appraised the use of

community-based organizations and state organizations and the reduction of consumption expenditure. Only 26.5% of the respondents used government sources of financing to reduce the economic burden on households. Whether the mean economic burden on households varied between sources of financing using one-way ANOVA was tested.

Table 4.16 Relationship between Sources of Financing and Economic Burden

	Sum of Squares '000	**df**	**Mean Square '000**	**F**	**Sig.**
Between groups	1161450.381	4	290362.595	7.347	<.001
Within groups	15295376.20	387	39522.936		
Total	16456826.58	391			

The results in Table 4.16 suggest that the average economic burden is significantly different among sources of financing at the 5% level of significance. Therefore it can be stated that different levels of economic burden lead to different sources of financing. In addition to the statistical difference the actual difference in economic burden between the groups was even more above the medium effect (the effect size calculated using eta squared was .07).

Furthermore, among the sources of financing there were significant differences in the economic burden on households between the following sources (Table 4.17) according to Tukey's multiple comparison.

Table 4. 17 Tukey's Multiple Comparison Regarding Sources of Financing and Economic Burden

	P value
Income/salary from previous month and savings of patient	<.001
Savings from patient and savings of family members	<.001
Savings of patient and support from children	.031
Savings of patient and in kind from others	.001

The study results indicated that salary, the savings of the patient, the savings of the family, the support of children, and receiving in kind from others had a significant difference compared to other sources of financing.

Therefore based on the study, there ~~was~~ enough evidence to reject null Hypothesis 11 (H11) and it can be concluded that there was a difference in economic burden on households with cancer patients and sources of financing at the 5% error level.

4.4.1 Relationship of the Sources of Financing and Direct Cost for Households with Cancer Patients

The study has more deeply analyzed how the sub-components of the economic burden have affected the sources of financing. It was tested whether the mean direct cost varied between sources of financing using one-way ANOVA.

The results in Table 4.17 suggest that the average direct cost was significantly different among the sources of financing at the 5% level of significance. In addition to the statistical difference the actual difference in economic burden between the groups was near to a medium effect (the effect size calculated using eta squared was .05). Therefore it can be stated that the different levels of economic cost lead to different sources of financing.

Table 4.18 Relationship between Sources of Financing and Direct Costs

	Sum of Squares '000	**df**	**Mean Square '000**	**F**	**Sig.**
Between groups	567996.490	4	141999.12	5.605	<.001
Within groups	9803718.35	387	25332.60		
Total	10371714.84	391			

Furthermore, among the sources of financing there were significant differences in economic burden between following sources (Table 4.19) according to Tukey's multiple comparison.

Table 4.19 Tukey's Multiple Comparison of the Sources of Financing and Direct Costs

Sources of Financing	**P-value**
Income/salary from previous month and savings of patient	.004
Savings of patient and savings of family members	.004
Savings of patient and support from children	.002
Savings of patient and in kind from others	.001

The study results indicated that salary, the savings of the patient, the savings of the family, the support of children and receiving in kind from others were significantly different compared to other sources of financing.

Therefore based on the study, there was enough evidence to reject null hypothesis 12 (H12) and it can be concluded that there was a difference in the economic burden of households with cancer patients and direct costs at the 5% error level.

4.4.2 Relationship of the Sources of Financing and Indirect Costs for Households with Cancer Patients

The results in Table 4. 20 suggest that the average indirect cost was significantly different among the sources of financing at the 5% level of significance. Therefore it can be stated that the different levels of economic costs lead to different sources of financing.

Table 4.20 Relationship between Sources of Financing and Indirect Costs

	Sum of Squares '000	**df**	**Mean Square '000**	**F**	**Sig.**
Between groups	206531.62	4	51632.90	3.667	.006
Within groups	5448729.75	387	14079.40		
Total	5655261.38	391			

The study found there was a difference in sources of financing based on indirect costs using one-way ANOVA. Furthermore, among the sources of financing there were significant differences in economic burden between the savings of family members and the support from children (p = .001) according to Tukey's multiple comparison. Therefore based on the study, there was enough evidence to reject null hypothesis 13 (H13) and it can be concluded that there was a difference in the economic burden of households with cancer patients and indirect costs at the 5% error level.

4.4.3 Relationship of the Sources of Financing and Impact on Household Costs of Households with Cancer Patients

The average costs of the impact on household costs across different sources of financing were approximately equal according to table 4.21.

Table 4.21 Relationship between Sources of Financing and Impact on Household Cost

	Sum of Squares '000	**df**	**Mean Square '000**	**F**	**Sig.**
Between groups	7382.15	4	1845.53	.791	.531
Within groups	902754.26	387	2332.69		
Total	910136.41	391			

According to the one-way ANOVA (p=.531) sources of financing were not significantly different from across the impact on household cost at the 5% error level. Therefore it can be stated that the different levels of the impact of household costs did not lead to different sources of financing.

Therefore based on the study, there was not enough evidence to reject null hypothesis 14 (H14) and it can be concluded that there was no difference in the economic burden on households with cancer patients and the impact of household costs at the 5% error level.

4.5 Challenges Faced in Financing the Economic Burden of Cancer on Households

There were many challenges faced by patients in the phase of financing the economic burden on households. It is necessary to consider the physical, emotional, social, spiritual, and financial challenges faced by cancer patients (MOHIMNCCP, 2015). But this study has focused on financial challenges. The study has revealed that the government has contributed in many ways to assisting with the financing of the burden, in addition to providing free healthcare facilities. Patients can request substantial financial grants for special medication and surgery from a special Presidential Fund established for health purposes. In addition, if any person is in the lowest income category, under the categories of the elderly, disabled, or have long-lasting ailments, he or she can obtain monthly allowances of varying amounts under the Department of Social Services (Provincial council). Generally such allowances are nominal and very small.

The respondents suggested mainly eight types of challenges faced in getting financial assistance under different sources, such as state assistance, medical insurance, personal loans, sale of their assets, etc. A high percentage of the respondents (32%) lacked knowledge about the financial assistance from the government and community sources. They were not aware of the monthly allowance that can be obtained from the Department of Social Services-Provincial Council.

Seventeen percent of the respondents regarded getting state monthly financial assistance as very difficult and challenging. They opined that this involved high opportunity costs. This has discouraged them from making any attempt to approach the state for financial assistance. This is specially applicable to most of the respondents that genuinely require assistance, that are not physically fit to make the visits, and that are required to attend to many demanding administrative procedures. Even if once they manage to get a regular monthly allowance, which has to be obtained from the nearest government post office, most of the respondents found that the cost of travelling involved in getting such a small amount, which generally requires a private means of conveyance such as a three wheeler, did not offer any benefit.

In addition to the above two issues faced in getting state financial assistance, about 13% of the respondents expressed that they experienced a long delay in physically getting the money in their hands even after the assistance was approved. This is due to the strict administrative procedures involved and the red tape generally involved in the state sector. They were in fact still waiting for their first assistance payment.

In addition to the many difficulties and challenges faced in getting financial assistance from state sources, the other issue that was considered the third highest challenge (15%) was the problem of paying back the installments on various mortgages. People that suffer from cancer mostly have either their income greatly reduced or have lost it altogether. Therefore, most of them are unable to settle the mortgages. Patients that have taken out loans (8%) also face difficulties in paying back the loans for the same reasons.

None of the respondents that had various types of medical and health/life insurance coverage, except schemes under the state insurance scheme for government employees, was happy about the benefits he or she get. The general complaint was that when they were in real need, they were unable to get the money back. One reason was the inability of the respondents to travel many times to insurance companies to get the payments. The other was that the insurance companies were unable to release any payments as most of the respondents had defaulted on their instalment payments, understandably, due to the financial difficulties faced by the respondents and because focusing all of their resources on treating the disease took priority in their lives.

4.6 Chapter Summary

This chapter has provided the data pertaining to the findings. The data were presented under each objective of the study. In addition the data analysis was done with the use of univariate, bivariate, and multivariate analysis. Univariate analysis was helpful in identifying the demographic characteristics of the respondents and it was used in analyzing the objective by using the cost of illness theory. Moreover, the challenges faced by the respondents in sourcing required finances were also analyzed using univariate analyses. Bivariate analysis was used to identify the relationship

between the determinants of the economic burden on households with cancer patients. In addition, it was also helpful in identifying the sources of financing. Multivariate analysis also was used in analyzing the relationships among the demographic, economic, and disease characteristics, and the economic burden on households. Based on the findings, hypotheses H1, H5, H7, H8, H9, H10, H11, H12, H13 were rejected. There was a difference between the economic burden on the households with cancer patients and gender, distance, income, type of cancer, severity of disease, and period of suffering. There was also a difference between the economic burden on households with people with cancer and sources of financing. Priorities for policy options were discussed in the conclusion of the chapter. The next chapter provides a qualitative analysis in order to triangulate the quantitative findings for more detailed analysis.

CHAPTER 5

QUALITATIVE ANALYSIS

This chapter provides a qualitative analysis of the study. The main purpose was mainly to triangulate the findings of the quantitative analysis. An attempt has been made to link the findings from the quantitative results. The detailed analysis was based on the economic burden and how it has affected the respondents of the study. This was very helpful in triangulating the findings of the quantitative analysis of the study. Some case studies were used to prove how far those variables were affected concerning the economic burden of households of cancer patients. Since the researcher filled out the questionnaire with the information obtained from all of the respondents, there were interviews with respondents, which enabled the researcher to clarify the responses received. However, this lengthy discussion was not forced upon the respondents, but was purely based on their willingness and consent. The case study method was used as the method of qualitative analysis for this study. All of the names in the qualitative analysis are anonymous. Additionally, the qualitative analysis as helpful in preparing policy options in arriving at priorities in the Sri Lankan context.

5.1 Relationship between Economic Burden on Households with Cancer Patients and Gender

The literature indicates that there is a relationship between economic burden with people with diseases and different genders. Therefore there was a necessity to study how gender differentiation affects the economic burden on households with cancer patients. It was found from both the quantitative and the qualitative analysis that gender has a different effect on the economic burden of households with cancer patients.

5.1.1 Relationship between Economic Burden on Households and Being a Male Cancer Patient

The researcher had a lengthy and open discussion with Mr. Siripala (pseudonym), who has been diagnosed with oral cancer and is presently taking treatment. His cancer has not spread to other organs, but he has not recovered fully from the initial cancer. During this in-depth interview followed by an informal discussion with him in filling out the questionnaire, he has narrated a lot about his background and sad experiences as to the extent that this malady has economically burdened him and his dependents. In the Sri Lankan context being a male invariably makes one the head of the family, who is looked up to be the breadwinner and the one to look after the family. However, where the wife too is earning, it supplements the main income from the male. Where it is not the case, however, whatever is earned by the male as the head of the family is the primary and most important source of income for the family or even for the extended family in most cases.

The following is a tale of woe in his own words:

> I am a father of two children and the sole bread winner of the family. Our family was living in a happy and contended life, relatively, until the revelation that I was suffering from cancer, which gradually changed the life around for me and my family. Earlier I was taking care of children's transportation to school and went for my office work. After school wife was taking care of children's travelling to home and taking care of household activities. With the onset and identification of the symptoms of cancer, it called giving all my attention and my family's to look for a permanent cure, as all of us were aware of this terminal illness and what it could mean to our family. Our world turned upside down. Having to spend time in looking for cures, where we left no stone unturned, I had to travel far and wide, from pillar to post, with whatever hint whoever gave me, which could cure me from dreaded cancer. This prevented me from attending to my place of employment regularly and by mutual understanding with the employer, I had to resign from my employment. I as well as my employer knew, that I had to spend more time, in fact full time, in the treatment of this terminal illness. Was it a bit too late

> for me? I thought so, as the most unfortunate aspect was that my initial diagnosis took a longer time since I was unable to devote that much of time to attend clinics due to my responsibilities of the employment, what I earned from my job is the one and only income that kept the fire in the kitchen burning for the family.

He was an informal employee and was not covered by any medical or health insurance policy by the employer, as is the practice in the majority of small businesses in Sri Lanka. Additionally, he did not receive any retirement benefits or a gratuity or other terminal benefits since he was working on a contract basis, which was renewed annually by the employer in order to avoid having to pay most of the statutory benefits to the employees. This is commonplace in Sri Lanka since the small businesses too are finding it difficult to comply with all of the regulations, and the employees too are content to get paid daily, weekly or monthly without seeking any additional benefits. However, the gravity of not having such social security coverage is hard felt by people like Mr. Siripala, who had to leave the job empty handed.

With no regular income which he was used to earning, the family had to depend on the meagre savings they had. It did not take long before he had spent the last penny he had as savings, which was used having to take care of the basic necessities of the family and the travelling and medication for his sickness. Had his wife been skilled in any trade or vocation, she could have earned something for the subsistence of the beleaguered family. However it was not to be since she had no special talent or any qualification which could give her easy employment. The other side of it was that she could not anyway be away from the house since she had to look after her ailing husband, the two children, and the household chores. Therefore, it was a death blow from having to resign from his job or losing his job that started the gradual deterioration of his family's economic condition, which determines all aspects of life in modern society. With his economic condition hitting rock bottom, he said that he sold his house in a last ditch attempt to seek a cure to this disease and also to maintain his life at the lowest level possible. However, this move, instead of giving him respite, piled up more problems on the family since they were left without a place to live. He said that “even the last square inch of land I owned on this earth was lost to

me, and I was thrown on to the street." With the hope of getting proper treatment, in addition to attending government hospital facilities, he had to seek private consultation from specialist oncologists, which was always expensive. All this added up to the economic burden that was crushing him, and at the same time there was no cure in sight from the cancer he was afflicted with. He knows that not only was he faced with a potential terminal illness, but he also was in desperate straits along with his wife and children if he were to live this world due to illness.

Since substantial facilities for cancer treatment are available only at specific hospitals, which are mainly in locations far away from the district where he lived, he has to spend long hours travelling to the hospital for consultation and clinical treatment. He spent nearly two days travelling by public transportation, where no direct facilities were available, to attend the clinic, which was a huge burden on him, both physically and economically. In addition he is not in a position to travel using private transportation, which has created an additional burden through using hired transportation. Normally he and his wife start travelling late during the night to reach the hospital clinic in time the next morning. With the gradual deterioration of his physical condition, he had to be accompanied by his wife and it was necessary for them to somehow hire some form of conveyance. Sometimes, in addition to the hire of the vehicle, he had to spend money on the meals for all three of them, including the driver of the vehicle. There have been days when they have arrived the previous night and spent the night at a public place such as a temple close to the hospital, which provides facilities to spend the nights for cancer patients seeking treatment. After spending the whole day at the clinic and after spending whatever he had in his possession, they would reach home late at night. So it is imaginable the mental pressure he has to go through to prepare for every visit to the clinic, as he stated the following:

> This single illness, could crumble down my whole life to the very ground, having lost my source of income and the place we called our home, where we could live without anybody forcing us out.

Finally, this is only a few of the aspects of his life after his being diagnosed with cancer. The days could well be numbered for Mr. Siripala. He might or might not come out of this malady. Whatever happens in the future, his and his family's future will not be the same again. From all perspectives, this is a tragedy on the greatest scale. He has lost his physical ability to work and the money he received from the sale of his house is fast drying up. However this study is only concerned about the economic burden that cancer patients could face, and this is only another case where untold economic hardships are heaped on a hapless family with no relief in sight. It is invariably the same story; having to give up what you do in earning a daily income and having to cope up with the immense burden of having to seek treatment, which is a case of "do or die"—in the majority of cases, "do and die."

Another story is from a male patient I will call Mr. Bandusena (pseudonym), who is suffering from lung cancer, which also proves what can be done to their lives economically. He was a self-employed mason involved in major housing construction, earning a good income of around Rs. 40,000 per month. Though his vocation earned him daily wages, he got contracts all the time and was highly sought after, as masons are in great demand with the construction boom that Sri Lanka has been experiencing for the last few decades. While he was working there were no financial problems since he was employed throughout the year and his wife was also looking after the children. However, getting symptoms of lung cancer was the starting point of the ruination of his life. He always had tacit plans to give proper education to his children and to upgrade their living standards, but with his diagnosis, he said “all my dreams went down the drain Though he spent most of his income on his children’s education and living a decent family life, today he is made to survive with the help from others by way of handouts mainly. He said that he could not work anymore until and unless he recovered sufficiently. Since he was a daily earner and spent that money on a daily basis, he could not save any substantial amount and did not have any money now for his expenditure.

Just as the case in most of the rural families, his wife too was not employed but was a good housewife, looking after the household chores and the children. Therefore, his financial situation has deteriorated. For receiving treatments, he needs to pay for private transportation since he is unable to travel by public transportation,

mainly due to the longer time it takes and also the need to break the journey, as no direct transportation is available from his place to the location of the hospital. Hence each visit to the hospital clinic costs him a huge amount of money, whereas he does not earn any. So far this has forced them to dispose of many of their household assets and also to mortgage almost all of his wife's jewelry. They face the prospect of losing such pawned jewelry since they are not in a position to redeem it. He has also either sold or mortgaged all of his valuable assets for the day-to-day spending for him and his family. Moreover, they have had to drastically curtail the consumption pattern of the family in order to save for his health-related expenses such as travelling and medication, prescribed but not available at the government hospital at times. According to him, "we have resorted to limit our main meals (normally three a day) to one, in order to meet the worsened family economic situation."

He admits that well-wishing neighbors and relatives have been helping him, but understandably this would not fully meet their financial needs. He knows that they could expect this not to continue as these people too are helping him with difficulties. He said that he is unable to picture the future if he is not cured soon enough, as things are getting worse by the day. To ease the family financial situation, mainly to help him with his treatments, his wife has found employment as domestic help at a neighboring residence. This too is only on a part-time basis, as she has an ailing husband and young children to look after as well. However, this income does not help them to make ends meet, and whatever she earns too has to be spent on the monthly visit to the hospital and related expenditure. In addition to the suffering he is undergoing, physically, mentally and financially, their children have been very badly affected. Their educational and social needs have to be put aside as their main and sole aim is to try and get him cured.

These are but two cases of families whose male breadwinners have been afflicted with cancer, resulting in the gradual but sure deterioration of the economic conditions of these families, which in most cases has no end in sight. These families become dependent on others, and live on the handouts they receive. The gravity of the economic burden increases, when the patient is the main income earner of the household and has to take the necessary regular treatment at a clinic.It is very plain to see. It was the same story, told by different individuals, over and over again, being heard by this researcher.

In contrast, the conditions, both social and economic, faced by families where the female members suffer from cancer are different compared to where the patients are male. Though both male and female cancer patients suffer physically from the disease, when the patient is a female, the economic burden on households becomes less severe compared to when the patient is a male bread winner.

5.1.2 Relationship between Economic Burden on Households and Being a Female Cancer Patient

A female that was suffering from breast cancer told her story. She has been a housewife since marriage and has not worked at any place and looks after the household. She was cooking for her own children and looking after the family. Once she was diagnosed with cancer, she immediately started taking treatment. She did not have to seek a leave from any employer to obtain treatment, since she was not employed. She prepares the food for the family early and leaves for the hospital to attend the clinic. Whenever she needs the support of an accompanying person, she finds a willing neighbor who is also a housewife. This good neighborly relation and the social network helps her a lot. Her husband, who is employed in the private sector, attends the office as usual, without having to take time off from his duties to accompany her, due to the above arrangement. She travels to the hospital with the neighbor accompanying her, and also could arrange yet another neighbor to look after her children at the neighbor's house, till she returns. Therefore, in her case the economic burden felt by the family, due to her sickness, is much less compared to the instance where the leading male of a household is afflicted with cancer and has to, invariably over time, lose the source of income. Therefore, in her case, the economic burden on the household is much less in comparison to the males, as the chief householder afflicted with cancer for a prolonged period loses his source of income. However, in terms of additional expenditure, she too has direct expenses such as transportation costs related to medical requirements and other expenses of the accompanying person. Financially, there are a lot of additional expenses due to her sickness that have not drastically affected their family income since her husband is carrying on as the bread winner. Further, comparatively, breast cancer is the most wide-spread cancer among women in Sri Lanka. This cancer site generally does not

severely affect the day-to-day living of the patient, as one of the patient's in the present study stated in the following:

> This breast cancer has not affected much since I have taken early treatment. But I am not allowed to freely use the hand on the side of the treated breast, which curtails my use of that hand to some extent. But I have got used to using other hand for all my household activities, hence this forced immobility of one hand, has no great impact on carrying out the day to day household activities.

Although there were no new economic hardships due to the sickness, she has additional expenditures for her physical appearance. This situation when she says:

> During the treatment period, I lost my hair and went totally bold. A woman being bold is a social stigma in this part of the world, and I was no exception to this. I had to avoid meeting people as much as and wherever possible. As a woman we, irrespective of the age, are always concerned about the physical beauty and having wholesome hair is one of that contributes to the beauty of a woman. In order to avoid being seen by the public, during that time I had to use private transportation, with the blessings of the husband who understood what I was going through. Though the use of private conveyance loaded additional economic burden on the family, it spared her a lot of mental agony, which was worth the cost, I feel.

The expenditure of seeking treatment from this potentially terminal illness in Sri Lanka is the same if you seek treatment from government clinics; there is no discrimination of sexes with regard to the expenses involved. These are mainly the regular conveyance to the hospitals (in most cases private transportation has to be sought due to the patients' physical inability to take public transportation), the expenses related to treatment (though the treatment at clinics are totally free of charge, it is not unusual for the hospital to recommend taking some drugs from outside pharmacies due to the unavailability of such medication at the hospital at that

very moment, and also specialized reports from outside laboratories if the patients cannot be on the waiting list of the hospital for many months), and the expenses related to the accompanying person or persons. The majority of the cancer patients are obliged to meet these expenses.

5.1.3 Conclusion Concerning the Relationship between Economic Burden and Gender

The difference between the male bread winner being the cancer victim and a female member of the family becoming the patient is enormous. The enormity mainly affects one sphere of the family—the economic situation. The male income earner becoming afflicted with cancer invariably incapacitates him physically, over time, forcing him out of work, resulting, in majority of the cases, the family losing its sole source of income. However, where a female member falls victim to cancer, the situation would not be so grave so long as the male member decides that he would look after the patient as well as his source of income at the same time. This is the general pattern that this researcher came across during the study.

It has been found from the quantitative analysis from both the bivariate and multivariate analysis that gender is a significant factor when determining the economic burden on the families where a member suffers from cancer. It also shows that households where the male is the cancer patient face higher prospects of having to bear the severe economic burden than households with female cancer patients.

5.2 Relationship between the Level of Education of Cancer Patient and Economic Burden on Households with Cancer Patients

The respondents comprised different education level groups, such as no formal school education, primary education, secondary education, higher secondary education and studied up to the university level. The descriptive analysis showed that there were only a few respondents in the two groups with no formal school education and at the degree level. The reason could well be that there is free education, which is also compulsory for all children of school-going age. However, only a few would go as far as completing university education leading to a degree. The majority of them

have completed secondary education, and it is secondary education that has suffered the most due to the economic burden on the families due to nursing a cancer patient.

The respondents that were in the group of having completed a degree or attained a higher education level were enjoying good employment. Therefore, those respondents who were currently employed in a recognized organization were able to obtain a leave with pay under varying leave categories allowed by their employment agreements for their treatment. Additionally, most of the respondents at a high degree level were covered by medical and health insurance schemes funded by the employer. This greatly helped them to recover the expenses they incurred for treatment.

In addition, since most of them have exposure to up-to-date information, they tend to study about their symptoms at websites as well as consult doctors at the very early stage when they are in some doubt. Since a cancer, if diagnosed at an early stage, has a greater chance of being cured or there is a greater chance of reducing the impact, this too helps to reduce the burden, which could have been greater if ignored, as in most of the cases with less-educated patients. One male respondent explained about his situation. He discussed with many authorities on the subject about the situation while gathering information from websites himself. He said "I have had studied very much on the disease from the Net, before meeting the doctor." This was possible since he was computer savvy and had ready access to the Internet. Therefore, his knowledge helped him to recover faster and he is now fully recovered. He comes to the clinic for follow-up treatments.

Therefore the additional burden related to taking cancer treatment, which was common to all groups, is felt to a lesser level by people that have achieved higher educational levels. The respondents that have retired from employment too do not have to face severe economic burdens compared to others that are presently employed, since they either receive monthly pensions or income from investment they have made outside the terminal benefits received at the time of retirement. Therefore, the patients that were either retired or presently well employed with a degree did not face as much economic burden as others, who were at a lesser educational level and not employed well due to a mediocre educational level.

A patient with a university degree explained things lightly as follows. "I am pensioner receiving my monthly pension each month. I started my treatments

immediately after diagnosing the disease. I used to read related articles and newspapers every day since I noticed the symptoms which, were likely to indicate cancer. I immediately consulted an oncologist. All the readings I had done on the subject helped me to take timely action, which saved my life. At the initial stage of the diagnosis, I went to a private hospital got all the diagnosis done within a short period of time. With the firm diagnosis of the cancer, I joined government hospital started treatments. Since I do not have another work or issues with leave, I can visit clinic at the prescribed dates and avail myself for the treatment. Since all treatment is free of charge at government hospital, I have to spend only on transportation. Generally, I visit the hospital alone but sometimes my wife accompanies me. Therefore, I did not waste time in receiving treatment since the diagnosis, I have now recovered from the disease and am receiving follow up treatments. Since I am a government pensioner I do not have to overly worry about financing my treatments since the pension I get regularly is sufficient to cover my household consumption and my treatment related expenses. I am not worried much since at present level of development in cancer treatment, it is not difficult to recover if we take treatments at early stages of the cancer. Some days, on my way home from visit to the clinic, I even watch a movie at a film hall and go home leisurely."

It has been shown that patients that have achieved a higher education or a higher degree tend to organize matters properly, which helps them to minimize economic burden compared to patients with a lower educational level. The respondents that had received a higher education studied their health condition, took treatments on time, and enjoyed their life and faced their life situation. However, it is noteworthy that there are a far few patients at this level of education compared to the vast majority of the patients that have had less education.

The majority of the respondents had attained the secondary education level and they were suffering from a higher economic burden compared to others with higher educational achievements. The main reason for this is the insufficient job security in the private sector, where a patient suffering from a terminal illness would either have to resign from the job or take a long-term leave on a no-pay basis for treatment. A few organizations have offered some benefits to the patients on sympathetic grounds, which is an exception and not the rule though. These benefits are mostly the payment

of the basic salary for the patient, despite the patient not attending the work in person. While this gesture was appreciated by the respondents, they said that this basic pay was only a small portion of their former regular income, which normally consists of many allowances and overtime, which they did not receive under this arrangement. Therefore, even though they received the basic salary they suffered from not having the major portion of the income they used to receive prior to being a cancer patient.

In addition, as mentioned earlier, the majority of the patients at the secondary education level had to suffer from having to leave the job, either by resignation or termination due to nonattendance, resulting in the loss of the only source of income for the family.

In addition, people with secondary education, who in particular are middle aged, are not used to reading articles about health issues. Moreover, it is very unlikely that they have any access to or any knowledge of the availability of information on the Internet or any websites. Due to their lack of knowledge, it is naturally difficult for them to take treatments at the early stages and the results are almost always clear and lead to their facing greater burden than those that are able to detect the disease at early stages and took proper action.

Therefore the level of education does not have much significance but it has some bearing on and relevance to the economic burden on households, depending on the level of education of the respondents.

5.3 Relationship between Income and the Economic Burden on Households with Cancer Patients

Income was significant in both the bivariate and multivariate analysis in the quantitative analysis. On the other hand the interviews with some of the respondents clearly depicted how income is significant in bearing the economic burden on households with cancer patients. Economic burden did not affect the respondents that have a very high income level because these respondents have established social networks that help them to mitigate the economic burden on households.

Another respondent suffering from cancer, called Mr.Senanayake (pseudonym), was a private sector employee and retired at due age and is now

enjoying retirement benefits. He has invested money in many places and once a month he receives his share of the interest. He receives a high monthly income from his investments. As he said he does not have to face many problems though physical pain is a burden. At the beginning he received a diagnosis of the disease characteristics from a private hospital and joined a public hospital for treatment. He received all of the treatments free of charge from the hospital. Moreover, he said that friends and subordinates from previous working places organized religious offerings called “bodi pooja” for providing relief. Thus he said:

> I did not do anything. They all organized and held several bodi pooja. In addition, I received all natural fruits produced without any artificial fertilizer freely from friends and relatives from villages. I did not have to spend money for special foods since it is received freely from others. I do not have to worry about getting leave since I am already retired.

When considering people with a high income, they are not very affected by the economic burden of cancer since they have capacity to pay. However, the majority of middle-income people suffer from the diseases compared to others.

When considering the people that receive very less income, they are mostly from the agricultural sector. This can be seen in the following story from Mr. Wijepala, who was working as a famer on his own land:

> I did not know about this disease and I took some home remedies when I face some sickness. I ate beetle leaves time to time it is much more common to us. Finally I got an oral cancer. Though I am suffering from the disease I do not give up my paddy cultivation. During the cultivation period I get some support from neighbors, family members and work as a group together. Daily I visit the paddy field and look after the paddy field which doesn’t make much burden to my day today activities. Moreover it’s my own work so I manage my work by considering clinic dates.

He regularly visits clinics and takes treatments but he does not have much knowledge about his health condition. He does not have to bear losing income since he can manage his agricultural work. However, people from other middle income levels suffer a lot more than people at a higher or lower income level. People at a higher income level can manage using different income methods, while low-income people mange income by arranging work. However, they have to spend money on transportation, which is not bearable for them. On the other hand, people at the middle-income level are in the formal employee category and they have to bear a huge economic burden compared to others.

5.4 Relationship between Having Dependents and Economic Burden on Households with Cancer Patients

The number of dependents is clearly seen to be an economic burden on households with cancer patients. However, it depends on the situation. Moreover, during the discussion, the researcher also found substantial differences between the patients that have dependents and the patients that do not. The patients that do not have dependents seem to enjoy, comparatively, a better life despite having to suffer from the disease. The patients with dependents suffer a heavier economic burden that those that do not. This became evident from the discussions that the researcher had with the respondents.

Mr. Karunapala (pseudonym) is a father of two children and his wife is a housewife. His situation is also the same as that of many male respondents that have had to leave their employment due to sickness. He stated the following in this connection:

> Before this unbearable issue took place, I had a good family life and I managed things without major financial issues. But once I was diagnosed with cancer it heralded the doom that was to hit our family. I had to leave the job and there was no one to take the burden since my kids were small. I had to stop all private tuition for kids since I could not afford it. They continue to attend the State run school because it is totally free. But the purchasing of

> some stationery and various other items, very often needed by students, has now become a heavy burden to our family. This situation has been made worse since my wife is a house wife and there is no other source of income, but all are now dependents on whatever small income I get from wherever. There is no sufficient source of income for spending on my health as well as to maintain family. At least if my children were grownups, then I would not have worried this much about them, and could have focused more on my health. In addition, I had to gradually dispose all valuable belongings, assets in order to maintain day to day living. The day when all what I have earned from the sale of our belongings are gone, what would be left for us is only the road where we would be paupers.

He was saying that if his children were grown up he could have easily looked after his life, but unfortunately, his children are still at school age and his wife too is not in a position to work.

In contrast, the following is a story, in his own words, of another respondent that does not have any dependents. All of his children are working and his wife is also a pensioner.

> It could have been my misfortune or even fortune that I got this sickness. I say this because only since I was diagnosed with cancer, I came to know and experienced the bond that was existing within our family members; my wife and three daughters. My three daughters are grown-ups and are employed in the private sector. My wife is a retired teacher drawing her pension monthly. They look after me for everything. My daughters never allow me to come to hospital alone, but arrange to take turns as mutually agreed amongst three of them, in accompanying me on my visits. If and when one daughter is unable to keep her accompanying schedule for any reason, another daughter would fill the void and come alone with me to the clinic. Also amongst three of them, they would always bear the total expenses involved in my visit to the clinic and would not allow me to spend anything. Also they make sure that weekly they bring whatever healthy foods that are supposed to be good for my

sickness. I bless them that they are able to do all these since they are independent financially and not depending on me or my wife. I do not go to market to buy grocery items. I go to temple every day pray for mental happiness for me and for all humans. I was lucky enough to have three daughters and they are financially stable. In the beginning I told that it could even be my fortune that I got this sickness; I feel that way as due to this situation only I could see how caring my family, especially my three daughters are caring for me, especially since I was diagnosed with cancer. This could have been the only way I and my wife would have known how our children would care for us when we are in need. This has allowed me to be more generous towards others who are less fortunate than I am. When I meet a patient whom I feel as in dire financial need, I sometimes help him/her financially, since I believe that I have been blessed and have what I need in this birth.

The above contrasting scenarios of two respondents, one burdened with hapless dependents and the other not having dependents, show a totally different picture of the extent of the economic burden that dependents could have on a household with a cancer patient. Cancer patients with dependents have to shoulder a huge added economic burden compared to the patients that do not have anybody depending on them for sustenance. They invariably seem to live, comparatively, a more comfortable life despite nursing a potentially terminal illness. This depends on the situation of each household.

5.5 The Relationship between Distance to the Treatment Center and the Economic Burden on Households with Cancer Patients

The distance to the cancer treatment clinic is one of the major burdens for all of the respondents that reside far from the clinic. There are only a few cancer treatment hospitals in Sri Lanka and these hospitals are located in only in seven districts out of the twenty-five districts of the island. Therefore, essentially, patients from all over the country have to travel substantial distances to take tests and to

receive treatments at the few available cancer clinics. All of the patients travelling from such distances narrated the difficulties and grievances they had to undergo in reaching the clinics, especially since they were required to be present at the clinics at early hours of the day, before they were open.

Mrs. Sumanawathi (pseudonym), a 60-year-old lady, living in a village far from the hospital, suffering from ovary cancer, had the following to say:

> I have to spend around three to four days for travelling to and from the clinic, using public transportation, as I have no means of using a private means of conveyance. The day before the clinic, we take a bus from my house to railway station which is also located quite a distance from where I live. I take night mail train to travel Centre. Train reaches the district where the hospital is located at late night. This leaves us with no choice but to sleep overnight at the railway station itself. But none of us can take any sleep at the station for numerous reasons. But at least we have a roof over our heads to protect us from dew and rain. Early next morning we take a public bus to town and from there another bus to travel the remaining distance of about two kilo meters to the clinic, since I am normally too tired both physically and mentally to walk that distance. There are instances that we take a three-wheeler from town to the clinic, if we happen to walk late for the clinic. This is an additional burden we cannot afford every time, but only as the last resort for reaching the clinic in time, since it is always better to be within the first few slots of the queue. Since it takes nearly three to four days for travelling, I always have to have someone accompanying me , not necessarily due to my deteriorate health, but mainly since it involves full night travelling and staying overnight at public places. If my treatments at the clinic take a longer time than expected, as it often does we find no way of travelling back and have to stay in the temple nearby which accommodate such patients who cannot afford paid rooms elsewhere. Then, it is the reversal of our trip, taking a bus from clinic to the immediate town, another bus to the main railway terminal to my district. The train would reach our destination dead at night and we have to stay overnight there and take a bus to home next morning. This takes full toll on my body

> and our purse. This trip normally puts me off for at least two days before I could be at least what I was before the clinic trip. Despite the fact is that this is an outpatient clinic, which takes only a few hours, most of the time, I have to spend three to four days. Added on to the time it take for the visit, each visit costs me nearly Rs. 3,000 for public transportation, which involves number of breaks in the journey. Though the medicine and laboratory diagnosis tests are provided free of charge under the free health programmed of the government, I have to spend lot of money for my transportation simply due the distance of my house from the hospital. This is a huge burden on me and my family.

Another respondent, Mr. Ranasinghe (pseudonym), is also suffering from colon and rectum cancer. He said that he was a single farmer with no family and was working alone in his own paddy field. Since paddy rice is harvested in Sri Lanka only during two seasons, he had already earned some money from selling the harvest from the previous season. He had spent the all money for previous clinic visits and now he did not have any money for the transportation. He stated the following:

> Now I have to get loans from relatives and neighbors for my transportation. If I fail to get any such loan, as often happens, I have to postpone the visit to the clinic, since there is no other option. I don't have to pay for any accommodation for the travelling since I stay in a temple near to the clinic during the night. Sometimes I pledge my future harvest for getting loans for transportation. This is a vicious circle which keeps me in debt all the while.

On the other hand, the respondents that reside close to the clinic come to the clinic regularly and early in the morning. This ensures that they will get the treatments early without having to waste long hours. Moreover, they more often than not do not need an accompanying person for this purpose, except for an event where deteriorated health conditions demand an additional helping hand. In addition, the respondents spend less money for travelling a comparatively shorter distance from home, and the economic burden will be less since hospital facilities are free of charge.

In conclusion, the situation faced by almost all that live far from the clinic is pathetic. It is all the more so, since the services and medication are given free of charge by the government. It is the distance that has made these free health facilities very difficult for most to receive as they are meant to be. So, the distance to the treatment center from where the patient lives is a clear determinant affecting the economic burden on households, as seen from the study.

5.6 The Relationship between Type of Cancer and the Economic Burden on Households with Cancer Patients

This study has focused on ten major types of diseases that people are suffering from in Sri Lanka. The main five types of cancer for females are breast, cervix uteri, thyroid gland, ovary, and oesophagus, while the main five types of cancer for males are lip, oral cavity and pharynx; trachea, bronchus and lungs; oesophagus, colon and rectum; and lymphoma. It was found from both the bivariate as well as the multivariate analysis that the type of cancer is one of the major determinants of the economic burden on households with cancer patients.

Mrs. Kusumawathi (pseudonym) is a housewife with two children. Once she found that she was suffering from breast cancer she immediately was admitted to the hospital for treatment. Due to this early action on her part, she underwent her surgery immediately and has now fully recovered, barely a few months after the diagnosis. She also is very consciously attending the follow-up treatments to make sure that there will be no chance of a recurrence, which is not uncommon in the case of breast cancer patients. She told her story in the following:

> Other than my immediate family no one knows about my disease. It did not affect for my life that much. Though the health is the most important thing, the cancer has not affected my life like it affects most of other patients. I was not in the hospital only for the surgery. Therefore, no one knows about my health issue. In addition it has not affected for my daily routine. I am under medical advice not to use the hand on the side of the operated breast. Therefore I do all my household chores using mainly the other hand. I am

> used to this change and it has not hindered my lifestyle at all. Even today, when I attend clinic once in six months, I tell neighbors that I travel to participate in a pooja activity in comes famous temple far away. Under these circumstance, I do not feel any uneasiness about the effect of this disease on my life, or any new burden. I underwent the surgery in a government hospital and attend public clinic for follow up treatments also in a government clinic. This ensure there is no medical cost. In addition there were no other additional household cost since I can carry out all household work as it used to be. Even during my absence from home due to surgery, which was for a few days, one of my close relatives took care of household activity there was no any additional burden on the family.

Though according to findings of the study it was not a substantial economic burden on households for a woman to have breast cancer, a male suffering from a lymphoma had to face a totally different situation due to his disease. He had to stay in the hospital for inpatient care and during that time his family had to spend a lot of money. It was not easy for him to recover from the disease compared to other respondents and he had to visit the hospital many times for treatment. As the bread winner of the family and because he started his own family only a few years ago, he was unable to save money even before this issue arose. He is self-employed and is unable to work due to his health situation, and the family has also lost its sole sources of income and has experienced huge opportunity costs.

For most women who are diagnosed with breast cancer, it has been found that if and where proper treatment has been taken at the early stage, they more often are cured fully and the disease does not prove to be a big burden on them or their families. They are instructed not to extensively use the hand on the side of their affected breast. In addition, new modern and cheaper technology has helped to solve many beautification problems that these breast cancer patients generally have to face after the surgery. If the patients receive treatments on time, recovery is quicker and they face fewer problems. Hence the treatment procedures and the severity of the disease vary based on the type of cancer, and the economic burden on households can change according to the type of cancer. Therefore, the type of cancer has proved to have a different bearing on the economic burden on households with cancer patients.

According to the respondents, it was found that people that have recovered from the cancer and are taking follow-up treatments have to spend less money due to fewer visits to the hospital. However, the respondents that have not recovered and are taking treatments have to bear a greater burden compared to others. Furthermore, people that have not recovered but in whom the disease has spread create a greater economic burden on households.

5.7 Findings and Discussion

The in-depth discussion and these case studies have proven how extensive the relationship is between these variables and the economic burdens on households of cancer patients. This was depicted in both the quantitative and qualitative analysis. The lengthy discussion was helpful in terms of identifying how demographic characteristics affect households differently. It was found that males have to bear a greater economic burden than females as the bread winner of the family. In addition, people that have a secondary education bear a greater burden compared to individuals with lower or higher education levels. Likewise, people that have a higher income pay more for recovering from the disease and the economic burden will be high. They have the ability and willingness to pay more since they are financially stable. However, people at a middle-income level suffer more from financing and employment compared to people at higher income levels. People that are poor suffer from financing transportation costs, and distance is a one of the main factors that affects the huge economic burden because of the costs for transportation, accommodations, and the costs for accompanying person, etc. In addition having dependents creates a burden on households but it is not very high. The type of cancer also was seen to affect the direct costs for the patients, leading to the ultimate burden on households; when the disease is severe they have to bear a greater burden compared to others. Moreover, when the respondents were suffering from a long time, it was mostly only the follow-up treatments that reduced the burden. In addition, if the patients and households have strong social network they experience less burden since they receive financial as well as non-financial support from others. Though the government allocates huge amounts of money for cancer patients, it is necessary to prioritize policy options in order to reduce the burden on households.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

This chapter provides a summary of the findings of the research and the conclusion. It provides policymakers, stakeholders and other parties recommendations based on the findings. This study offers both theoretical and practical contributions to the society. Theoretical contributions can be useful for future researchers and practical contributions in the form of providing policy options to prioritize the best options due to limited resources. Moreover it highlights the opportunity for future researchers to carry out research further and to deepen their understanding of the areas in the field that have not been covered by this study.

6.1 Summary of the Findings

The study has focused on identifying the economic burden on households of NCDs, especially referring to cancer. Since there are not many studies based on economic burden only referring to cancer, the literature has taken NCDs into consideration. In addition to identifying the economic burden it has found relationships among demographic, economic, and disease characteristics and the economic burden on households with people with NCDs. Moreover it has analyzed the relationship between the economic burden of illness in the case of NCDs, with special reference to cancer, and the sources of financing the burden. Furthermore, it has identified the challenges faced in terms of financing the economic burden of cancer and households. Finally, based on the findings, it has provided policy options in order to prioritize the reduction of the burden on households with cancer patients.

The first research question investigates the economic burden of cancer on households. Based on the literature it has identified direct costs, indirect costs, and the impact on households regarding the economic burden of the disease. It has used the cost of illness method and the human capital methodology approach to assess the

economic burden on households. Though the government of Sri Lanka provides all health facilities free for all patients, as stated earlier, still the direct costs are the major burden for households. In further analysis of direct costs, direct medical costs, and all types of transport costs (travel costs for the patient, additional travel costs, and travel costs for accompanying persons), it was seen that these two direct costs were higher than any other direct costs. Since most of the patients do not like to stay on a waiting list, they use private laboratory facilities immediately or else by considering the opportunity cost of the situation (despite affordability) at public hospitals they opt to use private laboratory facilities. In addition, during the in-patient time, households have to obtain assistance from caring supporters, which is also costly. Transport costs aggregating the sub-categories of travel costs become equal in terms of economic burden and are on a par with direct medical costs. Households have to bear huge transport costs for the patient, accompanying person, and other additional travel costs. In addition, patients have to take public and private transportation depending on the situation, health conditions, and the availability of public transportation.

The second research question of the study identifies the determinants such as demographic, economic, and disease characteristics affecting the economic burden of households with people with cancer. The study identified being a male as having a significant relationship with economic burden. Since males are often be the main income earner of the family, loss of income and no extra income leads to higher burden compared to females.

Education level was not seen to have very much of a difference in terms of the economic burden as per the findings. The majority used public health facilities respondents did not find much difference in economic burden, because all relevant medically-prescribed services were provided at the hospitals and clinics free of charge and it did not make much of a difference for them. However, it was found through the qualitative analysis that the people that were educated and that were familiar with new technology and information underwent treatment processes immediately after becoming aware of the disease compared to others.

Though age is another demographic factor regarding the economic burden, this study found that there was not much difference in in terms of economic burden in this regard. Since economic burden consists of different cost categories, different age

categories may have an effect on different cost categories as seen in the literature. It was found that the people of a working age had to face the burden of loss of income while people that had retired and elderly people did not face such as loss of income but some other indirect costs, such as the impact on other household members.

The type of employment especially referring to occupation was seen as a determinant in terms of economic burden in the study. This study has considered both the formal and informal sectors and a difference was not found among the occupation category and economic burden on households.

Distance was seen as a determinant in both the bivariate as well as the multivariate analysis of the study. In addition to the quantitative analysis, based on the qualitative analysis, distance was found to create an economic burden on households. Since there is only a number limited number of hospitals and centers for the cancer in Sri Lanka, patients have to spend more money on transportation and other related transport costs and this leads to an economic burden on households. In addition to the main transport cost they have to spend money on food and accommodation costs for both themselves and the accompanying person. When the distance to the clinic is great they have to spend more money on transport-related activities such as transport costs again both for themselves and the accompanying person, additional refreshments for travelling, accommodation costs if they have to stay in a rented place, gifts if they stay at a friend's place, etc. Moreover, when the disease condition is severe they have to take private transportation, which is more costly for them. Therefore distance to the hospital creates a burden for patients.

Income is a one of the determinants in the study and it was found in the analysis that income had an impact on the economic burden of households. Thus when people have the capacity to spend money on the disease, they are willing to pay more and try to recover from the disease as early as possible. Since the majority of people are afraid of this disease and when such people have a larger income they will spend higher amounts of money than those with smaller incomes. The study also revealed that people that have an income of Rs.40000 and above spend more compared to the income group earning below Rs.10000. Therefore, income was seen as a determinant affecting the economic burden on households. The contributory reason for this situation is the willingness and the ability to pay by such respondents.

In both the bivariate as well as the multivariate analysis, it was found that the type of cancer had an impact on the burden on households. In the detailed analyses it was found that the diseases characteristics of lymphoma exhibited a greater burden compared to lip, oral cavity and pharynx cancer. On the other hand, people that are suffering from oesophagus cancer were seen to have less of a burden compared to the people suffering from lip, oral cavity and pharynx cancer. According to the qualitative analysis it was found that the economic burden of the disease depends on the treatment procedure, duration of the treatments, medication needed, etc.

The severity of the disease was also seen to have a difference in regard to the economic burden on households in this study. The responses to the questionnaire obtained from the respondents were taken into consideration for the analysis and it was found that the respondents that had not recovered from the disease had a greater burden compared to the respondents that had recovered from the disease and that were taking follow-up treatments. People that have fully recovered from the disease have to make only few visits to treatment centers for follow-ups, but the people that have not recovered have to visit treatment centers more often for their treatments. Therefore the costs are less for the respondents that have recovered and that are attending follow-up treatments.

The duration of suffering also is a determinant of economic burden. When the duration is long the respondents have less economic burden compared to people suffering for a short period. It was found from the qualitative analysis that at the beginning, the patients have to spend money on diagnostic tests and other laboratory requirements as well as frequent visits to hospitals. However, when patients had cancer for a long time and they have recovered from the disease, they visit clinics only for follow up treatments once in a while and hence the economic burden becomes lesser for them.

Based on the findings of the study it was revealed that such factors as being a male, travelling a distance to and from the clinic, having a higher income, the type of cancer, the severity of the disease, and the period of suffering have become significant demographic, economic, and disease characteristics that affect the economic burden on households.

The third research question of the study was focused on identifying the relationship between the economic burden of the illness and the sources of financing. Each cost aspect as well as the overall economic burden were studied, and it was found that there was a difference in the sources of financing and the economic burden, such as the income of the patients and the savings of the patient, the savings of the patients and the savings of family members, the savings of the patients and support from children, the savings of the patients and payment in-kind from others compared to other sources of financing. Furthermore it was found that compared with direct costs, there as a difference in economic cost spending and sources of financing. The study found a similar situation with reference to indirect costs. There is a difference in sources o financing and indirect costs. Nevertheless, there was not difference in the costs referring to the impact on households and sources of financing.

The fourth research question of the study focused on the identifying the challenges that the respondents faced in terms of financing the burden of cancer on households. Though healthcare is totally free in Sri Lanka, people face several challenges with regard to financing the burden of cancer. It was found that though substantial grants have been allocated by the government people do not have enough information about those grants. In addition the government has arranged a small monthly allowance for the people that are needy but it is very small and opportunity costs for getting that allowance are much higher compared to the allowance. Therefore the majority do not receive that allowance. Other than the government insurance scheme for government servants, the people were not happy about the private insurance schemes in terms of the difficulties in getting their money back.

The fifth research question of the study concerned providing policy options to policymakers based on the study. These options were based on the significant determinants affecting the economic burden and provided recommendations.

6.2 Discussion

This discussion is mainly based on the comparison between the literature review reference to NCDs and the findings of the study. Economic burden on

households has been measured using the cost of illness method. The demographic, economic, and disease characteristics were selected based on the literature.

With reference to the demographic economic characteristics of the patients, one of the significant determinants was gender and how gender had a determinant effect on economic burden. One study has proven overall burden is higher on woman than men (Quah, 2011), and in contrast to that another study stated that males have a higher burden compared to females (Le et al., 2012). In addition another study in the Srilankan context also has shown that males have to bear a higher burden compared to females (Liyanage et al., 2012). The research findings also confirmed that males have a more burden compared to females in terms of cancer.

Though the literature revealed that spending on medication varies based on education (Mahal et al., 2013), the research did not find any significant difference related to education and economic burden. The majority of the respondents had school education (97.5%) due to the free education policy in Sri Lanka. Since they received free state health services they did not experience much difference in economic burden with regard to the level of education of the respondents.

Based on the literature one study found that age has a different effect on burden (Le et al., 2012), and this research did not find any significant difference in age as a determinant of economic burden on households. The majority of the respondents were in the age category of 51- 60 years.

Employment was also considered as a determinant in the study. The available literature showed that employment status affects for the economic burden (Bloom et al., 2013; Mahal et al., 2010). However, the research findings contradicted literature and not much difference was found regarding the type of employment and economic burden on households.

Distance was seen to have an effect on the economic burden of diseases in Sri Lanka (Attanayaka, 2005). This study has confirmed the literature and found that the distance to the treatment center from the person's home is a determinant affecting the economic burden on households with cancer patients.

The literature has indicated that income is a significant determinant of economic burden (Davies et al., 2011; Engelgau et al., 2012, as cited in Le et al., 2012; Van Minh & Tran, 2012). The findings of the research also confirmed the

literature, that income serves as a determinant affecting economic burden since people that have the capacity and willingness to pay will pay more and get more private facilities compared to what the lowest income group would receive.

All of the disease characteristics referred to in this study, namely type of cancer, severity of the disease, and period of suffering, were determinants affecting economic burden. The literature has stated that the condition of the disease has an effect on economic burden (Abdulkadri et al., 2009; Walsh, 2014) and this has been confirmed through the research.

6.3 Policy Options

The following suggestions can be used to prioritize policy options to reduce the economic burden on households. Since the government of Sri Lanka has limited resources it is necessary to prioritize options based on the severity of the burden. The government provides healthcare totally free for all under the free health policy in Sri Lanka and it has a guideline for the "protection of the right to health" under the National Policy and Strategic Framework on Cancer Prevention and Control in Sri Lanka (MOHIMNCCP, 2015). Though the government invests huge amounts of resources on public health, especially on cancer patients, it may not be of much use for households with cancer patients in reducing the burden due to some issues. Therefore, based on the significant determinants affecting the burden, policy options can be prioritized.

The study is helpful for use at different levels of policy. At the policy advocacy level it can be used to invest more on the direct cost aspect of health under the health policy. In addition provisions made in tax reform can be used as a motivational factor for buying certain medical treatment items for cancer patients. In addition other ministries can be linked for better delivery of services.

It is necessary to have a combination of both public, private sector, and citizen participation for better policy implementation. "Multidisciplinary and multi-sectorial approaches and encouraging appropriate public private partnerships" are two guidelines in related policy (MOHAIMNCCP, 2015). Since the private sector is always motivated by profit there should be a mechanism through tax concessions to

carry out some policy options. On the other hand the government also does not invest in high cost policy priorities in the short term, and it is necessary to introduce policies that are cost effective. In addition any healthcare system must have three functions; namely, direct delivery of services, a financing healthcare system, and modulating the market (Berman, 1995).

The means of financing the economic burden on households have posed a problem and direct costs have resulted in severe expenditure compared to other costs. Therefore, the public policies must focus on the direct cost aspect such as direct medical costs, travel costs, the cost of special foods, and other direct household costs.

Though the government provides free medical facilities such as consultancy, medicine, and laboratory tests and reports, patients have to bear the huge additional medical costs. Since obtaining the required reports from the hospital laboratories takes a long time due to the queues, the patients that require urgent diagnosis are most likely to take the required tests from private laboratories so they can get the required treatments as quickly as possible. In addition, visiting the hospital lab for many reports ordered by the doctors can be costly due to the travelling involved. Therefore, patients mostly opt to patronize the private laboratory nearest their residence in order to obtain laboratory services. These patients visit government clinics with the reports thus obtained. Therefore, in order to reduce the economic burden on households the government can arrange more laboratory facilities at the nearest government hospital, which would be more convenient for patients and households. Secondly, travelling costs are another aspect of economic burden which are also affected by the distance to the hospital. This cost factor has to be addressed in consultation with the state public transportation board, namely the Ceylon Transport Board. The cost of special nutritious foods recommended for patients taking treatment also affects the patients coming from impoverished households. Therefore, through the State Pharmaceutical Cooperation (SPC), the government can arrange to provide special milk and other food supplements for the patients that are needy. A special identity card for the people that are needy and cancer patients, issued after proper verification by the regulatory mechanism of the government hospital and village level officer as to the patient's true economic background, could prevent such relief provisions from being falling into the hands of crooked people that are looking for opportunities to make undue gains.

Moreover, the government can have partnerships with the private sector and the community to provide laboratory equipment to every hospital which would reduce much of the burden. It has already been seen how citizens have become generous in financing laboratory equipment.

The analysis has indicated that some demographic, economic, and disease characteristics have a clear relationship with the level of economic burden felt by the households with cancer patients. This information is useful in prioritizing policies. Presently, the government of Sri Lanka, under the Ministry of Health Nutrition and Indigenous Medicine, has introduced the National Policy and Strategic Framework for Cancer Prevention and Control and any policy suggestion, therefore, can be useful in the reduction of the economic burden on cancer patients. The proper analysis of the costs and benefits is a prerequisite of any good policy. If the cost of implementing the policy is less than the benefits to be gained, such policies have greater chances of being implemented. Such policies can be successful and sustainable in the long run with anticipated benefits to the society. Ideally such successful policies have to be shared with other government as well as non-government organizations, which grapple with the same or similar social issues.

One of the major significant factors affecting the economic burden on cancer patients and their households was seen to be as gender. This study has shown that male patients have to face a greater burden compared to female patients with regard to the economic domain.

Majority of the households in Sri Lanka are patriarchal, where males take the leading role in almost all aspects of family affairs, especially providing for the family as bread winners. When an employed male suffers from cancer, more often than not he is faced with the problem of obtaining leave from work to visits hospitals and clinics. While most of the employers allow a certain number of leaves on account of ill health, such leaves prove to be highly insufficient for a person seeking treatment for cancer. This invariably compels the patient to be absent from work without a paid leave and he will lose a part of or the total amount of his monthly salary in the process. This too would not go on forever, and to make matters worse, very few employers, if any, would allow an employee to be in his cadre for a long period if he cannot work. This would mean the loss of employment in most cases, if not all. In

order to address this situation, the government can introduce a special mechanism in the government sector. With regard to the private sector, the government can introduce tax concessions or exemptions through tax policy for the private sector for provision of some financial assistance to workers who are diagnosed with cancer while in their employment, and ensure the safety of their employment, till their recovery could alleviate the burden to a great deal, and can make a huge difference in the present scenario. However, such concessions, if introduced, would not benefit the cancer patients that are engaged in agriculture, or self-employed in a vast number of trades, and would not be covered under the formal private sector or the state sector.

The introduction of special insurance schemes for the category of patients that are in agriculture or self-employed could be an answer. The relevant statutory reforms with regard to this category could be introduced in association with many and varying community-based social welfare organizations. This should address the issue of not being able to repay the financial assistance obtained if the patient's health condition deteriorates to the lowest level. There should not be any discriminations between the insurance scheme impinging on either community-based organizations or state-run insurance schemes. If and when the government establishes and teams up with state-run community-based organizations, the question of outside intermediary institutions would not arise.

The distance to the health facilities was also seen to be one of the significant factors that contributed to the economic burden on households with cancer patients. Since medication and treatment facilities for cancer patients are available only in selected hospitals, all patients necessarily have to spend both time and money in going to such health facilities. Placing the required facilities at the nearest-based hospital could be the best solution, but it necessitates the government equipping all such hospitals, which could be prohibitively expensive in the short run. However, if the government could introduce the levying of special bus fares for cancer patients through the state’s own Ceylon Transport Board (CTB), it could reduce the major cost factor in going to the cancer treatment clinics for many patients. The identification of patients for such concessionary bus fares could be easily done with the assistance of the Grama Seva Officer (the grassroots level government agents appointed in all villages). Here again, when and where there are no direct transportation facilities

operated by the CTB, such a solution would be of little benefit. In the event of such a situation, the government can introduce special transport services starting at major cities in different districts. This transport system should consider the opening hours of the clinic, the opening days of the clinic and the buses must be able to reach the clinic before its opening. This could reduce the heavy burden, both physical and financial, for the many patients that otherwise spend days in meeting the clinics' operating time. Easy accessibility to free health facilities should be a must in policy implementation.

The type of cancer has also been shown to be another significant factor which adds to the economic burden of cancer patients. Some patients lamented that they did not have knowledge or enough information about the disease until it was too late for them. Some respondents said that some cancers can be treated immediately, with a very high success rate, but other respondents said that they require prolonged treatment. The patients indicated that they got to know information about the disease and consequences only after they attended the clinic. Therefore, it is an urgent necessity that the state health authorities, with the support of non-government organizations, launch a continuous campaign whereby all required information related to various cancer sites and disseminating vital information to the public in all areas of the country. Such government and non-government alliances should conduct free seminars and workshops in all three major languages in all work places, both state and private, with emphasis on how to identify the incidence of cancer and the steps to take. Such seminars, at village levels, with the coordination of the Grama Seva Office and various organizations, should be conducted to enable self-employed and non-employed general public. Additionally, free periodical screening services and professional advice from time to time can lead to the detection of cancer early and unnoticed cancer incidence and pave the way for early treatment, which could reduce all forms of burden due to cancer.

6.4 Conclusion

The economic burden on affected patients' families due to NCDs has proven to be higher compare to communicable diseases. In the Sri Lankan context, cancer is one of the major causes of deaths due to NCDs. While the government provides free

healthcare for cancer patients, necessarily there are other out-of-pocket expenditures that have to be borne by the patients. In addition, there are some opportunity costs due to the suffering that the patient undergoes from cancer. The gravity of the incidence of economic burden differs from patient to patient depending on certain general and/or unique factors. This study accordingly has endeavored to assess the salient factors that contribute to such economic burden on the patients and their families. These components of the economic burden show the extent to which such costs have become a burden to them.

In addition there are some determinants regarding the effect of any given burden from person to person. Such determining factors identified through the analysis have been used to prioritize policy options. Since the government has limited financial resources to deal with unlimited social issues, it has to identify its priorities in keeping with national importance when allocating resources. It is here that identification of the leading determinants that have the greatest bearing on the economic burden will be helpful in formulating policies that could mitigate the economic burden. In addition, it would be helpful to determine how the various sources of financing, available to patients, can be regulated as a means of reducing the economic burden. The recommendations below are based on the findings of the quantitative and qualitative data analysis of the determinants.

6.5 Recommendations

The recommendations for reducing the economic burden on households with cancer patients are mainly based on the policy options. The policy options suggested by the research have short-term and long-term options. Out of the available options, some options are easy to implement and take cognizance of the priority for implementation. Providing an identification card for patients that are needy can be used to reduce the burden in many aspects. It can be useful to have concessions for public transportation and to get some medications, and special foods from the State Pharmaceutical Corporation at less cost. General citizens are the most generous and powerful source of funding for laboratory equipment, which has been proven very recently. Relationships with media organizations and other private sector institutions

are also helpful in reducing the burden on households. The awareness of the diagnosis of cancer, and reducing the patient's fear, can also be done through public partnerships. These recommendations are possible under the existing guiding principles such as "equity and social justice, affordability, sustainable, and equitable accessibility to individuals and the community" under the National Policy and Strategic Framework on Cancer Prevention and Control in Sri Lanka (MOHIMNCCP, 2015).

6.6 Contributions of the Study

This study offers theoretical and practical contributions to the society. Policy options to prioritize the stakeholders can be a practical contribution since it could be felt within a short time by the affected people. In addition to providing policy options for prioritization, there is a theoretical contribution from this study; it has clearly shown how demographic, economic, and disease characteristics have an impact on the cost of illness method.

6.7 Future Research

There are some areas that can be focused on in the future as these have not been considered in the present study. In addition, in the establishment of the economic burden on households there are some social costs on the households that have not been considered. The social issues such as the impact on children regarding their education, participation in social work, and psychological aspects also have not been considered and these can be carried out in future research, extending the present scope of the study. In addition a detailed qualitative analysis also can be carried in further research.

6.8 Chapter Summary

The chapter provides a summary of the findings and a discussion with reference to related literature. It provides the conclusion of the research based on

these findings. Recommendations were based on the findings and the main types of burden and main determinants have been identified that contribute to the economic burden on households with cancer patients. In addition, it explains how far the study contributes both theoretically and practically to the interested parties, and shows an opening for future research into this subject.

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APPENDICES

APPENDIX A

SAMPLE SIZE UNDER DIFFERENT CATEGORIES

Criteria	Population	Sample
Sample Size Calculator (5% error level)		
2008 registration	16511	375
2014 registration	26300	379
Visits	125000	383
Cancer incidence rate (based on population)	17280	376
Based on Yamane formula		
	16511	390
	26300	394
	125000	398
	17280	390
Tabachnick and Fidell (2007)		338

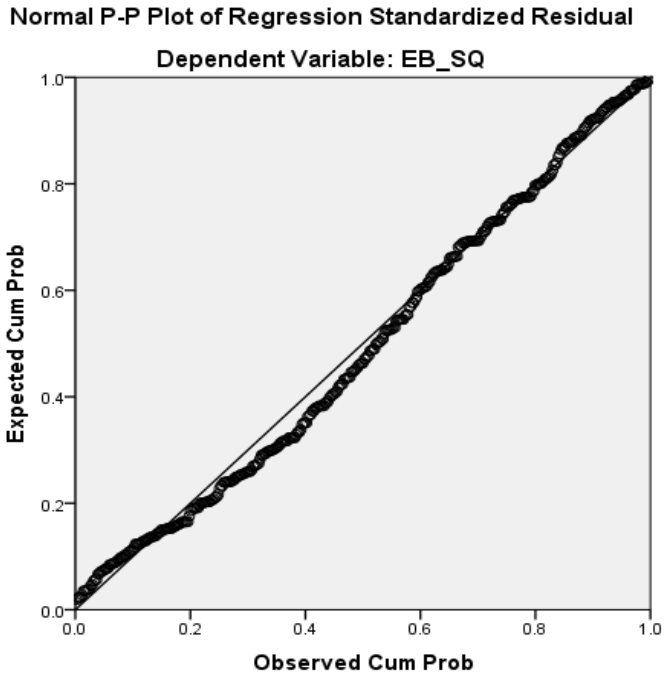
APPENDIX B

CASEWISE DIAGNOSTICS FOR OUTLIERS

Case Number	Std. Residual
86	-3.292
263	-3.942
370	-3.487

APPENDIX C

NORMALITY, LINEARITY OF THE DISTRIBUTION



APPENDIX D

COLLINEARITY STATISTICS FOR MULTICOLLINEARITY

Variable	Unstandardized Coefficient (B)	Standardized Coefficient (β)	VIF
Gender	90.141	.215	1.087
Distance	.351	.119	1.040
Income	111.419	.143	1.018
Type of cancer (Lymphoma)	118.943	.123	1.093
Type of cancer (Oesophagus)	-67.096	-.111	1.037
Severity of disease	124.369	.129	1.107
Period of suffering	-.690	-.178	1.037

APPENDIX E

SURVEY QUESTIONNAIRE

Ref. No : …..

Economic Burden on Households with People with Non-Communicable Diseases, with Special Reference to Cancer: Priorities for Policy Options Pertaining to the Sri Lankan Context

Instructions:

(Put √ mark in the appropriate box)

---

1. Demographic Characteristics

1.1 Age:

18 - 30 ☐ 31 - 40 ☐ 41 – 50 ☐ 51 – 60 ☐ 61 – 70 ☐

above70 ☐

1.2 Gender: 1. Female ☐ 2. Male ☐

1.3 Name of the Village/Town:…….

1.4 District:……

1.5 Distance to hospital from residence (km):…….

1.6 Education level:

No Schooling ☐ Primary (Grade 1- 5) ☐ Secondary (Grade 6 – 11) ☐

Passed G C E(O/L) ☐ Passed G C E (A/L) ☐ Degree/ Diploma ☐

1.7 Employment: Yes ☐ No ☐

1.8 If the answer for 1.7 is yes, what category of employment? Formal

Informal

1.9 If the above answer (1.7) is "yes," what is your occupation?

Government employee	
Semi government employee	
Private sector employee	
Employer	
Own account worker	
Contributing family business as a worker	

1.10 Income for the month:

Below 5000 ☐ 5000 – 9999 ☐ 10 000 – 19999 ☐ 20000 – 29999 ☐

30 000 – 39999 ☐ 40000 – 49999 ☐ 50 000 and above ☐

1.11 Number of household members (excluding respondent):

1.12 Number of dependents:

1.13 Basic information of household members

Member No.	1.13.1) HH member	1.13.2) Relationship to HH	1.13.3) Sex 1 Male 2 female	1.13.4) Age Year	1.13.5) Marital status	1.13.6) Main occupation	13.7) Monthy income Rs.
1.							
2.							
3.							
4.							

2. Disease Characteristics

2.1 Type of Disease (put a "√" mark to the relevant type)

Gender	Type of Disease				
Male	Lip, oral cavity and pharynx	Trachea, bronchus, and lungs	Oesophagus	Colon and rectum	Lymphoma
Female	Breast	Cervix uteri	Thyroid gland	Ovary	Oesophagus

2.2 How long have you been suffering from the disease?

2.3 Level of the cancer

Level I ☐ Level II ☐ Level III ☐ Level IV ☐

Recovered and taking follow-up treatments ☐

Not recovered but not spread and taking treatments ☐

Not recovered but spreading and taking treatments ☐

3. Economic Burden

3.1 Direct Medical Costs

3.1.1 Do you pay for any medication for the disease?

Yes ☐ No ☐ Sometimes ☐

3.1.2 If answer is "yes," or "sometimes," then why? And, approximately how much you spend for month?

Type of costs	Cost per month	times per year
Cost for diagnosis ……		
Cost for procedure ……		
Cost for drugs …….		
Cost for inpatient care ……		
Cost for outpatient care ……..		

3.2 Do you take any informal treatment for your disease? Yes / No

3.2.1 If the answer is yes, how much do you spend for month? Rs.

3.3 Travel Cost to the Patient

3.3.1 How often do you visit the hospital?

daily	☐	weekly	☐	Once in two weeks	☐
Once in three weeks	☐	once a month	☐	once in two months	☐
Once in three months	☐	Once in six months	☐	Once a year	☐
Other (specify)	☐				

3.3.2 How much do you have to pay for transportation for a visit? Rs.

3.3.3 Do you pay additional cost for a visit to hospital (e.g: accommodation) ? Yes/No

3.3.4 If the answer is yes, what are those costs?

Type of Cost	**Amount Per Visit**

3.4 Travel Cost for Accompanying Person

3.4.1 Do you travel to hospital with an accompanying person? Yes / No

3.4.2 If *yes*, then please provide information about the accompanying person. Status of the accompanying person: employed/not employed/student/ retired/ other If other, then please explain……

3.4.3 How much do you pay for the accompanying person?

Type of Cost	**Cost (Rs)**
Travel cost	
Cost for accommodations	
Cost of hiring person	
other	

3.4.4 If the accompanying person is employed, does he/she gets paid leave for the travel? Yes/No

3.4.5 If answer is "No," then what is the lost per travel? Rs

3.5 Cost for Special Food

3.5.1 Do you consume any special food especially concerning disease, other than medicine? Yes ☐ No ☐

Yes, but unable to afford ☐ Yes, getting free ☐

No, unable to afford ☐

3.5.2 If the answer is "yes," what are those? And how much do you pay per month for special food?

Special Food	**Cost per Month**

3.6 Other household costs

3.6.1 Do you pay for any other household costs especially for your disease (e.g.: domestic helper, attendant, cleaning)? Yes ☐ No ☐ Getting free ☐

3.6.2 If the answer is *yes* then how much per the month

Type of Other Cost	**Cost Per Month**

3.7 Indirect Cost

3.7.1 Have you resigned or retired early from the employment due to the disease? Yes/No

3.7.2 If the answer is "yes," how much do you lose per the month when you resigned/early resigned? Rs……

3.7.3 Month and year of resigned

Due month and year of retirement?

3.7.4 If you have not resigned from the employment, do you receive a paid leave for the visit to the hospital? Yes / No

3.7.5 If the answer is "*No,"* or if you are self-employed how much do you lose per visit?

3.7.6 If you are self-employed, do you hire labour when you are unavailable for work due to the disease? Yes /No

3.7.7 If the answer is yes then how much does it cost per month? Rs ……

3.8 Impact on other households

3.8.1 Have any of your family members resigned from employment due to your ill-health? Yes /No

3.8.2 If the answer is "yes," then how much does he/she lose per month?,

3.8.3 Month and year resigned

Due month and year of retirement?.

3.8.4 If no one in the family has resigned from employment, has your household lost any income due to your ill-health? Yes /No

Loss of income per month ……

3.9 Consumption Expenditure

3.9.1 How much on average do you spend per month as your household expenses? Rs……

3.9.2 How much on average do you spend per month on health-related matters? Rs……

4. Sources of Financing

4.1 How did you cover the above expenses for treatment? (rank according to priority)

1. From the salary/earnings of the previous month	
2. Using cash and savings of the patient	
3. Using the savings of family member/s	
4. Insurance	
5. Mortgage jewelry	
6. Selling livestock	

7. Selling durable and productive assets	
8. Borrowing money from relatives and friends	
9. Borrowing money from money lenders	
10. Receiving support from children	
11. Receiving in-kind help from friends and relatives	
12. Reducing consumption expenditure(explain)	
13. Support from community organizations	
14. If any other (please specify)	

4.2 Do you receive any financial assistance from the government to manage your ill-health? 1. Yes 2. No

If yes what is it?

4.3 Do you use all of the above methods for your ways of financing? Yes/No

4.3.1 If the answer is *yes* then why?

4.3.2 If the answer is *no* then why?

4.4 What are the problems or challenges have you faced with ways of financing?

Savings:……..

Loans:…….

Insurance:……

Social capital:……..

Sale of assets:……..

State capital:.....

Community-based organizations:……

Do you have any comments?

……

……

……

……

……

Ref. No : ……

Consent Form

Date :

Title of the Research: Economic burden on households with people with non-communicable diseases, with special reference to cancer: Priorities for policy options pertaining to the Sri Lankan context

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I have read/ heard and I understood the attached "Information sheet" for this study. The interviewer has clearly informed the participation that the interview was voluntary and he/she could leave the interview at any time.

There were no any force to participate for the interview and this has been clearly informed.

……

Signature of the interviewee

BIOGRAPHY

NAME	Rajapaksha Pathirathnage Chamarie Kanchana Jayasinghe
ACADEMIC BACKGROUND	B.Sc. Management (Public) (Special) Degree from University of Sri Jayewardenepura Postgraduate Diploma in International Relations from Bandaranaike Centre for International Studies Master in Public Policy at National University of Singapore Postgraduate Diploma in Development Studies with a Distinction Pass from the University of Colombo
PRESENT POSITION	Senior Lecturer in the Department of Public Administration, Faculty of Management Studies and Commerce, University of Sri Jayewardenepura
EXPERIENCE	Worked as a lecturer for ten years and contributed to teaching in public universities and programs for twelve years Political Environment, International Relations, Economics, Public Sector Project Management, Rural Development, Public Finance, Public Administration are the fields of teaching during the past service