

**The evaluation of household economic burden of secondary  
treatment for childhood leukemia and informal payments to  
physicians in Armenia**

(A cross-sectional study)

Master of Public Health Integrating Experience Project

Professional Publication Framework

by

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2009

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## **Abbreviations**

**WHO** World Health Organization

**ALL** Acute Lymphocytic Leukemia

**CLL** Chronic Lymphocytic Leukemia

**AML** Acute Myelogenous Leukemia

**CML** Chronic Myelogenous Leukemia

**SES** Socio-Economic Status

## **Acknowledgements**

I would like to express my deep gratitude to my adviser Dr. Byron Crape for his continuous assistance and encouragement during the most difficult periods of studying at AUA

I am grateful to my reader George Pilikyan for their advices and comments.

I appreciate Dr. Varduhi Petrosyan for her support and encouragement.

I am thankful to my family members for their patience and encouragement and my friends.

## Abstract

**Background:** Leukemia is the most common blood cancer. Worldwide, leukemia accounts for 2.8% of all new cancer cases and 222,000 deaths each year. It accounts for 30% of all cancers diagnosed in children aged less than 15 years. On the other hand, the economic burden of cancer is substantial and growing. The economic burden on patients and their families for cancer treatment may include the immediate cost of treatment, out-of-pocket and future costs required for cancer surveillance, follow-up care, and treatment of persistent symptoms. Information on economic burden due to cancer is largely absent from common literature that offer information to cancer patients and their families-leaving patients in the untenable position of having to make treatment choices without fully understanding the costs and the impact on their ability to work.

**Objective:** The study assessed the financial problems faced by the households from Yerevan, having a child with leukemia registered in the Hematology Center in Yerevan, Armenia.

**Methods:** The analytical cross-sectional telephone survey was conducted with the study population that consisted of a sample of 97 participants, with children registered at the Hematology Center from 2005-2008. Among survey items were questions adopted from Prescription Drug Affordability: A 2004 AARP Montana Survey and also from Access & Affordability of Prescription Drugs: An AARP Study of New Jersey's Hispanic Population.

**Results:** Among the respondents 33% reported that it was a major financial problem for them to pay for the secondary treatment of leukemia, 29% reported that it was a minor financial problem and only 12% reported that it was not a financial problem. Among the respondents 16% reported that their doctor suggested a specific pharmacy from which to purchase the prescribed drugs. About 31% of those interviewed are very concerned about affording the costs of prescribed secondary-treatment drugs for their child with leukemia over the next two months, 46% were somewhat concerned and only 11% were not concerned et al. According to the bivariate analysis, household financial problems connected with secondary-treatment drugs for leukemia was associated with having cut back on other necessary items such as food or utilities to be able to afford a prescription medication for secondary treatment was also associated with household financial problems connected with secondary-treatment drugs for leukemia: the parents of patients with leukemia who cut back on other necessary items such as food or utilities were 4.4 times likely to have major financial problem compared to those that did not cut back on above mention items ( OR=4.4, 95%CI=1.46;13.21).

**Conclusion:** Consistent with the literature, the factors associated to financial problems faced by the households, having a child with leukemia were concern about being able to afford secondary treatment, and having cut back on other necessary items such as food or utilities to be able to afford a prescription medication. Almost one third of the household with a child with leukemia face major financial problems in Armenia. Additional means should be applied to target these families for further financial assistance. For the real measurement of economic burden further more detailed study could be conducted considering the direct and indirect costs of the treatment.

# **1. Introduction**

## **1.1 Background/ Literature review**

Cancer is a leading cause of death worldwide. WHO report estimated that 7.6 million people died of cancer in 2005, representing 13% of all deaths worldwide. The report suggests that 84 million people will die of cancer between 2005 and 2015. Cancer is the second leading cause of death in developed countries and among the three leading causes of death in developing countries (1). More than 70% of cancer deaths occur in low and middle income countries (2).

Leukemia is the most common blood cancer and encompasses multiple diseases, including four major types: acute lymphocytic leukemia (ALL), chronic lymphocytic leukemia (CLL), acute myelogenous leukemia (AML), and chronic myelogenous leukemia (CML) (3). Worldwide, leukemia accounts for 2.8% of all new cancer cases and 222,000 deaths each year. There is very little geographic variation in incidence rates, but survival rates in developed countries are twice that of developing countries, perhaps due to lack of access in developing countries to the complex treatment regimens required (4). Table 1 presents the age-standardized world incidence and mortality rates per 100,000 population for leukemia. In the US, approximately 44,000 new cases of leukemia (approximately 3% of all new cancers) and 21,800 deaths due to leukemia (approximately 4% of all deaths due to cancer) are predicted for 2007 (5).

CML accounts for 15% of all adult leukemia (6). CML is a clonal disorder that is usually easily diagnosed because more than 95% of patients have a distinctive cytogenetic abnormality in the leukemic cells, the Philadelphia chromosome (7).

Leukemia is the most common childhood malignancy. It accounts for 30% of all cancers diagnosed in children aged less than 15 years (8). In the 1990s the average incidence rate in Europe for this age group was 42 cases per million per year, with a slightly lower level in eastern European countries than western. European population-based registries of leukemia diagnosed between 1970 and 1999 show an average increase in the incidence of leukemia during this period of 0.7% per year (8).

Acute lymphocytic leukemia (ALL) is the most common subtype (9). Low incidence rates usually are observed in developing countries. Advances in therapy have improved the prognosis of childhood leukemia dramatically in the last 30 years. In the U.S. and Europe, the current 5-year survival rates for children with ALL and acute myeloid leukemia (AML) are approximately 80% and 40%, respectively (10; 11), compared with mortality rates of 61% and 23%, respectively, observed from 1975 to 1984. In the majority of cases of childhood leukemia the causes are unknown. While a number of causes and highly suspected risk factors have been identified, reviews indicate that these are responsible for only a very small number of cases. The known and highly suspected causes include genetic factors (2–3% of cases are associated with Down syndrome), exposure to Epstein-Barr virus (for certain types of childhood Hodgkin lymphoma), exposure to ionizing radiation in utero and after birth and a number of drug treatments (for example, chlorambucil and chloramphenicol at birth) (12;13). Several studies suggest that children exposed to certain hazardous chemicals (benzene, hazardous air pollutants) have an increased risk of childhood leukemia, with benzene being the suspected causal agent (14). A number of papers have shown statistical associations between the risk of childhood leukemia and exposure to household insecticides used on plants and lawns and in head lice shampoos (15).

Paradoxically, improvements in treatment have widened the gap of inequality between children in resource-rich countries and children in poor nations. The most important factors are availability of drugs at affordable cost and development of centers or groups of excellence to ensure the efficacy and safety of chemotherapy (16). Socioeconomic characteristics have been associated with discrepancies in health and with disease incidence and mortality in many developed countries (17-19). The relation between social inequalities and cancer has been studied well for adults, but there are few reports regarding the influence of those inequalities for childhood leukemia incidence, mortality, and survival (20-26).

The economic burden of cancer is substantial and growing. The diagnosis of new cases has been increasing at an exponential rate since 1990. Health care needs are unlimited, whereas resources are restricted. Public expenditures on health care have to compete with other societal priorities such as education, the environment, defense and infrastructure. Even in relatively wealthy, developed countries, scarcity is the defining characteristic of resource allocation problems. Economic studies are playing an increasing role in helping both clinicians and the institutions that fund and provide health care to evaluate resource allocation challenges in a rational, evidence-based manner (27).

The economic burden of any disease can be defined in terms of the direct and indirect costs incurred by patients and society as a whole. The direct costs reflect the value of goods and services for health care or resources that could have been used for other purposes in the absence of illness (28). These include the costs of care provided by physicians and other health care professionals, care provided in hospitals and other health care institutions, drugs, laboratory

services and research. Indirect costs represent the reduced productivity associated with lost or impaired ability to work because of illness and the loss of economic productivity because of premature death. There are 2 main approaches to estimating indirect costs: the human capital method and the willingness-to-pay approach. Human capital method evaluates productivity lost because of disability or premature death, on the basis of lost earnings (29-32).

The willingness-to-pay approach considers the amount people are willing to pay to reduce the risk of illness or death (33, 34). In most instances, willingness-to-pay estimates are higher than those based on foregone earnings. The human capital approach, although widely used because of the availability of reliable statistics on individual income and earnings, is often criticized because it tends to discriminate against economically disadvantaged people and groups with lower rates of participation in the labor force (33-35).

There is a significant disconnect between cancer research discovery/development and the delivery of care to cancer patients. This disconnect is an important factor contributing to an imbalanced and unjust burden of cancer in our society: the burden falling on individuals with low socioeconomic status (SES), residents in certain geographic locations, and other medically underserved groups (36).

Economic burden is defined as expenditure on seeking treatment (direct cost), production and income losses (indirect cost), related coping strategies, and their consequences for the household livelihood in terms of indicators such as the number of workers and working days, asset portfolios, income and food consumption levels (37). Household survey methods are suited to measuring illness cost indicators and their statistical power gives them a comparative advantage over smaller case study samples. Numerous cross-sectional survey studies have measured patient

or household direct costs of illness, and to a lesser extent indirect costs, for specific diseases.

(38). A few of these survey instruments included questions on income to calculate cost burdens, and one study analyzed large income and expenditure survey data sets from 59 countries to calculate the extent of “catastrophic” health care payments in different health care settings, using a threshold of 40% of capacity to pay (39).

The purchase of medicines contributes significantly to the health care budget of developing countries, and drug expenditures may range from 50%–90% of the family budget (40). In developing countries, studies and data on medicine prices are scanty. Measuring and understanding the reasons for the price of medicines is the first stage in developing medicine pricing policies that would ensure the affordability of medicines.

The World Health Organization has estimated that one-third of the people of the world cannot afford the medicines they need. An important reason for this problem is that prices are often too high for people or government-funded health systems to afford. In developing countries, most people who need medicines have to pay for them out of their own pockets. Where the cost of drugs is covered by health systems, spending on medicines is a major part of the total healthcare budget (41).

Among its activities aimed at improving drug access in developing countries (including technical services such as help in drug procurement and performance of needs estimates), WHO has drawn up a Model List of Essential Drugs, which is updated every two years. The tenth list (1997) has 308 priority drugs that provide safe, effective treatment for the infectious and chronic diseases which affect the vast majority of the world’s population. The drugs are selected on the basis of cost-effectiveness within each drug class (e.g. of the dozens of penicillin only eight appear on the

Essential Drugs list). With WHO's encouragement, more than 140 countries have developed their own national essential drug lists taking into account local needs, costs and available resources (42).

Financial constraints are a reality in almost all aspects of medicine. Pharmaceutical expenditure ranges from 8.5% to 29.6% of health-care spending within Organization for Economic Co-operation and Development countries and is increasing faster than other areas of health-care spending in almost all these countries (43).

Drug prices differ, sometimes very substantially, between countries, even between those countries with similar social economic conditions (44) The World Health Organization (WHO) estimates that over one third of the world's population has no guaranteed access to essential drugs. Worldwide, the most important factor for access is affordability of drugs (45).

The global burden of disease resulting from all non-communicable conditions, which includes premature death and disability, is 49%: a total of 80% of this burden of disease occurs in low- and middle-income countries (46). Medicines represent a substantial proportion of the economic costs of treating chronic diseases in these countries (47). A significant proportion of chronic disease morbidity and mortality can be prevented if medications are made accessible and affordable (48).

Several studies have examined the availability, price and affordability of essential medicines; however few have focused specifically on medicines used to treat only chronic diseases (49). Little data exist on whether patients have access to affordable medicines for chronic diseases in low- and middle-income countries. This includes cancers such as leukemia (50).

Financial concerns can add to the stress of living with cancer. Patients who do not have adequate health coverage worry about how they will pay for care. Those who have coverage often find that it does not cover all the costs related to their illness (51).

Information on economic burden due to cancer is largely absent from common literature that offer information to cancer patients and their families—leaving patients in the untenable position of having to make treatment choices without fully understanding the costs and the impact on their ability to work (52).

Two important dimensions of economic data: medical and productivity costs are relevant to patients, physicians, and society. Direct medical costs are defined as the cost of medical care, including inpatient, outpatient, physician and other provider services, pharmaceuticals, and supportive care. From a patient's perspective, these costs are highly relevant since the costs associated with cancer care can be very expensive and perhaps prohibitive—even for patients who have generous health insurance benefits. As these costs rise, physicians and other health care providers may find themselves in the position of discussing with patients the trade-offs of treatment in terms of their relative costs and benefits (53; 54).

The economic burden on patients and their families for cancer treatment may include the immediate cost of treatment, out-of-pocket expenses (e.g. supportive care medication, co-payments, child care), and future costs required for cancer surveillance, follow-up care, and treatment of persistent symptoms (e.g. pain, fatigue). Out-of-pocket expenses will be incurred by all patients, and these costs can vary widely depending on where the patient lives and shops. For example, prescription drug costs vary from local pharmacies, to discount pharmacies, to Internet pharmacies. Other out-of-pocket costs include transportation, child care, and home care

services—all of which can add to a significant amount of money. More significantly, out-of-pocket expenses can also include the cost of participation in a clinical trial (55).

For families with children diagnosed with cancer, financial issues emerged as a significant concern at a time when these families were already consumed with other challenges. This economic burden can have long-term effects on the financial security, quality of life, and future well-being of the entire family, including the siblings of the affected child, but in particular the mother. Financial assistance programs for families of seriously ill children need to be revisited and expanded (56).

## **1.2 Aim of the Study/ Research Questions**

The aim of the study is to assess the financial problems faced by the households from Yerevan Armenia, having a child with leukemia registered in the Hematology Center in Yerevan from 2005 to 2008.

Research questions are the following:

What are the factors associated with the financial burden faced by the households with a child 18-and-under with leukemia living at home with their parents in Yerevan Armenia?

What is the proportion of parents with children with leukemia who reported making informal payments to physicians?

## **2. Methods**

### **2.1 Study Design**

A cross-sectional study design was selected to answer the research questions of the study. The selection of this study design is justified by the fact that the study population (parents of children with leukemia who lived with their parents) was limited in size, and the design required only one interview at only one point of time. In addition, the research questions were based on the evaluations of internal associations. The study was conducted by telephone interview technique. The parents of the patients with leukemia were contacted by the student investigator.

### **2.2 Study population**

The target population of the study was the parents of patients who were diagnosed with leukemia during the period of 2005 to 2008, were under the age of 18 years at the time of diagnosis, were registered in the Hematology Center in Yerevan from 2005 to 2008 and were still alive at the time of the study interview. The sampling frame, which was extracted from the Hematology Center register, included a list of parents with children under age 18 who were diagnosed with leukemia and were not at hospital at that time. The information included telephone number, demographic data, date of diagnosis of leukemia and a summary of primary and secondary treatments.

The inclusion and exclusion criteria were applied for eligibility.

The inclusion criteria were the following:

- parents of patients who were under the age of 18 years at the time of diagnosis

- parents of patients who were registered at the Hematology Center from 2005-2008
- parents who spoke Armenian

The exclusion criterion was the following:

- parents of patients who were hospitalized.

Parents of patients who were hospitalized were excluded because they were less likely to be purchasing secondary-treatment drugs for leukemia if their child was in the acute stage of leukemia and was hospitalized.

### **2.3 Sampling methodology**

After getting the permission from the head of the hematology center the medical records from 01.01.2005 to 31.12.08 were used to identify the study population starting. The names and contact information (telephone number) of parents were obtained from medical records for telephone based interviews. All the cases that met the eligibility criteria were chosen and contacted by the student investigator.

### **2.4 Sample size**

Sample Size calculations were based on the sample size formula for a population survey, provided by EpiInfo 3.4.1 (provided by the U.S.CDC and the WHO). One of the research questions addressed informal payments to physicians for leukemia secondary-treatment drugs; this question was selected for sample size calculations. Assumptions included a confidence interval of 99% (this precision was selected because the sampling frame permitted adequate sample size) and a power of 80%, with the assumption that 15% of the parents who purchased

secondary treatment drugs for leukemia costs were informally inflated by physicians and that the sample would fall within 10 percentage points of the true population value. The sample size calculation was 85; adjusting for a 10% refusal rate, the final sample size was computed to be 95. This was computed to be an adequate sample size for a measurement that reasonably reflects the true measure of the percent of parents with children afflicted with leukemia who made informal payments to their physicians to purchase secondary treatment drugs.

## **2.5 Study instrument**

The study instrument was formed from questions from validated questionnaires adapted for the study purposes and to the Hematology Center context. Generally the questions included information about patients' and their parents' demographic characteristics, financial problem of secondary treatment of leukemia. Questions were adopted from Prescription Drug Affordability: A 2004 AARP Montana Survey (57) and also from Access & Affordability of Prescription Drugs: An AARP Study of New Jersey's Hispanic Population (58).

## **3. Ethical Considerations**

The research proposal was reviewed and approved by the Institutional Review Board (IRB) at the AUA. For those eligible parents who answered the phone and showed interest in starting the interview, consent was read over the telephone. The patient's parents were informed that participation was voluntary and they could stop the interview at anytime with no consequence. They were informed that there was no risk in participating in the interview except for the inconvenience due to the fifteen minutes of time necessary to complete the interview and that

there were no direct benefits to the participant. They were informed that the results of the study might be used to improve affordability and decrease household economic burden from this disease in the future.

It was explained that the survey does not include any private sensitive issues and their confidentiality is assured. The sampling frame included patients' names and telephone numbers, but these data were not entered into the computerized database; no personal identifiers were entered into the database. After the data was entered into the computerized database and cleaned, the sampling frame which included personal information about the patients were destroyed to ensure confidentiality. Only the researcher and faculty staff had access to the secured computer database and all reporting was in aggregate form.

#### **4. Data Analysis**

After data collection the available data were entered into SPSS-11 software. After recoding and cleaning procedures through range checking and spot checking, the data were transferred into STATA-10 statistical package for statistical analysis.

Data were analyzed using SPSS 11.0 and Stata 10 statistical software packages. Univariate analyses (frequencies and means) were performed for all the variables of interest.

One of the outcome variables (household financial problems connected with secondary-treatment drugs for leukemia) is considered as a self-reported measure on economic burden on families

with a child having leukemia. The second outcome variable is informal payments to the physician for the prescribed secondary treatment drugs.

The independent variables were the following:

- gender of parent interviewed
- parent's concern about economic burden due to leukemia secondary treatment drug costs
- membership in drug discount programs
- household income
- drug purchasing behaviors

Bivariate analyses were conducted between the outcome variables and independent variables.

Standard 2-tailed t-test (for continuous variables) or a  $\chi^2$  tests (for dichotomous variables) were used to compare differences in characteristics among groups with different financial problems, and between groups with and without payments to physicians.

Crude odds ratios were used to assess the relationship between each of the independent variables and each of the dependent variables.

## **5. Results**

### **5.1 Descriptive analyses**

Out of 97 participants selected for the interview, 93 completed the interviews. Data collection started in May 1 and ended in May 30. The refusal rate, calculated as number of people refused

to answer to the questions divided by total number of participants contacted, was found to be 7%. The non-contact rate was 11%. Additionally, four people stopped the interview midway.

Descriptive characteristics for the households and for the children with leukemia are depicted in Table 2. Results show that 31% of those interviewed are very concerned about affording the costs of prescribed secondary-treatment drugs for their child with leukemia over the next two months, 46% were somewhat concerned and only 11% were not concerned about the affordability of these drugs.

According to the results, 90% of the participants reported that they did not participate in any drug discount program either by pharmacy or by doctor (Table 2).

Among the respondents 16% reported that their doctor suggested a specific pharmacy from which to purchase the prescribed drugs and 72% answered that their doctor never did suggestions from where to buy, 8% answered that they did not know or remember and 4% refused to answer (Table 2).

According to the results, 14% of respondents reported that they had ever paid directly to the doctor for getting the prescribed drugs. Only one interviewee reported that during the last 2 months he had given to the doctor 20.000 AMD for getting the prescribed drugs. The child of the interviewee each day took 2-3 prescribed medications for secondary treatment. Among the parents 95% who had paid for medication directly to the doctor, answered that they did not know how much they had paid for the last 2 months. 74% answered that they have never paid directly to the doctor for prescribed drugs, and 7% answered that they do not know/do not remember and 5% refused to answer (Table 2).

The parents that provided information about their children reported that only 3% of children with leukemia do not take prescribed secondary medication on a regular basis. Other 86% take prescribed medication for secondary treatment on regular basis, by different quantity of drugs. 8% of the parents did not know if their child was taking secondary medication on a regular basis, and 3% refused to answer (Table 2).

To the question “How much money did you spent out of your pocket in the last month for the secondary treatment of leukemia?” 7% of respondents reported that they had not spent any amount of money, 17% reported that they had spent less than 5000AMD, 19% spent from 5000 to 10000AMD, 24% from 10000 to 50000AMD, 10% from 50000 to 70000AMD and finally 18% spent more than 70000AMD (Table 2).

Among the respondents 33% reported that it was a major financial problem for them to pay for the secondary treatment medicine, 29% reported that it was a minor financial problem and only 12% reported that it was not a financial problem to pay for the secondary treatment of their child with leukemia, 15% did not know and 11% refused to answer (Table 2).

The results of the study showed that 33% of respondents reported that they had cut back necessary item such as food or utilities to buy secondary treatment drugs, and 40% answered that they did not cut necessary item such as food or utilities to buy secondary treatment drugs, 15% did not know and 12% refused to answer (Table 2).

Among the respondents 85% reported not having put off getting a prescription not filled and only 4% reported having putt of the prescribed medicine for secondary treatment, 8% did not know and 3% refused to answer (Table 2).

## 5.2 Bivariate analyses

According to the bivariate analysis, the first outcome variable (household financial problems connected with secondary-treatment drugs for leukemia) was associated with having cut back on other necessary items such as food or utilities to be able to afford a prescription medication for secondary treatment was also associated with household financial problems connected with secondary-treatment drugs for leukemia. Those who had cut back on other necessary items to be able to afford a prescription medication for secondary treatment were more likely to have major financial problems (65%), compared to those who do not have financial problem (Table 3).

According to the bivariate analysis, the first outcome variable (household financial problems connected with secondary-treatment drugs for leukemia) was not associated to any other independent variable (Table 3).

According to bivariate analysis no statistically significant association was found between the second outcome (informal payments to the physician for the prescribed secondary treatment drugs) and the remained variables (Table 4).

According to the bivariate logistic regression analyses, the parents of patients with leukemia who cut back on other necessary items such as food or utilities had a 4.4 times greater odds for having major financial problem compared to those that did not cut back on above mention items (OR=4.4, 95%CI=1.46;13.21).

Simple Linear Regression with percent of household income spent on secondary treatment drugs in previous month as the outcome with household monthly income as the independent variable.

Household economic burden was greater for poorer families than for richer families (Pearson's  $R=0.79$ ,  $p<0.0005$ ), as shown in graph 1.

Based on simple linear regression, for every decrease of 10,000 AMD in household income there was an average increase of 5% in household income spent on secondary treatment ( $p=0.015$ ).

The summary of the results by research questions are as follows:

Among parents having child with leukemia under age 18 for 33.33% major financial problem.

Also having major financial problem was associated with having cut back on other necessary items such as food or utilities.

The proportion of parents with children with leukemia who reported making informal payments to physicians was 14.0%.

## **6. Discussion**

The study aimed to assess the financial problems faced by the households from Yerevan Armenia, having a child with leukemia registered in the Hematology Center in Yerevan from 2005 to 2008.

According to the results, 33.33% of the respondents reported that it was a major financial problem for them to pay for the secondary treatment medicine, 29% reported that it was a minor financial problem and only 12% reported that it was not a financial problem to pay for the secondary treatment of their child with leukemia. The remained 26% refused to answer. It

becomes evident that one third of the household with a child with leukemia face major financial problems with the costs of secondary treatment drugs, and that poorer families were more impacted than wealthier families. The factors associated to financial problems faced by the households, having a child with leukemia were concern about being able to afford secondary treatment, and having cut back on other necessary items such as food or utilities to be able to afford a prescription medication.

Among the respondents 14.0% had performed informal payments to the physician for the prescribed secondary treatment drugs. The result could be even higher, because one would suspect that some of the respondent would try to hide the informal payments, not to have any further risks connected with the treatment in the center. The factors associated with informal payments to the physician for the prescribed secondary treatment drugs, were having cut back on other necessary items such as food or utilities to be able to afford a prescription medication for secondary treatment and with practices for purchasing secondary treatment drug.

Among the respondents 16% reported that their doctor suggested a specific pharmacy from which to purchase the prescribed drugs. From the data one can conclude that the doctors who suggested purchasing from directed pharmacy can have a communication with that pharmacy and get back some percentage of money out of their prescription. Another explanation could be the fact that as the interviewed reported, the doctor suggested purchasing from direct pharmacy because it was cheap comparing to the others.

## **7. Limitations**

One of the study limitations was having small sample size because of having finite number of patients for the mentioned time period. However, assumptions included a confidence interval of 99% for better precision.

Since not all the patients that are registered have phone numbers, some of them were dropped out. In case of incompleteness the data are potentially biased in some way. For instance, patients without registered phone numbers might be more likely to live in regions of the country, where some villages do not have phone. They also may not have phone because of being poor so as they are not able to afford having such kind of service. This may be a threat to external validity.

The determination of the type of financial problem for the household and out-of-pocket payments were self-reported measures, and could not correspond to the reality; could be over- or underestimated. The proxy measure for economic burden was chosen the self-reported determination of the type of financial problem. In ideal situation it could consider the direct and indirect costs of the treatment.

## **8. Conclusions/Recommendations**

According to the results of the study, one third of the household with a child with leukemia face major financial problems, and 14% of the households had performed informal payments to the physician for the prescribed secondary treatment drugs. By these findings there is a conclusion that the economic burden on the families with a child with leukemia should be reduced. There is

a serious problem with household economic burden due to secondary treatment drugs for leukemia.

The economic household burden substantially reduces the expenditures on other household necessities such as food and utilities for many households. This impacts the poor households more than richer households.

Additional means should be applied to target these families for further financial assistance.

For the real measurement of economic burden further more detailed study could be conducted considering the direct and indirect costs of the treatment.

## Reference List

1. Ferlay J, Bray F, Pisani P et al. GLOBOCAN 2002: Cancer Incidence, Mortality and Prevalence Worldwide. IARC CancerBase No. 5. version 2.0, IARCPress, Lyon, 2004. Available at: <http://www-dep.iarc.fr/> (Accessed 2 August 2007).
2. World Health Organization. (2006, February). Cancer. Fact Sheet No. 297. Available at: <http://www.who.int/mediacentre/factsheets/fs297/en/index.html> (Accessed 2 August 2007).
3. National Cancer Institute. A Snapshot of Leukemia, 2006. Available at: <http://planning.cancer.gov/disease/Leukemia-Snapshot.pdf> (Accessed 23 August 2007).
4. Parkin DM, Bray F, Ferlay J, Pisani, P. Estimating the world cancer burden: Globocan 2000. International Journal of Cancer 2001; 94(2): 153-156.
5. Jemal A, Siegel R, Ward E, et al. Cancer Statistics, 2007. CA A Cancer Journal for Clinicians. 2007; 57(1): 43-66.
6. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology: Chronic Myelogenous Leukemia. (Version 1.2008), 2007c. Available

at: [http://www.nccn.org/professionals/physician\\_gls/PDF/cml.pdf](http://www.nccn.org/professionals/physician_gls/PDF/cml.pdf) (Accessed 29

August 2007).

7. National Cancer Institute. Chronic Myeloproliferative Disorders (PDQ®): Treatment,

2007c. Available at:

<http://www.cancer.gov/cancertopics/pdq/treatment/myeloproliferative/healthprofe>

[ssional/allpages](#) (Accessed 23 August 2007).

8. Seay M, Varma P (2005) Pharmaceuticals: Pharmaceutical cost controls—2005. End of Year Issue Brief. Issue Brief Health Policy Track Serv 31: 1–20.

9. Petridou E, Trichopoulos D. Leukemias. In: Adami HO, Hunter D, Trichopoulos D, editors. Textbook of Cancer Epidemiology. New York, NY: Oxford, 2002:556–572.

10. Ries LAG, Smith MA, Gurney JG, et al., eds. Cancer Incidence and Survival Among Children and Adolescents: United States SEER Program 1975–1995. National Cancer Institute, SEER Program. NIH Pub. No. 99–4649. Bethesda, Md: National Cancer Institute; 1999.

11. Gatta G, Corazziari I, Magnani C, Peris-Bonet R, Roazzi P, Stiller C;EUROCARE Working Group. Childhood cancer survival in Europe. Ann Oncol. 2003;14:119–127

12. Goldman DP, Joyce GF, Escarce JJ, Pace JE, Solomon MD, et al. (2004) Pharmacy benefits and the use of drugs by the chronically ill. JAMA 291: 2344–2350.

13. Soumerai S, Ross-Degnan D, Avorn J, McLaughlin TJ, Choodnovskiv I (1991) Effects of medicaid drug-payment limits on admission to hospitals and nursing homes. *N Eng J Med* 325: 1072–1077.
14. Tamblyn R, Laprise R, Hanley JA, Abrahamowicz M, Scott S, et al. (2001) Adverse events associated with prescription drug cost-sharing among poor and elderly persons. *JAMA* 285: 421–429.
15. Lexchin J, Grootendorst P (2004) Effects of prescription drug users fees on drug and health services use and on health status in vulnerable populations: A systematic review of the evidence. *Int J Health Serv* 34: 101–122.
16. Tognoni G, Masera G, Pui CH, et al. Statement by members of the Ponte di Legno Group on the right of children with leukemia to have full access to essential treatment for acute lymphoblastic leukemia. *Ann Oncol.* 2005;16:169–170.
17. Sorlie PD, Backlund E, Keller JB. U.S. mortality by economic, demographic, and social characteristics: the National Longitudinal Mortality Study. *Am J Public Health.* 1995;85:949–956.
18. Adler NE, Ostrove JM. Socioeconomic status and health: what we know and what we don't. *Ann N Y Acad Sci.* 1999;896:3–15.
19. Singh GK, Miller BA, Hankey BF, Edwards BK. Area Socioeconomic Variations in U.S. Cancer Incidence, Mortality, Stage, Treatment, and Survival, 1975–1999. *NCI Cancer*

Surveillance Monograph Series No. 4. NIH Pub. No. 03–5417. Bethesda, Md: National Cancer Institute; 2003.

20. Petridou E, Kosmidis H, Haidas S, et al. Survival from childhood leukemia depending on socioeconomic status in Athens. *Oncology*. 1994;51:391–395.

21. Swensen AR, Ross JA, Severson RK, Pollock BH, Robison LL. The age peak in childhood acute lymphoblastic leukemia: exploring the potential relationship with socioeconomic status. *Cancer*. 1997;79:2045–2051.

22. Viana MB, Fernandes RA, de Carvalho MI, Murao M. Low socioeconomic status is a strong independent predictor of relapse in childhood acute lymphoblastic leukemia. *Int J Cancer*. 1998;11(suppl):56–61.

23. Hrusak O, Trka J, Zuna J, et al. Acute lymphoblastic leukemia incidence during socioeconomic transition: selective increase in children from 1 to 4 years. *Leukemia*. 2002;16:720–725.

24. Bhatia S. Influence of race and socioeconomic status on outcome of children treated for childhood acute lymphoblastic leukemia. *Curr Opin Pediatr*. 2004;16:9–14.

25. Borugian MJ, Spinelli JJ, Mezei G, Wilkins R, Abanto Z, McBride ML. Childhood leukemia and socioeconomic status in Canada. *Epidemiology*. 2005;16:526–531.

26. Raaschou-Nielsen O, Obel J, Dalton S, Tjonneland A, Hansen J. Socioeconomic status and risk of childhood leukaemia in Denmark. *Scand J Public Health*. 2004;32:279–286.

27. Levy IG, Iscoe NA, Klotz LH. Prostate cancer: 1. The descriptive epidemiology in Canada. *CMAJ* 1998;159(5):509-13.
28. Moore R, Mao Y, Zhang J, Clarke K. Economic burden of illness in Canada, 1993. Ottawa: Health Canada; 1997.
29. Cooper BS, Rice DP. The economic costs of illness revisited. *Soc Secur Bull* 1976;39:21-36.
30. Hodgson TA. The state of the art of cost-of-illness estimates. *Adv Health Econ Health Serv Res* 1983;4:129-64.
31. Robinson JC. Philosophical origins of the economic valuation of life. *Millbank Q* 1986;64:133-55.
32. Rice DP. Estimating the cost of illness. Washington: US Department of Health, Education and Welfare; 1966. Public Health Service, Health Economics Series 6.
33. Robinson JC. Philosophical origins of the economic valuation of life. *Millbank Q* 1986;64:133-55.
34. Rice DP. Estimating the cost of illness. Washington: US Department of Health, Education and Welfare; 1966. Public Health Service, Health Economics Series 6.
35. O'Brien B, Viramontes JL. Willingness to pay: a valid and reliable measure of health state preference. *Med Decis Making* 1994;14:289-97
36. Freeman HP. Poverty, culture, and social injustice: determinants of cancer disparities. *CA Cancer J Clin* 2004;54(2):72-7.

37. Scoones I. 1998. Sustainable rural livelihoods: a framework for analysis. IDS Working Paper 72. Brighton: Institute of Development Studies.
38. Russell S. 2004. The economic burden of illness for households in developing countries: a review of studies focusing on malaria, tuberculosis and HIV/AIDS. *American Journal of Tropical Medicine and Hygiene* 7 (Suppl 2): 147–55.
39. Xu K, Evans DB, Kawabata K et al. 2003. Household catastrophic health expenditure: a multi-country analysis. *The Lancet* 362: 111–7.
40. Levy IG, Iscoe NA, Klotz LH. Prostate cancer: 1. The descriptive epidemiology in Canada. *CMAJ* 1998;159(5):509-13.
41. Fryback DG, Craig BM. Measuring economic outcomes of cancer. *J Natl Cancer Inst Monogr* 2004(33):134-141.
42. The world health report 2003: shaping the future. Geneva: WHO; 2003.
43. Zaheer Ud Din Babar, Mohamed Izham Mohamed Ibrahim, Harpal Singh, et al, Evaluating Drug Prices, Availability, Affordability, and Price Components: Implications for Access to Drugs in Malaysia.
44. Steward GJ (ed). *Managing HIV*. Sydney: The Australasian Medical Publishing Company, 1996.
45. IMS Health, IMS Health reports 10% growth in 2000 audited pharmaceutical sales to \$317.2 billion, 6 March 2001, <http://www.imshealth.com>

46. Canadian Institute for Health Information (2005) Drug expenditure in Canada 1985 to 2004. Ottawa: Canadian Institute for Health Information.
47. Garrison L, Towse A (2003) The drug budget silo mentality in Europe: An overview. *Value Health* 6: S1–S9.
48. Belson M, Kingsley B, Holmes A. Risk factors for acute leukaemia in children: a review. *Environmental Health Perspectives*, 2007, 115(1):138–145.
49. Zahm 1998. Pesticides and childhood cancer. *Environmental Health Perspectives*, 1998, 106(Suppl. 3):893–908.
50. Ma X et al. Critical windows of exposure to household pesticides and risk of childhood leukaemia. *Environmental Health Perspectives*, 2002, 110(9):955–960
51. Anis AH, Guh DP, Lacaille D, Marra CA, Rashidi AA, et al. (2005) When patients have to pay a share of drug costs: Effects on frequency of physician visits, hospital admissions and filling of prescriptions. *CMAJ* 173: 1335–1339.
52. Hsu J, Price M, Huang J, Brand R, Fung V, et al. (2006) Unintended consequences of caps on medicare drug benefits. *N Eng J Med* 354: 2349–2359
53. Maxwell M, Heaney D, Howie JGR, Noble S (1993) General practice fundholding: Observations of prescribing patterns and costs using the defined daily dose method. *BMJ* 307: 1190–1195.

54. Ess SM, Schneeweiss S, Szucs TD (2003) European healthcare policies for controlling drug expenditure. *Pharmacoeconomics* 21: 89–103.

55. Aaserud M, Dahlgren A, Kusters J, Oxman A, Ramsay C, et al. (2006) Pharmaceutical policies: Effects of reference pricing, other pricing, and purchasing policies. *Cochrane Database Syst Rev* 2006: CD005979. Available:

<http://www.mrw.interscience.wiley.com/cochrane/clsystrev/articles/CD005979/frame.html>.

(Accessed 19 April 2006).

56. B. Miedema, J. Easley, P. Fortin PhD, R. Hamilton MSES, and M. Mathews, The economic impact on families when a child is diagnosed with cancer.

57. Prescription Drug Affordability: A 2004 AARP Montana Survey.

58. Access & Affordability of Prescription Drugs: An AARP Study of New Jersey's Hispanic Population.

## Tables

**Table 1. Age-standardized world incidence and mortality rates/100,000 for leukemia**

	<b>Worldwide</b>	<b>More developed regions</b>	<b>Less developed regions</b>
<b>Incidence</b>			
Males	5.8	9.1	4.4
Females	4.1	5.9	3.2
<b>Mortality</b>			
Males	4.3	5.5	3.5
Females	3.1	3.6	2.6

**Table 2. Descriptive characteristics of the participants**

<b>Variable name</b>	<b>percent (fraction)</b>	
Age of patient (mean)	10.04	
Gender of a parent		
Male	44.09%	(41/93)
Female	55.91%	(52/93)
Did the doctor of your child prescribed medicines for secondary treatment for leukemia to your child for you to purchase?		
Yes	86.02%	(80/93)
No	9.68%	(9/93)
Don't know/don't remember	2.15 %	(2/93)
Refused	2.15 %	(2/93)
How concerned are you about being able to afford the cost of prescription drugs for your child (for secondary treatment) over the next two months?		
Very concerned		
Somewhat concerned	31.18%	(29/93)
Not very concerned	46.24%	(43/93)
Not at all concerned	10.75%	(10/93)
Don't know/not sure	10.75%	(10/93)
Refused	1.08%	(1/93)
Do you participate in any prescription drug discount programs or have a prescription discount card?		
Yes	4.30 %	(4/93)
No	90.32%	(84/93)
Don't know/not sure	5.38%	(5/93)
Did the doctor suggest a specific pharmacy from which to purchase the drugs for secondary treatment?		
Yes	16.13%	(15/93)
No	72.04%	(67/93)
Do not know	7.53%	(7/93)
Refused	4.30%	(4/93)
Have you ever paid directly to the doctor for the prescribed secondary treatment drugs?		
Yes	13.98%	(13/93)
No	74.19%	(69/93)
Do not know	6.45%	(6/93)
Refused	5.38%	(5/93)
If you have paid the physician directly for the prescribed drugs, how much have you paid for the last 2 months?		
0	98.92%	(92/93)
20.000AMD	1.08%	(1/93)

Did you taken for your child any prescription medications for a secondary treatment in the last 12 months?		
Yes	87.10%	(81/93)
No	5.38%	(5/93)
Don't know/not sure	4.30%	(4/93)
Refused	3.23%	(3/93)
Is your child currently taking prescription medications for secondary treatment on a regular basis?		
Yes	86.02%	(80/93)
No	3.23%	(3/93)
Don't know/not sure	7.53%	(7/93)
Refused	3.23 %	(3/93)
Approximately how many different prescription medications for secondary treatment did your child take each day?		
1	30.11%	(28/93)
2 – 3	44.09%	(41/93)
4 – 5	4.30%	(4/93)
6 or more	5.38%	(5/93)
Don't know/not sure	13.98%	13/93)
Refused	2.15%	(2/93)
In the last months or 30 days, approximately how much money did you spend out of your own pocket on prescription drugs for secondary treatment?		
Nothing	6.45%	(6/93)
Less than 5000 AMD	17.20%	(16/93)
From 5000-10000 AMD	19.35%	(18/93)
From 10000-50000 AMD	23.66%	(22/93)
From 50000-70000AMD	9.68%	(9/93)
More than 70000 AMD	18.28%	(17/93)
Don't know/don't remember	5.38%	(5/93)
Would you say that paying for these prescription medications is a major financial problem, a minor financial problem, or not a financial problem for you?		
Major Financial Problem	33.33%	(31/93)
Minor Financial Problem	29.03%	(27/93)
Not a Financial problem	11.83%	(11/93)
Don't know/not sure	15.05%	(14/93)
Refused	10.75%	(10/93)
In the past 2 months, have you cut back on other necessary items such as food or utilities to be able to afford a prescription medication for secondary treatment?		
Yes	33.33%	(31/93)
No	39.78%	(37/93)
Don't know/not sure	15.05%	(14/93)
Refused	11.83%	(11/93)

In the past 2 months have you put off getting a prescription of secondary treatment filled because you didn't have enough money to pay for it?		
Yes	4.30%	(4/93)
No	84.95%	(79/93)
Don't know/not sure	7.53%	(7/93)
Refused	3.23%	(3/93)
Do you think the price of prescription drugs for secondary treatment		
Are the same regardless of where you buy them	18.28%	(17/93)
Vary a little from pharmacy to pharmacy	36.56%	(34/93)
Vary a lot from pharmacy to pharmacy	34.41%	(32/93)
Not sure	10.75%	(20/93)
In the past 2 months, have you or a family member delayed getting a prescription for secondary treatment filled or not gotten a prescription filled because you didn't have enough money to pay for it?		
Yes	16.13%	(15/93)
No	83.87%	(78/93)
In the past 2 months, have you or a family member taken less medicine than your doctor prescribed to make it last longer?		
Yes	12.90%	(12/93)
No	87.10%	(81/93)
In the past 2 months, have you or a family member ordered your prescription drugs for secondary treatment from a company in another country because they cost less?		
Yes	7.53%	(7/93)
No	92.47%	(86/93)
In the past 2 months, have you or a family member checked prices with more than one pharmacy before buying to get the best price?		
Yes		
No	86.02%	(80/93)
	13.98%	(13/93)
When you purchase a prescription drug for secondary treatment, which of the following are you most likely to do?		
Check prices with more than one pharmacy before buying to get the best price	29.03%	(27/93)
Purchase the prescription from the pharmacy that is closest to your home	13.98%	(13/93)
Purchase the prescription from the pharmacy that is closest to your doctor's office	6.45%	(6/93)
Purchase the prescription at a pharmacy within a store you frequently shop in	3.23%	(3/93)

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Last month, the approximate amount of household income spent by your entire household members was:		
Less than 25,000 drams	11.83%	(11/93)
From 25,000 - 50,000 drams	25.81%	(24/93)
From 51,000 - 100,000 drams	27.96%	(26/93)
From 101,000 - 250,000 drams	2.15%	(2/93)
Above 250,000drams	2.15%	(2/93)
Don't know	30.11%	(28/93)

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**Table 3. Results of  $\chi^2$  tests (differences in characteristics among groups with different financial problems)**

<b>Variable</b>	<b>Financial problem (n %)</b>	<b>Not a Financial Problem (n %)</b>	<b>p-value</b>
Gender of a parent			
male	38.7 (12/31)	55.3 (21/38)	0.171
female	61.3 (19/31)	44.7 (17/38)	
How concerned are you about being able to afford the cost of prescription drugs for your child (for secondary treatment) over the next two months?			<b>0.922</b>
Very concerned	83.3 (25/30)	84.2 (32/38)	
Not concerned	16.7 (5/30)	15.8 (6/38)	
Do you participate in any prescription drug discount programs or have a prescription discount card?			0.687
Yes	3.4 (1/29)	5.5 (2/36)	
No	96.6 (28/29)	94.5 (34/36)	
Did the doctor suggest a specific pharmacy from which to purchase the drugs?			0.359
Yes	14.3 (4/28)	23.5 (8/34)	
No	85.7 (24/28)	76.5 (26/34)	
Have you ever paid the doctor directly for the prescribed secondary treatment drugs?			0.840
Yes	13.8 (4/29)	15.6 (5/32)	
No	86.2(25/29)	84.4 (27/32)	
In the last months or 30 days, approximately how much money did you spend out of your own pocket on prescription drugs for secondary treatment?			0.599
From 0-10000 AMD	44.8 (13/29)	51.4 (19/37)	
From 10000 and more than 70000 AMD	55.2 (16/29)	48.6 (18/37)	
In the past 2 months, have you cut back on other necessary items such as food or utilities to be able to afford a prescription medication for secondary treatment?			<b>0.006</b>
Yes	65.0 (13/20)	24.0 (6/25)	
No	35.0 (7/20)	76.0 (19/25)	

In the past 2 months have you put off getting a prescription of secondary treatment filled because you didn't have enough money to pay for it?			0.872
Yes	3.6 (1/28)	2.9 (1/35)	
No	96.4 (27/28)	97.1 (34/35)	
In the past 2 months, have you or a family member delay getting a prescription for secondary treatment filled or not gotten a prescription filled because you didn't have enough money to pay for it?			0.759
Yes	12.9 (4/31)	10.5 (4/38)	
No	87.1 (27/31)	84.5 (34/38)	
In the past 2 months, have you or a family member taken less medicine than your doctor prescribed to make it last longer?			0.975
Yes	12.9 (4/31)	13.2 (5/38)	
No	87.1 (27/31)	86.8 (33/38)	
In the past 2 months, have you or a family member ordered your prescription drugs for secondary treatment from a company in another country because they cost less?			0.482
Yes	9.7 (3/31)	5.3 (2/38)	
No	90.3 (28/31)	94.7 (36/38)	
In the past 2 months, have you or a family member checked prices with more than one pharmacy before buying to get the best price?			0.975
Yes	87.1 (27/31)	86.8 (33/38)	
No	12.9 (4/31)	13.2 (5/38)	
Last month, the approximate amount of household income spent by your entire household members was:			0.959
From 0 - 50,000 drams	58.8 (10/17)	58.1 (18/31)	
51,000 - 250,000 and more drams	41.2 (7/17)	41.9 (13/31)	

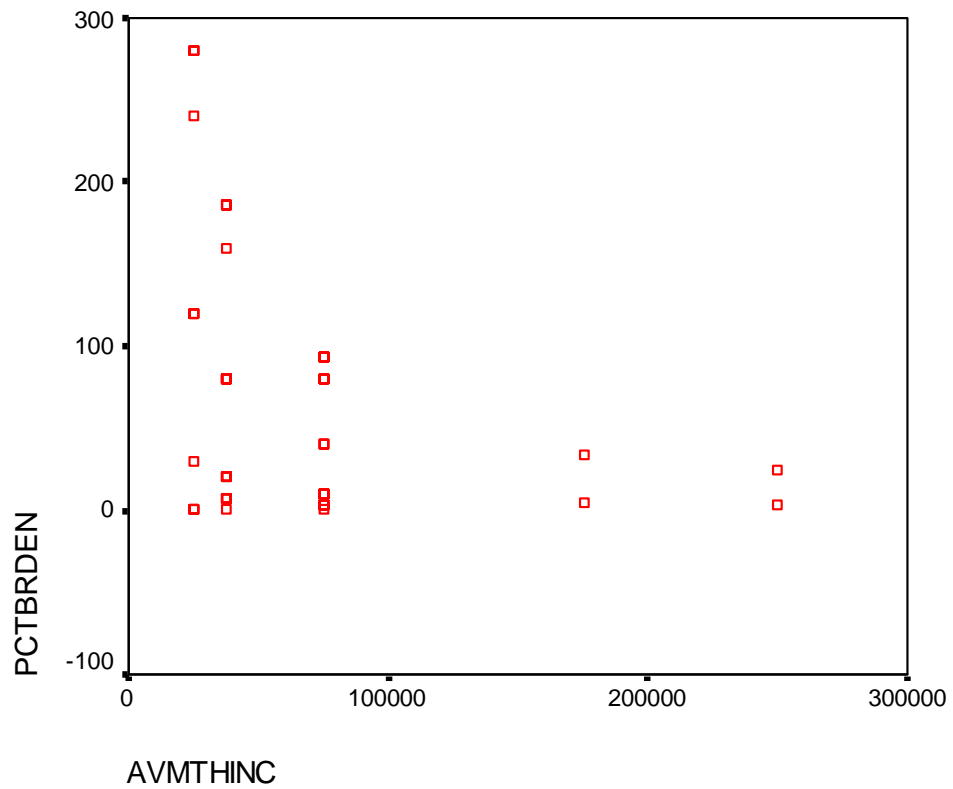
**Table 4. Results of  $\chi^2$  tests differences in characteristics (between groups with and without payments to physicians)**

<b>Variable</b>	<b>Yes (n %)</b>	<b>No (n %)</b>	<b>p-value</b>
Gender of a parent			0.988
male	46.2 (6/13)	46.4 (32/69)	
female	53.8 (7/13)	53.6 (37/69)	
How concerned are you about being able to afford the cost of prescription drugs for your child (for secondary treatment) over the next two months?			0.169
Very concerned	92.3 (12/13)	75.0 (51/68)	
Not concerned	7.7 (1/13)	25.0 (17/68)	
Did the doctor suggest a specific pharmacy from which to purchase the drugs?			0.381
Yes	25.0 (3/12)	14.8 (9/61)	
No	75.0 (9/12)	85.2 (52/61)	
In the last months or 30 days, approximately how much money did you spend out of your own pocket on prescription drugs for secondary treatment?			0.701
From 0-10000 AMD	41.7 (5/12)	47.7 (31/65)	
From 11000-more than 70000	58.3 (7/12)	52.3 (34/65)	
Would you say that paying for these prescription medications is a major financial problem, a minor financial problem, or not a financial problem for you?			0.840
Major financial problem	44.4 (4/9)	48.1 (25/52)	
Not a financial problem	55.6 (5/9)	51.9 (27/52)	
In the past 2 months, have you cut back on other necessary items such as food or utilities to be able to afford a prescription medication for secondary treatment?			0.259
Yes	60.0 (6/10)	59.3 (22/54)	
No	40.0 (4/10)	40.7 (32/54)	
In the past 2 months have you put off getting a prescription of secondary treatment filled because you didn't have enough money to pay for it?			0.645
Yes	9.1 (1/12)	5.0 (3/60)	
No	90.9 (11/12)	95.0 (57/60)	

In the past 2 months, have you or a family member delay getting a prescription for secondary treatment filled or not gotten a prescription filled because you didn't have enough money to pay for it?			0.860
Yes	15.4 (2/13)	17.4 (12/69)	
No	84.6 (11/13)	82.6 (57/69)	
In the past 2 months, have you or a family member taken less medicine than your doctor prescribed to make it last longer?			0.680
Yes	7.7 (1/13)	11.6 (8/69)	
No	92.3 (12/13)	88.4 (61/69)	
In the past 2 months, have you or a family member checked prices with more than one pharmacy before buying to get the best price?			0.820
Yes	84.6 (11/13)	87 (60/69)	
No	15.4 (2/13)	13 (9/69)	
Last month, the approximate amount of household income spent by your entire household members was:			0.561
From 0 - 50,000 drams	66.6 (6/9)	56.3 (27/48)	
51,000 - 250,000 and more drams	33.4 (3/9)	43.7 (21/48)	

## Graphs

**Graph 1. Relationship between household monthly income and spending for secondary treatment drugs for leukemia**



Pearson's  $R=0.79$ ,  $p<0.0005$



## Appendix 2. Questionnaire (English & Armenian)

ID-----

Date of the interview----- (Day/Month/Year)

Start time of the interview----- (Hour/Minute)

End time of the interview ----- (Hour/Minute)

Are you a parent or guardian of the patient?

If not may I speak to a parent or guardian???

### 1. Gender of the parent/guardian being interviewed:

1. Male
2. Female

2. Age of the patient: \_\_\_\_\_

### 3. Did the doctor of your child prescribed secondary treatment medicines for your child for you to purchase?

- a) Yes
- b) No
- c) Don't know/don't remember
- d) Refused

### 4. How concerned are you about being able to afford the cost of your child prescription drugs over the next two years? Would you say you are.....[READ]

- a) Very concerned
- b) Somewhat concerned
- c) Not very concerned
- d) Not at all concerned
- e) Don't know/don't remember
- f) Refused

### 5. Do you participate in any prescription drug discount programs or have a prescription discount card? [IF NECESSARY ADD: "Discount prescription cards or programs such as those offered through a local drug store or pharmacy, a doctor's office, a membership organization." ] If no go to question 10

- a) Yes
- b) No
- c) Don't know/don't remember

d) Refused

**6. If you have received prescription drug discount card or program from whom did you receive it?**

a) Doctor

b) The pharmacy

c) Other \_\_\_\_\_

d) Do not know

e) Refused

**7. Did the doctor suggest a specific pharmacy from which to purchase secondary treatment drugs?**

a) Yes

b) No

c) Do not know

d) Refused

**8. Have you ever paid the doctor directly for the secondary treatment drugs? If no go to question 10.**

a) Yes

b) No

c) Do not know

d) Refused

**9. If you have paid the physician directly for the prescribed drugs, how much have you paid for the last 2 months?**

a) \_\_\_\_\_

b) Do not know

c) Refused

**10. Has your child taken any prescription medications in the last 12 months?**

a) Yes

b) No

c) Don't know/don't remember

d) Refused

**11. Is your child currently taking secondary treatment prescription medications on a regular basis? [IF NECESSARY: "By regularly we mean any medication that you have to take daily, weekly, monthly for an extended period of time].**

a) Yes

b) No

c) Don't know/don't remember

d) Refused

**12. Approximately how many different prescription medications did your child take each day? [DO NOT READ CATEGORIES]**

- a) 1
- b) 2 – 3
- c) 4 – 5
- d) 6 or more
- e) Don't know/don't remember
- f) Refused

**13. In the last months or 30 days, approximately how much money did you spend out of your own pocket on secondary treatment drugs?**

- a) Nothing
- b) Less than 5000 AMD
- c) From 5000-10000 AMD
- d) From 10000-50000 AMD
- e) From 50000-70000AMD
- f) More than 70000
- g) Don't know/don't remember
- h) Refused

**14. Would you say that paying for these secondary treatment medications is a.**

- a) Major Financial Problem
- b) Minor Financial Problem
- c) Not a Financial problem
- d) Don't know/don't remember
- e) Refused

**15. In the past 2 months, have you cut back on other necessary items such as food or utilities to be able to afford a secondary treatment medication?**

- a) Yes
- b) No
- c) Don't know/don't remember
- d) Refused

**16. In the past 2 months have you put off getting a secondary treatment medication because you didn't have enough money to pay for it?**

- a) Yes
- b) No
- c) Don't know/don't remember
- d) Refused

**17. Do you think the price of secondary treatment medication**

- a) Are the same regardless of where you buy them
- b) Vary a little from pharmacy to pharmacy
- c) Vary a lot from pharmacy to pharmacy
- d) NOT SURE (DO NOT READ)
- e) Refused (DO NOT READ)

**18. Many people face difficult decisions when buying secondary treatment medication. In the past 2 months, have you or a family member done any of the following? (RECORD AS MULTIPLE RESPONSE)**

- a) Delayed getting a prescription filled or not gotten a prescription filled because you didn't have enough money to pay for it?
- b) Taken less medicine than your doctor prescribed to make it last longer?
- c) Ordered your prescription drugs from a company **in another country** because they cost less?
- d) Checked prices with more than one pharmacy before buying to get the best price?
- e) None of above (Do not read)
- f) Not Sure (Do not read)
- g) Refused (Do not read)

**19. When you purchase a secondary treatment medication for your child, which of the following are you most likely to do?**

- a) Check prices with more than one pharmacy before buying to get the best price
- b) Purchase the prescription from the pharmacy that is closest to your home
- c) Purchase the prescription from the pharmacy that is closest to your doctor's office
- d) Purchase the prescription at a pharmacy within a store you frequently shop in
- e) NOT SURE (DO NOT READ)
- f) DO NOT PURCHASE PRESCRIPTIONS (DO NOT READ)
- g) NONE OF THESE (DO NOT READ)
- h) REFUSED (DO NOT READ)

**20. Last month, the approximate amount of household income spent by all of your household members was:**

- a) Less than 25,000 drams
- b) From 25,000 - 50,000 drams
- c) From 51,000 - 100,000 drams
- d) From 101,000 - 250,000 drams
- e) Above 250,000drams
- f) Don't know

## Հարցաթերթիկ

### Տարբերակման համարը \_\_\_\_\_

Հարցման օրը \_\_\_\_\_ օր/ամիս/տարի)

Հարցման սկիզբը \_\_\_\_\_ (ժամ/րոպե)

Հարցման ավարտը \_\_\_\_\_ (ժամ/րոպե)

Պատասխանը պետք է նշվի՝ շրջանակի մեջ վերցնելով տարբերակին համապատասխանող թիվը կամ լրացնելով տողերը

Դուք եք հիվանդի ծնողը կամ խնամակալը:

Եթե ոչ կարող ե՞մ խոսել հիվանդի ծնողի կամ խնամակալի հետ:

1. Հարցվող ծնողի կամ խնամակալի սեռը \_\_\_\_\_

1)արական

2)իգական

2. Հիվանդի տարիքը-----

3. Ձեր բժիշկը Ձեզ երեխայի համար դեղորայք նշանակե՞լ է, որը Դուք պետք է ձեռք բերեք

1. այո

2. ոչ

3. չգիտեմ/ չեմ հիշում

4. մերժված

4. Որքանով եք անհանգստացած հաջորդ 2 ամսվա ընթացքում Ձեր երեխային նշանակված երկրորդային բուժման համար նախատեսված դեղորայքի ձեռք բերման վերաբերյալ՝ ֆինանսական մատչելիության առումով

1. շատ եք անհանգստացած

2. ինչ որ չափով եք անհանգստացած

3. այնքան էլ անհանգստացած չեմ

4. ընդհանրապես անհանգստացած չեմ

5. չգիտեմ/ չեմ հիշում

6. մերժված

5. Դուք երբևիցե մասնակցել եք Ձեր երեխային նշանակված դեղորայքների գեղչային ծրագրերի կամ ունեք գեղչային քարտ (Ձեղչային քարտերը կամ ծրագրերը նրանք են, որոնք տրամադրվում են տարածքային դեղատների, բժիշկների կամ որոշակի կազմակերպությունների կողմից): Եթե ոչ անցնել հարց 10ին:

1. այո

2. ոչ

3. չգիտեմ/ չեմ հիշում

4.մերժված

6.Եթե ստացել եք գեղչային ծրագրեր կամ քարտեր, ապա ումից եք ստացել

1. բժիշկ

2. դեղատուն

3. ուրիշ

4. չգիտեմ/ չեմ հիշում

5. մերժված

7. Երբևէ Ձեր բժիշկը առաջարկել է որոշակի դեղատներ որտեղից կարող եք ձեռք բերել երկրորդային բուժման դեղորայք

1. այո

2. ոչ

3. չգիտեմ/ չեմ հիշում

4. մերժված

8. Երբևէ Դուք Ձեր երեխային նշանակված երկրորդային բուժման դեղի համար անմիջականորեն վճարել եք բժշկին: Եթե ոչ անցնել հարց 10ին:

1. այո

2. ոչ

3. չգիտեմ/ չեմ հիշում

4. մերժված

9. Եթե անմիջականորեն վճարել եք բժշկին նշանակված երկրորդային բուժման դեղերի համար, ապա վերջին երկու ամսվա ընթացքում որքան եք վճարել

1. -----

2. չգիտեմ/ չեմ հիշում

3. մերժված

10. Վերջին 12 ամսվա ընթացքում Ձեր երեխան ընդունում է երկրորդային բուժման համար նախատեսված դեղորայք

1. այո

2. ոչ

3. չգիտեմ/ չեմ հիշում

4. մերժված

11. Այժմ Ձեր երեխան կանոնավոր կերպով նշանակված երկրորդային բուժման դեղորայք ընդունում ե՞ք (կանոնավոր ասելով հասկանում ենք դեղորայք, որը ընդունում ենք յուրաքանչյուր օր, շաբաթ, ամիս որոշակի ժամանակահատվածով)

1. այո

2. ոչ

3. չգիտեմ/ չեմ հիշում

4. մերժված

12. Օրեկան մոտավորապես քանի՞ դեղորայք է ընդունում Ձեր երեխան երկրորդային բուժման համար

1. 1

2. 2-3

3. 4-5

4. 6 կամ ավելի

5. չգիտեմ/ չեմ հիշում

6.մերժված

13. Վերջին մեկ ամսվա կամ 30 օրվա ընթացքում մոտավորապես որքան գումար եք ծախսել նշանակված երկրորդային բուժման դեղորայքը գնելու համար

1. չեմ ծախսել
2. 5000 դրամից քիչ
3. 5000-10000դրամ
- 4.10000-50000դրամ
- 5.50000-70000դրամ
- 6.70000 դրամից ավել
- 7.չգիտեմ/ չեմ հիշում
- 8.մերժված

14. Դուք կարծում եք, որ նշանակված երկրորդային բուժման համար նախատեսված դեղորայքի գնումը`

1. մեծ ֆինանսական խնդիր է
2. փոքր ֆինանսական խնդիր է
3. ընդհանրապես ֆինանսական խնդիր չէ
- 4.չգիտեմ/ չեմ հիշում
- 5.մերժված

15. Վերջին 2 ամսվա ընթացքում Դուք գրկել եք Ձեզ որևէ սննդից կամ կոմունալ ծախսերից երեխային նշանակված երկրորդային դեղորայքը գնելու պատճառով

- 1.այո
- 2.ոչ
- 3.չգիտեմ/ չեմ հիշում
- 4.մերժված

16. Վերջին 2 ամսվա ընթացքում Դուք հետաձգել եք Ձեր երեխայի երկրորդային դեղորայքի ընդունումը , քանի որ բավարար գումար չեք ունեցել դեղորայքը գնելու համար

- 1.այո
- 2.ոչ
- 3.չգիտեմ/ չեմ հիշում
- 4.մերժված

17. Դուք կարծում եք, որ նշանակված երկրորդային դեղորայքի գները

- 1.անկախ գնելու տեղից միևնույնն են
- 2.փոքր ինչ տարբերվում են դեղատնից դեղատուն
3. շատ են տարբերվում դեղատնից դեղատուն
4. չգիտեմ/ չեմ հիշում
5. մերժված

18. Շատերը տարբեր որոշումներ են կայացնում, երբ գնում են դեղորայք: Վերջին 2 ամսվա ընթացքում Դուք կամ Ձեր ընտանիքի անդամները դիմել են հետևյալ քայլերի (հնարավոր է մեկից ավելի պատասխան)

1. Հետաձգել դեղորայքի գնումը կամ չգնել դեղորայքը գումար չունենալու պատճառով
2. ավելի քիչ դեղորայք ընդունել, քան նշանակված է

3. պատվիրել եք Ձեզ անհրաժեշտ դեղորայքը ուրիշ երկրից, քանի որ այնտեղ ավելի մատչելի է
4. ստուգում եք տարբեր դեղատներում նշանակված դեղորայքի գները և ընտրում ամենամատչելի դեղատունը
5. թվարկվածներից ոչ մեկը
6. չգիտեմ/ չեմ հիշում
7. մերժված

19. Սովորաբար ինչպես եք ձեռք բերում նշանակված երկրորդային դեղորայքը,

1. ստուգում եք տարբեր դեղատներում նշանակված դեղորայքի գները և ընտրում ամենամատչելի դեղատունը
2. գնում եք այն դեղատնից, որն ավելի մոտիկ է տանը
3. գնում եք այն դեղատնից, որն ավելի մոտիկ է Ձեր երեխային բուժող բժշկի աշխատավայրին
4. գնում եք այն դեղատնից, որը գտնվում է այն խանութի մեջ որտեղից գնումներ եք կատարել
5. վատահ չեմ
6. չեմ գնում նշանակված դեղորայքը
7. թվարկվածներից ոչ մեկը
8. մերժված

20. Անցյալ ամիս Ձեր ընտանիքի բոլոր անդամների կողմից ունեցած միջին ամսեկան եկամուտը կազմել է՝

1. ոչ ավելի, քան 25,000 դրամ
2. 25,000-50,000 դրամ
3. 51,000-100,000 դրամ
4. 101,000-250,000 դրամ
5. ավելի քան 250,000 դրամ
6. չգիտեմ

### **Appendix 3. Consent Form (English & Armenian)**

Hello, My Name is Marta Simonyan. I am 2<sup>nd</sup> year student of Public Health Department at American University of Armenia. I am going to do a study about the household economic burden of the secondary treatment for leukemia. You are asked to participate in the study because you are randomly selected parents of a leukemia patient who had registered in the Hematology Center from 2005-2008 in Yerevan. Questions will not be of personal or of a sensitive nature. Questions will not cause any harm to your child and your participation or refusal is not connected with your further treatment at the Hematology Center. Your confidentiality is assured. The interview will take less than 15 minutes. You will not be compensated for your time, but your participation is highly valued by AUA and may help improve the access to secondary treatment drugs for leukemia. If you would like to get more information you can contact Varduhi Petrosyan, Associate Dean, College of Health Sciences: (010) 51 25 64, e-mail: [vpetrosi@aua.am](mailto:vpetrosi@aua.am) or the student investigator Marta Simonyan, (091) 368248, e-mail: [marta\\_simonyan@edu.aua.am](mailto:marta_simonyan@edu.aua.am). If you want to talk to anyone about the study as you feel that you have been treated unfairly or have been hurt, you can contact Yelena Amirkhanyan, chair of Institutional Review Board: (010) 512592, e-mail: [yamirkh@aua.am](mailto:yamirkh@aua.am).

## Հարցման մասնակցության համաձայնագիր

Բարև Ձեզ, իմ անունը Մարթա Սիմոնյան է: Ես Հայաստանի Ամերիկյան Համալսարանի Հանրային առողջապահության ֆակուլտետի ուսանող եմ: Ես հետազոտություն եմ կատարում՝ գնահատելու դեղերի մատչելիություն լեուկեմիայով հիվանդների համար: Խնդրում եմ, որ Դուք մասնակցեք այս հարցմանը, որովհետև դուք պատահականորեն ընտրվել եք Արյունաբանական կենտրոնում 2005-2008 թթ գրանցվածների ցուցակից: Հարցերը անձնական կամ նուրբ զգայական բնույթի չեն: Հարցերը ոչ մի վնաս չեն պատճառի Ձեր երեխայի և Ձեր մասնակցությունը կամ մերժումը ոչ մի կապ չի ունենա Արյունաբանական կենտրոնում Ձեր երեխայի հետագա բուժման հետ: Ձեր գաղտնիությունը ապահովված է: Հարցումը կտևի առավելագույնս տասնհինգ րոպե: Դուք չեք կոմպենսացվի Ձեր ծախսած ժամանակի համար, բայց Ձեր մասնակցությունը մեծ արժեք կունենա ՀԱՀի համար և կօգնի բարելավել լեուկեմիայով հիվանդների երկրորդային դեղորայքային բուժման հասանելիությունը:

Եթե Դուք կցանկանաք ստանալ ավելի մանրամասն տեղեկություններ, ապա կարող եք դիմել Վարդուհի Պետրոսյանին՝ Առողջապահական գիտությունների քոլեջի փոխդեկանին, (010) 51 25 92, էլ-փոստ՝ [vpetrosi@aua.am](mailto:vpetrosi@aua.am), կամ ինձ՝ Մարթա Սիմոնյանիս, (091) 368248, էլ-փոստ՝ [marta\\_simonyan@edu.aua.am](mailto:marta_simonyan@edu.aua.am): Եթե Դուք ցանկանաք խոսել հետազոտության մասին, քանի որ գտնում եք, որ Ձեր հետ ոչ ազնիվ կամ վատ են վերաբերվել ապա կարող եք զանգահարել Ելենա Ամիրխանյանին՝ էթիկայի հանձնաժողովի նախագահին, (010) 51 25 92, էլ-փոստ՝ [yamirkh@aua.am](mailto:yamirkh@aua.am)