Research Report No. 61

CANCER: SOCIAL IMPLICATIONS OF TREATMENT AND FINANCIAL BURDEN

SOCIAL POLICY AND DEVELOPMENT CENTRE

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SOCIAL IMPLICATIONS OF TREATMENT AND FINANCIAL BURDEN

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CANCER: SOCIAL IMPLICATIONS OF TREATMENT AND FINANCIAL BURDEN

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ABSTRACT

The purpose of the study was to assess the high cost of cancer and depletion of assets of the patients suffering from cancer. The investigations were conducted with the guidance from oncologists and other health professionals. The objectives of the study were: to estimate and highlight the cost of the cancer treatment, to describe how persons fighting with terminal disease and their carers are coping with the medical, psychosocial and economic stresses; to gauge the depletion of health and financial capital of the cancer patients and their families.

The study employed two methods, namely individual interviews and a questionnaire survey to provide detailed socioeconomic assessments. Patients and their caregivers belonging to middle-income group of the society were selected from the private hospitals with the help of oncologists. A total of twenty patients diagnosed with cancer were identified. Information on fifteen patients was obtained from the patients and their caregivers. It was revealed that the assets depletion due to high cost treatment was very frequent even among these middle income families.

Based on the study results, five recommendations are set out to address the unmet needs of the patients and their caregivers. 1) Carry out publications, leaflets for patients and family members on various topics related to cancer. 2) The state must ensure health care facilities for cancer patients at government hospitals. 3) Hospitals must be equipped with all modern facilities for cancer treatment and research including palliative care services. 4) Formulation of appropriate health policies and care plans especially designed for cancer patients. 5) Enhance prevention through community and information sharing programs on health. Furthermore, this analysis suggests the need for multidisciplinary inputs into the design and implementation of health policies and projects, for systematic collection and use of cancer-disaggregated data in health policy and planning, and for non-health sector strategies to address socio-economic constraints to improved health.

I INTRODUCTION

The burden of cancer, in the worldwide context, continues to grow with an increasing number of new cases and deaths each year. A significant percentage of cancer patients, at all stages of the disease, suffer social, financial, emotional and psychological distress as a result of cancer diagnosis and treatment [Carison and Barry (2003)]. Cancer will soon be one of the leading causes of death in Pakistan, unless concerted preventive measures are adopted immediately. Exact figures from Pakistan are not available, but it is estimated that more than 250,000 new cases of cancer are expected each year (8th Biennial Cancer Conference). In this study, it is intended to investigate the financial and social burden of the terminal disease and its incidence on the lives of patients and caregivers. In Pakistan, most of the patients cannot afford adequate treatment because of the high cost of treatment and medicines.

Cancer[1] can occur at any age and may affect any organ or tissue in the body. A countrywide hospital-based survey conducted during the years 1995-2001 (Dawn, 17/7/2002) revealed different types of cancers i.e. skin, ovary, leukemia, cervix, lymph node, colorectal, gall bladder, breast, thyroid, and bone cancers that occurs in all age groups in Pakistan. Around 100-120 children get cancer out of every million under 15 year of age. At this rate, it is estimated that about five to six thousand children get cancer every year in Pakistan. Pakistan is a developing country with a population of about 149 million people. The country has a very limited health budget –only 0.8 percent of gross domestic product is allocated to health[2]. Around 32% people living below the poverty line[3] have access only to the government hospitals where the facilities are far from satisfactory. On the other hand, private sector hospitals that are expensive cater to patients from the upper socioeconomic class. There is lack of reliable tumor registry. Most of the available information on cancer comes from hospital-based data or data from other agencies supported registry in selected cities.

Therefore, the picture of human suffering, combined with fear, lack of awareness, and unavailability of sufficient resources, is corroborated by the working experiences of experts

[1] Every minute, ten million cells divide in the human body. Normally, cell division, accompanied by growth and specialized development, takes place in an orderly pattern. But when a cell becomes malignant, it acts in profoundly abnormal ways (Hoag Cancer Center). Cancer is a disease where body cells start multiplying in an uncontrolled fashion to form a tumor or affect other organs adversely after mixing with the blood and altering the physiological function of normal cell.

[2] Social Development in Pakistan (SDIP) Annual Review 2004.

[3] SDIP Annual Review 2004.

addressing health needs in both rural and urban Pakistan. Yet, more rigorous information about levels and management of cancer, where perception and related concerns, is virtually non-existent in this country. Thus, there is acute need of studies evaluating and analyzing the economic costs of this disease in Pakistan. Studies based on the various income groups, and the frequency of cancer and economic burden of the disease within the family can provide information to health planners and policy makers regarding appropriate strategies to improve resources to fight cancer. It is also a fact that large sections of people are deprived of many vital facilities and patient care, and many die without medicines. The march of civilization seems to be meaningless, when millions of children and adults are left to suffer or die for lack of medical care.

This paper is intended to study the social and economic burden of cancer on the families belonging to middle-income class of the society. We prospectively examined the high financial cost met by depleting of assets and other costs such as psychosocial and occupational impact of caring for a person with a terminal illness. The purpose of this research is to draw attention of the health planners and policy makers towards the availability of the health facilities, which the patients and their household need in case of affliction of cancer. The financial cost of cancer treatment is a burden to people diagnosed with it, their families, and society as a whole, especially in the developing countries. The families whose relations suffer this malignant disease have a burden of long-term management of their illness and also the responsibilities of their households to take into consideration. In our study the majority of patients discussed belong to the middle-income group. The study will give the readers an overview of the alarming situation that exists in Pakistan regarding the cost of the cancer treatment that far exceeds the affordability of the common person.

Objectives

Considering the magnitude and complexities of the problem, there were many objectives to be considered for the study, but due to the time constraints, the focus of the study was limited to the following objectives:

1. To survey and highlight the cost of the cancer treatment.
2. To gauge the depletion of health and financial capital of the cancer patients and their families.

3. To describe how persons fighting with terminal disease and their carers are coping with the medical, psychosocial and economic stresses;
4. To identify the lack of resources and underlying reasons of high cost treatment.

II METHODOLOGICAL FRAMEWORK:

Qualitative research techniques seem to be the most suitable one for this study. The participatory approach is adopted for the evaluation of socio economic costs and depletion of assets of patients and their caregivers. Open-ended questionnaires were constructed to collect information from patients and their caregivers. To collect further relevant information, interviews were conducted with other important stakeholders that included caregivers, oncologists, and health professionals.

The following steps were taken for this purpose:

1. Patients were selected (male, female, and children) suffering from different cancers and receiving care at private hospitals.
2. Middle-income group patients were identified to study the depletion of their resources and income during the process of treatment.
3. Caregiver and patient socio-demographic and economic data were collected by means of a self-administered questionnaire.

Interviews with oncologists and technical persons in Intensive Care Units (ICUs) of government and private hospitals were the part of this study.

a) Study design:

This study was divided in two parts: (1) is the information collection in the field and (2) the analysis and synthesis of the problem. Open-ended questionnaires were structured and filled at the place where the patients were located. Interviews were conducted with oncologists, health professional in the hospitals. In this way, a set of information was collected from patients, family caregivers, oncologists, and health professional.

b) Sample selection

A main and difficult task of the study design was the selection of sample. The sample was selected on the basis of following criteria:

a) To target the middle income earners

b) To target patients who were in the third and forth stage of terminal disease

c) To select patients from both rural and urban backgrounds

As this study concentrates on the asset depletion issue (given that the treatment of this disease is very costly), the best representative class is the middle-income earner. Early detection of the disease is very rare, due to lack of awareness and facilities available on medical grounds. Generally, the disease is diagnosed in the third and forth stages, where the financial and social costs are substantially higher than the limited earnings of the cancer victimized family. To have a better insight into the socioeconomic crisis that the afflicted family is facing due to unavailability of health services up to standard, the sample was made balanced by including the rural cases also.

The fifteen cases of patients were selected to be investigated during the entire period of the study. The oncologists and health professional were also asked to assist during the course of data collection. It was also intended to revisit the oncologists and health professionals to better understand the conditions of specific patients.

c) Time frame

Resource limitation and time constraints did not allow the researchers to go for a study. Thus, a six-month period was allocated for information gathering and two months for analysis.

d) Interviews

The subjects were patients in their 3rd and 4th stages of cancer. This is because of a lack of awareness and understanding of the disease in the patients and their families. Ineffective and prolonged non-related laboratory tests wastes not only money but also delay in diagnosis was a major factor that makes cancer fatal in most patients. Meanwhile, when diagnosed, the deadly disease is already often into its 3rd and 4th stage where cure becomes impossible.

Oncologists were requested to assist in the recruitment of subjects and to provide information identifying those patients belonging to middle-income group. Investigators then explained the study design to patients and carers. All patients and their caregivers were interviewed. The objectives of interviews were to: (a) identify medical, financial, and psychosocial stresses of

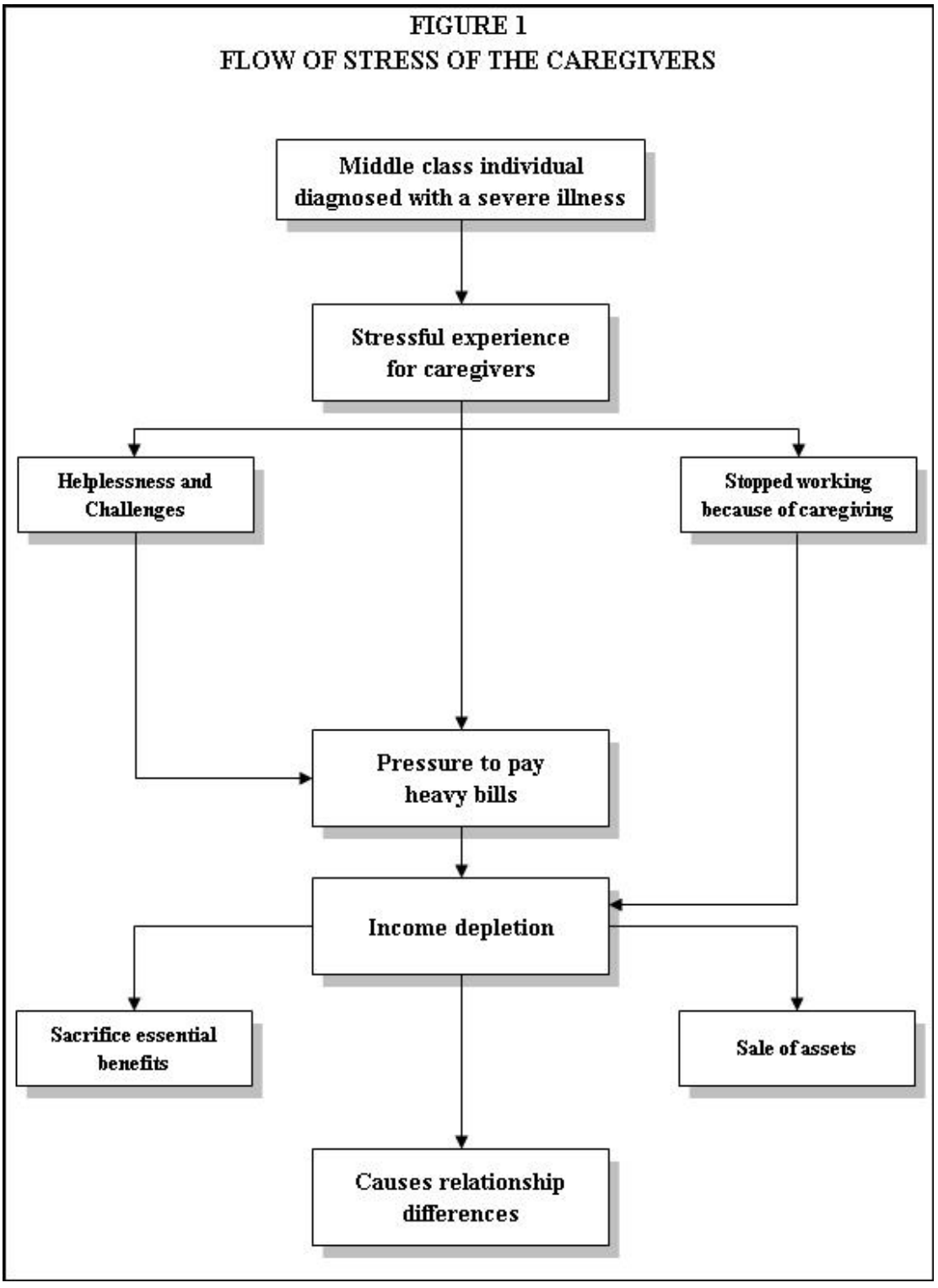
individual patient; (b) explore their strategies for coping; (c) identify areas of problems arising due to the high cost of the treatment. The interviews were well structured, during which questionnaires were administered by interviewers. Flexibility was allowed regarding the location and time of interviews.

e) Questionnaire survey

Interviewers administered questionnaires during individual interviews to obtain essential information regarding the size of the family, monthly income, assets, household expenditures (before and after the detection of the disease), medical bills and others.

We selected patients with advanced cancer who were receiving care either at private hospitals or cancer centers. The private hospitals are principal providers of tertiary cancer services. The information in the study is based mainly on interviews with the patients and their caregivers, news clippings, and interviews with oncologists and experts. Field visits and interviews were made possible with the cooperation of oncologists, patients, and their family members as they pointed out main causes of late diagnosis and delayed treatment. In rural areas where possible, we interviewed daughters, sisters, sons and husbands. Assessments were initially made fortnightly and changed to one month when the patients' functional status deteriorated and at the same time their assets and savings were stated to diminish. Patients were asked to identify principal family member who would be most responsible for ongoing care and financial support. Of the 20 patients enrolled in the study, 15 patients and their family members consented to reveal the economic burden and loss during and after treatment. Consenting patients and their concerned family members were followed prospectively until the patient's death or the data collection time constraint of six months, which ever come first. The most common feature measured in the study was deviations in financial status due to high cost surgeries, chemotherapies, radiation spells, hospitalization, medication and laboratory. The family member's burden was measured through the questionnaire filled in the hospital and their homes. Anxiety and depression scale was measured through recorded interviews and the high costs of medicines were measured by the interviews of the patients, oncologist and family caregivers. Figure 1 summarizes the processes that the family members of the patients go through from the palliative period until the end of the patient's life.

FIGURE 1
FLOW OF STRESS OF THE CAREGIVERS



Direct financial burden to the patient or the family members consisting of both direct treatment and related costs was obtained through administered questionnaires at each assessment. Financial burden is presented for the palliative and terminal periods as a cumulative burden over the entire study period.

III DATA ANALYSIS TECHNIQUE:

At the end of each day, the team recorded the information. Interviews were audio recorded and field notes were taken. All study materials and data collected were transcribed in English. Data of the individual patients obtained from the questionnaire survey were analyzed. In almost every case, the process of the sale of their assets was documented. To report the details of illness and infuse hope for the life of the patients became a sort of challenge for the team. A few hurdles are always there in this situation. First, there was this fear of losing the patient's confidence at some stage, while getting information about the sale of their belongings during and after the treatment process. Caregivers were often reluctant to disclose any information about the disease and its financial burden on the household. In order to ensure the privacy of the patient for the moral reasons, the data presented in this reports are either in the descriptive statistics form or in aggregate manner.

Apart from the main objective of the study, that is the evaluation of the financial cost of the terminal disease, other social mishaps and distress were observed during the interviews so these are also included in the evaluation of social loss. The diagnosis and treatment of breast cancer in women may provoke various emotional disturbances in their husbands; the feeling of anxiety during investigation period and during the course of treatment is very common among spouses of breast cancer patients [Iqbal et al. (2001)]. These and many other hurdles held us up at various times, but the study went on ahead after continuous trial-and-error methods with different patients and their households.

IV FINANCIAL COST AND ASSET DEPLETION ASSESSMENT:

Over half of the patients died during the period of study due to non-curable 3rd or 4th stage of cancer. Caregivers were depressed and had a higher level of perceived burden at the start of the terminal period than at the start of the palliative period. Financial burden was the most important predictor of both anxiety and depression. Most of the caregivers reported missing work because of caregiving responsibilities. Prescription of drugs & hospitalization, chemotherapies, surgery and laboratory were the most important components of the financial burden.

Financial Constraints:

In all patients who belong to middle class socioeconomic status, the financial constraint was expressed as a major concern. Those patients living in rural areas had higher expenditure for

commuting to and from hospitals, purchase of health related services (consulting oncologists, chemotherapies, radiation spells and laboratory), and stay in the city.

Financial burden- a reflection on the issue:

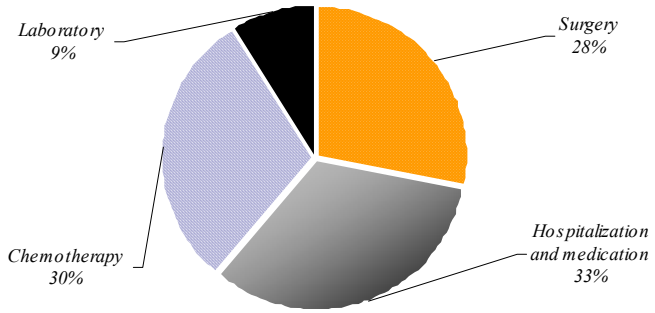
Cancer patients:

This is a profile of 15 cancer patients who were treated in the private hospitals of the country due to non-availability of the resources involved in cancer treatment at the government hospitals. All of them belong to middle-income group of the society. This profile is drawn from excerpts of interviews with patients, caregivers, oncologists and experts. In all the cases, patients were brought to the hospitals in 3rd or 4th stages of the disease due to late diagnosis or delayed in treatment by the patient's family. Patients selected from private hospitals belonged to different age groups from 1 - 40 years. Due to financial constraints many patients stopped their treatment in between. This is also reflected in their household life as children dropped out from the schools and suffered malnutrition. The study shows that a large proportion of families suffered from anxiety and depression due to loss of income, assets, savings, funds and the life of the patient. One of the major problems of the cancer treatment is inability to afford it, as the treatment is very expensive. The cost depends very much upon the type and status of the disease, the complications that may occur during the course of management, and the treatment center. On an average, it costs about one hundred to four hundred thousand rupees (Rs100, 000-400,000) for the treatment.

Surgery, hospitalization, medication, and chemotherapy are the major parts of the expenditure. Patients belonging to families in the rural areas are more susceptible to delayed diagnosis.

The cost structure of the disease, plotted in the pie chart shown in figure 2, is based on the aggregation of the individual data collected during the fieldwork. There are a lot of direct and indirect costs of the disease-- the direct financial costs are

FIGURE 2
PERCENTAGE OF INDIVIDUAL HEADS IN TOTAL EXPENDITURE ON CANCER



evaluated in this section and presented in the graph, while the social costs resulting from the financial burden are discussed in the next section.

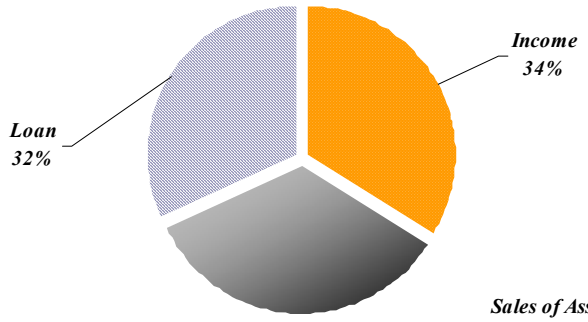
The major direct cost evaluated during the course of study are surgery, hospitalization, medicines, laboratory related costs, and spells of chemotherapy and radiation. Other minor costs that were not considered due to unavailability of the expenditures are transportation cost (cost of commuting from far flung area), consultation fees, and cost of special dietary requirements. As shown in the chart, surgery contributed 28 percent of the major expenditures, hospitalization & medication 33 percent; laboratory related cost 9 percent and chemotherapy and radiation cost 30 percent. In the case of surgeries, delayed surgery due to financial constraint might lead to more complexities. In some cases it is observed that delayed surgeries caused the expiry of the patient.

Loan, Debts, Loss of Assets: Pilfering of the Future:

The subject in the study often asserted that after going for high cost cancer treatment in the hospitals, they have limited or no funds available to bear the further expenses for emergencies and daily expenditures. Most of them turn to relatives and friends for debts. The contributed amount is quickly spent in the difficult period. The high-priced cycles of chemotherapy and radiation spells make life complex and miserable, both to the patient and caregivers. It was noted that in such a difficult situation, the family was forced to sell their belongings at low prices. The patients from rural areas and of those districts, where access to cancer treatment or any other medical services is nil, suffer from acute frustration, loss of money and time, and uncertainty of life. The repeated dilemma of illness pushes the families into pain and disaster. The finding that a large proportion of caregivers suffered from both anxiety and depression suggests that there are unmet needs that are measurable at an early stage of the patient's life-limiting illness, and potential intervention [Grenfeld et al. (2004)]. Our research with a subset of these same caregivers during their bereavement suggests that they are so focused on their care giving role that their own medical needs go unattended [Coristine et al. (2003)]. The tradeoff is between, on the one hand, pain, disability, and perhaps death, and, on the other hand, loss of precious assets to pay for treatment, leading later to less food and income and even starvation. Those asset depletions are certainly driven through the high cost discussed in

the previous section. (Percentage of expenditures on cancer is shown in Figure 2 and the resource depletion picture shown in Figure 3).

FIGURE 3
PERCENTAGE OF INDIVIDUAL HEADS IN TOTAL RESOURCE DEPLETION



In defining cancer-prone poverty and insecurity, middle-income group speak about their precarious lives, lack of assets, and their limited ability to cope with shocks. Insecurity of those families, who had someone suffering from cancer increases. Their economic opportunities decline due to caregiving services. The study findings brought to light the effects of being unable to work, when the body flips from an asset to a liability, and of the costs of getting curable treatment.

Income: As shown in figure 3, this head represents the salaries of the family members of the patient, which is around 34% of total resources of the family. This income is shared in a common dwelling unit who are related by blood, marriage. This income caters to household expenses i.e. food, shelter, education, health care, clothing, and transportation etc. In the case of terminal illness to any of the family member, the major expense is on high cost treatment, which then leads to need of extra financial support. Although, a minor part of this head can be spent on the health care, but in order to evaluate the total resource picture as well as financial strength of the family of the patient we included this.

Loan/debt: This head includes the amount borrowed from the close relatives, friends and employers. In extreme need of money (routine in this type of terminal disease), it is observed that families frequently borrowed from the sources. One third of total resources consist of loan and debt.

Sales of assets: This consists of 34% of total resources. Assets sold by the afflicted families include land, jewelry, electronics, cattle, saving certificates etc.

TABLE 1
FINANCIAL BURDEN OF CANCER

	Household income (Yearly Rs.)	Medical expenditures (Yearly Rs.)	Asset depletion and indebtness	Medical expenditures as % of Household income	Asset depletion and indebtness as % of Yearly household income
Mean	150,286	156,678	289,500[1]	104	193
Minimum	58,500	242,500	197,500[2]	415	338
Maximum	345,000	340,078	135,000[3]	99	39

[1] On average over a period of almost one year.
[2] Over a period of nine months.
[3] Over a period of two years.

Figure 3 gives only the percentages. Therefore, data regarding the actual amount of asset depletion and indebtness are reported in table 1. The results are quite consistent with the intuition that asset depletion plays a vital role in adding the suffering to the patient and its caregivers. The average of the data reflects that yearly household funds arranged from selling of existing valuables or past savings are 200 percent. Medical expenditures are exceeding the total income of the household. Data of the patients that have the minimum and maximum income in the sample is also reported. The medical expenditures at the maximum point are just equal to the total income. At the other end the highest asset depletion to income ratio was nearly 340 percent in our sample.

Role of government and philanthropists in cost reduction:

The high cost of treatment and drugs, are problems in Pakistan and cannot be met through the Zakat fund (eight Biennial Cancer Conference, Pakistan). In such cases of sickness, the patient has to buy his/her own medicines, which, considering average income rates is practically impossible. The costs compound the stress of sickness. Typically, health care financing systems disadvantage the poor. In developing countries, low government spending in health usually means that a substantial proportion of health care expenditures-up to 80 percent in some countries are borne by users through out-of-pocket payments [Carr, (2004)]. The costs associated with ill health-including medical bills and indirect costs such as low income can be catastrophic for the poor [Hsiao & Liu (2000)]. In India, one study found that nearly 25 percent of those hospitalized fell below the poverty line because of medical costs (World Bank, 2001). A World Bank study identified health problems as the single most common trigger for the descent into poverty (The World Bank, 2002). The health care system in Pakistan is beset with numerous problems—structure fragmentation, gender insensitivity, resource scarcity, inefficiency and lack of functional specificity and accessibility. Faced with a wobbly economic situation role for maneuvering, health sector reform in Pakistan appears to be quite limited [Islam A. (2002)].

BOX 1 THEIR BREAD EARNER IS DEAD!

"My husband never allowed me to go out alone or to use any public transport. His arms were always around me with a sense of security, affection and comfort. Those eleven and half years of sharing and caring built a trust shell to prevent me from all visible harms", said 30 years old Tanzila in a low voice.

All seemed normal when a 40 years old Ali felt uneasiness and heavy breaths while climbing the stairs of the fourth floor of his rented apartment. A physician was consulted who took it very normally as exertion at workplace and a little weakness or lack of vitamins. But the persistence of the same health situation forced him to get access to the technology of the laboratory tests i.e. Blood/ CT/ Urine, Ultra sound and X-rays. The home and the office started getting affected from the threats of his illness.

In November 2003 certain cancer parasites began to grow in different channels of liver involving pancreas and intestines of Ali's body, which gradually became malignant. These factors became the main cause of damaging a middle class house emotionally, economically and physically.

Although Tanzila was aware of the 4th stage of the stomach and the pancreas cancer in Ali's body, his inexplicable and non-specific decline in health, discomfort in stomach region and the loss of appetite presented the picture of the late diagnosis.

The burden of ill health and the high percentage of investment to the life cure drastically affected the economic grounds of Ali's family. The cost associated with ill health was beyond his reach. Ali's average income, Rs. 5,500 from Govt. vehicle department and Rs. 10,000 from his father's shop were not sufficient to bear the heavy medical expenses.

The surgical excision took place at Hamdard Hospital for Rs. 30,000, which disclosed the abnormal situation and the advanced stage of spread out tumours in the body channels. So, the operation was in vain and the little savings started to be spent in various spells. After being treated and consulted by the different doctors he landed at the Oncology Department of the Liaquat National Hospital, where acute malignancy began to eat into heavy amounts from the pockets of the middle-income group. Ali's survival prospects were worsening day-by-day, but the medical philosophers kept on insisting on heavy amounts. Seventeen days in Incentive care unit after the second surgery pulled him on to the ventilators. A cousin who was too close to Ali sold his car for Rs. 3,00000, Ali's sister drew Rs. 40,000 from her provident fund and his wife borrowed Rs. 70,000 from her sisters to pay medical bills as asked by the management each passing day.

All forms of therapies failed to save Ali, and finally the cardiac arrest stopped all his functions. A malignancy of six months cost him his life and huge deficit for his family.

Tanzila with her three kids has fewer components to survive on. Her in-laws have planned to sale out their 2-bedroom apartment at Gulistan-e-jauhar for Rs. 7,00000 and repay the debts of Ali's cousin and installments of loan and credit card. The reimbursement of medical bill of Rs. 64,000 from Ali's office is a drop in the ocean. Somehow a bold lady with confidence has tied her laces to work and prove herself a survivor in the most difficult of conditions.

The requirements and improvements to finance health care systems fairly should be emphasized. The majority of the health budget is not directed to the patient care departments. The allocation of less percentage to the health resources for the poor pull them on to infectious diseases, nutritional deficiencies, complications, deaths, disabilities, abuse and violence.

V ASSESSMENT OF SOCIAL CONSTRAINTS:

Vulnerability, stress, loss, and anguish

The experience of illbeing is inextricably psychological. The dimensions of bad quality of health contribute to bad states of mind and being. It is striking how often patients and their caregivers raise aspects of mental distress when describing the effects of high costs treatment on household, schooling, and relationships. The majority of caregivers experienced an adverse impact on their employment, particularly during the terminal period. This is

consistent with the results of the **1996 General Social Survey**[4] and other studies of family care givers of cancer patients. In some cases, caregivers had to quit their jobs or declined advancement and a large proportion lost work hours or used special leave or holidays to fulfill their caregiving responsibilities [Grunfeld et al. (2004)]. One common deeply felt deprivation was not being able to save beloved's life even after putting efforts physically and economically. Often cited, also, was not being able to entertain them or enjoy their respective social lives. Family members of a child with cancer may suffer various forms of distress in regards to the child's illness. Parents report feelings of uncertainty about the expected life, loneliness, low self-esteem, and distress related to the adjustment of the child's siblings [Sarah McDoughal, (1997)]. Agony, loss and misery are in so many life histories of cancer patients and these speak through the pages of the case studies. Anguish, when loved ones are sick and treatment is known but cannot be afforded was found in many cases of the study. A senior doctor quoted that the government should take immediate steps to provide modern equipment to cancer management departments in Pakistan. The major referrals centers for free cancer treatment lack equipped radiation bank, infrastructure and trained staff (eighth Biennial Cancer Conference, Pakistan). Psychological illbeing is marked where there has been a sharp decline in the levels of living, and people from middle class have become impoverished. The effects of economic misery are listed as patients' and caregivers' psychological health, distancing oneself from others, insecurity, apathy, nervousness and dissatisfaction. Cancer affects all aspects of relationships, and communication becomes especially important. Lack of communication can lead to isolation, frustration, and unmet needs. People with cancer who do not discuss their illness often feel they are facing cancer alone. There is another viewpoint that protecting patients from knowing the truth could be counter productive. Lack of information can increase anxiety, dissatisfaction, stress and uncertainty. Studies have also shown that the level of psychological distress in seriously ill patients is far less when they think that they have received an adequate information[5] Our findings indicate that, caregivers were anxious for treatment at the start of the disease, but gradually experienced higher level of economic burden that affected employment, education of children, environment of the house, and relationships within the family members.

[4] Cranwick K. Canada's caregivers. Canadian social trends backgrounder. Ottawa: Statistics Canada; 2001. Available: www.hc-sc.gc.ca/seniors-aines/pubs/unsorted/survey.htm (accessed 2004 Feb 17).

[5] Audit Commission, 1993 "What seems to be the matter? Communication between hospitals and patients". London: HMSO, (NHS Report No.12).

Caregivers' stresses:

Caring for patients suffering from cancer has been a traumatic event for many of those interviewed. The experience generally limits one's social function, creates significant psychological stresses and even affects the physical and mental health of the caregivers. Stresses stemmed from concerns about health status of patients (chemotherapy & radiation spells and frequent emergency visits to the hospitals), fear and uncertainty about patient's life, and problems in handling of disclosure of the disease to patients (when and how) and to other relatives. Isolation of the caregivers results from devotion of much time in taking care of patients. Financial difficulty was a particular concern for caregivers, who sell their belongings even knowing that the patient's life span is limited. The need for taking care of the patients often also limits the caregivers' employment options. One caregiver expressed that he actually could not concentrate on work since his son was diagnosed with cancer. He often needed to take time off from work, and basically could not perform well.

BOX 2 **HOPE LINGERS ON!**

It was an early July 2003 morning at the Samad Siddiqui home, and the scene was one of frenetic activity. As Samad prepares sandwiches for his daughter's breakfast, his wife washes out dishes in the kitchen. The four-year-old son has boisterously brought his favourite action figures to the table, while 1-year-old Mahad was engaged in his grandmother's lap, playing with a rattle. This happy episode was played out many times, yet it was unlikely that anyone in the family takes interest in their activity. In the months following Mahad's diagnosis of Blood Cancer just after his first birthday. The blood count at the local hospital showed high numbers of white cells, an indication of Leukemia, and he was referred to an Oncologist. His medical treatment was started immediately at the Ziauddin Hospital.

That ordeal, along with the chemotherapy, radiation and surgery that followed, took their toll on each member of the close-knit household. Dealing with the fear and pain of the illness was difficult, and, as close as they were Samad and his wife often had trouble discussing it with each other or with his mother.

During chemotherapy spells of Mahad the couple has to deal with the stress of the illness. They supported each other and the family. For Samad, Mahad's father, the biggest hurdle was economical pressure, and how to talk about it with his wife. "It's really a hard news to deal with, and when I came home tired at the end of the day, my tendency was just to run away from it," Samad admits.

Samad works on contract at Phillips Company and earns Rs. 14,000 plus over time per month. All his savings (Rs.1,00,000) and more were spent in heavy expenses of the treatment. Soon after three months, he asked for 50% discount in medical bills, as it was hard for him to bear the expenses of medication and household at the same time. He filled the Zakat form confidentially.

Samad got Rs. 3,00,000 from his father's property, and Rs. 5,00,000 from golden shake hand scheme, from which he bought a two-bedroom house at Gulshan. But, unfortunately, Mahad's illness made him helpless to deal with. He asked his brothers' abroad to help him fight through financial crisis.

Samad's boss is too cooperative, as he realizes that he is going through a painful phase of his child's illness. Samad is often absent from his job to negotiate difficulties with the doctors and the family.

Mahad is still under treatment and the doctor says that he is under ' Maintenance', which will take another two more years. The family has stopped all the outings, as to keep the child in isolation to make the doses of medication more effective, as per doctor's recommendation.

Children with cancer and its impact on the family:

Leukemia or blood cancer is one of the deadliest diseases, claiming many lives of children all over the world. The developed countries have been carrying on research on leukemia. In poverty-stricken countries with limited budget and resources on health, the recovery percentage from this deadly disease is almost nil. Scarcity of medicines and high cost and long-term treatment of leukemia makes the parents poor. Child health emerged as a key issue in the interviews. Parents of these kids go through difficult phases of their lives when they are asked by the doctors to stay home, leaving all social activities for the sake of their children's wellbeing. The study shows that in some cases, fathers have to take short leaves to run after the appointments at clinics and hospitals. Some missed work because of caregiving. The parents often neglect siblings of cancer children; their schooling suffers and behavior problems develop, apart from emotional difficulties, and relationship difficulties. Treatment of leukemia consists of different procedures that are lengthy and costly. During this treatment, high doses of chemotherapy and sometimes radiation are administered to the patient to kill the existing bone marrow and it's functioning [Sarah McDougal, (1997)].

Associations, hope, and cancer:

When cancer is diagnosed, family experiences sadness, anxiety, anger, and hopelessness. For some couples, facing the challenges of cancer may develop stress and can have impact on marriage as well. This study found that when the partner with cancer has to stop working, the other partner may need to go to work for extra hours, as well as take on the responsibility of caregiving, providing nursing care and emotional and physical support. These added responsibilities become overwhelming, and lead to frustration, resentment, and guilt. The person with cancer also feels guilty for burdening his or her partner, as well as feels sad and frustrated by his or her own limitations.

The study reveals the drastic change in hopes and dreams that couples and family shared before the diagnosis of the disease. The plans of travel and purchasing more assets are put on hold as immense sadness and anger crawls in to the happiness of the family. The noticeable dropouts of children from the school due to financial constraints were recorded. The demands of cancer and treatment make it difficult to take care of young children. For children, nothing is worse than the thought of losing a parent and many parents try to hide the truth from their children that something is wrong, frightening and unexpected for them.

BOX 3 THE PRICE IS TOO HEAVY!

Faisal breathed his last in mid of June 2004. The biopsies from the section of right femur in the year 2002 revealed a Neoplasm, which is composed of small round cells and were stained with a panel of Monoclonal Antibodies using, envision system. The seventeen years old lad, studying in Inter First year had lots of dreams in his eyes for future prospects. It was the 4th stage of Malignant Tumor, which began its parasitical life after a minor accident of the right knee. The family from Quetta was unaware of the upcoming danger. Faisal was in great pain when he was brought to Ankle Sirya hospital to visit an Oncologist. He already lost his right eyesight. His father and other relatives were imploring the doctor for the relief of his continuous pain.

"We are here to save our child's life. I put all my money and efforts to make him live long", said Abdul Rehman Shah, the father who gathered all his hopes to give the best treatment to his son. Many doctors put their heads together at Quetta, Larkana and Karachi with an expensive treatment of the Cancer. All six cycles of chemotherapy and the spells of radiation were applied to him. The family sold all their belongings i.e. the small house at Quetta Mastoon was sold for Rs. 80,000, the Motor cycle for Rs. 15000, jewelry for Rs. 16,000, and an old television for Rs.1000 only, to meet the expenses of the treatment.

Faisal's father is a driver who earns Rs. 3,500 per month and his technician brother earns Rs. 4,500 to feed the seven members of the family. The whole family was burdened with debts of around Rs. 70,000. All their savings went into the treatment. Since May 2004, they were in Karachi living in hotel rooms for Rs. 200 per day. The illiterate father and brother kept on consulting doctors and were desperate for his admission in some charity hospital. The unaffordable circumstances to bear the cost of the room and at the same time the expense of Faisal's medicines, made them helpless and weak. Karachi was new for them, so it was easy to exploit them whether in context of lab test expenses, medication or approaching a proper Oncologist.

After being treated at Cenar institute, Quetta and Larkana Cancer hospital, he was than admitted at Jinnah Hospital Karachi. They were told that nothing could be done after the findings of MRI, which says multiple high intensity signals in front-parietal sub-cortical region. The father took his son back to Quetta. Medical Oncologist, Radiation Oncologist, and the surgeon had their respective revenues but they do not admit. They say doctors are human and can make mistake, but it seems that they did not know, that cancer is an unusual disease for many reasons and had no second chance because it grows geometrically.

Faith in spiritual healers:

The narrow escape or a diversion from the word cancer allows the family members to find assistance from some spiritual healers, shrines or mosques. The different pictures of assurance and low confidence in own self emerged while interviewing the caregivers. Despite the fact that patient will not survive, the family follows the instructions as to make the situation hopeful for them and the patients.

Experiences:

It was a relatively difficult task to schedule meetings with the patients and their families due to the fact that the affliction of cancer is considered a stigma in most families, and also because it is considered a waste of time by the households to talk about this disease, as they feel that they have to deal with the chemotherapy and radiation spells timings. Moreover, most such initiatives are considered in vain, because any sponsors or donors in the health sector in this country mostly provide no financial assistance. This problem is most acute when you talk of the rural patients, as most of their time is spent in travel arrangements and having to provide for the rarely available

modern facilities. The rural patients and their immediate caregivers, included in the study, were silent during discussions undertaken about their financial status. Sometimes, it was hard to explain the study objectives to the patients and their families in one or two visits. Caregivers experienced psychological morbidity (anxiety and depression) at the onset of the patient's illness and a substantial increase in caregivers' burden when the patients reached a terminal stage of the illness. In addition to psychological morbidity, caregivers bear both economic and occupational problems [Grunfeld et al. (2004)]. Most of the patients died during the course of six months of the follow-ups. We knew well the critical importance of establishing trust. A variety of methods were used to build understanding. In some cases, doctors were approached to form a bridge between the patients and us. In order to gain their attention, they were coaxed and interviewed at their homes or the hospitals.

VI CONCLUSION AND RECOMMENDATIONS:

This study aims to investigate the financial cost and social burden of the afflicted families. It is observed that the financial cost lead to sale of important belongings of the family while social burden generated disorder and disturbance in the relationship between the patient and caregivers. However, those events are not mutually exclusive, as financial cost lead to social stress. Thus the sole main factor that affects the entire family is the financial burden of the treatment. To counter the burden afflicted families sold their assets as well as borrowed heavily. The borrowing money from relatives, friends, employer have to be repaid so afflicted families have to borne the burden in future too and it might last for next generation depending upon the earning profiles.

Each year, the cancer statistics look more and more formidable and the cost of the treatment more insurmountable. There is the need for more extensive efforts from the health ministries to unfold more comprehensive campaigns to the far-flung areas and to the urban and rural areas to make the people understand how to approach the crisis when they face the terminal disease. This will make the families realize that any delay to reach the medical centers and hospitals would aggravate the situation for the patients.

The need to finance health services especially to high cost treatments for terminal diseases such as cancer is urgent. These cancer patients not only face the issues that surround the illness, but also psychological, and social issues. The policy makers must take immediate steps to provide modern equipment to the oncology departments of the hospitals so that the

poor cancer patients could have an affordable treatment and retain some quality of life. Concrete efforts to educate the physicians, public and patients about cancer with involvement of the government and media should be stressed. Free cancer treatment, in each province, keeping in mind the economic realities, has to be put into practice. There are proven techniques for increasing the benefits of affordable health facilities, which could make things easier and less tense for the poor. This issue could be tackled with much success through the publicly funded health programs [Carr, (2004)]. Practical and realistic efforts with sincerity are the real need of the hour for fighting against the terminal disease. The issue is the survival of the mankind suffering from terminal disease that requires health treatment on time. Therefore successful implementation of resources and services in government hospitals is the main thrust of the issue. One of the main reasons of poor outcome of cancer in the country is lack of awareness not only among general public but also among medical professionals.

The recommendations can be described as follows:

1. Dissemination regarding the aftermaths of cancer being diagnosed,
2. State should ensure health care facilities for cancer patients at government hospitals; in case of lack of funds in the treasury, the government should encourage private sector to join hands in combating the evils of the terminal disease.
3. Hospitals must be equipped with all modern facilities for cancer treatment and research, including palliative care services.
4. Formulation of appropriate health policies and care plans especially designed for cancer patients.
5. Enhance prevention through community and information sharing programs on health.

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BOX 4 FRUSTRATING CIRCUMSTANCES!

The Oncology ward of Liaquat National Hospital was crowded with patients and their attendants. Although it is an exclusive care section for Cancer patients, where nurses were only seen on the front desk. They attended none of the patients, as most of were in the last stage of disease. Hameeda, 35, a Lab assistant at the NawabShah Medical College, was lying straight on one of the beds near the door. Her mother-in-law and sister-in-law were busy in making her comfortable from the severe pain in the stomach region. She suffered from Colon Cancer with Liver Metastases.

Since the initial pain in mid May 2003, the pain had grown worse by the day. The pain would go on cycles, a few days really agonizing, a few days just kind of annoying. After consulting with the doctor at NawabShah, he gave some pain killers along with other medications and assured her it probably may not occur, so that was some relief. But soon after she realized that there was lack of energy in her body and she was getting anemic day-by-day. The doctor then raised some concerns. He prescribed some blood tests, which came out with positive cancer cells in the body. Surgeon Hashim Langa at NawabShah Hospital did the first surgery that cost Rs. 30,000.

However, Hameeda took an early retirement from the job. She got rupees **two lakh** out of her provident fund for serving the institution for 15 years. Her surgery went in vain, as cancer gradually got control of her body. Being the mother of 3 kids, she was unable to be energetic enough for household chores. Her husband, Faizullah, who works as a technician at WAPDA, insisted to take her to Karachi. Oncologists at Ziauddin Hospital suggested a second surgery to stop the cancer cells from increasing. Well, surgery was set 2 weeks from that appointment. The body could not find any solution as most of the organs got affected with the disease. Faizullah spent Rs. 50,000 on the expenses of surgery and hospitalization. Half of the family was staying at some relative's house at Gulistan-e-Jauhar. Their days and nights became restless. Hameeda was still in pain. Major complications occurred during surgery. CT scan and MRI along with other tests showed negative response, as the cancer had now progressed into its 4th and the last stage. Desperate husband than admitted his wife at Liaquat National Hospital, where he paid Rs. 94,000 at the time of admission. The chemotherapy spells started but within 19 days she breathed her last in May 2004.

"Hameeda was a hard working lady, and was very lively in her activities", said mother-in-law. Faizullah tried hard to save his wife's life by selling her jewelry for Rs. 20,000, a plot for Rs. 65,000, through saving certificates of Rs. 1,00000, and borrowed Rs. 2 and half lakhs. Whole of the family kept on travelling from NawabShah to Karachi since May 2003. Most of their money was spent on travelling. The schooling of the kids got affected. Her elder son dropped out of the school and other two were shifted to Government schools.

"My daughter-in-law was Masters in Urdu and Islamic studies. She wanted her sons to get educated like her, but fate went against her", said mother-in-law sobbing. The family also suffered from another shock, as their very young son of 25 years became handicapped after a severe accident at NawabShah. He is on a wheel chair forever.

BOX 5 **SORROWS OF THE MIGRANT!**

Ovarian cancer seldom produces any symptoms at all until the latest stages. So, it was with Maulooda, an Afghani woman, who came to Pakistan along with her two sons and 3 daughters. This was the time when Afghanistan was under the control of Russian forces. Her husband married his old girl friend. Maulooda accepted the fact, but never appealed for divorce.

It was November 2003, at the age of 40; Maulooda noticed a lump in the lower abdomen, frequent pains, bleeding and restlessness that forced her to see the physician immediately. The doctor scheduled her CT Scan, saying this could be just fibroid or it could be something else. He referred her to a gynecologist who would take care of everything and could refer her for any therapy. Being an illiterate lady, she could not understand her uncomfortable situation occurring into the stomach region. It could be any number of things: cyst, fibroids, uterine, ovarian or pancreatic cancer. She was hoping for the best at her appointment with the gynecologist. The CT Scan showed a large mass and blood test showed an elevated CA 125 level. CA 125 is a tumour marker for ovarian cancer. The doctor discussed the situation with her son Naseer, who could hardly understand the technical terms of different tests. He requested the doctor not to brief his mother about the acute illness.

The gynecologist scheduled her surgery the next day. Maulooda felt her condition was being taken very seriously and getting the best treatment. Of course, she wanted to get rid of the pains. Her operation took place at Aga Khan Hospital that cost around Rs. 75,500 to an Afghani family, which could hardly meet their household expenses through minimal salaries of the two sons. The elder son acted in a mature manner. He did not break down in front of his mother, as she was already crying of pains and it would have just made things that much worse. The gynecologist said that it was one of the worst cases she had seen. She removed the uterus, but the cancer cells were spread out in other regions of the body. She was then referred to an Oncologist. Naseer brought his mother to Ziauddin hospital. Again going through several tests, she was recommended chemotherapy and radiation spells. Naseer was so confused that medical oncologist spoke of chemotherapy, and radiologist suggested radiation therapy. But who could understand the economic situation of the family.

Naseer and his brother Basheer work at leather factory. They earn Rs. 8,000 and Rs. 5,000 per month, respectively. To seek out the financial problem regarding the expenditures of the whole treatment, Naseer borrowed Rs. 3,00,000 from his factory owner, who also belongs to Afghanistan. Living in a rented apartment at Super High Way of Rs. 2,800 (utility bills included), it was difficult to cope up with the situation.

Naseer had to make excuses at his job, as to take his mother for therapy sessions. He was unable to bear the expenses of hospitalization after two chemotherapies. Each time he hired a taxi for Rs. 200 to pick and drop his mother from home to the hospital. Naseer had no support from his father. He had to work hard for his mother's treatment. "We had nothing left to sell and obtain money for my mother. We sold all our belongings at Afghanistan, when we planned to move to Pakistan", said Naseer. His all three sisters and wife are uneducated. "We do not have enough financial support for our monthly household expenditures, that is around 10,000 and more", said Naseer's wife. They do not allow their women to even peep out of the windows. His pretty sisters are unaware of the danger of their mother's ill health.

Maulooda went through five cycles of chemos. Each time, she had to go through different tests as to assess the medications and other therapy spells to fight cancer. She had to suffer with acute side effects of the chemotherapy. Vomiting, dizziness, and lack of energy have now forced her to keep away from more medications. The remaining cycle of chemotherapy is essential to remove the cancer cells from the body. "I did not know any cancer charity hospital in the town. The money that I borrowed was all spent. Now one of my uncles from Australia has sent Rs. 60,000 for her treatment", said Naseer.

BOX 6 WRONG BEGINNINGS!

A 19 year-old rural girl from the interior of Punjab suffers from Nasal Cancer since May 2002. Many factors that contributed to the development of malignancies dragged her to Nishtar Hospital, Multan where her Nasal Cancer was diagnosed. The time that was wasted in making remedies from quacks and Hakims, allowed the cancer-producing agents to multiply and form a chronic condition. The Chemotherapy and radiation cycles have inhabited the growth of viruses, but the remaining two Chemotherapys, which are unaffordable for the family, can revert the situation. The middle-class family had a distinct change in their financial status after the disease was diagnosed. The decline in economic station has forced the family to eke out a hand-to-mouth existence.

"My sister is on antibiotic treatments. She still suffers from frequent flu attacks and cough that causes fever. We can not afford much, but can only provide a little substandard treatment", says Ashar Kamran.

A one-room house at Drigh Road with no proper bedding represents the distressing situation of the family, who lost their assets to save their daughter. All three brothers work as technicians at ICU departments of different hospitals to meet the ends of both homes in Multan and Karachi at the same time. Their all-together approximate monthly income is Rs. 15000. This amount takes in view the total expenditure i.e.

- House rent Rs. 1,800,
- Utility bills (electricity & gas), 1,000
- Daily transportation of three brothers from home to workplace Rs. 2,000.
- Family at Multan Rs. 4,000
- Naima's medicines Rs. 1,500
- Household at Karachi Rs. 4,500, and much more in case of emergencies.

"We have already spent 3 to 4 lakhs on Naima's treatment, but two cycles of chemos are still pending. Her weak health worries all of us, says a depressed mother. The poor family is unaware of the recurrences of the cancer, which may allow tumours to grow and weaken the blood brain carrier, potentially inviting cancer cells into the nervous system.

Naima's Nasal cancer was diagnosed in its 3rd stage that got operated at Nishtar Hospital, Multan, for Rs. 30,000, but due to unavailability of earlier diagnosis and substandard treatment at Multan, she was dragged to Karachi, where another operation was done. Naima was in need of help from an Oncologist but due to initial failure, the family kept on changing different hospitals for best possible treatment.

Her younger sister has dropped out of school and all three brothers could not manage to continue their studies in their respective fields.

From Ziauddin hospital to Liaquat hospital and again to Ziauddin, the family could not manage to afford a rented house in the city. Debts and poverty forced them to live in the worst living conditions.