

Thesis
Measuring cost to avail free cancer treatment for ultra-poor: The case study of Individual Financial Assistance (IFA)
Pakistan Bait ul Mal(PBM)



Submitted by:

Muhammad Saeed Ahmad
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Supervisor:

Dr. Nasir Iqbal
Associate Professor (PIDE)

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PIDE School of Public Policy
Pakistan Institute of Development Economics (PIDE)
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CERTIFICATE

This is to certify that this thesis entitled: "*Measuring Cost to Avail Free Cancer Treatment for Ultra-poor: The Case Study of Individual Financial Assistance (IFA), Pakistan Bait ul Mal (PBM)*" submitted by **Mr. M. Saeed Ahmed** accepted in its present form by the School of Public Policy, Pakistan Institute of Development Economics (PIDE), Islamabad as satisfying the requirements for partial fulfillment of the degree in Master of Philosophy in Public Policy.

Supervisor:

Dr. Nasir Iqbal
Associate Professor,
Pakistan Institute of Development Economics,
(PIDE) Islamabad

External Examiner:

Dr. Miraj ul Haq
Assistant professor,
IIIE, IIUI University, Islamabad

Head,
PIDE School of Public Policy:

Dr. Abedullah
Chief of Research,
Pakistan Institute of Development Economics,
(PIDE) Islamabad.

**Dedicated to My Beloved Parents and
all of My Teachers**

Who helped me to learn in my life

DECLARATION

I, Muhammad Saeed Ahmad, solemnly declare that this is an original piece of my work. I am the sole author of this thesis and during period of registered study in PIDE, this work has not been submitted in any other University for an award of a degree.

Muhammad Saeed Ahmad

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ABSTRACT

This thesis aims to measure the extra costs of cancer patients registered with PBM (A public sector entity) providing free fund through Individual Financial Assistance (IFA) program. IFA program supports ultra-poor people including cancer patients. To avail this facility, the poor cancer patients have to bear costs like traveling cost, opportunity cost, medicine cost, food cost and other costs linked with treatment. It is clear that a poor cancer patient or his family has great difficulty to meet both ends in presence of expensive cancer treatment. For estimation of different costs, we randomly selected a sample of three hundred (300) patients, from MIS-PBM (data base of registered cancer patients). Univariate analysis has been used to measure the opportunity cost while multivariate analysis has been used to find the key determinants of costs such as distance, time, number of visits, waiting time and other.

As per survey, the average income of household is about Rs.14000 per month. In the light of survey results, about Rs.27000 shifts to patient as direct costs whereas Rs.8500 of opportunity cost is informal cost not paid in cash. PBM supports about Rs.10000 per month. The adjustment of difference of Rs.17000 is made by patient through borrowing of about Rs.10000 to meet with direct cost requirements. About Rs.7000 is still left even after combined support of Rs.20000 arranged from loan and PBM. The left over direct cost is adjusted with monthly income of Rs.14000 leaving behind Rs.7000 for household activities. Household is compelled to dispose of savings, reduce food intake, kids' drop-out, selling of property to bridge the gap.

The borrowing of about Rs.10000 per month remains a future liability to the poor family. The direct, indirect and loans have irrational match with surveyed income of household that require of policy to revisit to save future human capital.

LIST OF ABBREVIATIONS

Avg./avg.	-	Average
BISP	-	Benazir Income Support Program
BMB	-	Bait-ul-Mal Board
BMS	-	Beneficiary Management System
CAPI	-	Computer Assisted Personal Interviewing (CAPI)
CBOs	-	Community Based Organizations
CCT	-	Conditional Cash Transfer
CNIC	-	Computerized National Identity Card
COI	-	Cost of Illness
CS-NGOs	-	Civil Society & Non-Government Organizations
CSP	-	Child Support Program
D.R	-	Dispatch Rider
DuE	-	Dar ul Ehsas
FSP	-	Food Support Program
H.H.	-	House Hold
H.H.H	-	House Hold Head
HCA	-	Human Capital Approach
HCI	-	Human Capital Index
HCM	-	Human Capital Method
IFA	-	Individual Financial Assistance
JAD	-	Joint Application Development
KSrelief,	-	King Salman Humanitarian Relief Center
LAN	-	Local Area Network
M&E	-	Monitoring and Evaluation
MIS	-	Management Information System
MS	-	Medical Superintendent
NADRA	-	National Database and Registration Authority
NGOs	-	Non-Government Organizations
P.O./R.O./H.O.	-	Provincial Office/ Regional Office/Head Office
PBM	-	Pakistan Bait-ul-Mal
PBM-SRCL	-	PBM- School for Rehabilitation of Child Labor
PSH	-	Pakistan Sweet Home
Rs.	-	Rupees (Currency of Pakistan)
SDGs	-	Sustainable Development Goals
SMO	-	Social Medical Officer
SOP	-	Standard Operating Procedures
UNICEF	-	United Nations International Children's Emergency Fund
WECs	-	Women Empowerment Centers
WFO	-	World Food Organization
WTP	-	Willingness to Pay

CHAPTER 1

INTRODUCTION

1.1 Background of study

Healthy society plays a vital role for dynamic economic prosperity. Absence of health facilities in poor segment of society can be fatal to allied economic /social sections of society. The poor patients are the most vulnerable people in the world. The governments across the world have implemented various health programs with an aim to benefits poor and to provide free health coverage (Tseng & Khan, 2015). However, to avail these services, individual has to cover catastrophic health expenditure from their available income (Daneshkohan et al., 2011; Xu et al., 2003). This may push these poorest of poor families into extreme poverty (Xu et al., 2003). Catastrophic health expenditures are out-of-pocket spending to obtain health care facilities emanating either from direct expense or from indirect expense in shape of opportunity costs to avail free health facilities. Among poor, these expenses exceed a certain limit of household's income that has negative implications to the poorest segments of society. There is a dire need to eliminate barriers to accede to healthcare facilities, especially in low and underdeveloped economies. Protecting the ultra-poor people from out-of-pocket payments is widely considered as a core objective of health policy in these countries (Filmer et al., 2002; Sachs, 2001; Xu et al., 2003). Though availability and accessibility to health care services and products have substantially increased, yet the poorest of poor remain excluded and often benefited the least due to high mobility costs (Amin et al., 2010; Tseng & Khan, 2015). As a result, delayed seeking health care services, even they are freely available, owing to their low capacity to cover opportunity costs, may finally lead to catastrophic health spending (Xu et al., 2003).

Working with the poorest of the poor to improve their well-being and welfare has been key goal of Sustainable Development Goals (SDGs) agenda (Mustafa, Iqbal, & Rehman, 2019; Nawaz & Iqbal, 2019). The Goal-3 of SDGs' agenda stated that every country should “ensure healthy lives and promote wellbeing for all at all ages”¹. The unequal access to health care facilities lead to health inequalities in the society (Iqbal & Nawaz, 2017). To this end, there is a need to ensure the provision of health services to no or minimal opportunity costs to the poorest of the poor to make sure that these people get health facilities provided by the government and even by the non-governmental actors. Free health care programs or financial assistance aim to benefits the poor and excluded segments of the society, but whether these services reach the poor remain an open question (Tseng & Khan, 2015). Developing countries have adopted a policy of free health care services to the poorest of the poor and vulnerable people (Subedi, 2015). This study intends to measure the costs to avail financial assistance from funds of PBM meant for the poorest.

1.2 Motivation of study: The case of Pakistan Bait ul Mal (PBM)

The role of human capital in economic development is well documented (Ali, Egbetokun, & Memon, 2018; Iqbal & Daly, 2014). Health is one of the fundamental component of human capital (Iqbal & Nawaz, 2017). It is established fact that healthy people can effectively contribute to economic activities by dedicating more time to economic activities (Khaliq & Ahmad, 2018). However, Pakistan has a miserable situation in provision of health services that lead health poverty in Pakistan (Iqbal & Nawaz, 2017). It is due to lack of provision of health services, especially for poor people.

¹ <https://www.who.int/sdg/targets>

The government of Pakistan has initiated a number of programs to facilitate poor segments of the society in provision of health care services. Pakistan Bait ul Mal (PBM) is a public sector organ of state. It is the largest social safety net in Pakistan as far diversity of its poor focused services are concerned. PBM has been given mandate through an act of Parliament to care the needs of the poorest of the poor segment i.e. destitute, widows, orphans, invalid, infirm, other needy persons. The financial assistance is provided in the sectors of education, health, housing, and rehabilitation. The institutional assistance to NGOs (Non-Government Organizations) and CBOs (Community Based Organizations) are also supported. PBM provides free funding facilities to the poorest of the poor patients in secondary care medical treatments including cancer patients through an Individual Financial Assistance (IFA) Program.

The deserving cancer patients have to bear out of pocket expense which is beyond their meager resources. On one hand, medical facility extended by PBM is free but on the other hand, procedural requirement to avail this facility is not cost effective as assumed before this study initiated. In view of all the procedures involved, the hospital cost of medicine and surgery etc., is released by the PBM, whereas there are still extra costs that are afforded by patients at their own. PBM focuses on the poorest of the poor families with cut off income level of Rs.15000/- only and extra costs for fulfillment of procedural requirements are unmatched with this cut off income. The extra costs of cancer patients to avail free funds of PBM are overwhelming as compared to the prescribed bench mark of income and very objective of public agenda.

1.3 Research questions

This study aims to look at the following questions.

- i. What is the average cost to avail free fund from PBM for cancer treatment?
- ii. Does the current mode of care provide the best to serve the interest of the poorest?

1.4 Objectives of study

This thesis is the attempt to measure the costs of cancer patients to avail free cancer treatment fund from PBM under the Individual Financial Assistance (IFA) program. Furthermore, this thesis intends to investigate the socioeconomic profile of patients availing health facilities from PBM for treatment of cancer. This thesis also performs the cost benefits analysis of IFA program and discusses some opportunities and practical issues faced by patients.

1.5 Significance of study

This study is the first of its kind to measure the cost of poor cancer patients in Pakistan under the IFA program of PBM. By this study, clear understanding of costs to poor cancer patients can be translated into evidence-based policies of the government while designing schemes to improve the health coverage and accessibility. This research is based on telephonic survey of random sample of cross sectional data of cancer patients Jan.2017 to Dec19. This data is being used for the first time. The inferences of this research may directly influence the bases of Modus Operandi of Individual Financial Assistance (IFA) Program of Pakistan Bait ul Mal (PBM), influence other concerned policies and may contribute academically for future researches.

1.6 Organization of study

The study constitutes six chapters. Chapter.1 is related to the Introduction of study. Chapter.2 is about Pakistan Bait ul Mal interpreting its objectives, functions, management and procedures etc. Chapter.3 comprises the review of literature. Chapter.4 encompasses Data and Methodology of this study. Chapter.5 constitutes Analysis and discussion. Chapter.6 contains Policy recommendations and conclusions.

At the end of sixth chapter, references and appendix (questionnaire) have been placed for ready reference. In the beginning of the all the chapters, list of abbreviations, summary of tables, summary of graphs, dedication and abstract have been provided.

CHAPTER 2

PAKISTAN BAIT UL MAL (PBM)

2.1 Introduction to Pakistan Bait ul Mal (PBM)

Pakistan Bait-ul-Mal (PBM) is a public service organization established to serve the poorest of the poor segment of society in the light of its mandate conferred by parliament through an act of parliament called PBM act 1991 and promulgated in 1992 after the assent of the president. The PBM act of 1991 is the step to implement the public policy of the constitution of Pakistan, 1973. PBM is the largest social safety net in Pakistan as far as variety of its poverty oriented services are concerned. The main areas of PBM services are related to provision of *food, clothing, housing, education and medical relief* to the vulnerable segment of society. For implementation of public agenda, PBM initiated number of projects with the approval of its Board of Management.

In order to get by its mandate, Pakistan Bait-ul-Mal initiated poverty focused projects like child laborers and established child labor schools-158 Nos., Women Empowerment Centers-WECs-156 Nos., Orphanages -55-Nos. In addition to above, PBM is the donor to NGOs all over Pakistan and extends substantial grant in aid. PBM provides candid support to qualified NGOs under relevant strategies of CS-NGOs policy. PBM supports free 'Eye Cataract Surgery' to poor through a strategy of CS-NGO policy as the largest eye cataract supporting agency under Federal Govt. PBM had run Food Support Program (FSP) under millennium goals of United Nations in lieu of food security for the first time with the advent of 21st century. Subsequently, on the foundations thereof; Benazir Income Support Program (BISP) was erected.

Further, the disbursement of Conditional Cash Transfer (CCT) through Child Support Program (CSP) to reduce drop out ratio of children to fulfill agenda of

Universal Primary Education under millennium objectives with the assistance of World Bank was also initiated by PBM. The establishing of Thalassemia Center for free treatment of thalassemia patients is the state of the art project established in a building at F-9 Park, Islamabad. PBM has also served its clientele with the worthwhile donations of international donor organizations like World Bank, UNICEF, World Food Organization (WFO), King Salman Humanitarian Relief Center Jeddah KSA (KSrelief), Qatar Charity, Muslim Aid International and Penny Appeal, ABCTE-USA etc. The brief of salient features of PBM funded projects are available at website¹ of Pakistan Bait ul Mal.

Individual Financial Assistance (IFA) Program is an intervention of PBM with the approval of its Board. This program encircles free medical treatment, rehabilitation, free education stipend and general financial assistance to poor individuals as per laid down procedures of program. Before the introduction of IFA program, the bases of the foundation of PBM is detailed as under.

2.2 Constitutional background of PBM ACT

Constitution of Pakistan 1973 (**PART- II**) deals with '**Fundamental Rights and Principles of Policy**'. Part-II of constitution of Pakistan has two chapters i.e. Chapter-I and Chapter-II. As far Chapter-I is concerned, it explains 'Fundamental Rights' and Chapter-II deals with '**Principles of Policy**'. To explain the constitutional background of PBM, following clauses of constitution are essential to explain the rationale for the foundation of PBM Act.

The article 29(1) of chapter-II (**PART- II**) is read as:

“The principles set out in this chapter shall be known as the principles of policy and it is the responsibility of each organ and authority of the

¹ www.pbm.gov.pk

state, and of each person performing functions on behalf of an organ or authority of the state, to act in accordance with those principles in so far as they relate to the functions of the organ or authority”

Article, 29, section-38; sub-section (d) of Chapter-II, 1973, constitution of Pakistan, is read as:

“Provide basic necessities of life, such as food, clothing. Housing, education and medical relief, for all such citizens, irrespective of sex, caste, creed or race as are permanently or temporarily unable to earn their livelihood on account of infirmary, sickness or unemployment”

2.3 Introduction to ACT of Parliament

2.3.1 Mandate of PBM ACT 1991 amended 2002

*“WHEREAS it is the duty of the State to provide for basic necessities of life such as **food, clothing, housing, education and medical relief** for all citizens, irrespective of their **sex, caste, creed or race**, who are permanently or temporarily unable to earn their livelihood on account of **sickness or unemployment or circumstances beyond their control**”*

*“AND WHEREAS it is expedient to establish a *Bait-ul-Mal* fund for providing assistance to **destitute and needy widows, orphans, invalid, infirm and such other persons**, and thereby save them from hardship and suffering and to enable them to lead an honorable life in the society”.*

This act is enforceable to whole of Pakistan and liable to come in force at once. According to this act Bait ul Mal means ‘welfare fund’ and Board means ‘Bait ul Mal Board’ (BMB).

2.3.2 Administration and objectives (PBM)

Administration

- I. Act of Parliament authorizes *Bait-ul-Mal* –Board to administer PBM
- II. Moneys in PBM accounts are for the objectives of PBM

Objectives

- I. Provision of financial assistance to destitute and needy widows, invalid, orphans, infirm and needy persons.
- II. Helping for rehabilitation of the persons in various professions or vocations in accordance to this act.
- III. Provision of assistance to the children of the poorest of the poor for their education in accordance to this act
- IV. Provision of residential accommodation and facilities to the persons in accordance to this act.
- V. Provision of *free medical treatment* to sick persons and to set up free hospitals, and rehabilitation centers, poor houses and to give financial aid to charitable institutions, including industrial homes and educational institutions established for poor and needy only.
- VI. Provision of stipends to educated youth for their training and provision of stipend during their unemployment.
- VII. Provision of stipends and financial assistance to brilliant but poor students who cannot afford higher technical or medical education abroad for lack of money.
- VIII. Sponsor and promote self-employment scheme.
- IX. Any other purpose approved by the Board with regard to the aims and objects of PBM.

2.4 Functions of PBM board

- I. Formulating Policies with regard to its mandate
- II. Over all planning together with consideration and approval of annual work plan and budgeting
- III. Consideration of statements of accounts/audit.
- IV. Receive the progress reports from all concerned
- V. Ensuring implementation of approved plans, programs, budgets and ensuring transparency and accountability in administration.
- VI. Coordinating to poverty alleviation programs (Government /public and private)
- VII. Any other prescribed functions.

2.5 Funding source of PBM

- I. Funding from transfer of receipts from tax levied for this purpose
- II. Receiving of grants from the Federal Government, Provincial Governments, national organizations, local authorities and international agencies.
- III. Donations, '*Sudqat* and *Atiyyat*' by individuals, bodies, institutions societies or organizations.
- IV. Amount received from sale of *Bait-ul-Mal property* and income from properties, investments and assets

2.6 Reporting mechanism

- I. PBM, Board is responsible to maintain books of accounts in connection to its responsibilities and delegated by Board to its officers and staff.
- II. The accounts of *Bait-ul-Mal* are supposed to be audited yearly by the Auditor General of Pakistan.
- III. AGP presents copy of Annual Audit Report to the Board for comments /remedial measures/actions.

- IV. In January of each year, the Board is responsible to submit a statement of estimated receipts and expenditures to the Federal Government for approval of next financial year.
- V. The Board is responsible to submit an annual report, on the conduct of its affairs for the current year, to the Federal Government but no later than 30th September of each year.
- VI. The Federal Government is responsible to submit copy of the annual report to National Assembly of Pakistan
- VII. Federal Govt. may demand from Board any information or statements regarding its responsibilities and Board is legally bound for compliance without any delay.
- VIII. The board appoints officers, servants, experts, consultants/advisors for performance of its functions. The procedures and terms & conditions of service are prescribed by board and board is competent to take disciplinary action against these appointed officers.

2.7 Composition of PBM board

- I. Federal Secretary, Government of Pakistan (Controlling Ministry/Division) who shall be its *ex-officio* Chairperson (Ameen)
- II. Managing Director (*Bait-ul-Mal, Board*) *official member*
- III. Five non-official Members (at least) are appointed by the Federal Government one each from the Provinces and one to represent Islamabad Capital Territory, Northern Areas and Azad Jammu and Kashmir.(Provided that one of the non-official members is a woman, at least)
- IV. Representative of the Federal Ministry of Religious Affairs and Interfaith Harmony (official member)

- V. Representative of the National Database and Registration Authority (NADRA) as official member
- VI. Representative of the Federal Ministry of Finance (official member)

2.8 Conduct of business (PBM board)

- I. PBM- Board has power to conduct its business and regulate its proceedings, as prescribed by Board, from time to time.
- II. Board appoints Provincial, Divisional, District or other special Committees or sub-committees consisting of members as prescribed.
- III. Board meets at time, place and manner as prescribed in regulations provided that until such regulations are formulated the Board meetings are to be convened by the Chairperson.
- IV. Chairperson and five members may constitute the quorum. In case of the absence of Chairperson, at least six members may constitute the same. If there is lack of quorum, the meeting may be without a quorum restriction but subject to the issuance of prior written notice to all Members.
- V. In absence/abroad/leave of the Chairperson, the chairperson may nominate any member to convene and preside over the Board Meetings
- VI. Within the meaning of section-21 of Pakistan Penal Code the Chairperson, members, officers and servants (during implementation of this act) are the public servants. The board may delegate any of its powers to chairperson/member/any officer of the board for performance of duties and functions under this act subject to conditions. Federal Govt. to make rules to carry out purpose of this act. The board can make regulations with the approval of federal government but the same should not be inconsistent with rules for conduct of its business and its meetings.

2.9 Managing Director and non-official members

Federal Government is responsible to appoint Managing Director. All powers (administrative and financial) are exercised by Managing Director subject to the condition that all appointments and powers used are reported to Board for information. The non-official member is selected from social workers, elected representatives, a person well versed in law & jurisprudence, ulema, jurists, persons with reputation of honesty, integrity & devotion to Islamic Ideology in line with injunctions of Quran & Sunnah. Federal government may appoint non official members who perform their duties till the pleasure of the appointing authority. The non-official member is not authorized to draw a salary but facilities and privileges may be drawn as prescribed. The handwritten resignation addressed to the chairperson is accepted subject to the acceptance by the Federal Government. In absence of chairperson, the senior most member (in age) chairs the Board meeting but this acting period may not be more than 60 days. Chairperson, members, officers and servants of Board are liable to sign an oath on prescribed format. The oath of officers and servants are desired to be placed in their personal files.

2.10 Individual Financial Assistance (IFA) program

2.10.1 Introduction

The constitution of Pakistan 1973 obligates to provide food, clothing, housing, education and medical relief, to citizens, irrespective of sex, caste, creed or race to those who are permanently/temporarily unable to earn due to infirmity, sickness or unemployment. In lieu thereof, PBM Act endorses constitutional obligations and further explain its clientele i.e destitute, needy widows, orphans, invalid, infirm and such other persons for provision of free medical treatment.

IFA Program of Pakistan Bait ul Mal is the apparatus of PBM Act for fulfilling constitutional obligations to address. For the purpose, PBM Board has approved a Standard Operating Procedures (SOP-called IFA policy) to operationalize the IFA program. The salient features of SOP of IFA program are detailed below.

2.10.2 Standard operating procedures (SOP) of IFA program

Targets of IFA program

- I. Providing **free Medical** treatment to ‘poor and destitute’ patients
- II. Providing free education stipend to poor students
- III. Supporting rehabilitation for eligible poor to set up small vocation in order to make them self-reliant
- IV. Extending General Financial Assistance to poor individuals (disable, infirm, handicapped, orphans or widows and those who are victims of circumstances beyond their control i.e. protracted ailment or death of earning member, natural calamity etc. as economic shock therapy.)

2.10.3 Implementation mechanism

- I. PBM implements its IFA program through countrywide network of Provincial, Regional and district offices.
- II. A person having monthly income up to Rs.15,000/- (as per IFA policy, 2016) is treated as poor and is eligible for receiving financial assistance under IFA medical, education, general and rehabilitation
- III. A poor, destitute, orphan, widow, invalid and infirm is eligible to apply for IFA on plain paper along with a copy of Computerized National Identity Card (CNIC) issued by National Database and Registration Authority (NADRA) or production of its computerized receipt.
- IV. Any poor can apply for general financial assistance (cash grant) once in a year.

- a. Any of the two services may be granted to the same beneficiary in same year but rehabilitation and general assistance can't be combined together.
 - i. IFA- Medical Treatment
 - ii. IFA- General Financial Assistance
 - iii. IFA- Education stipend
 - iv. IFA- Individual Rehabilitation
- b. For IFA-General (a need based cash grant), the preference is given to widows, infirm and disabled each year whereas other categories of individuals are accommodated twice in entire life. But, preference is given to them in other policy areas like IFA (Medical), IFA (Education) and IFA (Rehabilitation).
- c. Approving/sanctioning authority may regret any application based on assessment report. The authority may also convert the requested service to any other, keeping in view the information provided by the applicant i.e. financial assistance, medical treatment or education stipend etc.
- d. Financial assistance is provided through crossed cheque by means of registered post at the address of beneficiary/applicant but in case of medical and education stipend, the same is dispatched to the head of respective hospital or institute respectively.
- e. A disable applying for a particular aid/appliance is liable to provide disability certificate duly verified by an authorized doctor with relevant specialization.
- f. In case of orphan girl/boy, the CNIC of guardian is also accepted for convenience.

2.10.4 Limitations of IFA program

- I. Financial assistance for diseases like Cancer, Heart disease, Hepatitis, Tuberculosis, Vital Organ Surgeries - Kidney up to Rs.600,000/- is forwarded through crossed cheque to Government Hospitals for treatment purpose only.
- II. PBM may extend upto one million (Rs.10,00,000) for treatment of chronic diseases like (Myeloid Leukemia (CML), Thalassemia, Dialysis, renal transplant, bone marrow transplant and treatment of solid tumors and other diseases etc.
- III. The expenditures incurred on treatment excluding hospital charges is also remitted in case of private hospitals (Doctors Hospital Lahore. Bilal Hospital Rawalpindi, Shifa International Hospital Islamabad, NMI Karachi and NIBD Karachi) to the applicant or patient provided that the hospitals are agreed to provide treatment at government hospitals' rates and the subject treatment is not available in Govt. Hospitals. Managing Director PBM is Competent for approval of treatment from private hospitals.
- IV. In case of diagnosis/tests where the diagnostic facility does not exist in a government hospital, the payment could be made direct to the private test laboratories or paid through government hospitals.
- V. Applications are submitted on plain paper with copy of CNIC with duly verified set of medical templates of PBM duly endorsed by designated hospital committees. Subsequently, applications are investigated by the concerned authorized officer of district to assess economic status. The case is scrutinized/analyzed and recommended for amount through Medical Directorate of PBM in case of head office and that of Deputy Director/Assistant Director medical at Provincial/Regional offices' level.

- VI. All payments regarding medical assistance are made through crossed cheque in favor of head of hospital.
- VII. Medical cases with estimated cost up to Rs.100000/-(one lac) are not required to be sent to Deputy Director Health/SMO Head Office rather such cases are disposed-off by the provinces/regions themselves on the basis of cost estimates received from hospitals.
- VIII. Eligible applicants/patients are provided treatments on first come first serve basis.
- IX. Medical bills, of past treatment, are not reimbursed from PBM funds.

2.10.5 Budgeting and monitoring mechanism

- I. Annual budget of IFA is distributed proportionally on the basis of provincial/regional population quota and subsequent disbursement is made to districts based on poverty ranking score. A considerable portion of annual budget is retained at PBM-Head Office. This retained budget is utilized for priority cases of IFA. In case of depletion of budget of few districts, the district wise budget is re-appropriated at provincial/regional level on the basis of demand/requirement thereof.
- II. Monitoring and Evaluation (M&E) Directorate at Head Office performs M&E functions for IFA Program and other projects. Survey is part of policy to be conducted by designated officers for all districts on random basis. PBM officers, BMB members also visit the districts to ascertain service delivery. An impact assessment report on prescribed forms is submitted by authorized officer of PBM to concerned provincial/ regional offices.
- III. The provincial/regional headquarters maintain monthly record of applications received and cases processed, either finalized or regretted, for need assessment

and performance evaluation. These reports are required to be furnished to Head Office on quarterly basis.

2.10.6 Different roles of officers at hospitals in context of IFA policy

Role of hospital committee

- I. Government Hospitals constitute hospital committees comprising of following members for supporting poor patients to avail PBM funds for treatment:
 - a. Consultant (Doctor treating patient)
 - b. Budget and Accounts Officer of hospital concerned
 - c. Pharmacist of hospital concerned
 - d. Medical Social Officer of hospital concerned
- II. The committee identifies the medical cases of poor patients having better clinical outcome and forwards the same to concerned PBM office after verification of MS/Director/Head of concerned Hospital.
- III. Hospital committee is responsible for best utilization and monitoring of PBM funds for all deserving cases and ensures co-ordination with PBM staff visiting internal audit.

Role of hospital authority (Procurements/Estimates)

The responsibility of hospital authority is to utilize PBM funds as per institutional rebate rate for following purchases:

- a. Unavailable, life-saving drugs / essential medicines including interferon for Hepatitis and first line Chemotherapy drugs for Cancer Patients etc.
- b. Essential, life-saving surgical disposables including Cardiac Disposables i.e. Heart Valves, Oxygenator and Permanent Pace Maker (PPM) etc. Surgical Grafts/ Ortho Implants, V-P Shunts, Desferol Injections, Infusion Pumps and Nebulizer etc.

- c. Rehabilitative devices like hearing-aids, artificial limbs, wheel chair, tri-cycle, crutches and electro-larynx etc. through Special Friends' Cell of PBM.
- d. Unregistered/smuggled medicines of any kind cannot be purchased from PBM funds.
- e. All the empty Vials of Cancer Chemotherapy drugs purchased from PBM funds are supposed to be retained/preserved by the hospital authority and those would be inspected by the PBM internal audit team on random basis.
- f. Correct cost estimates, duly verified by the Consultant, Pharmacist/Medical Social Officer and Head of the Hospital as per PBM clinical forms for life threatening diseases, is considered for process and only hospital committee is responsible for any fake estimate
- g. In case the discount prices to the PBM patients are not, genuine then PBM has the right to inform the concerned provincial health department as well as to Ministry of Health Islamabad, that the system introduced by PBM is not being followed by the concerned.

Role of hospital authority (Accounts /Reconciliation)

- a. Hospital authority is responsible to open separate account for PBM
- b. Maintaining the separate cash book for PBM
- c. Maintaining and keeping record of personal files of PBM patients containing clinical papers, medicines' vouchers/bills etc.
- d. Keeping record of unspent/balance amount (if any) for refunding to PBM along with complete utilization report to respective PBM offices on quarterly basis as per format retained by MSO of hospital.

- e. Hospital charges/government dues of any kind is not deducted from the PBM funds such as; consultation fee, hospital charges i.e. (ICU, CCU, OT etc.) food ,service and nursing charges.

Role of medical social officer (MSO)

- I. Retaining and issuing of PBM forms to Cancer, Heart, Hepatitis, Surgical patients and providing Medicines, Hearing Aids and Artificial Limbs/Caliper to the consultants for handing over the same to poor patients and also referring patients/cases to the concerned provincial/regional directors/deputy directors.
- II. Maintaining complete record of PBM patients.
- III. Sending Monthly Progress Reports, duly verified by the Hospital Authority regarding utilization of PBM funds.

2.10.7 Ineligibility from IFA program

Applicant should not be the beneficiary of similar subsistence from any other government organization i.e. Zakat, Khushali Bank, Provincial Bait-ul-Mal etc. Further, the employees of PBM (even on contract) and their family members are not eligible to apply. And, applicant serving in public sector organizations, corporations, and autonomous bodies etc., is also ineligible.

2.10.8 Annual review of IFA program

On the basis of the visits of inspecting/monitoring officers, monthly, quarterly annual progress reports, case studies of rehabilitations under IFA program, PBM publishes Annual Review. Further, based on analysis of review, any change in procedure or policy is placed before PBM-Board.

2.10.9 A brief introduction of education and rehabilitation assistance (IFA)

The education stipend and boarding charges for the students of primary and high school are paid for uniform, books & stationary and tuition fee to the students' parents.

Education stipend and boarding charges for post matric students shall be paid to the institution including admission fee, tuition fee, examination fee, library fee and board/university registration fee, boarding charges and transportation charges. All payments are paid through crossed cheque to the applicant for first semester on reimbursement basis but in case of subsequent semesters, the approved amount is transferred to the account of the institute. Students of M. Phil & PhD are also eligible for IFA Education. The first semester/first year fee (if already deposited by the student) is reimbursed to the students. Deserving and brilliant students are paid education stipends in accordance with prescribed fee of government institutions including technical training from recognized Government Polytechnic Institutes. The students are required to submit application for education stipend along with academic testimonials and bonafide certificate. Subsequently, the cases are verified/investigated to assess their genuineness. Education stipend can be provided to all members of the same family at a time but limit should not be more than Rs.100, 000/-

Table 2.1: Limitations of IFA education

Level	Education Stipend (per month)	Boarding Charges (per month)
Primary	Rs.100	-
High School	Rs.200	Rs.500
Post Matric studies upto University	Equivalent to prescribed fee of Govt. institution (maximum to Rs. 100,000/-) per annum including boarding charges @ Rs.1500/- per month or actual (whichever is less).	Rs.1500
M.Phil. & Ph.D.	Board decided that M.Phil. & Ph.D. students should also be accommodated under IFA education scheme.	Rs.100,000/- (in lump sum in a specified tenure)

Source: PBM IFA policy 2016.

The rehabilitation program of IFA is further classified into two categories:

Rehabilitation of those lacking physical, human, or financial resources under general rehabilitation program. Artificial limbs, crutches, and wheel chairs etc. are also provided by PBM through same procedures.

Rehabilitation of those lacking financial resources or technical skills can be facilitated through CBO/NGO based rehabilitation Module.

Table 2.2: Year wise allocations to cancer patients by PBM (F/Y 2008-2020)

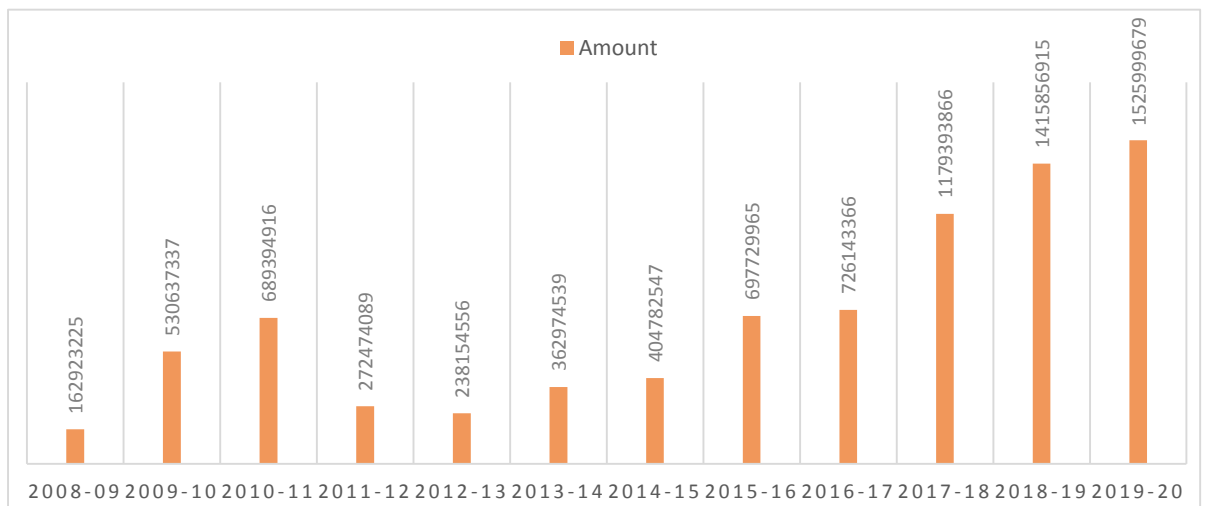
Fin. Year	Balochistan		Gilgit Baltistan		ICT		Khyber Pakhtunkhwa		Punjab		Sindh		Total	
	No of cases	Amount	No of cases	Amount	No of cases	Amount	No of cases	Amount	No of cases	Amount	No of cases	Amount	No of cases	Amount
2008-09	84	4033300			320	25534501	349	27654901	1386	101618023	80	4082500	2219	162923225
2009-10	121	9928298			450	74197368	658	95212847	2549	318588362	404	32710462	4182	530637337
2010-11	98	11113462			476	88126483	1003	150844654	2359	401764287	389	37546030	4325	689394916
2011-12	187	18152067			363	32701004	745	57657845	1539	139577127	228	24386046	3062	272474089
2012-13	139	11244400			375	29960403	655	47818188	1774	135367435	142	13764130	3085	238154556
2013-14	95	9277891			525	40733313	1026	80703163	3014	221665084	72	10595088	4732	362974539
2014-15	107	9046600			697	48892036	804	57657446	3831	280335829	64	8850636	5503	404782547
2015-16	167	17014900			809	79587625	1260	125320153	4643	462594614	96	13212673	6975	697729965
2016-17	242	19782600			892	78194560	1527	118536653	5379	475093032	217	34536521	8257	726143366
2017-18	506	43481844			1152	100144360	2601	214316860	7890	727041801	631	94409001	12780	1179393866
2018-19	581	58092613	60	7457000	1042	113322232	2710	261748813	7324	797369755	1104	177866502	12821	1415856915
2019-20	532	69246528	105	14375594	1057	161459720	2369	288513078	5959	785574087	979	206830672	11001	1525999679
Grand Total	2859	280414503	165	21832594	8158	872853605	15707	1525984601	47647	4846589436	4406	658790261	78942	8206465000

SOURCE: PBM-MIS

Note:

Data of cancer patients of AJK & GB was combined from 2008 to 2018, as GB was part of ICT Region. After 2018, the data of GB and ICT was separated in MIS of PBM.

Figure 2.1: Allocation of funds (F.Y. 2008-20)



Formation based on MIS PBM 2008-20

CHAPTER 3

REVIEW OF LITERATURE

3.1 Introduction

Cancer is a dread disease with its worldwide presence.¹ In Pakistan, treatments for poor cancer patients of PBM are linked to the few Cancer Hospitals, mostly located at rare locations². The poor have to bear (additional) costs to get free funding from PBM. These costs may be direct, indirect, social and miscellaneous.

The Goal-3 of SDGs agenda states that every country should ensure healthy life and promote wellbeing for all at all ages. The unequal access to health care facilities lead to health inequalities in the society (Iqbal & Nawaz, 2017). Developing countries have adopted a policy of free health care services to the poorest of the poor and vulnerable people (Subedi, 2015). Whether these services reach the poor remains an open question. The governments across the world have implemented various health programs with an aim to benefits poor and to provide free health coverage (Tseng & Khan, 2015). Health is one of the fundamental component of human capital and Pakistan has a miserable situation in provision of health services that lead health poverty in Pakistan (Iqbal & Nawaz, 2017).

The treatment costs are linked to direct costs like travel cost and medicine costs etc. while indirect costs have informal financial impacts like opportunity cost of the attendants (Yabroff et al., 2011). The stage of treatment and the facilities provided by the health system effect the burden of indirect and direct costs and influence access to treatment and choice (Russel, 2004). The people of poor class have not enough economic resources to opt health facilities even available free in presence of obstacles

¹ (Jemal, A., Bray, F., Center, M. M., Ferlay, J., Ward, E., & Forman, D. (2011). Global cancer statistics. *CA: a cancer journal for clinicians*, 61(2), 69–90.)

² "List of PAEC Cancer Hospitals in Pakistan PakInfoMedics". www.pakinfomedics.com

of informal costs and finally have to face unbearable expenditures. This may push these poorest of the poor families into deeper poverty (Daneshkohan et al., 2011; Xu et al., 2003). The patients or his family has to afford excessive medical costs to avail these services and have to cover huge health expenses from their incomes. Protecting poorest of the poor from co-payments is one of the main objectives of health policies of these countries (Filmer et al., 2002; Sachs, 2001; Xu et al., 2003). The poorest of poor remain excluded and often benefitted the least due to high mobility costs (Amin et al., 2010; Tseng & Khan, 2015). Cost analysis for policy effectiveness, coverage and expansion is necessary for such programs (Adam & Murry, 2003; Drummond & McGuire, 2001). The total cost will cover money & time cost and resources associated with the provision of free health care services (Amjad et al., 2017; James, 2010; Mogyorosy & Smith, 2005).

The costs are not affordable when balance of household consumption and health expenditure is out of range. The income level, method of research and education level play important role for deciding the out of pocket expenses (Pal, 2012). Measuring cost of illness help the policy makers for rational decision (Jo, 2014). The enhanced education level of household impacts national income and in turn play significant role to reduce economic constraints for poor and poverty (Afzal et al., 2011).

David et al. (2003) the constraints to receive health facilities lead to expenses beyond the control of household and cause to enhance poverty. When household compulsorily compromises to reduce basic household expense to compensate health costs, the point of ‘catastrophic out of pocket expense’ starts. The paying capacity of household is the income left after basic needs and it is 40%. The reduction to rely on traditional health system imbedded with ‘out of pocket’ expenses and to protect household from financial risks should be included in policy design (David et al., 2003).

The various costs on health engulf large portion of the budget of household and also leave patient to face further unseen expenses (Donnell, 2007). The costs of treatment shifting to the household is directly related to the features of health system. The proportion of public benefits subsidizing health costs, income sources, vulnerability, the access and limits to availability depend on configuration of health system (Wagstaff, 2007). Multivariate analysis will be used to find the key determinants of opportunity cost e.g. distance, time, visits, waiting time, and other social factors (Amjad et al., 2017; Iqbal & Awan, 2015)

3.2 Theoretical framework

The cost theories may be categorized in Traditional Cost Theory and Modern Cost Theory. Cost may be termed as the sacrifice made to obtain something, or as the valuation of efforts like materials, time, resources, utilities, risk and opportunities intended for goods and services. There are different types of costs e.g. economic cost, production cost, real cost, opportunity cost, private and social cost, sunk cost, incremental cost. (Nwokoye et al., 2018)

3.2.1 Direct costs

The lack of finances and transportation facility is the reason for delaying the medical diagnosis and treatment (Needham et al., 2004). The transportation cost varies with the location of rural or urban residence (Needham et al., 1998; Russel, 2004). It is estimated that direct cost is 5-21% of annual household income. Direct costs are unevenly distributed amongst households (Russel, 2004)

3.2.2 Indirect costs

The lost income, the lost working days, decreased capacity to earn, the change in job with lower salary and reducing food of house hold are some of the indirect costs (Kemp et al., 2007). Half of the population was selling assets or taking loans for

treatments (Croft, 1998). The economic loss was grave for self-employed persons (Needham, 1998)

3.2.3 Total cost

The burden of each unit (\$) of cost spent is significantly higher for the poor (Russel, 2004). Impact of different costs on ordinary family with patients living in Low and Middle Income Countries (LMICs) was studied and concluded that direct, indirect and other costs have impoverishing impacts on the households (McIntyre *et al.*, 2006). Due to the health system weaknesses of different countries of the world, poor households have great economic impact in shape of the extra medical costs on their incomes and suggested that the indirect costs associated with health systems should be curtailed through government interventions/public policy initiatives (Russell, 2004). Studied health inequalities in the health systems due to extra cost burden of treatment in contrast to the costs shared by health systems and observed inequalities in (8) selected developing countries (Makinen *et al.*, 2000).

3.2.4 Social cost

The firms usually produce to satisfy the demand of their consumers. On one hand, firms produce for the benefit of their clients but on the other hand, this production creates harm for third group. For example, during manufacturing of products like production of chemicals, steel etc. environmental pollution is the definite phenomenon causing harm to other citizens. Further, on positive side, education, health and other public services contribute to enhance income, wisdom; out puts and satisfaction level for whom these services were designed. The private cost used for production of goods and services cause economic loss to other citizens for example environmental pollution lead to social cost. Hence, social cost is private cost plus cost to third party. (Nwokoye *et al.*, 2018)

3.3 Approaches to measure cost

There are four main approaches for estimation of cost.

3.3.1 Human capital method/approach (HCM)

Introduction to human capital

Human capital approach encompasses natural abilities, physical fitness and healthiness. Human capital is too important that Human Capital Flight from one country to another had been the talk of the town in 1990s because of the reason that one country invested to train its men and other country took them away without any investment. The investment, on health by the nations' states, is basically to preserve their human capital.

Human capital is a collective phenomenon and set of knowledge, skills, experience training along with intelligence, talents, wisdom, traits, abilities, judgment of individuals and of people. Human capital is further categorized in social, emotional and intellectual capital. To save this capital, every rich or poor country tries to provide the maximum health facilities to their citizens.

Source of human capital approach

Adam Smith (1723-1790) in his book "The Wealth of Nations" discussed the Land, Labor, and Capital as factors of production. The Labor is termed as human capital by economists. Smith (1776) "The acquisition... talents during ... education, study, or apprenticeship, costs a real expense, which is capital in [a] person. Those talents [are] part of his fortune [and] likewise that of society". Irving Fisher used the term "human capital" in 1897¹ for the first time. Arthur Cecil Pigou (1949) contributed the investment in human capital with its pros and cons. Jacob Mincer (1958) used the term human capital in his paper "Investment in Human Capital and Personal Income Distribution".

¹ The Historical Roots of the Concept of Human Capital, B. F. Kiker, Journal of Political Economy Vol. 74, No. 5 (Oct., 1966)

Schultz (1961) reviewed that ‘free people were not to be equated with property and marketable assets’ as it implied slavery and explained importance of human capital concept while interpreting the economic misconceptions. Gary Becker (1964) termed human capital as similar to physical factors of production in his book “Human Capital” but physical factors of production are transferable in contrast to human capital. Mincer (1974) estimated rate of return of schooling as blocks of building to measure any country’s human capital strength. Lucas (1988) stated that human capital disproportions and specified a basic role in study for growth & development. Bleakley (2010) stated that poor nations incline to be unhealthy and vice a versa and increase in incomes cause to improve in health. Health is termed as human capital and causes for production of human capitals of other forms and based on study explored that unhealthiness decrease productivity, ability to work and cause disincentive to invest in human capital and observed that disease and the portion of income to be spent depends on the world income distribution pattern and ratio of outcome of health policies. Manuelli & Seshadri (2014) followed the pioneering work of Becker & Ben and modeled human capital acquisition as part of standard income maximization. Paul Romer (2018) introduced ‘innovation’ in human capital approach for economic growth.

Healthy people can effectively contribute the economic activities by dedicating more time in these activities. The policies can be upgraded to minimize poverty by means of human capital (Khaliq & Ahmad, 2018). HCM, as compared to Willingness to Pay Method (WTP), underestimates the economic burden on household (Malaney, 2003). The role of human capital in economic development is well documented (Ali et al., 2018; Iqbal & Daly, 2014).

Health is one of the fundamental component of human capital (Iqbal & Nawaz, 2017). By using index for human, resulted that human capital and high technology

exports are mean to reduce poverty in developing countries during study from 2004 to 2017 for forty four countries (Ahmad at el., 2018). The human capital composes health, education and nutritious food that return in future (Mauro, 1995; Knack & Keefer, 1996). The human capital is essential for attaining modern technology for improvement of national out puts and outline to increase incomes and better economic results (Barro, 1991; Mankiw et al., 1992; Romer, 1990).

Malaney (2003) Human Capital Approach is also known as ‘Top down Approach’. It includes direct and indirect cost. The accumulative effect of all paths of costs pertaining to disease is calculated in Human Capital Method. Cross-country regression analysis, willingness-to-pay, and the production function approach miss the link. The estimated costs derived through each of these approaches would depend on selection of methodology. The estimation include time cost of lost work. The formula for cost estimation is as under:

[Costs of patients’ treatment = Private medical costs+ non-private medical costs+ foregone costs + costs linked with pains and sufferings]

The HCM is criticized for its inaccuracy of results. It worsens, in case of women, when she becomes financially unproductive. It excludes future activities and ‘leisure time’. Further, converting of qualitative things to the numerical values is not easy in the HCM approach. The traditional estimation through human capital should be made good with distinct concept of indirect costs rather to fix it with foregone income related to traditional HCM approach. The gap exists and be fulfilled between different methodologies. To find out the range of costs linked to patients, the bottom up approach may find aggregates (Malaney, 2003).

Human capital index (HCI)

Since 2012, World Bank is regularly publishing Human Capital Index (HCI). According to this index, the scores of Pakistan, India, Bangladesh, USA, United Kingdom and Singapur are 0.39, 0.44, 0.48, 0.76, 0.78 and 0.88 out of '01' respectively. Public service extends lower quality input to produce human capital. ¹

3.3.2 Willingness to pay method (WTP)

This approach is also called a 'Bottom up Approach'. HCM, as compared to WTP, underestimates the economic cost on household (Malaney, 2003). When services are not obtained due to financial constraints, the cost of availing health facility is affordable. It is indicated that 3-5 % cost of annual income may not be burdened. Willingness to pay is not always equal to the ability to pay. It may be possible that one is willing to pay but at the cost of sacrificing household essentials (Russel, 1996).

The health expenditures are tolerable if same are not effecting social status and health of household (Fabricant et al., 1999). If the cost of diagnosis is curtailed, patients will go for early detection (Jack, 2000).

3.3.3 The Production function approach

The policy makers should also focus on the factors which are lying outside the system for example employment, productivity, development and economic growth to increase health status (Bayati at el., 2013).

This approach does not estimate direct cost. It is not to specify costs and data issues. The method of production function for estimation of out puts (in shape of crop, house hold, land etc.) is used to evaluate the monetary loss. Decreased productivity, of chronic industrial units and those workers who could not be recovered fully is discussed/estimated here.

¹ The world development report-2019, the changing nature of work, Chapter-3, building human capital

3.3.4 Friction cost approach (FCA)

Indirect costs are estimated to restore the production unit at its initial stage of production after identifying sick firm. This method is used simultaneously for firms and society alike. Therefore, it is not used to calculate the costs of patients. Usually the researchers, in this approach, determine to calculate indirect costs for the time period (depending upon capacity/education of worker and location of sick unit) of firms to restore original or optimum level of production till the firm gets rid of being sick. (Drummond, 1997; koopmanschap et al., 1995). Most studies of FCA links its origin to Canada, Germany and Netherlands where it is officially endorsed to find ‘Cost of Illness (COI)’. FCA represents small productivity loss than HCA /HCM comparatively. It has been argued by scientists that the HCA overestimates loss of productivity hence they recommend Friction Cost Approach. (Jamison and Scott, 2018)

3.4 Literature review

Daroudi et al. (2017) examined clinical data/medical expenses of sample patients for five years, in Iran, from 2006 to 2009. Based on given constants, calculated incidence rate, survival rate and direct cost by means of consequent prevalence analysis. Through estimation of average costs, incidence costs, prevalence analysis and comparing the results with national economic indicators, explored the substantial shifting of ‘economic burden’ on Chronic Myeloid Leukemia (CML) cancer patients. Alireza et al. (2016) conducted study in the year 2012 in Iran for the estimation of the costs of colorectal cancer patients and divided his study in two phases i.e initial and continuing. To estimate indirect cost, the average cost of patients was calculated from a given sample was further multiplied to the total population of patients. Average costs of initial and continuing phase (disease wise) was later on multiplied with total numeric figure of patients. For indirect cost estimation, used ‘Human Capital Method’ and

indicated the medical costs shifted to colorectal cancer patients. Laudicella et al. (2016) examined colorectal, breast, prostate and lungs cancer in the years 2001 to 2010, for the patients between 18 years to 64 years. Based on data; calculated incidence, prevalence and costs of care separately, in England. The treatment and control population samples were identified for comparison of costs involved in pre & post diagnosis treatment. Alen et al. (2014) used 'Micro Simulation Modeling' for the analysis of 'Comparative Effectiveness' for those selected patients who screened, prevented, met to death and estimated their survived number of years in relation to the costs of treatment to uninsured/poor population of South Carolina, in the light of two programs i.e 'Colonoscopy and Annual fit' and evaluating the number of prevented patients (no of cases, deaths, life years gained) in a fixed given budget and given time period. Lang et al. (2012) explored upward trend of cost burden in all phases of cancer patients under observation i.e. phase-1 (initial), phase-2 (continuing) and phase-3 (terminal). The average cost of particular phase, for each one of five types of cancers, was combined with survival rate and mortality rate to calculate the total cost over the life years. Kim et al. (2008) studied on the basis of data base of Korean National Cancer Registry and estimated the expenditures incurred to the cancer patients who died during the treatment. The number of deaths for cost calculations were obtained from National statistics office of Korea. Based on difference of cost between the cancer patient and the non-cancer patients in cohort study and the costs related to different phases of diseases (diagnostic, treatment and death), used survival analysis to estimate patients' follow up costs and total economic costs. Based on results, derived indicators for policy decision in order to curtail cost that shifts on the cancer patients. Song et al. (2011) revealed that the patients costs estimated in 2008 were more than measured in 2004 (25% increase observed). Costs of mortality/deaths of women due to breast cancer, in

California was estimated as the product of value of future earning and the number of deaths reported for that disease after the 'biologic therapies' were applied to the cancer patients. Max et al. (2009) studied the patients inflicted with 'Metastatic Colorectal Cancer' in category of newly diagnosed patients. The control and treatment groups were separately studied as per given criteria. For follow up measurement of cost, both selected groups were applied with 'Survival Analysis Technique'. Clerc et al. (2008) examined the time frame from date of diagnosis and costs to incur over the span of 12-months for the patients of colorectal cancer in France. They found nil significant difference in relation to age, and of sex. Estimated mean cost of colorectal cancer management procedures and evaluation was carried out in relation to age of patient, stage of diagnosis, health facility providing pattern and unhealthy conditions (morbidity) and explored that the cost of treatment is directly proportional to the stage of the cancer, explored decreasing estimates for hospitalization costs, medical costs, outpatient costs and transportation costs and suggested for early diagnosis to grip the disease timely. The early diagnostic measures may be taken up by governments through policy making. Yabroff et al. (2007) studied the cost of colorectal cancer patients in three phases for time cost i.e. initial, continuing and terminal phases that averaged 12-month (19.3% of direct cost), per month (15.8 % of direct cost) and 12-months (36.8% of direct cost) respectively. Based on study, explored hospitalization cost as much as two third of total cost along with other calculations and explored frequency of category in different services and costs associated with different cancer types from 1995-2001. 'Cohort' study was conducted on Medicare claims related to Breast, Corpus Uteri, Lung, Head & Neck, Gastric, Melanoma of skin, ovary, prostate, renal, urinary bladder and colorectal cancers with experimental design. Each group was matched in all respects and results of two groups were compared and analyzed (Yabroff et al., 2007).

Studied travel expenses for those participants who were engaged in screening programs in UK. The mean of the total cost of travel and time was calculated for further analysis and explored that travel cost burden is 3 x times more than time cost. The costs have average trends by estimating mean of the total time of travel for each visit through a quantified response received through a questionnaire (Woolley et al., 2007). Based on cohort study estimated out of pocket cost per patient in three phases of treatment i.e. initial, continuing and terminal. Mean cost, incidence cost, continuing costs, costs in relation to treatment type, long term costs, prevalence costs (on the basis of aggregate national expenses). The net cost was estimated after getting difference of means from control group and treatment group (Brown et al., 2002). The study was conducted, in Canada in 1995, for the women with breast cancers, and distributed the disease in 4-stages of breast cancer and explored relationship of costs and the resources by estimating costs distributed over the treatment periods, through a cohort study. The variables of age, stage etc. were observed to calculate costs related to life span of cancer disease and cancer patient. 'Disease Costing Models' proved significant tools for adjustment between limited budget and costs of patients. 'The Breast Cancer Costing Model' for cost impact versus effectiveness of radiotherapy for patients who had gone through breast cancer operation (Will et al., 1999). Examined the sample of patients with cancer equally matched with the patients without cancer in all aspects. The phases of treatment were economically related to the life time of colorectal cancer patients by estimating phase wise costs and treatment costs in cohort study. A secondary analysis was performed to estimate the cost of 10-years that was further extrapolated to next 25-years and deduced that the stage of cancer is directly proportional to the cost of treatment (Lang et al., 2009). Estimated mean costs of travelling, non-medical, indirect and total costs and compared the same with total population of Great-Brittan, exploring

detailed relationship of life time and phased costs of colorectal cancer (Frew et al., 1999). Examined the cost burden shifted to colorectal cancer patients and revealed that almost all such patients have to have born extra costs (Hanly et al., 2013). Studied the “poor” in ‘Low and Middle Income Countries (LMICs)’ and examined the disparities in poor and rich countries. The patients of rich countries avail better health facilities as compared to poor. By using ‘Universal Approach’, involving all stake holders coupled with multi-pronged strategy, the vulnerability associated with poor patients and poor countries revealed that direct, indirect and other costs impoverish households (Peters et al., 2008).

Russell, (2004) reviewed previous studies which had measured the economic costs and consequences of illness on household. Health service systems’ weaknesses in many countries, including low coverage, user charges, and poor quality of care, contributed to high costs of treatment to the patients and suggested that indirect costs associated with health systems should be curtailed through government interventions/public policy initiatives. Makinen et al. (2000) studied 8-countries and examined inequality. Based on study, explored health costs in relation to house hold data and revealed that richer quintile from within each country has better excess to health facility than poor. After analyzing data of household with health service distribution mechanism in each respective country and sub-dividing income groups of each country into different sub-groups, explored health inequalities in the health systems due to extra cost burden of treatment in contrast to the costs shared by health systems. Gwatkin, (2004) studied relationship of subsidized free government services and the poor segments of the society and explored that ultimate advantage of poor focused services are used by the well-off income groups comparatively and introduced two approaches to tackle this issue by adoption of targeting measures to increase the

proportion of benefits to serve the poor and self-sustaining service financing and delivery mechanism to serve the better off to reach the target of 'Universal Free Coverage'. Jemal et al. (2011) examined the adoption of cancer causing behaviors and indicated smoking and aging are the main causes for spread of cancer in different regions of world. In this research, weightage of each country and region was introduced. The cancer survival rate in poor countries is less comparatively and revealed that the late diagnosis of breast cancers caused increased death ratio in females as compared to cervical cancer and further explored that the death rate of cancer in developing countries is 64 % as compared to other world. This poor result is due to late diagnosis, untimely start of treatment and absence of treatment facilities in such countries. Based on study suggested that vaccinations and tobacco controls alone can reduce cancer cases. Kanavos & Scherer, (2010) study 17-countries including Russian Federation and explored that 'awareness, affordability, access, and quality' in service-delivery may curtail costs of cancer patients. On the basis of study authors suggested that 'data collection, screening, timely diagnosis, public and political awareness, endoscopic facilities, principle of equity and national guide lines' should be addressed to minimize the costs of cancer patients. Arndt et al. (2004) explored financial difficulties for the cancer patients in lieu of medical costs by examining health profiles of countries in comparative ratios to estimate costs of colorectal cancer patients on 'Social Functional Scale' and 'Symptom Sub-Scales' of fatigue, dyspepsia, insomnia, constipation, diarrhea and estimated cost of care taker by Median wage of daily labor . Yabroff & Youngmee, (2009) explored that informal costs attached with attendant can't be ignored by studying time period of care taker of cancer patients for two years i.e. 2003-2006 and used median of wage to estimate the time cost of attendant. Further, 'Sensitivity Analysis' was used to assess time cost and explored that highest time cost was

associated to lungs' cancer patients and the cost of care increases with increase of the time period of patient's treatment. Gellad and Provenzale, (2010) examined the importance of colorectal cancer in perspective of its life expectancy period and ailing time period and explored that USA is the only country where cases of colorectal are going to minimize. Based on research indicated that elimination of cost barriers etc. can provide access the patients to better quality, decrease the rate of spread of cancer and suggested that countries may adopt 'tailored approach, to combat according to their own settings. Hayman, (2001) conducted a 'Longitudinal Survey' based on 'AHEAD' (a study) for above 70 years' patients of cancer by using 'Two Part Multivariate Regression Model' and estimated time cost for monthly cost. In this study, author divided patients in two groups i.e receiving no treatment in last year despite diagnosis and receiving treatment in last year after diagnosis. Wage estimation was based on average cost per hour and estimated per year cost per patient to be shifted each patient. This research estimated \$1 billion as total cost (yearly cost \$1200 per patient @3.1 hours per week in 2001). Longo et al. (2006) studied per month 'out of pocket costs' of the patients/family in the form of travel costs, attendant costs by means of data obtained through a questionnaire and estimated monthly costs. Based on research, explored that 1/3rd of attendant cost was equal to 20% of economic pressure on patients' income. Longo et al. (2007) studied and revealed that uninsured patients have to bear more 'Out of Pocket Costs' than insured patients using 'Linear Regression Model' and 'Multivariate Analysis' for breast, colorectal, lungs and prostate cancer patients to find 'Out of Pocket Expenses' based on cross-sectional data. Out of pocket, expenses were taken as dependent variables for urban and rural patients of Ontario Canada. The results revealed that the patient with breast cancer were costing more as compared to other cancers and cost burden may be varying with treatment of tumor type. Based on results,

suggested that traditional health coverage system should be substituted with necessity based health system. Longo and Bereza, (2011) examined cross-sectional data of urban and village patients. In this study, regression analysis was performed while dependent variable was taken as 'out of pocket expense'. The study explored that the costs vary with type of tumor and suggested that the breast cancer patients need special care and policy makers should incorporate them in programs. Van and Spawn, (2006) investigated the cost related to the attendant of the cancer patient. The time was quantified through two recall methods i.e 'Diary Recall Method and Test-Retest Recall method'. On the bases of the recall methods, data acquired through questionnaire with comparatives of time spent on routine house works and time spent to attend the patient, recommended 'diary' as the most appropriate for estimation of informal costs associated with attendants. Van et al. (2004) revealed that quantifying time is not an easy job therefore, suggested that valuation method should be sound enough for estimation of opportunity cost of attendant of cancer patient, recognition of services of attendant in policy making, research studies be assigned weightage before valuation to formal and informal services and expected way outs, to quantify informal services, to policy makers/researchers.

Van et al. (2010) evaluated monetary relationship between the attendant of patient and the patient himself and explored that the care takers' opportunity cost is costly to caretaker himself comparatively while serving the patients of lungs cancer, colorectal cancer of different types and phases. The paper established the relationship of ages and stages (initial, continuing and terminal phase) of sample (with effect from the time of diagnosis) and quantified it. A 'cross-sectional survey' of attendants was selected. The 'fixed-effect generalized least square estimation' model was used to assess the cost of patients in given variables and constants. Suggested inclusion of

attendants' opportunity cost before policy making. Arozullah, (2004) examined the women breast cancer patients associated with 'Medicare and Medicaid programs'. This study is based on personal interviews. The out of pocket expenses were estimated in this study. The study revealed that despite insurance coverage, the women with breast cancer faced extra financial costs and lower income persons bear greater financial impact in terms of extra medical cost. Grunfeld et al. (2004) conducted study in Ottawa and Hamilton in Ontario, Canada. The study is based on questionnaire and subsequent calculation of sample mean of died cancer patients by examining role of the attendants. Hollenbeak, (2011) examined the working spouses of survivor cancer patients in their duration of treatment based on panel survey. The sample based on spouses without cancer and that of with cancer was selected and revealed that both the samples were almost same in connection to the working hours spent.

3.5 Summary of literature review

During literature review, it has been observed that previous researchers have targeted different types of cancer, framed different questionnaires, selected different locales while estimating costs of patients, attendants etc. According to their local settings, researchers have used different data bases like national registries, national statistics, health care systems, multiple secondary data sources, low-income uninsured population data, national surveys, inventories, FAMCARE & Medical Outcomes Study and Social Support Survey etc.

The researchers analyzed their panel data/longitudinal data/ cross-sectional data sampled from different data bases. They used different approaches, techniques, models, methods, scales and analysis i.e. experimental technique, prevalence approach, incidence cost technique, comparative effectiveness analysis, survival analysis techniques, statistical mean and median , the Kaplan-Meier sample average estimator,

sensitivity analyses, multivariate analysis, regression model, fixed-effects generalized least square estimation, disease costing model, breast cancer costing model, Karnofsky Performance Status-KPS index, the Medical Outcome Study, Hospital Anxiety Performance Scale and Depression scale. Diary Recall Method, Test-Retest Recall method and Human Capital Method.

The purpose of using data basis, selection of data type, selection of sample and devising of survey design or experimental design by the researchers was to explore opportunity cost, out of pocket costs, time cost, monthly cost, mean cost, incidence costs, continuing costs, costs in relation to treatment type, long term costs, prevalence costs, average cost, indirect and direct costs.

As far as target of my study is concerned, it is to estimate direct cost, indirect costs, and other extra costs for treatment of cancer patients registered with PBM. For the purpose, a questionnaire based on survey design was devised for data collection through telephonic survey. A random sample of cancer patients from a cross-section (2017-2019) of MIS-PBM (June 2008- Dec.2019) was obtained for the survey. Different analysis and techniques have been applied on the surveyed data. The empirical results and analysis of the surveyed data have been presented in the proceeding chapter i.e chapter no.5 of this study.

CHAPTER 4

DATA AND METHODOLOGY

4.1 Data sources

The primary objective of this thesis is to measure the extra costs shifting to cancer patients to avail free funds for their treatment from PBM. Pakistan Bait ul Mal has developed Management Information System (MIS). The data of all registered patients for all diseases including cancer patients have been entered from 2008-to date in MIS. The data of cancer patients in MIS (2008-19) has been taken as secondary data where from a cross-section has been taken for random selection. In PBM-MIS, data is available under different heads like type of disease, CNIC, name of patient, father's name, province, district, tehsil, residential address, sex, cycle wise amount paid, hospital name and mobile no. of patient/respondent etc.

In this study, a telephonic survey has been conducted. In proceeding paragraphs, survey methodology, questionnaire development process, data collection procedure and analysis has been explained.

4.2 Definition of respondents

In this academic study, the respondent is the patient or any other family member of the patient.

4.3 Sampling framework

In order to identify interviewees for collection of primary data, a simple random sampling method has been used. Cross section of cancer patients' data (January 2017- Dec 2019) from MIS of PBM 2008-19 has been obtained to perform operation of simple random sampling technique for selection of sample. By using randomly selected stratified sample/ probability sampling technique, a computerized structured

questionnaire, constituting cost oriented fields, has been developed. The primary data of targeted costs related to cancer patients has been collected through a telephonic survey via personal calls made to patients’ mobile numbers, already available in MIS. Population based proportionate share of randomly selected sample was taken from each province/ region. According to the selected sample, interviews of 300 patients have been conducted.

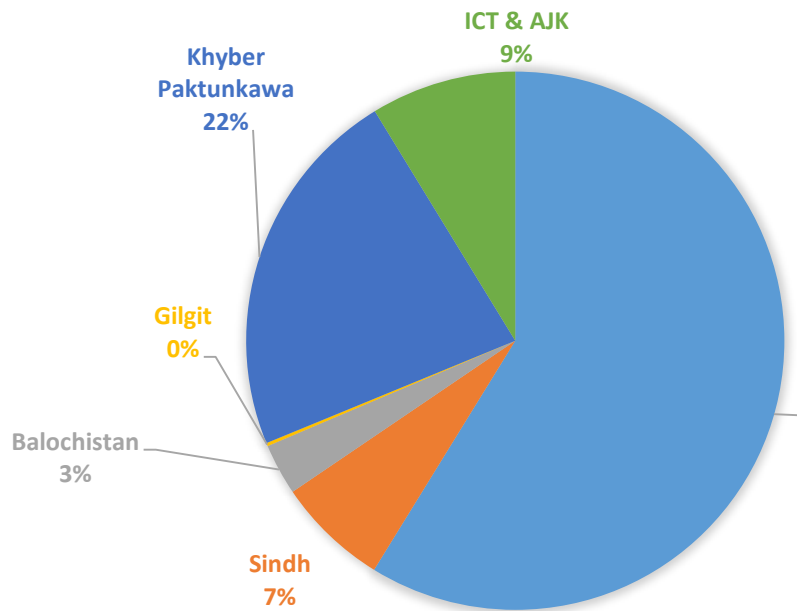
Table 4.1 provides detail of province/region wise patients with population of 33033 cancer patients. This sample was supposed to result 5% margin of error and 90% confidence of interval.

Table 4.1: Cancer Patients’ Province / Region wise data (Jan. 2017 to Dec.2019)

Province / Region	Total Cancer Cases
Punjab	19421
Sindh	2220
Balochistan	1019
Gilgit	64
Khyber Paktunkawa	7422
ICT & AJK	2887
Total	33033

Source: based on PMB-MIS.

Figure 4.1: Cancer patients from Jan 2017-Dec. 2019



Source: based on data of (PBM-MIS)

4.4 Questionnaire development

A structured questionnaire has been developed to collect the data for information of costs linked to cancer patients and registered in PBM-MIS. During telephonic survey, every respondent was asked questions regarding treatment history, cost incurred and income loss during process. It was also asked about assets like, livestock, land and other household items. It was also inquired as to how their community supported during ailing period of patient. This questionnaire covers multiple sections like basic roster of household information, household assets and livestock, treatment history, costs and satisfaction with PBM service. Before the survey was conducted, the questions were asked in Urdu language to make sure that the questions are understood easily and capture complete information needed to meet the purpose¹.

¹ The draft questionnaire is provided in the appendix.

4.5 Digitization of questionnaire and data collection procedure

The “Survey Solution”- an online software, developed by World Bank, has been used to collect data. At first stage, questionnaire was digitized using the survey designed application, specifically developed by World Bank¹. This technique called Computer Assisted Personal Interviewing (CAPI). This provided a platform to collect data using android systems. It provides live coverage and transparency. For data collection, four enumerators were assigned. The training to each enumerator was imparted so as to go through each question and to guide each respondent of the survey easily. The training sessions also covered the use of CAPI system to collect data, and knowledge necessary for survey and questionnaires. After training session, the telephonic survey was conducted for targeted sample.

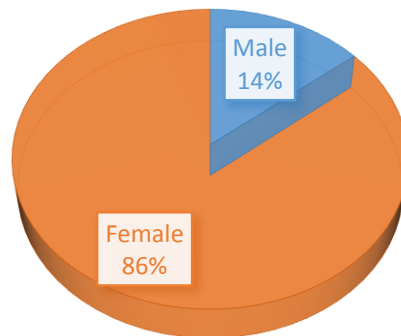
4.6 Response ratio

4.6.1 Gender of response

It has been observed that male respondents are 14% only and female response is of 86% out of total sample. The cases of breast cancers are the highest as per surveyed results and shown in table 5.2. The similar ratio might be in other cancer types but highest ratio in breast cancer is conspicuous indicator of female factor constituting cancer ratio. The response of female may be due to the reason that the males are mostly related to labor class and may miss the calls of hospitals; donations, health asking callers or PBM official calls but female patient herself /other female may rarely miss the call in presence of cancer disease at home .

¹ <https://designer.mysurvey.solutions/Identity/Account/Login?ReturnUrl=%2F>

Figure 4.2: Gender of response

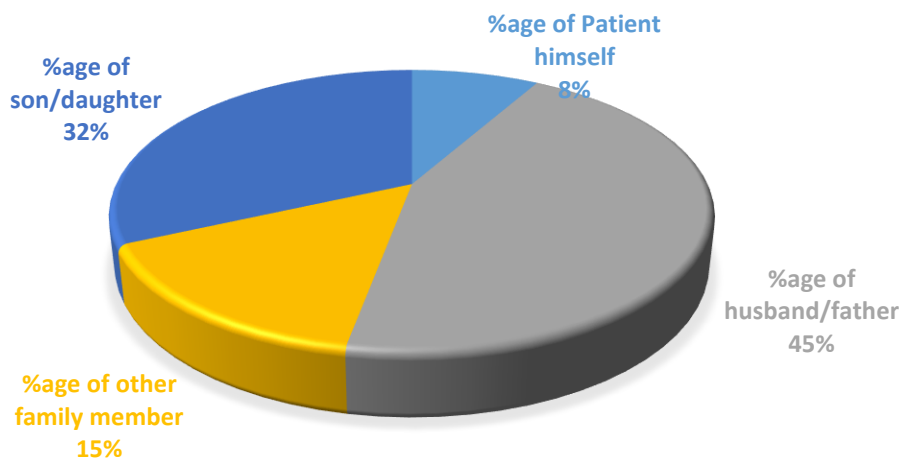


Formation based on surveyed data

4.6.2 Type of response

Figure 4.3, shows that the patient was too weak to attend the call. In other case, he might be on bed rest or unable to move due to painful disease. That may be why only 8% of sample response was patients themselves. The response of 47 % is son/daughter/other family member. The response of 45 % of sample has been belonged to husband/father etc.

Figure 4.3: Type of respondent



Formation based on surveyed data

4.7 Cost components

The patient has to follow the following steps to obtain funds for his treatment; all these steps surround monetary costs. Pakistan Bait ul Mal (PBM) helps the poor to get treatment from the Govt., hospitals in areas of surgery, cancer, hepatitis, transplant, dialysis, heart and medicines etc. It has been observed that the patients or his poor relatives on his behalf (belonging to either Sub-district or any of the UCs at far flung locations) have to follow procedures of head office/provincial offices /district offices etc. Different costs are afforded by cancer patient as extra financial burden on their incomes to avail free funds from PBM. The cost components are hereby mentioned as under.

- i. For all diseases, including ‘Cancer’ separate forms are mandatory for patients to get filled in by hospital committee of hospitals. Separate set of forms comprising of estimate, undertaking, and medical status of beneficiary and investigation report have been devised by PBM for procedural requirement to issue funds to patients through public hospitals.
- ii. Selection of public hospitals is the choice of patient/family. In this respect, patient himself/family member of patient visits consultant of hospital under consultancy of whom, he is provided treatment. Here, he obtains detail of medicine, surgical requirement and the estimated cost of treatment on prescribed forms of PBM. Then, he visits pharmacist of same hospital for endorsement of forms, as the pharmacist is the member of Hospital Committee as per policy. Having signed by the pharmacist, the forms are got endorsed by MSO as member of hospital committee. Administrative Head/MS of same hospital finally endorses the forms with his signature/seal. If any of above authorized signatory is not available, the patient has to bear travelling cost/food costs/time cost etc. to visit again. It is worth mentioning that offices of all the above signatories may not contiguous like one

window and not all officers are usually present in their offices in the same bracket of time-the time when beneficiary visits hospital. Therefore, patient visits many times, for availability of officers concerned, to complete the documents of case.

- iii. After completion of above mentioned set of prescribed medical forms from Government Hospital, investigation is another step to get ascertained patients' deservingness which is supposed to be done from native town/ as per CNIC .The personal appearance of patient/family member of patient before PBM investigating officer or district officer personally visits the address of the home of his native town, if he considers it necessary. The investigation report is faxed/ mailed to concerned P.O/R.O/H.O., in response of official letter issued from P.O/R.O/H.O. In case of migration of beneficiary to a big city, he has to travel to his native town at the cost of his wage.
- iv. Another form, to be signed by two witnesses of valid CNIC numbers and counter verified by the gazetted officer or popular representative (Councilors/MPAs/MNAs etc.), has to be completed by patient in addition to the undertaking. The applicant has to travel from one place to another to complete forms for procedural requirement. In this regard, time, travel, and food costs etc. are obvious results.
- v. Procedure starts at H.O/P.O/R.O. by entering of case in JADD/BMS and subsequent necessary actions performed by the Individual Financial Assistance (IFA) Branch, Medical Branch, Audit Branch, Accounts Branch and that of Administration Branch for delivery of cheques to hospitals through courier/D.R. After completion of forms, it takes 15-20 days at PBM Provincial/H.O. If procedural objections are raised by Audit, the case of patient may further be delayed. The patient has to afford risk of late treatment and may be prone to risk of next stage of cancer. The

procedural delay is present in system, causing risks of extra costs to shift on to the patients.

- vi. Utilization report is necessary for subsequent installments of cheques for treatment, as PBM does not extend total fund to hospitals in lump sum rather installment pattern is adopted. After utilization of funds, the patient has to go through same hassle linked to extra costs to complete procedures.
- vii. The cost is the evident factor for availing free medical fund and formalities that aggravate the sufferings of patient. Different types of costs [opportunity cost, time cost, travelling cost, food cost, social cost, residential cost and attendant cost, etc.] are afforded by the patient or his relatives.
- viii. The attendant has to lose opportunity cost too, to take care of cancer patient. He may be relative /clan member/friend/ neighbor.
- ix. Patients are heavily indebted and become destitute after selling all belongings spending on costly treatment of cancers before he gets informed of free medical funds from PBM. But, even getting free funds, cost is the obvious and evident factor to create economic burden on household.
- x. The patient belonging to poor class, mostly linked with physical labor market, loses job as being unproductive and unable to perform labor work. Therefore, a substitute of a family sacrifice on his behalf.

CHAPTER 5

ANALYSIS AND DISCUSSIONS

5.1 Introduction

This section covers the analysis, discussion, estimations, inferences, ratios and averages of the surveyed data to explain the cost of cancer patients. In this regard, some costs are linked to the treatment of the cancer and some are linked to the activities for availing PBM funds. The indirect costs like attendant cost, time cost has also been measured and analyzed. The qualitative response of surveyed data had also been mentioned in proceeding sections.

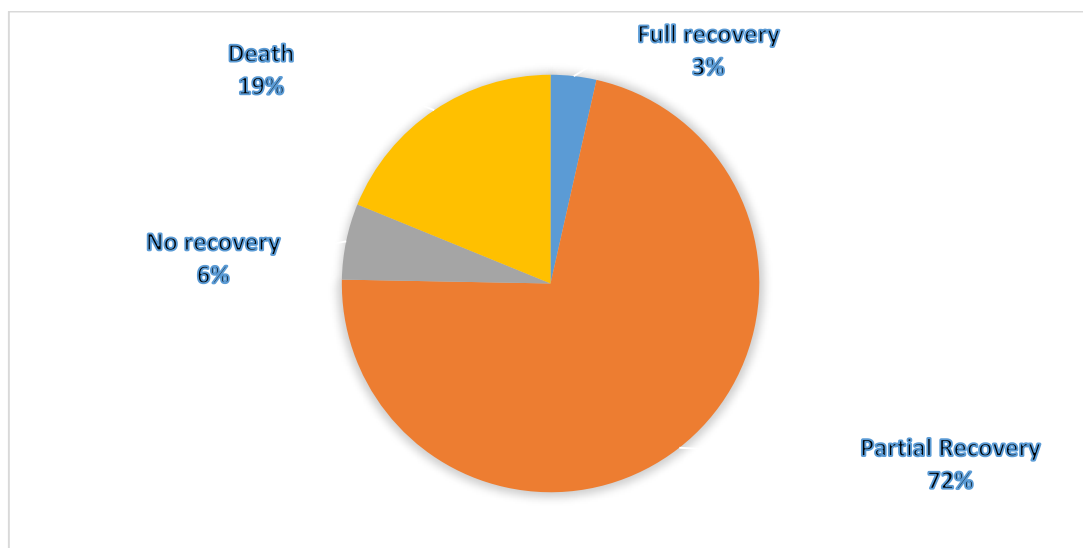
5.2 Analysis: Patient profiling

5.2.1 Recovery rate

It is important to know the recovery rate of any investment. For this purpose, we have asked the respondent to tell about the recovery of patient after getting treatment from PBM. Figure 5.1 shows that only 3.53% patient fully recovered, while 71% patients partially recovered. Full recovery of only 3.53% is alarming in connection to the impact. Death rate of 18.82% needs special attention to know that either it happened due to human negligence, medicine issue and late diagnosis or inability of patients to care of his/her disease due to cost issue. Partial recovery is 71.76 % which shoes indicator of the data of patients under treatment. During survey, the response of 5.9 % has been observed as non-recovered patients showing that this category may be in last stage of cancer, late diagnosis of case, or failure of health system. Cancer medicines effect the least to treat the last stage of cancer. There may be negligence on the part of patient for being casual about his disease in beginning, fault in health system, ignorance about disease, non-provision of authentic medicines by medical stores as prescribed by

consultants, late procedures on the part of any concerned, follow up issue by the patient or may be due to unavailability of attendant etc. As huge public funds are involved, therefore, maximum facilities should be provided by the state components involved in health delivery mechanism to save public funds and human capital as well. The combined ratio of unrecovered (5.9 %) and the death cases (19 %) come up with 25 %. Meaning by that the 25 % of cancer patients have died or at the verge of death. The public funds are going to be depleted both on death cases and the unrecovered patients. Pakistan stands at 0.39 in HCI of World Bank 2019 that may further be declined, if prevailing health system persists and is not reorganized on modern lines. If the human capital is not saved with the help of efficient service delivery, patients' families may further impoverish. If the patient is household-head and loose economic means, supposed to be provided by him only, then his family may trap in spiral of poverty. On the other hand, 3.53% patients have fully recovered. This ratio of recovery is too small to compare with the volume of funds issued. If this recovery factor remains constant in future, then it can be forecasted that only 3.53 % would continue to recover out of remaining 72% cancer patients who are partially recovered.

Figure 5.1: Outcome Ratio

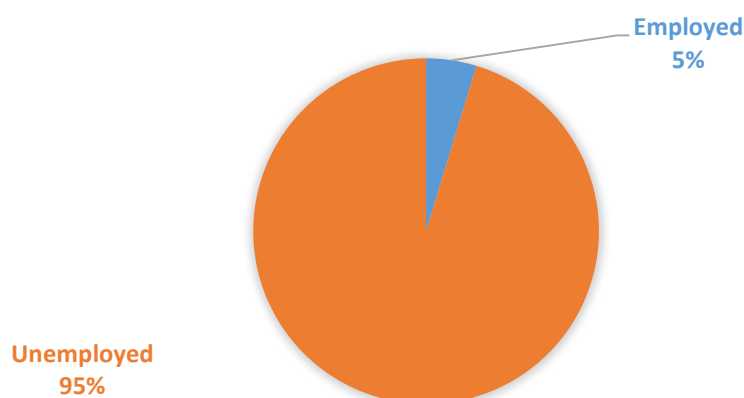


Formation based on surveyed data

5.2.2 Employment status and main income earner

Figure 5.2 shows that mostly the cancer patients are jobless and someone else, as substitute, is working to finance patients and taking care of family. Around 95 % patients are unemployed while 5 % of cancer patients are on job indicating that cancer patients are too dependent to work. The cancer patient has to leave job when he becomes unproductive. The excessive cost on cancer treatment coupled with joblessness; aggravate the economic miseries of household.

Figure 5.2: Employment status of patient

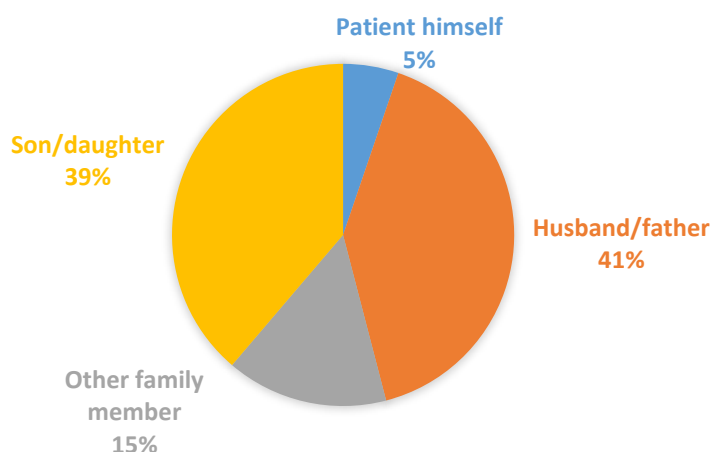


Formation based on surveyed data.

It was asked respondents to tell: Who is the primary earner in your household? The analysis as presented in Figure 5.3 shows that Only 5 % patients are supporting themselves, the rest are being supported by else one. The policy needs special attention for such cancer patients. The zero contribution of women towards earning shows the tilt of society, discouraging work of women. The 41% contribution of husbands/ fathers indicates that huge portion of our society relies on one earner, the earning of whom whole family is fed. The ratio of 39 % shows combined support of alternate family members (son/daughter) in absence of the main earner, here it can be inferred that father of this poor family had died or too weak to work. If savings of this extra earner (15%) would not have been spent on the treatment of patient, this income source had changed

the economic conditions of family. If the cancer patient is financially supported by state to cover all components of cost, the economic problems may be minimized.

Figure 5.3: Earning pattern in household



Formation based on surveyed data.

5.3 Treatment cost: Direct and indirect

It has been observed in survey that the patient faces around Rs.27000 of extra cost to obtain the cancer treatment apart from Rs.10000 covered by PBM. The opportunity cost of attendant is Rs.8600 and average per month borrowing is estimated to Rs.9709 as indirect costs. If borrowing amount and opportunity cost is added in direct cost of Rs.27000, the figure reaches at about Rs.37000 and Rs.46000 per month respectively. The survey shows that it takes around 22.5 months to complete the cancer treatment cycle with cost of Rs.0.615 million as shown in table 5.1.

The average income of household is Rs.14161 per month approximately as per surveyed data. The loan of Rs.9709/- per month shifts on the liabilities of patient. The accumulated effect of all the formal costs is Rs.27167. If direct cost of Rs.27167 is adjusted with loan of Rs.9709 and PBM support of Rs.10134, the estimated figure after adjustment stands at Rs.19843. If the adjustment of Rs.19843 is made with direct cost of Rs.27167, the rest of the amount of Rs.7324 is that amount which pressurizes his monthly income of Rs.14161 for further adjustment. If the same is adjusted with his

monthly income, the rest of the amount which is left with household for its activities remains at Rs.6837. To meet both ends, household is compelled to dispose of savings, reduce food intake, kids' drop-out, selling of property to bridge the gap.

The borrowing of about Rs.10000 per month continue to remain a future liability for the poor family. The direct costs, indirect costs and loans have irrational relationship with income of household as survey results indicate. Further, amount supported by PBM (Rs.10134) is nearly equal to the medicine cost (Rs.10140) as per survey results indicating that PBM provided assistance is matching to the cost of medicine only. The rest of the costs are afforded by the poor cancer patients at their own, as detailed below (table 5.1).

Table 5.1: Cost factors of survey (average estimations)

Cost heads	Monthly Average
Duration of the treatment? (in months)	22.65 months
Average Income of house hold	Rs.14161 per month
Amount paid by PBM? (Rs)	Rs.10134 per month
Medicine cost (Rs)	Rs.10140 per month
Average monthly cost (visiting hospital + offices) without medicine cost	Rs.15270 per month
Accommodation cost when hospital and PBM offices are visited (Rs)	Rs.278 per month
Consultation cost other than Govt. hospital (Rs)	Rs.463 per month
Extra medicine cost other than arranged from fund of PBM (Rs per month)	Rs.1017 per month
Value of labor cost of attendant (informal cost)	Rs.8686 per month
Loan /borrowing (coping cost)	Rs.9709 per month
Total monthly expense (formal cost)	Rs.27167 per month
Avg. treatment cost (formal)for full treatment cycle	Rs.615332
Avg. treatment cost for full treatment cycle (including opportunity cost +loan)	Rs.1031979

Source: Based on surveyed data.

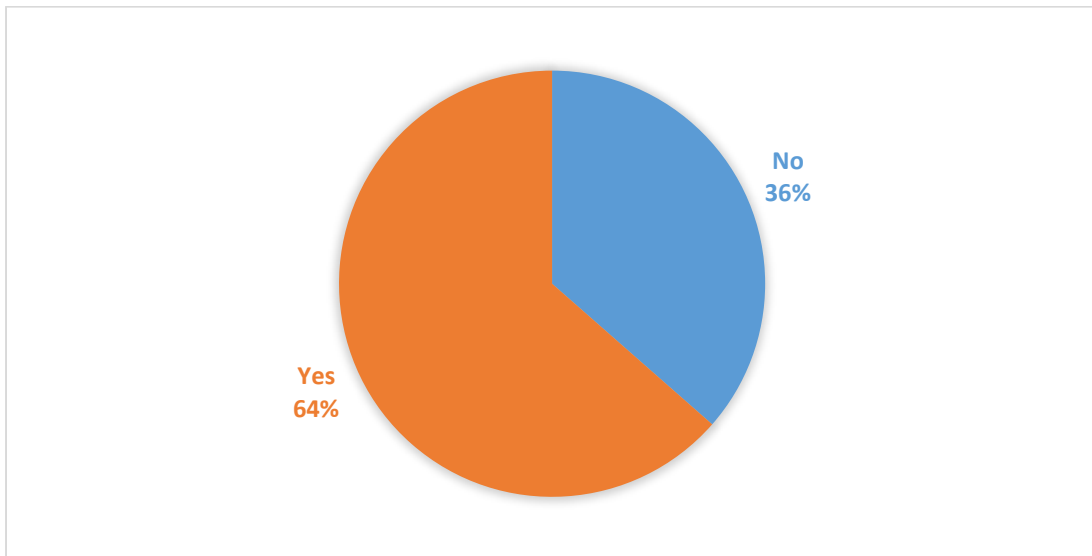
Due to the collateral issues of banks, mostly patients inclined to borrow from family and friends i.e. 62.35% and 49.41% respectively whereas bank borrowings are

14.12%. But, poor get loan where it is easily available from, to support their over-towering cost of treatment. Many poor could not even avail any loan from family or friends and banks. What will happen when they need money in presence of high cost of treatment? The other portion, from amongst poor, can't even avail loan because people know that they haven't capacity to return it. The public fund has limited policy coverage to meet with such awkward situation.

5.4 Level of satisfaction with services

Around 64 % respondents showed satisfaction with the role of PBM in the time of difficult stage of life (Figure 5.4). About 36% were not satisfied due to late issuing of funds. Resultantly, their injections/therapies/surgeries were delayed and they might have to start chemo therapies from very beginning again and may be prone to next stage of cancer. The cost of next stage of cancer is more as compared to previous stage in addition to prolonged time of treatment. But, PBM is the first and the last hope for poor to get treated from free funds. If the stage of cancer moves to next, the cancer treatment is prolonged and cost is enhanced. Obviously, PBM will have to pay that enhanced cost too out of same public fund. In this context, the accumulative extra expenses of such cancer patients may reach to millions of rupees when the same are shifted to the total population.

Figure 5.4: Level of satisfaction



Formation based on surveyed data

5.5 Cancer types- ratio of surveyed results

The breast cancer ratio has been observed as the highest. It can be deduced that more cost is spent on breast cancer patients out of PBM funds. The share of proportionate cost shifting to breast cancer patients is more as observed. As surgeries are also required as part of treatment in these cases; therefore, special policy measures should be carried out for the breast cancer patients. Accordingly, major costs are spent on breast cancer patients than others. Five percent (5%) of patients fall under category of Stomach, Ovary and NHL cancers. About 7% did not know about the exact name of their cancers as being unable to pronounce English name of disease. The other cancer types have little ratio in total population as shown in table 5.2. The blood cancer and breast cancer patients have highest ratio, therefore special policy measures should be taken to care for them.

Table 5.2: Estimated ratios of cancer patients (type wise)

Type (cancer) in sample	%age	Type (cancer) in sample	%age
Breast Cancer	31.76	Metastatic	2.35
Hodgkin .Disease	1.18	Non Hodgkin Lymphoma	4.71
Blood	13.9	Ovary	4.71
Brain	3.53	Prostate	2.35
Mentioned cancer only(did t know)	10.77	Rectum	1.18
Cervix	1.18	Bone	1.18
Colorectal	3.53	SQ Cell Carcinoma Skin	3.53
Chronic ITP	1.18	Stomach	4.71
Kidney	3.53	Throat	1.18
CA Larynx	1.18	Metastatic	2.35
Liver	1.18	Non Hodgkin Lymphoma	4.71
Lungs	1.18	Ovary	4.71

Formation based on survey data

5.6 Survey results of cost components

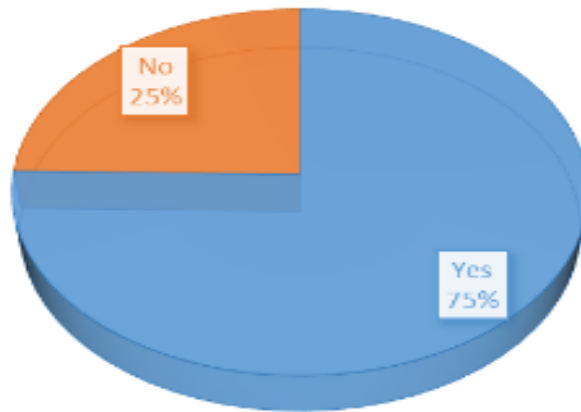
The cancer patients spend extra amount to obtain free funds from PBM other than the running cost of medicines, tests, consultancy and allied costs. In scenario of meagre income source of the poor patient, he is compelled to bridge the gap of the income and expenditures. The compulsions lead patient to different actions given below. The patients spend money for completion of forms of PBM and follow up of the case for free fund of PBM.

5.6.1 Actions taken by the family due to cancer disease

Using savings

As given in figure 5.5 the percentage equal to 75 % of patients have used their savings to support their cancer disease. The rest of 25% had no savings. But, the major portion of 75 % drain their savings on treatment that further impoverishes this poor segment of society.

Figure 5.5: Use of saving

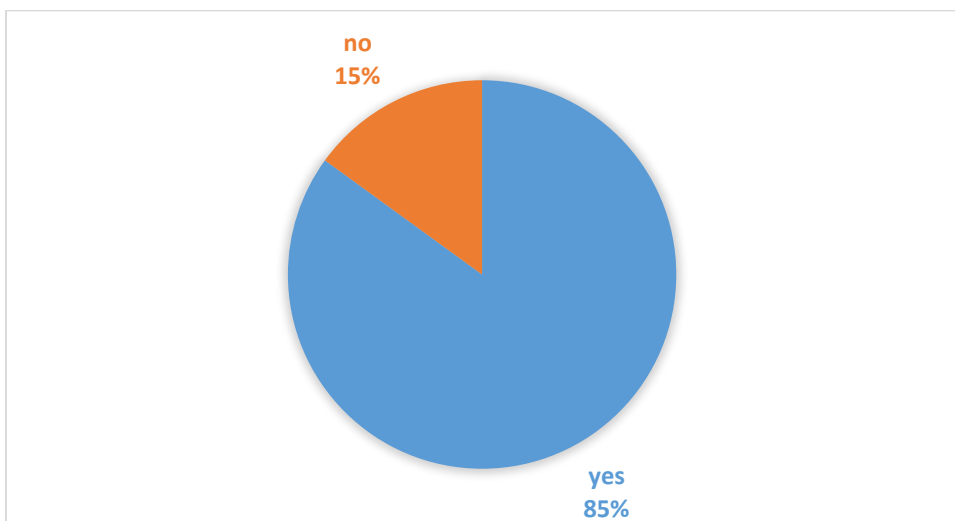


Formation based on surveyed data

Reduction in food

According to survey of this study, 85 % of response showed that there is heavy reduction in food because of unaffordable extra costs, despite provision of free funds from PBM as shown in figure 5.6. The patient is compelled to reduce food when he has to chose on option i.e. either to save life of cancer patient or to reduce in food intake. Such action is taken at that time when he has no option of loan, sale of saving and sale of property at all.

Figure 5.6: Reduction in food

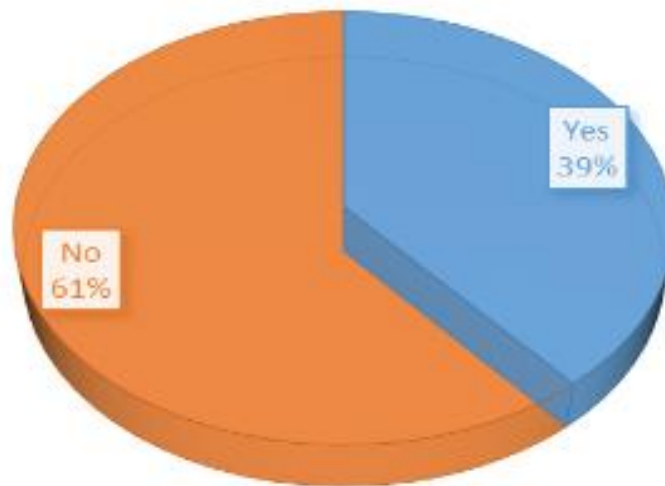


Formation based on surveyed data

Kids' drop out

Out of total sample, 39 % responded that kids have been dropped out due to unfortunate cancer disease and subsequent unaffordability to retain the kids in schools. As the breast cancer patients are more in surveyed results as shown in table 5.2, therefore, it is hereby assessed from the overall cultural settings that as substitute the girl student either has to sacrifice her education for nursing of her mother being female or has to substitute herself for kitchen work. Male children may also be dropped but as alternate of wage substitute or as an attendant of the ailing family member.

Figure 5.7: Drop-out of kids



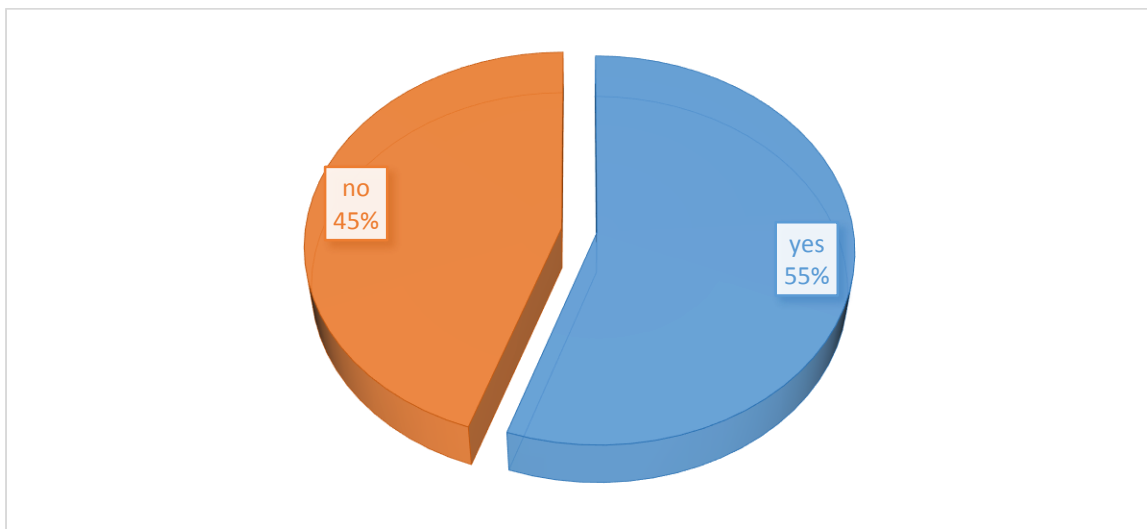
Formation based on surveyed data

Social exclusion

The cancer treatment is expensive. For the poor, it becomes more expensive in comparison to his/her lower income resources. As Pakistan Bait ul Mal extends funds for the treatment to the poorest of poor only, therefore the data of survey was encompassed accordingly thereof. During survey, the question of social exclusion was asked from respondent. The respondent replied variety of responses with similar agonies. Some replied that in start, the people were very sympathetic but with passage of time, they adopted distance. Out of 55 % (socially excluded), all sold everything

imbedding price. It has been observed that the family with patient of breast cancer and blood cancer are supposed to go through surgeries and blood tests as primary requirement of further medical procedures. The 45 % of the sample result showed satisfaction and didn't complain for social exclusion. It may be due to the religious/cultural bonds, tribe/clan/family, and area wise supportive traits.

Figure 5.8: Social exclusion

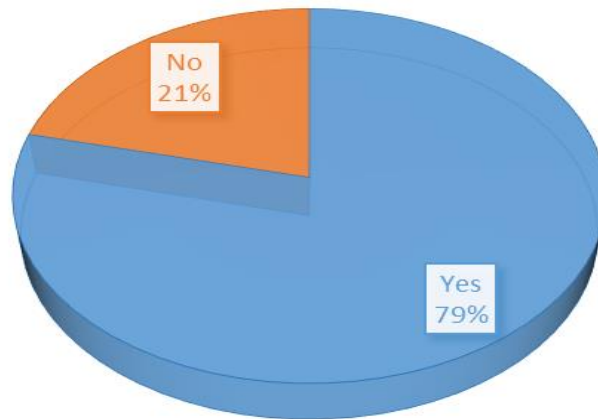


Formation based on surveyed data

5.6.2 Borrowing pattern

As observed in responded data, approximately 79% of surveyed patients were inclined towards borrowing due to the costly treatment. The borrowing is usually difficult to return by the poor patient causing different social and economic issues in case of late or unreturned loan. The most borrowings are from family and friends. These poor families might have rich family traits and socio-religious bonds that might have played main role for timely loan facility. The rest of 21% did not borrow either they could not borrow or this class of poor has limited access to such friends who are financially too strong to extend loaning facility.

Figure 5.9: Borrowing pattern

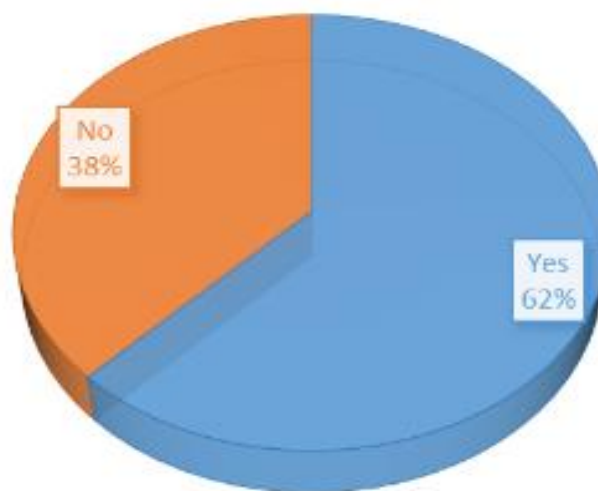


Formation based on surveyed data

Family Borrowing

Mostly the poor patients have collateral issues, therefore; they, usually, could not get much from organized loaning agencies like banks demanding a lot of paper procedures and subsequent markups for such loans. However, families' cultural bonds seem better in Pakistan particularly in poor, due to the reason majority got substantial borrowing of 62 % in contrast to 38% who could not as shown in figure 5.10.

Figure 5.10: Borrowing from family

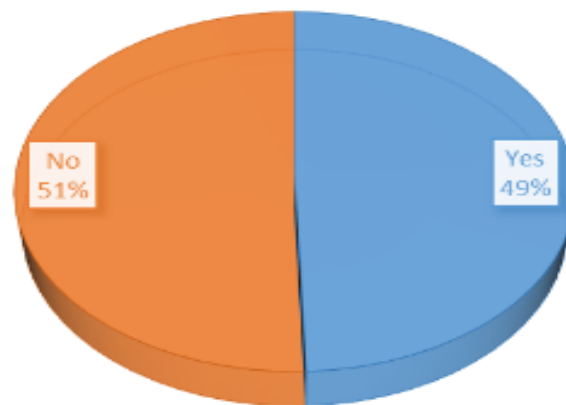


Formation based on surveyed data.

Neighbors/ Friends borrowings

As the treatment of cancer is costly, therefore even the well to do family becomes poor during treatment. They, with the irony of fate, have to get the loan mostly from all-weather friends and sincere neighbors during this economic shock during protracted ailment. In figure 5.11, the ratio of 51 % loan from friends and neighbors shows that this significant ratio of loaning may be based on the hope that patient or his family will return it soon and based on reliable past relations.

Figure 5.11: Borrowing from neighbors /friends

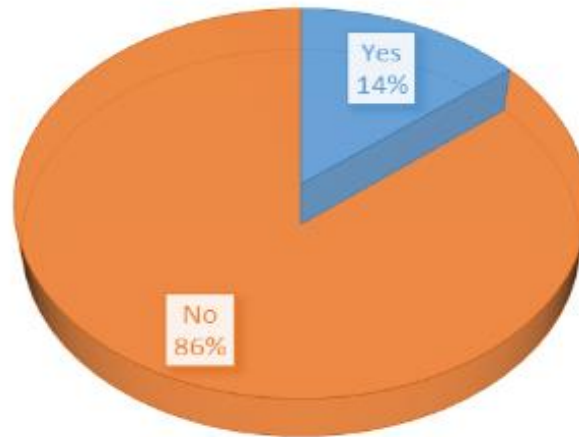


Formation based on surveyed data.

Private bank borrowing

Private bank issues loans to the prospects clients on the bases of personal guarantees as per its procedures. This procedure needs a considerable time to complete the case of loan and also demands collateral as prerequisites in contrast to the spontaneous need of ready cash to cope with the on spot payments of tests and medicines. As poor cancer patient has nothing to present as collateral. That is why, only 20 % could undergo for loan either through mortgaging of land/home or through guarantee extended by family/clan officer of Government.

Figure 5. 12 Borrowing from private bank

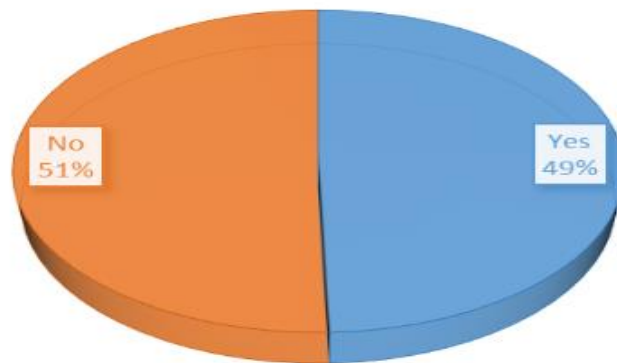


Formation based on surveyed data.

5.6.3 Property selling pattern

This pattern show that the poor of PBM can be found on both sides of a defined poverty line or round the cut-off point. The 49 % poor are comparatively better having ancestral property in the form of home for living or agricultural land to earn their livelihood and 51% have none to sell. The 49% poor having property in shape of agricultural land/home or else sell the same and incline to prone to become the part of that group who had none to sell at all. The group comprising of 51 % portion, as mentioned in figure. 5.13, is supposed to have none to sell at this critical time of cash requirement. The poor and unproductive health condition and complete dependence on the state provided health facilities; this segment has nowhere to run except to face the unwelcome music. But, actually, present health system demands fundamental transformations.

Figure 5.13: Property selling pattern

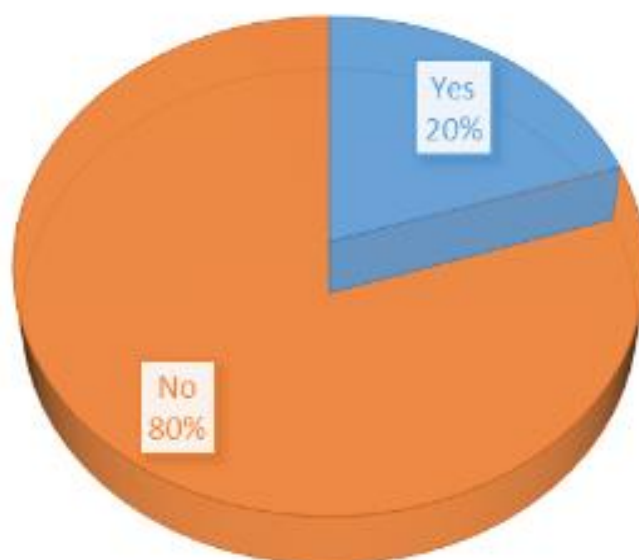


Formation based on surveyed data.

Selling live stock

As livestock is, mostly, the phenomenon of rural life therefore, only 20% response was linked to the selling of livestock. Live stock is meant for provision of milk to the poor family and additional income by selling extra milk. When the livestock is sold, the children of poor family may have been fallen prey to mal-nutrition. The continuing phenomenon of such actions disturb future output of human capital in larger context. This segment proportion 20%. On the other hand, urban population sold household items instead of livestock.

Figure 5.14: Live stock sold by patient

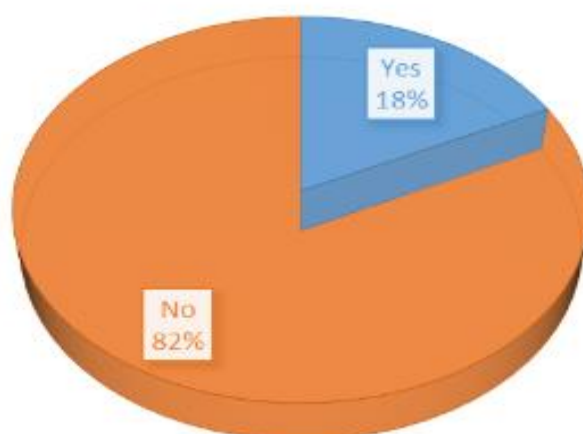


Formation based on surveyed data.

Selling land

The land is again the phenomenon of rural population. In the light of figure 5.15, the percentage (18 %) of patients sold their land. As everybody knows that, the land is the need and sometimes the only source of income to the rural family. Selling land may directly hit the economy of a family and lead to other social hazards. The portion of 18% (having property) shows that the beneficiaries of nearest income groups revolve around the same poverty line. A small economic shock is enough to shift poor from comparatively better level to the worst. The ratio of 82% has not land to sell being part of poor segment mostly belong to daily wage laborer class.

Figure 5.15: Selling land



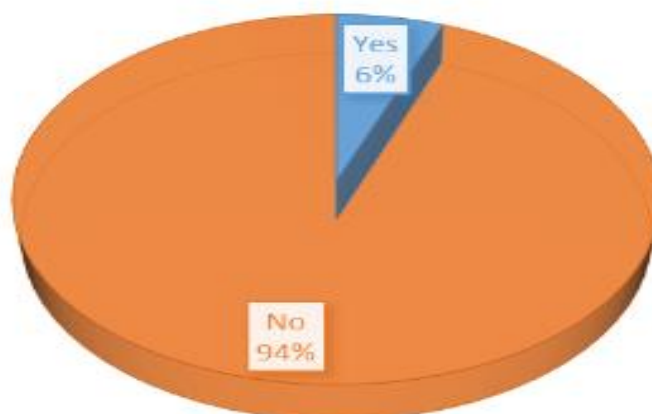
Formation based on surveyed data.

Selling transport/ vehicle

As shown in figure 5.16, the percentage of only 6% shows that most poor have no vehicle to sell. Those who sold vehicle belonged to better income group of same poor class and after economic shock, due to cancer, have to sell their transport. The transport includes motorcycles too. Further, some mentioned selling of machinery but it was beyond the scope of the questionnaire of this study. Some poor also depended on their transport means to earn their livelihood. The selling of transport left them in lurch.

The economic disorder of household led it to be the part of vicious spiral of poverty. Such groups are needed to be addressed on emergent grounds with policy change.

Figure 5.16. Selling transport/vehicle



Formation based on surveyed data.

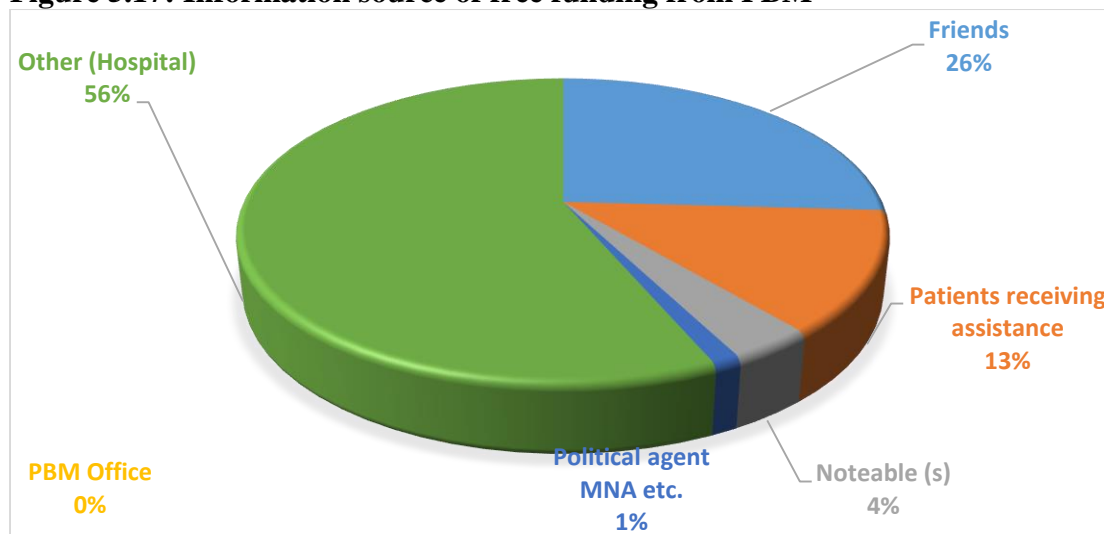
5.6.4 Pattern of information source for free funds from PBM

Public information is the vital part for service delivery to the tail of the target. Without information, people cannot know about the particular public service provided by the state organs. As per survey, it has been explored that none of the respondent got informed from PBM provided information source. Further, role of public representatives is also negligible (01%) to guide patients in this time of crucial need. The popular role should have been visible but observed in contrast, in this study. The contribution of notables is also negligible i.e 04 % only.

Most of the patients got information from other patients/hospital staff while visiting the cancer hospitals. PBM should focus this strong information source by enhancing role of hospital for provision of information to the general public. In this aspect, information of getting fund for treatment should be displayed at public places like offices of the administrators of sub-districts/districts.

Regular Public information and media campaigns may enhance the coverage in order to fulfil constitutional obligations conferred.

Figure 5.17: Information source of free funding from PBM



Information based on survey data

5.6.5 The cost elements of survey

As estimated from the results of survey, the cost shifting to the poor patient is not rational i.e. Rs.46000 in comparison to his average surveyed income of about Rs.14000 per month meant for expense of his kitchen. PBM shares about Rs.10000 per month leaving behind major portion of amount to be paid by the patient himself at his own. The amount of Rs.37000 after adjusting of support of PBM is enough to choke the household economy by pressurizing for borrowings, selling of property, kids' dropout and exhausting the saving etc.

The total medicine cost is about Rs.10000 per month which clearly indicates the expensive medicines and treatment of cancer disease. The diagnostic cost is about Rs.6000 per month that again shows expensive trend of diagnostic tests as compared to normal tests of other diseases. While visiting the hospital, time cost of attendant stands at about Rs.2500 per month as opportunity cost (indirect cost) though not paid in cash like other expenses. The travel and food cost is about Rs.2000 per month while visiting hospitals and laboratories.

The patient or his attendant has to travel to visit PBM offices for inquiries and further follow up visits to complete the procedures of his case for medical financial help i.e. notables for attestation on prescribed forms developed by PBM and visits of hospitals to get endorsed the same from hospital committee as introduced in section 2.10.6. As per table 5.3, travel expense is about Rs.2600 per month, time cost for completion of PBM forms, hospital visits and follow up is about Rs.3100 per month, food cost is about Rs.1500 per month and other costs are nearly Rs.1800 per month. The expense on cancer medicine is about Rs.10000 and on general medicine is about Rs.1000. The accommodation cost, while visiting hospital and PBM, is about Rs.300 per month. The consultation cost is estimated as about Rs.450 per month. Borrowing is about Rs.10000 per month per patient in the light of survey results.

PBM shares about Rs.10000 and cost on cancer medicine is also equal to Rs.10000 approximately. Therefore, PBM provided funds are adjusted with medicine alone. The rest of the costs have to be afforded by the family of cancer patient itself. It has also been explored from surveyed data that about Rs.10000 is the cost of patient in lieu of travel, time, food, general medicine and other costs affecting the household activities. The combined effect of consultancy and accommodation cost during visit of hospital and PBM is Rs.750 which again requires ready cash to cope with the situation.

All the costs mentioned in table 5.3 are directly or indirectly affect the household activities and cause social exclusion, poverty trap and in larger context damage human capital.

Table 5.3: Summary of average costs

Questionnaire code	Cost Factors	Average Per Month Per Patient
A-10	Amount paid by PBM	Rs.10134
A-15	Average income of household	Rs.14161
B-21	Cancer Medicine cost (Rs.)	Rs.10140
B-22	Test Cost/diagnostics (X-ray, blood test etc.)	Rs.6247
B-23+B-41	Time cost	Rs.3096
B-24+B-42	Travel (travel expenses)	Rs.2597
B-25+B-43	Food Cost	Rs.1522
B-44	Other cost (Rs)	Rs.1790
B-45	Form Attestation visits	Rs.17
B-5XB-6	Attendant cost	Rs.8686
B-7	Accommodation cost (visits of hospital/PBM)	Rs.278
B-8	Consultation cost	Rs.463
(B-9)	Other Medicine cost	Rs.1017
(B-12)	Loan/Borrowing	Rs.9709

Source: Based on surveyed data

5.6.6 Visits to PBM offices /Hospitals

The visits to hospitals for their treatment, consultancy, or medical tests and to different PBM offices or hospital committee for completion of forms for obtaining free funds are given below in table 5.4. The patient or his attendant makes (27) visits on average to hospital before PBM funds and makes (24) visits to different offices of PBM or hospital as part of procedure to complete documents for free funding. All these visits are made in 22.65 months' time frame of treatment as observed in survey results.

Table 5.4: Visit wise average cost estimation [Hospitals/PBM offices etc.]

Questionnaire code	Cost Factors	Avg. cost of visit
B-21	Medicine cost	Rs.8433
B-22	X-ray, blood test etc.	Rs.5195
B-23	Time cost	Rs.2128
B-24	Travel cost	Rs.1359
B-25	Food Cost	Rs.551
Avg. cost (B-21 to B-25) per patient per visit		Rs.17666
B-41	District office	Rs.1646
B-42	Provincial office	Rs.2564
B-43	Head office	Rs.7793
B-44	Hospital	Rs.5904
B-45	Notables for attestation	Rs.764
Avg. cost(B-41 to B-45) per patient per visit		Rs.18672

5.6.7 Overview of survey results

In aspect of the appendix-II , wherein surveyed results have been given, it has been observed that about 93 % of sample responded the questionnaire while 7% could not respond as they declined to receive the call. The average age of respondents is about 39 years indicating the respondents' matured age group. The 45 % of survey response is husband or father and about 30 % is of son/daughter that is matching with high ratio of breast cancer cases linked to females because either they themselves attended or their caretakers. The average age of patients is about 48 years that shows early trap of cancer before reaching their 50s indicating that the custodian of culture and mature group is vulnerable to cancer. If this age group is continuously trapped on the same pattern, the youth, immature and unskilled, population will continue. Breast, Blood, stomach,

kidney, ovary, colorectal, prostate, NHL and SQ-CCS are major cancer diseases as explored during survey.

On average, the treatment period is 22.65 months per patient per treatment cycle. Average family size of household is 8.29 persons per family that is the huge size in comparison to the house hold income which is about Rs.14000 per month. This family size, kitchen expenses and costly treatment of cancer has no match with monthly incomes. A cancer patient makes 27 visits to hospital before getting funds from PBM. He visits 24 times to different PBM offices to complete the case. The average cost of visits to hospital for tests, medicines etc. is Rs.21000 per month whereas average cost to complete the case from PBM offices is Rs.4000 per month approx. as most cases are submitted in district offices and few patients visit respective provincial offices and in rare circumstance, Head office. The cost of Gilgit-Baltistan (GB) patients has been more as compared to other patients of other provinces due to travel expense from GB to Islamabad and vice versa. Due to lack of transport in KP, GB and Baluchistan, patients have to pay more in shape of private hiring of vehicle and pay higher fare of public transport because of long distances. Further, GB has not any cancer hospital in its jurisdiction so residents of GB have to visit Islamabad for treatment and follow up. Despite facility of consultants at public hospitals, the patients have to visit private consultants too that burden the patient with Rs.450 per month.

CHAPTER 6

CONCLUSION, RECOMMENDATIONS AND FUTURE PROSPECTS OF STUDY AND E-MODEL

6.1 Conclusion

It is famous saying that “Prevention is better than cure”, therefore early and timely diagnostic facilities and simple procedures may lower financial constraints and may protect cancer patients to shift to the next. The revision of federal/provincial policies regulations for introducing screening facilities of cancers in all or selected District Head Quarters Hospitals like free vaccinating counters of cholera, TB, whooping cough and measles. This precaution may reduce the risk of next stage and may cause a big cut on spending of public fund in future.

The timely diagnostics and in time necessary measures thereof not only save loss of precious lives but also maintain our family bonds, cultural traits, social norms, economic life and human capital.

Although PBM helps cancer treatment through free funds, yet the poor patients are still burdened with extra cost of treatment. In absence of proper solution in this scenario, the poor may continue to struggle for filling the financial gap and continue to shift to lower side of poverty line. The financial gap is filled with by loans, selling assets, selling household items, dropping out of kids. The indirect cost/opportunity cost of attendant is also a burden on household.

6.2 Recommendations

- i. All procedural activities should be shifted to ‘**Telco-Model**’. It will not only save administrative cost of PBM but also wipe out extra costs. This model may be a way forward for efficient and effective service delivery to serve poor and to address public agenda.

- ii. Due to expensive treatment an equitable policy, for all cancer patients on cost sharing formula basis by including white colored families, may be introduced. White colored families approach PBM after drainage of savings and burdening family with liabilities.
- iii. The vaccination facility may be introduced in Health System for the poor to protect human capital and to avoid future costs. Vaccinations of few cancer types like liver and cervical cancer etc. are available. In view of surveyed results and surging breast cancer patients; the policy of treatment, based on reimbursement or through private hospitals offering the rates equal to that offered by government hospitals, may be introduced.
- iv. Costs being out of range of patients, patients may be linked to Social Security Packages of provinces and general financial assistance of PBM-IFA program. The attendant of patient who serve to lose opportunity cost may be supported through IFA education of PBM or other package of government.

- iii. This study focused on cancer patients in particular. In future, individual cancers, exclusive diseases, education assistance and other programs and projects of PBM may be studied using PBM data base.
- iv. This study includes only patients registered with PBM data Base. Therefore, the inferences/results may not be generalized with health systems different in context. Further, cost linked to kids' drop out has not been quantified in this study.

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APPENDIX-I

(Questionnaire)

**Pakistan Bait al Mal
Individual Financial Assistance (IFA)
Questionnaire**

Section A: General Information

Code	Question	Response
A1	Name of Respondent	
A2	Respondent' age (in years)	
A3	Type of respondent (tick the relevant box)?	[1] PBM Beneficiary himself (actual patient) [2] Relative of patient [3] Others (specify)
A4	Gender of respondent	[1] Male [2] Female [3] Other
A5	Are you or any member of your household currently a BISP beneficiary? (tick the relevant box)	[1] Yes [2] No
A6	PBM ID (Code used in PBM to identify the patient filled by enumerator)	
A7	Age of patient in completed years	
A8	What was the main disease?	[1] Cancer [2] Any other (write name)
A9	What is/was the duration of the treatment? (in months)	
A10	What was the amount paid by PBM? (Rs)	
A11	Has the patient recovered from the disease?	[1] Full recovery [2] Partial recovery [3] No recovery [4] Death
A12	What is your level of employment ?	Head of household: [1] Employed [2] Unemployed Patient: [1] Employed [2] Unemployed
A13	How many people (including children) live in your house? All members	
A14	Who is the primary income earner in the household?	[1] Patient [2] Wife/mother [3] Husband/father [4] Other family member [5] Son/daughter
A15	How much do you estimate is the average income of your household per month NOW? (Rs)	

Section B: Cost of service delivery

Code	Question	Response
B1	How many visits you make to hospital before getting financial assistance from PBM (no of visits)	
B2	Average cost of each visit for followings	Activity
		B21: Medicine cost
		B22: Test Cost (X-ray, blood test etc.)
		B23: Time cost (hours)
		B24: Travel (travel expenses)
B25: Food Cost		
B3	Number of visits to different office to get financial assistance from PBM	
B4	Gender of respondent	Activity
		No of visit
		Time cost (Rs)
		Travel expenses (Rs)
		Food cost (Rs)
Other cost (Rs)		
B41: District office		
B42: Provincial office		
B43: Head office		
B44: Hospital		
B45: Notables for attestation		
B5	What was the value of labor cost of attendant? (Rs)	
B6	For how many days attendant served the patient? (Days)	
B7	Accommodation cost when hospital and PBM offices are visited (Rs)	
B8	Consultation cost other than govt hospital (Rs)	
B9	Medicine cost other than arranged from fund of PBM (Rs per month)	
B10	Did you take following action due to CANCER DISEASE (Yes/ No)	[1] Yes [2] No Use saving to meet medical expense [1] Yes [2] No Reduction in food intake of family [1] Yes [2] No Kids dropout [1] Yes [2] No Social exclusion
B11	Did you borrow any money to cover costs to get financial assistance?	[1] Yes [2] No
B12	If Yes how much did you borrow?	
B13	From whom did you borrow?	[1] Yes [2] No Family [1] Yes [2] No Neighbors/friends [1] Yes [2] No Private Bank
B14	Have you sold any of your property to finance these costs?	[1] Yes [2] No
B15	If Yes what did you sell?	[1] Yes [2] No Land
		[1] Yes [2] No Livestock
		[1] Yes [2] No Transport/vehicle
		[1] Yes [2] No Household item
		[1] Yes [2] No Farm produce
B16	How do you know about the possibility of financial assistance from PBM (tick all possible options)	[1] Friends [2] other patient those receive assistance [3] notable [4] PBM office [5] political agent (MNA/MPA) [6] other
B117	Are you satisfied with services of PBM	[1] Yes [2] No
B18	Can you use internet or social media ?	[1] Yes [2] No

APPENDIX-II

Summary of averages of questionnaire

Code	Description (Codes)	Sub Description (Codes)	Percentages (%)/Avg.	
A1	Name of Respondent	Responded Not responded	92.94 % 7.05 %	
A2	Respondent' age (in years)	-	(Avg. 38.65 years)	
A3	Type of respondent (tick the relevant box)?	Beneficiary himself Son/daughter Relative/family Husband/father	8% 32% 15% 44.7%	
A4	Gender of Respondent	Male Female	14.11 % 85.88%	
A5	Are you or any member of your household currently a BISP beneficiary? (tick the relevant box)	Duplicate beneficiaries=20% PBM beneficiary only =80%	20% 80%	
A6	PBM ID (Code used in PBM to identify the patient filled by enumerator)	Ratio of response	92.94%	
A7	Age of patient in completed years		Average 47.24 years	
A8	What was the main disease?	Types of cancer.	Type of cancer	% age
			Blood	13.9
			Bone	1.18
			Brain	3.53
			Breast	31.76
			CA Larynx	1.18
			Chronic ITP	1.18
			Cervix	1.18
			Colorectal	3.53
			Hodgkin .Disease	1.18
			Kidney	3.53
			Liver	1.18
			Lungs	1.18
			Mentioned cancer only	10.77
			Metastatic	2.35
			Non Hodgkin Lymphoma	4.71
Ovary	4.71			
Prostate	2.35			
Rectum	1.18			
SQ Cell Carcinoma	3.53			
Skin				

			Stomach	4.71
			Throat	1.18
A9	What is/was the duration of the treatment? (in months)		Avg. 22.65 months	
A10	What was the amount paid by PBM? (Rs.)		(Avg. Rs.10134/- per month)	
A11	Has the patient recovered from the disease?	Full recovery Partial recovery No recovery Deaths cases	3.5% 71.8% 5.9% 18.8%	
A12	What is your level of employment?	H.H. Head employed Patient employed H.H. Head unemployed Patient unemployed	68.24% 4.71% 31.76% 95.29%	
A13	How many people (including children) live in your house? All members		(Avg. family size 8.29 members)	
A14	Who is the primary income earner in the household?	Patient himself Wife/mother Husband/father Other family member Son/daughter	8.24% 0.00% 44.71% 15.29% 31.76%	
A-15	How much do you estimate is the average income of your house		Avg. Rs.14161 per month	
B1	How many visits you make to hospital before getting financial assistance from PBM (number of visits)		Avg. 27.24 visits per patient	
B2	Average cost of visits for followings	B21 [Medicine cost] per month B22 [X-ray, blood test etc.] per month B23 [Time cost] per month B24 [Travel cost] per month B25 [Food Cost] per month [Avg. cost per patient per month] (hours converted into rupees @ Rs.1050/8 hrs. based on surveyed wage response.	Rs.10140 Rs.6247 Rs.2558 Rs.1634 Rs.662 Rs.21242	
B3	Number of visits to different offices to get financial assistance from PBM		Avg. visits =24.73 per month	

B4	Visits to PBM Offices	(B-41) [District office] (B-42) [Provincial office] (B-43) [Head office] (B-44) [Hospital] (B-45) [Notables for attestation] [Avg. cost per patient per month] (hours converted into rupees @ Rs.1050/8 hrs. i.e based on surveyed wage response.	Rs.538 Rs.963 Rs.860 Rs.1790 Rs.17 Rs.4168
B5	What was the value of labor cost of attendant? (Rs.)	On the bases of average wage	Rs.8686 per month
B6	For how many days attendant served the patient? (Days)	Average	Attendant served 10.16 days per month
B7	Accommodation cost when hospital and PBM offices are visited (Rs.)	Average	Average Rs.278 per month
B8	Consultation cost other than govt hospital (Rs.)	Average	Average Rs.463 per month
B9	Medicine cost other than arranged from fund of PBM (Rs. per month)	Average	Average Rs.1017 per month
B10	Did you take following action due to cancer disease (Yes/ No)	Use saving to meet medical expense	Yes 75.29% No 24.71%
		Reduction in food intake of family	Yes 84.71% No 15.29%
		Kids' dropout	Yes 38.82% No 61.18%
		Social exclusion	Yes 55.29% No 44.71%
B11	Did you borrow any money to cover costs to get financial assistance?	Response(yes/no)	Yes 78.82% No 21.18%
B12	If Yes how much did you borrow?	Borrowed Not Borrowed	68.2% 31.8%
B13	From whom did you borrow?	Family	Yes 62.35% No 37.65%
		Neighbors/friends	Yes 49.41% No 50.59%
		Private Bank	Yes 14.12% No 85.88%
B14	Have you sold any of your property to finance these costs?	Response (yes/no)	Yes 49.41 % No 50.49 %
B15	If yes, what did you sell?	Land	Yes 17.65 % No 82.35 %
		Livestock	Yes 20 % No 80 %
		Transport/Vehicle	Yes 5.88 % No 94.12 %

		Household Item	Yes 22.35 % No 77.65 %
		Farm Produce	Yes 5.88 % No 94.12 %
B16	How do you know about the possibility of financial assistance from PBM (tick all possible options)?	<ul style="list-style-type: none"> • Friends • Other patients • Note able • PBM Office • Political agent MNA etc. • Other patients 	25.88 % 12.94 % 3.53 % 00 % 1.18 % 56.47 %
B17	Are you satisfied with services of PBM	Response (yes/no)	Yes 63.53 % No 36.47 %
B18	Can you use internet or social media	Response (yes/no)	Yes 48.24 % No 51.76 %