IMPACT OF THALASSEM
PATIENTS FAMILIES



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THESIS

ON

IMPACT OF THALASSEMIA MAJOR ON PATIENTS' FAMILIES IN PAKISTAN

Submitted To:

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2008-2009



In The Name Of

ALLAH

The Most Beneficent And Merciful

Dat 13-8-15 Cert of Ethan' Vop

Dedication

to

My

Sweet Parents

&

Uncle family!

ACKNOWLEDGEMENT

All praise is for almighty Allah alone, the most merciful and the most compassionate and the Holy Prophet Hazrat Muhammad (P.B.U.H).the most perfect and exalted among and of the ever born on the surface of earth, which is, for ever a torch of guidance and knowledge of the humanity.

I am highly indebted to Prof. Dr. Johar Ali, Supervisor/ Vice Chancellor of Malakand University, for his inspiring guidance and enlightened supervision throughout the course of this research endeavor. Besides, his gentle and tender disposition always provided me a source of encouragement during my research efforts.

I am also thankful to the Chairman Department of Sociology, Prof. Dr. Niaz Ahmad and Coordinator Prof. Dr. Anwar Alam for their guidance and support during the academic session in the University. I would like to express a lot of thanks to my sweet Mother who always gave me emotional and moral support in every field of my life. My task was greatly facilitated by magnificent co-operation of my sincere friends through their cooperation, well wishes and moral support from time to time during the course of study. At last I am deeply grateful to Safdar Hussain and Shabbir Chaudhry and Imran Hashmi who always supported me morally and helped me to complete my research. Last but not least I feel great depth of obligation to all my relatives and teachers who always wish to see me glittering high in the sky of success. My entity at this stage is the result of their effort and inspiring sentiments for me in all aspects. Without their prayers, untiring help, kind behavior, encouragement, moral support and enlightened supervision, my life would have been barren land. I would like to thank all respondents who spent the valuable time with me and also for their willingness to get part in this study.

Kamran Ishfaq

DECLARATION

I hereby declare that the work described in this thesis with the title of **"Impact of Thalassemia Major on Patients' Families In Pakistan"** has been carried out by me for the Degree of Doctor of Philosophy in Sociology. I also hereby declare that the whole substance of this research has neither been submitted elsewhere nor has it been concurrently submitted for any degree.

Kamran Ishfaq
PhD Scholar, Sociology

CERTIFICATE

It is certified that the work contained in this research thesis **"Impact of Thalassemia Major on Patients' Families In Pakistan"** carried out under my supervision and is approved for submission in fulfillment of the requirement for the award of the degree of Doctor of Philosophy in Sociology, Department of Sociology, University of Peshawar.

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LIST OF ABRIVATIONS AND ACRONYMS

ABF	Amina Blood Foundation
BMT	Bone Marrow Transplant
CH&ICH	Children's Hospital & the Institute of Child Health Multan
FBFM	Fatimid Blood Foundation Multan
GHQ	General Health Questionnaire
HB	Hemoglobin
HBS	Hepatitis B Surface
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HLA	Human Leukocyte Antigens
HRQOL	Health Related Quality of Life
MULQ	Minhaj Ul Quran
PND	Pre-natal Diagnosis
PMD	Pre-marital Diagnosis
QOL	Quality of Life
TM	Thalassemia Major
TM	Thalassemia Minor

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ABSTRACT

The objectives of this study were to determine the impact of Thalassemia major on patients' families in Pakistan; to describe the awareness among the parents regarding Thalassemia Major; the cost of treatment of Thalassemia Major and the sufferings it brings to the families; the social problems faced by patients' families; to identify the barriers patients' families face in the treatment of Thalassemia child. Population of the study was parents of Thalassemia major children, visited for blood transfusions at the Thalassemia / Hemophilia Centers of The Children's Hospital & the Institute of Child Health Multan, Minhaj ul Quran, Amina Blood Foundation, Fatimid Blood Foundation Multan. A sample of 500 respondents was drawn from the total population and structured interview was administrated. Data were analyzed and interpreted by using SPSS (Statistical Package for Social Sciences) 19.0 version software. A structured interview was conducted for data collection. Interview schedule was developed after detailed literature review and also accessing the situation of peripheries in district Multan. The structured interview was discussed with two experts of sociology and two senior doctors (>8 years' experience) working in the Thalassemia centers, Government Health Institutions. It was revised to incorporate recommended improvements. Focus Groups Discussion was also conducted. A total of (N=64) sample was drawn from the population and participants were divided equally (n=16) from 04 blood transfusions centers. Descriptive and inferential statistics were applied to analyze the data that includes: frequency, percent, mean, standard deviations, one way ANOVA and Pearson correlation while for the data analysis of FGDs NVivo 7 software was used.

The study summarized that the health care providers should be encouraged to talk about Thalassemia as a public health problem in Pakistan and should enhance the public awareness to eliminate the Thalassemia in Pakistan.

Chapter No 1

1.1 Introduction

Thalassemia major is an inherited hematological disorder leading to anemia in affected children. It is an autosomal recessive disease in which chromosome 11 is involved. It affects synthesis of the B globin chain of hemoglobin which is either decreased or absent leading to early turnover of Red Blood Cell (RBC). When one of the beta globin chain genes is normal and other abnormal, it is Thalassemia minor. If both the genes are involved and disorder presents late in life (older children and adults), it is called as Thalassemia intermediate. If both the genes are involved and disorder is manifested early in life (infants) it is called as Thalassemia major which is a more aggressive disease. Abnormal shaped RBCs are rapidly destroyed by the reticuloendothelial system particularly spleen leading to microcrystal hypo chromic anemia and iron overloads (Porecha, Udani, Mehta, and Gami, 2010). Patients of Thalassemia cannot have an adequate h emoglobin in their bodies and consequently suffer from anemia. The victims of Thalassemia do not produce red cells in their bodies and need a regular blood transfusion for survival. It is an inherent disease rather than infectious and does not affect by living, sleeping, eating and breathing but it passes from parents to children (Bills, 2001). Thalassemia major is the most common genetic disorder which causes a great genetic problem for mankind throughout the world (Imran, 2006).

Thalassemia is preventable but unlikely, it is a serious health problem in Pakistan; approximately 5 to 6 million children are suffering from this disease or carrying its symptoms (Khattak, 2006), over 5000 Thalassemia homozygotes are born every year (Ishaq, Abid, Koktab, Akhtar and Mehmood, 2012), and 6% people are carrying the genes of Thalassemia due to

abnormal production of hemoglobin (Saif-ur-Rehman, 2002). These numbers are alarmingly growing due to lack of awareness, insufficient educational campaigns, as reported by Saif-ur-Rehman (2002) that most of the parents with Thalassemia traits never come to know that they are carrying the genes as Thalassemic carriers which are the main source of spreading the disease. Disease can only be diagnosed through blood investigation but people fear to get the carrier test due to discrimination and adverse implications in marriage prospects, unawareness to disease is another reason for not getting screened. Thalassemia poses tremendous physical problem in the affected children, as they are dependent on regular blood transfusions (Cohen, 2000; Prasomsuk and Jetsrisuparp, 2007) and need to be treated throughout their lives (Sattari, et al, 2012). As a result, the disease causes some other medical problems to the patients i.e. patients will have pale color, Thalassemic faces, exhaust and cannot do hard work (Anie & Massaglia, 2001; Goldbeck et al., 2000; Louthrenoo et al, 2002). Moreover, the disease causes effects to the brain of patients, feeling of helplessness, un-acceptance, loss and grief (Aydin et al, Nash, 1990; Politis, 1998; Tsiantis et al., 1982).

Similarly, Thalassemia is a major disease and its complications carry an important psychological, social and financial impact on families of patients, causing emotional burden, hopelessness, disease management, financial constraint and complexity with social integration (Mazzone, Battaglia, Andreozzi, and Romeo, 2009; Liem, Gilgour, Pelligra, Mason & Thompson, 2011). The spouses afflicted with Thalassemia minor cause the birth of a child with Thalassemia major. Such children are dependent on regular blood transfusion for their entire lives. The majority of Thalassemia major patients are unable to get proper treatment and sufficient blood transfusion and the iron chelation therapy. The number of such patient's is about one hundred thousand. Meeting the international criteria of treatment of such patients need more

than Rs. 900 million monthly and Rs.7.2 billion annually. Such a huge amount cannot be afforded by health budget. Imported equipment is needed for the treatment; Items like blood bags, blood screening kits used for Hepatitis C, B and HIV are all imported and foreign exchange is needed to purchase such items. Owing to inability of achieving such standards, it becomes mandatory to adopt the only alternative that is to stop the birth of Thalassemia children. Countries like Cyprus and Turkey have adopted the policy of stopping birth of new Thalassemic children. In Iran, blood test for pre-marriage and the genetic counseling have been made mandatory by the Government. This strategy has produced good results in this respect. Observing the socio-economic scenario and the low rate of literacy in Pakistan, we need a workable strategy to solve this issue (Bhushan, 1992). A limited numbers of studies have been carried out in Pakistan. These studies have reported the impact of Thalassemia major on patients and their families, is alarming. Thalassemia not only affects the child's health but also devastates the socio-economic condition of the families and leaves overwhelming psychological and financial burden on patients' families (Saif-ur-Rehman, 2002; Zaman, 2006; & Arif, 2008).

Many other studies carried out around the world have reported poverty, illiteracy, endogamous marriages, lack of anti Thalassemic programs and lack of awareness to disease are among the major barriers towards the better treatment of the Thalassemic children and prevalence of the disease (Nikam, Dama and Patil 2012; Arif, Fiaz and Hamid, 2008; Zaman and Salahuddin, 2006; Sharghi, Karbakhsh, Nabaei, Meysamie and Farrokhi, 2006). Parents of the patients have very little awareness and knowledge regarding the disease and its impact on patients and families. In adding, Thalassemia-related needs for prevention have hardly been studied in our population. According to Wong, George and Tan (2011) an effective educational

campaign is essential to launch for in detail understanding of attitudes, awareness, perceptions, and the screening reservations regarding Thalassemia to overcome the disease prevalence.

1.2 Kinds of Thalassemia

There are two kinds of Thalassemia. They are Thalassemia major and Thalassemia minor (which is also called Cooley's anemia).

1.2.1 Thalassemia Minor

Thalassemia minor is also known as Thalassemia traits 'Carriers' Thalassemia. Most of the people having Thalassemia traits are not known that they are suffering with Thalassemia minor. It is only probe through a special investigation of blood test or if the one's child suffering from Thalassemia major. The Thalassemia trait presented at the time of birth. It remains the same for the whole life and can be passed from parents to their children. The Thalassemia comes down from parents to their children in the following ways.

- If one parent has the beta Thalassemia feature, it is a one in two (50%) chance that each of their children will have beta Thalassemia traits.
- If both parents put up with Thalassemia trait in each pregnancy, there is a likelihood of each pregnancy having a one in four (25%) that child will become the disease of Thalassemia major.
- If both have normal blood all children are normal.

1.2.2 Thalassemia Major

Thalassemia major begins in the early childhood. The major Thalassemia children are normal at the birth, but anemic between the age of three and eighteen months. These children need regular medical treatment and transfused every three to four weeks with the component of blood called red blood cells. These children are regular transfusion dependent. So the regular transfusions cause the accumulated iron in the body which is first stored in the liver. If the children with Thalassemia major are not treated they usually die between the age of one and eight years. These patients have to be treated the whole time their lives.

1.3. Bone Marrow Transplantation

The expensive treatment for the patient of Thalassemia major is bone-marrow transplantation. The procedure of bone-marrow transplantation is very expensive costing more than two million rupees. It is necessary that to have full compatible donor with tissues that match the Thalassemia patient exactly. Most likely the donors can be a brother or a sister of Thalassemia major patient.

1.4 Prevention of Thalassemia in Pakistan

In Pakistan death rate among new born children is very high. One of the biggest reasons is that Pakistan is a developing country. Pakistan is striving to control mortality among immature children by covering the infectious diseases through many programmes. Congenital and genetic disorders with other problems have been a cause of early death among premature children. Thalassemia is perhaps the most common genetic disorder in Pakistan (Ahmad et al, 2002). More than forty thousand children have been suffering from Thalassemia major and there is an

increase of five thousand in the above mentioned every year (Hafeez et al, 2007). Due to this ancestral disease the child becomes anemic in the very first year of his life he necessitates frequent blood transfusion throughout his life. Although the child is given regular blood transfusion yet due to the iron overload and metabolic impediments in about second decade he slowly slinks towards death. The treatment is very costly and the burden of the family increases up to extreme. This burden of Thalassemia major can be reduced throughout Pakistan by taking preventive methods at all the health care levels. The four essential steps for prevention of Thalassemia include (i) Awareness programmes should be initiated for the general people, (ii) Everyone should strictly undergo through screening of Thalassemia, (iii) Genetic counseling should be made compulsory among couples, and (iv) Supposes or affected fetus should undergo a thorough Pre-natal diagnosis (Ahmad et al, 2002).

1.4.1 Extended Family Screening

The complete family screening is performed with the purpose of identifying Thalassemia carrier in the community. As compared to the general population, individuals connected with any Thalassemic child are more likely to be carrying the Thalassemia gene. The extended family screening means screening of all living family members with Thalassemia child (having of Thalassemia Major) for the carrier status of Thalassemia. The only laboratory procedure is a blood test for the Thalassemia gene. This family test may include 50 to 100 individuals around the three generations. Any marriage between the two Thalassemia carriers will have 25 percent chances of producing a child suffer from Thalassemia major in every pregnancy. Family and endogamy marriages are very much common in Pakistan. It can be calculated without the screening that any married couple who are closely or distantly linked to a Thalassemia patient, would have a 10 % chance that the both of them are carriers of Thalassemia gene. Though, the

individual screening is very important in order to calculate the correct risk and there should be genetic counseling.

1.4.2 Genetic Counseling

After the members of a complete family of Thalassemic children have been screened for the determination of their carrier status, the genetic counseling needs to be accessible to affected members of the family. The reason of this counseling is to bring up to date the unmarried persons and married couples about their chances of producing a Thalassemic child. If an unmarried person is a carrier of Thalassemia, he may be kept away from becoming the parent of a Thalassemic child by marrying with non-carrier individual, within or outside the family. The boy or girl planned for marriage may be requested to please obtain a blood test for Thalassemia carrier type. In some cases, it may be much more difficult to request for carrier status or the testing of spouse. In such cases the carrier testing of spouse may be postponed till after the marriage. In case of the married persons, if both the husband and wife are found to be the carriers of Thalassemia gene, the chances of a Thalassemic child born in this family are 25 percent. For said couples, prenatal diagnosis is a recommended alternative.

1.4.3 Prenatal Diagnosis

In first trimester pregnancy, chronic villous biopsy is one of the best methods through which the pre-natal diagnosis of Thalassemia major can be evaluated. The results can be procured within two weeks. If the results show that only one pair of fetus is abnormal, this means the fetus is abnormal and suffering from minor Thalassemia (Thalassemia carrier), however, the pregnancy can be carried out and in case the result is in the form that both the fetus are defective, the fetus is suffering with Thalassemia (Thalassemia major), so in this situation the termination of pregnancy should be advised in the strict sense of word.

1.4.4 Termination of Pregnancy

The termination of pregnancy is one of an ethical issue which has been debated on the different forums. The different opinions on the said topic have been held by the religious scholars of revealed religions and the secular ethical philosophers. Medical professionals dealing with these problems in the Islamic countries have taken opinion of Muslim religious scholars on the subject. Muslim scholars all over the world follow a decision made by the committee of Islamic Fiqh Academy in Makah in 1990 (Qasmi, 2001). The decision was:

"If the pregnancy (conception) is about 120 days, its termination is not permissible, even if the medical diagnostic reports a malformed fetus. If the pregnancy is less than 120 days, and the suitable investigations performed by most specialist professionals prove that fetus is malformed and untreatable and his life will become a burden and will be the source of grief for his family; termination of pregnancy is allowed if the parents demand so" (Mishal, 2003). As the doctors and family counselors, it should take more stress on the screening of all relatives of the Thalassemic children in Pakistan, and the individual counseling of the prospective couples before marriage. These steps gradually decrease the number of marriages at risk of producing the Thalassemic child. The knowledge, skills and resources for prevention of Thalassemia are now available in major cities of Pakistan. The community and families having the Thalassemic children needed to join hands in order to prevent birth of further Thalassemia children in Pakistan (Iqbal, 2009).

1.5 Thalassemia Prevention Strategies in Global Scenario

Thorough out the world, a lot of preventive measures have been taken to shun the effects of Thalassemia. This is perhaps one of the most obnoxious disease on which lot of efforts have

been made to diminish it. All the possible methods have been used to exterminate this disease like mass education, prenatal diagnosis, termination of pregnancy and extended family screening for those who are the candidates of marriage. The number of children suffering from Thalassemia major in Pakistan is round about 22,000 which are registered with various Thalassemia centers throughout Pakistan and approximately more than this fraction is present in the country sides of Pakistan which are registered nowhere and have no approach to Thalassemia centers or hospitals (Shamsi, 2004). On national level Pakistan has no facility of such registry. A very few large cities have the facility of diagnosis of Thalassemia. No national programmes have been initiated by the Government of Pakistan to stay away from this disease. Our neighboring country had 20,000 Thalassemia major patients and 3.75 million people were Thalassemia carriers. Iran decided to diminish this fatal disease by giving an up to date systematized program in previous ten years. The couples willing for marriages were asked to undergo for Thalassemia tests before getting married. Accordingly in Saudi Arabia and UAE pre- marriage screening for Thalassemia is compulsory. This kind of control on disease resulted in the decrease of ailment yet it was not over. The above cited example is a real instance of a country that has religious. social and the cultural jaded eye like Pakistan.

1.5.1 Thalassemia Prevention in Pakistan

The average life expectancy of the major Thalassemia child is about 10 to 12 years. A programme must be started to save a Thalassemic children in the best way for providing them with the normal iron therapy and sufficient blood supply with psycho-social and medical management. For regular iron chelation therapy with medicines, blood transfusions and other supportive therapy cost approximately US $2800 to US $3,000 per child per year and standard income in Pakistan is less than US $100 per month. The outcome of the condition is very

difficult for a family to accept the burden of treatment and most of the Thalassemic children get less optimal treatment. The current health expenditure of the Government is four percent which does not meet the requirement of Thalassemia management. The screening is the great help to identify the carriers. Pre-natal screening and counseling are useful to decrease the birth rate of the affected Thalassemia children.

1.5.2 Mass Education

Mass education is big tool through which this fatal disease can be controlled by conducting seminars, community health education, debates through media and by giving training to local general practitioners, nurses, symposia, obstetricians, pediatricians, generalists, people working in social organizations and floating information regarding genetically transmitted diseases at schools, colleges and university levels. In this context regarding the termination of pregnancy and pre-natal tests religion can provide enormous support. By using the proper application of religion this scourge can be controlled. The strategies discussed above have been proved to be a pivotal way to exterminate the disease but it all also depends on the political system of a country, education of masses and the more important factor is the contribution of the government.

1.5.3 Mass Screening

Mass screening is the best way to control the disease but it is only possible in the countries like Denmark, Maldives etc. because the population in the countries like these is very low and mass screening is easily possible but in countries like Pakistan and India where population level is tremendous it is not possible to screen everybody.

1.5.4 Ethical Viewpoints

On ethical issues the opinions are different. One of the schools of thought among the common people is of the view that if the couple is Thalassemia career the pregnancy should not be terminated in any case. They are of the view that in this case society should step forward and help the victims of disease at all levels like they should support them socially, ethically, economically, psychologically and emotionally. Whereas the other group has a contrary view. They are of the opinion that with the advance information the parents who have got the information should exterminate the fetus to avoid lifelong misery.

1.5.4.1 Opinion on the Prenatal Diagnosis in most Practicing Religions

Most of the societies and religions of the world do not allow pre-natal diagnosis and the termination of pregnancy because to them it is immoral. Even though, the educated societies have a better trend. The societies with better education are seeking help from the religious groups to eradicate this disease. This is a wise and useful for the prevention of disease to seek help from the religion which is certainly a big stakeholder of the society and this is certainly a significant strategy.

1.5.4.2 Christian Viewpoint

In the country like Cyprus with help of Church a mass screening program and pre-natal diagnosis were launched and the results were marvelous. There was not a single case found after adopting this strategy. Similarly, in France when Orthodox Church powerfully supported the Thalassemia prevention program in the last twenty years it is very difficult to find a single case of Thalassemia.

1.5.4.3 Islamic Perspective

According to the Holy Quran "soul of the fetus is breathed at the 120th day of gestation". Thus, it is not prohibited in Islam if the fetus is affected by the disease that may cause the serious disabilities after the birth, abortion is lawful. But some illiterate and local religious leaders (Imams) oppose it without any sense. In some important Muslim countries screening of Thalassemia carrier has been necessitated before marriage and the carrier status should be mentioned on marriage certificate.

1.5.4.4 Buddhist Viewpoint

Buddhism strongly opposes abortion. In Thailand, where we find the major Buddhist population, pre-natal diagnosis is banned and in Srilanka the Buddhist people also reject pre-natal diagnosis by following religions law. But if the mother has a life threatening situation, in this case sometimes the abortion is allowed.

1.5.4.5 Hindu Viewpoint

Hinduism like Buddhism does not favor abortion. However, today for the awareness of fetal disease and disabilities, a lot of discussion has been started among the various fields of life to find the ways how to tackle the matter according to religion.

1.5.4.6 Modern World View

In the USA and Canada, where populations belong to different religious and social background we see diverse practices. But in general the most of the people believe that the patients have right to make decision on the principal of autonomy. Therefore it is up to the patients whether they choose to continue or to block the pregnancy (Ansari, Shamsi, 2010).

In Pakistan beta Thalassemia is a main health issue. Thalassemia is the major common genetically disorder of blood it shows the carrier rate of 5% to 8% and approximately 5000

patients are detected every year. Iron chelation therapy and blood transfusion is basis of cure. A struggle is going on to prevent the disorder by screening the patients, discouraging cousin marriages, giving pre-marital counseling and mass education.

The researchers seem to be looking for novel methods of treatment so that a better chance of living may be obtained and the patients may survive as long as possible. We did not have any source to locate Thalassemic disorder properly but now the modern diagnostic facilities are available to locate the thousands of patients each year. Authentic Thalassemia centers got established in early eighties, they enhanced the patients' quality of life almost in their life. But in general, almost all the patients get sub-optimal transfusion. At the time of blood transfusion almost iron chelation is provided to a number of patients. But during the last four years, just a few Thalassemia centers are giving them normal iron chelation therapy protocols. Alternative for beta Thalassemia major the Bone Marrow Transplantation (BMT) is said to be the single curative treatment. So there are several issues that need be addressed in a new transplant program. Firstly, through the European bone marrow transplant registry or the international bone marrow registry, the successful transplant changes their data. There are also national and local registries. Sooner or later, the data of the national transplant registry should be connected to the data of European transplant registry and the international bone marrow registry. Secondly, though in Pakistan there is large families' size, every third patients does not have HLA matching sibling donors. It is necessary to provide HLA matched district doer bone marrow stem cells. Thirdly, training programmes for the post fellowship are considered to be started for the doctors who what to shadow carriers in this area of expertise. The Nursing staffs should be made the part in transplantation programme (Shamsi, 2009).

1.6 Statement of the Problem

Pakistan is a developing country with a high infant mortality rate. Country is struggling to overcome the infectious diseases particularly in children. At the same time, other problems including genetic and congenital disorders have emerged as a main cause of early death and chronic disability. Thalassemia could easily be the most common genetic disorder in Pakistan. The number of children suffering from Thalassemia major in Pakistan is more than forty thousand and about five thousand suffer from Thalassemia every year (Ahmad at al, 2002; Hafeez at al, 2007). Thalassemia major happens worldwide, it effects mostly the Mediterranean population in Pakistan, India and South East Asia, Middle East (Khattak, Saleem, 1992). The average life expectancy of at Thalassemic patient is almost ten to twelve years in Pakistan and at present almost ninety thousand to one hundred thousand patients are expected to be present here (Lodhi, 2003). In the developing countries the management of Thalassemia major is a main challengeable to the health services and besides it, be short of coordination and facilities to this problem makes the management of this disease very difficult (Rahman, Lodhi, 2004).

Disease awareness among caretakers is quite inadequate and also availability of antenatal diagnosis is not very famous in Pakistan due to religion and lack of awareness issues. For the most parents financial constrain is the biggest hurdle for bone marrow transplantation (Rahman, Lodhi, 2004; Zakerinia et al, 2005; Lucarelli et al, 1993). Therefore the old method of treatment is practiced in the developing countries like Pakistan (Rahman, Lodhi, 2004). Parental awareness can be a great help to deal the problem of Thalassemic major (Hassan, Aslam and Ikram, 2002). Much attention has prevented this disease in the large scale with the help of detection of marriage counseling and Thalassemia carriers. For example in Sardinia the prevalence of Thalassemia children has been reduced from 1:250 live births to 1:1000 live births by using the

prevention programme similar is the situation in Cyprus (Cao at al, 1989., Buki, Qayum and Siddiqui, 1998).

It is imperative to take necessary steps toward limiting a prevalence of Thalassemia. There is dire need that professional from Social Sciences should come forward and explore the Social and Economic problems related to this deadly disease. Therefore, this study has been carried out to explore the impact of Thalassemia major on patients' families and also to provide a guideline for practical preventive measures which could help in overcoming the prevalence of this disease in Pakistan.

1.7 Rationale of the Study

In Pakistan socio-religious phenomenon of cousin marriages are at its extreme which is the basic cause of Thalassemia. Pre-marriage blood tests and genetic counseling are unfamiliar concepts in Pakistan. A great majority of Pakistani community considers abortion as an ethical and religious prohibition. In this scenario, the only alternative is Bone Marrow Transplantation but this way of treatment is highly expensive and cannot be afforded by poverty affected population of Pakistan. At present, the best possible way is to prevent the disease and minimize the mortality rate, to educate and familiarize the people with the gravity of the issue.

The limited number of studies conducted in Pakistan regarding Thalassemia includes: Socio-economic status impact of Thalassemia child on families (Rehman, 2002), association between the education and Thalassemia (Zaman, 2006) and Awareness among Parents of Children with Thalassemia major (Arif, 2008). The studies mentioned above reflect that the effects of Thalassemia major on patients and their families are alarming as it is not only tragedy that affects the health of their children but also affects the socio-economic conditions of the

families. So therefore in this situation it is necessary to find all the possible medical and socio-economic reasons of Thalassemia major.

1.8 Objectives of the Study

The Present study is based on the following objectives:

1. To describe the belief of Thalassemic child's parents about child's disease.
2. To evaluate the awareness and the knowledge of patients' parents about Thalassemia disease.
3. To identify the socio-economic impact of Thalassemia major on patients' families.
4. To identify the barriers patients' families face.
5. To suggest recommendation for the prevention of Thalassemia.

1.9 Research Questions

1. What are the beliefs of Thalassemic child's parents about their child's disease?
2. What are the awareness and the knowledge of Thalassemic patients' parents regarding pre-marital screening and pre-natal diagnosis?
3. What is the status of carriers screening and genetic counseling regarding Thalassemia?
4. What is the frequency of blood transfusions and socio-economic impact it brings on patients and their families?
5. What are the financial constraints that patients' families face?
6. What is the social impact of the disease on patients' families?
7. What are the major barriers patients' families face in treatment of Thalassemia child?

1.10 Significance of the Study

Thalassemia is the biggest inherent disease in Pakistan and people do not give much attention to it. But in many parts of the world, its treatment is done with the help of Bone Marrow Transplantation. It is an expensive treatment and is not easily affordable. So parents indulge mental stress due to the disease of their children. In Pakistan, no single functional department of blood disease is available in public hospitals. The parents of such children are unfortunate because the doctors inform them before the birth of the first child that it would not survive for more than the age of 14 or 15. This study will be very helpful for the stakeholders like general public, parents of Thalassemia children, Central Government of Pakistan, Provincial Health Departments, Political and Religious Workers, Social Welfare Organizations and the Organizations which are working for Thalassemia and its preventive strategies.

1.11 Delimitation and Limitation of the Study

The study is delimited to the District of Multan, Punjab, Pakistan only. The reason, for which Multan District is preferred for this study is that it has easy access for the research scholar to study units and it also paves way to the researcher to understand the problem in detail within the limited time frame. Researcher has also delimited focus group discussion to only mothers of the Thalassemic patients while father and close relative of the patients have been excluded from focus group discussion, though they are included in interview schedule.

On the other hand, study has few limitations; such as results of this study reflect the overall situation of Southern Punjab but these results should be generalized over the whole population of Pakistan with care. Another limitation is the non availability of adequate

evidence reported in literature at National and local level which has measured the impact of Thalassemia major on patients' families in Pakistan, and it has been taken as a barrier while building a theoretical framework of this study although internationally such evidence is available which reports the impact of Thalassemia major on patients' families.

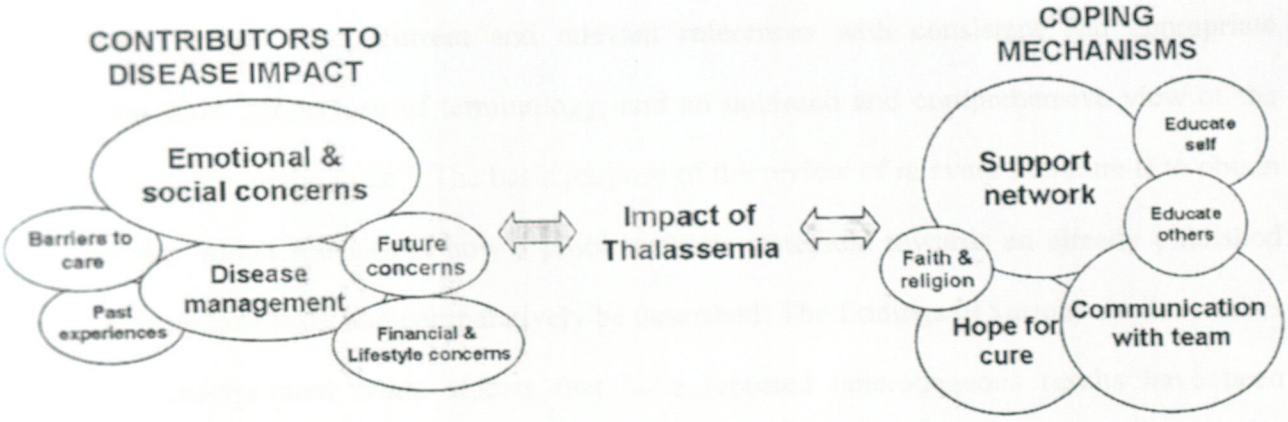


Figure 1.1 Model portrays the relationship amid impact of disease, contributors to impact and managing mechanisms.

Chapter No 2

Review of the Relevant Literature

2.1 Introduction

The review of literature is an integral part of academic research. It helps in developing the scope of research. According to Cooper (1988) a good literature review can be portrayed by "a logical flow of ideas, current and relevant references with consistent and appropriate referencing style, proper use of terminology, and an unbiased and comprehensive view of the previous research on the topic". The basic purpose of the review of relevant literature is to obtain is an essence which speaks out how a problem/thesis statement towards an already published work can simultaneously and comparatively be described. The findings of various similar studies have been incorporated while studies that have reported heterogeneous results have been reported as comparatively towards Thalassemia.

Thalassemia is a blood disorder which is inherited to a child by his parents. It is basically a genetic disorder in which hemoglobin of the child becomes abnormal when RBC is done, in this disease the red blood cell of the child are malformed and broken down after their formation. This leads to a drop in HB% and the result is severe anemia. The only treatment for the blood disorder is blood transfusion. Most of our fraction approximately 5-7% (9-13 million) is suffering from this disease carrying the genes of the disease known as Thalassemia minor. The people suffering from Thalassemia minor need not any kind of blood transfusion but by chance if such two people suffering from Thalassemia minor get married, they will certainly be a cause of Thalassemia major because the baby they will give birth will certainly be suffering from Thalassemia major that child will be in need of blood transfusion throughout his life. In Pakistan the carrier of this disease are high in number therefore, there are more than 6000 – 7000 children

born every year with Thalassemia major. A rough calculation shows that in Pakistan more than 120,000 children are the victim of this disease and they are deprived of the basic health facilities getting half hearted treatment with frequent blood transfusions and insufficient iron chelation therapy. Every Thalassemic child needs a special treatment. He should be given a full provision of frequent blood transfusion in the form of screened packed red blood cells with regular chelation therapy. This provision requires a cost of Rs.10, 000 to 16,000 per month which neither the government affords nor the family of the child. The only one alternative remains in this form is a complete full stop in giving birth to Thalassemic children. This can be done easily because we have already the examples of countries that stopped the birth of Thalassemic children. Countries like Cyprus and Turkey who had a high carrier rate few years ago. More than 18% population of above said countries suffered from this disease. By taking some certain steps now even a single case of Thalassemia major is not found in these countries. Iran made it compulsory for the people who were going to be married; they must undergo Pre-natal tests and genetic counseling before marriage. The result was a high success rate. In Pakistan where most of the people are illiterate and ignorant, where there is poverty and destitution, this problem should be tackle in a very sensitive way. The intention of this study is to identify the impact of Thalassemia major on patients' families in Pakistan. This literature review will presents the related (1) Mother's beliefs and attitudes (2) Religious beliefs and ethics towards Thalassemia (3) Awareness to Thalassemia (4) Inadequate awareness of parents towards Thalassemia (5) Parents knowledge about pre-natal and pre-marital screening of Thalassemia (6) The perception of Thalassemia patients and their families toward the disease of Thalassemia (7) Thalassemia major patients and their families' knowledge about Thalassemia (8) Parental knowledge about Thalassemia disease (9) Public awareness programs (10) Thalassemia prevention.

2.2 Mothers Beliefs and Attitudes

Prasomsuk et al (2007) conducted a semi structured interview of the fifteen mothers of children who were suffering from Thalassemia major for the purpose of qualitative study. The data was analyzed with the help of content analysis. The basic target was to check the experience of the mothers of the children who suffer from Thalassemia major so that the attitude and beliefs of the mothers may be understood and represent. The other object of the study was to see what mothers felt and what the troubles they face while caring for their Thalassemic children and to educate the mothers and the nurses so that the mothers' experience and feeling of their own life and perception may be known. A qualitative and exploratory research design was applied in the study to know the mothers' experiences. During an interview they signed a consent form. These findings must be considered in helpful for the Thalassemia patient. In South East Asia Thalassemic has become the biggest health problem especially in the Northeast Thailand almost 1% of the people (almost 600,000 people) are Thalassemic. All the Thalassemic parents were much worried about their child's disease. They could not deny the fact that major Thalassemia has affected their life considerably. The total number of six themes were identified, psychosocial problems that the mothers experienced, lack of knowledge about Thalassemia, financial difficulties mother faced, social support systems, concerns for their future, and effectiveness of healthcare services. All of the participants accepted that they had no proper sources to receive appropriate information. But they could do nothing then and they had to face the horrible consequences. It is essential to provide psychological support to the mothers and maximum management. There is need for psychosocial support to these mothers and it is essential to give maximum complete the management of Thalassemia children and it also incorporates economic and psychosocial support from the supportive members of the community.

2.3 Religious Beliefs and Ethics toward Thalassemia

Wong, George and Tan (2011) pointed out some mixed views towards termination of abortions due to Thalassemia major. After the group discussion majority of the participants declared the all forms of abortions together with Thalassemia major are immoral. Besides abortion, health problems due to abortion, the right to live and the progress in medicine were the other reason for their opposing. But some changes in attitudes toward the abortion were observed when the participants were told the miseries of Thalassemia major. Among the groups the Indians and the Chinese were almost in favor of abortion of affected fetuses. While the Muslims participants were against the abortion until the life of mother was in danger, whereas a big number of the Muslim participants confessed that they did not have understanding of the Islamic viewpoint on abortion. But some responded that abortion could be practiced before four months as the fetuses was believed to have a living soul (p. 71).

Arif, Fayyaz and Hammid (2008) describe that in Pakistan, no perception of pre-marital screening and counseling of individuals, consanguineous marriages, differences against abortion are the big issues, with this Thalassemia is treated conventionally with all its inherent complications which result in death unless alternative treatment like bone marrow transplant is applied but it is not affordable for a large portion of population. To educate the general population can prevent the disease (p. 621).

Pre-marital screening instead of pre-natal test (CVS) may be a good approach in the prevention and control of Thalassemia in Pakistan as (87.8%) couples in existing study suggest a need for legislation for compulsory Thalassemia screening before marriage. In their view, religious beliefs in society compose it difficult to have therapeutic abortion following a positive CVS test even though, services for termination of pregnancy is being offered in the hospital soon

after diagnosis. Consequently, more emphasis on pre-marital test is required to prevent the marriages among carriers which may ultimately prevent the birth of Thalassemia babies. In this study 88 knew regarding prenatal diagnosis (76.5%), consistent with another study conducted in Bahawalpur. In this study participants who were aware of prenatal diagnosis were only 39.1% mothers had undergone this test during their pregnancies while others did not avail this facility. One possible reason could be high cost of CVS test because the majority of participant families belonged to poorer socio-income group but another contributory factor may be religious restriction on abortion as the only available option for the pregnant woman with affected fetus that prevents them to have prenatal testing (Ahmad, 2006; Ahmed, Green and Hewison, 2006, p. 220).

2.4 Awareness to Thalassemia

Zaman and Salahuddin (2006) concluded that according to this study, cousin marriages, illiteracy among the parents, their negative response against family planning and poverty of the parent are the causes which have been held responsible for the spread of Thalassemia. Thalassemia, a hereditary disease is a blood disorder which causes abnormality in one of more of the globin genes. Two major types have been told i.e. A Thalassemia and B Thalassemia. In Pakistan Beta Thalassemia is prevalent, it is further classified in to Thalassemia Major, Thalassemia Intermediate and Thalassemia Minor. For this research, data has been collected form Fatimid Foundation Peshawar. According to this representative data of the whole province of Khabyer Pakhtoon Khawah, the following findings have been concluded that majority of the carriers who suffer blood disorder, their parents were first cousins, while 23.7 percent patient's parents were not relative before marriage. This makes it clear that marriages for different families can also cause this disease. A great majority of the patients 94.7 percent belong to the

positive blood group. So the lack of education among the families is one of the major causes of the prevalence of the disease. They are unfamiliar with the importance of this factor during pregnancy test. Most of the parents are victim of poverty which is a great hindrance against proper and complete treatment of the disease. Moreover, they do not follow family planning (pp. 103-110).

2.4.1 Inadequate Awareness of Parents toward Thalassemia

Arif, Fiaz and Hamid (2008) conducted a cross sectional study at pediatric Civil Hospital Karachi, Pakistan from May, 2007 to October, 2007 on awareness among Thalassemic children's parents. Parents of Thalassemia children who visited Out Patient Department were interviewed by using pre-designed questionnaire. Total one hundred and twenty care takers were interviewed. Questions were based on screening of blood, source of blood, knowle dge about the blood products, prevention, treatment of children through chelation therapy and antenatal diagnosis were asked. Out of 120 respondents (91.7%) had an income less than five thousand per month. Two third (66.7 %) were uneducated and the just (2.5%) were educated. Majority (89.2 %) of the respondents had no experience regarding the blood screening and just (7.5%) believed that blood test were necessary for their hepatitis B and C and HIV and only (3.3%) knew that screening was for the purpose of fever, cold, mismatch and only (5 %) had no idea about blood screening. This research shows a horrible conclusion that parent's awareness about Thalassemia was insufficient and this would continue to suffer the parents severely (pp, 621-23).

2.4.2. Parents Knowledge about Pre-natal and Pre-marital Screening of Thalassemia

Ishaq et al (2012) ascertained that in Pakistan, the carrier statuses are estimated around 5~~7~~ percent and over 5000 the Thalassemia homozygote are born in every year. It is a preventable disease demonstrated in the countries like Greece, Italy, and Cyprus. The main prevention strategies consist of proper knowledge of the general public and the professionals. All facilities are available to detect Thalassemia before marriage but public awareness is little and it is costly due to which screening and counseling are so limited. The main purpose of the present research is to establish the awareness among Thalassemic parents regarding Thalassemia major and their preferences of protective strategies like pre-natal diagnosis and pre-marital screening tests. There was an observational questionnaire based on study conducted from July to September, 2009 at the Thalassemia Centre, Sir Ganga Ram Hospital, Lahore. The total 115 parents (either father or mother) of Thalassemia major children were taken on in the study by using the non- probability and consecutive technique for sampling. Written consent on the form was taken from parents who were interviewed. Parents of Thalassemia patients with other blood disorders like Thalassemia Intermediate, Alpha-Thalassemia etc were excluded. The semi-structured questionnaire was set to gather the data from study participants. Data was analyzed by using the Epi-Info version 6, CDC, Atlanta Georgia. Information has been presented in the form of frequency distribution and percentages. The total numbers of 115 Thalassemia patients' families were enrolled in this study. Among the Thalassemic children, 74 were males and 41 were females. The total of 88 patients (76.5. %) who visited Thalassemia Centre were accompanied by the mothers and rest by their fathers. In the 115 studied families, 45 families (39.1%) had total earning which was below the 6000 Rupees (PKR), 54 of families (47%) were earning between PKR 6000 to 15000 and the only 16 were earning more than PKR 15000 per

month (13.9%). The division of the disease between different caste groups exposed that 77 of parents (33.5%) were Rajput followed by 28 the Arain (12.8%), Mughal (9.5%), Jatt (11.7%), and Sheikh (8.2%). The total of 94 had consanguineous marriages (81.7%), 75 were the first cousins (65.3%). The remaining 21 had the non-consanguineous marriages (18.3%). Sixteen were from same caste (14%) and the only 5 couples (4.3%) had performed marriage outside their caste. The parents, 52 knew that Thalassemia was an inherited blood disorder (44.6%), while 63 parents (55.6%) did not know regarding its etiology, only 37 parents (32.2%) had information that both parents were carriers for the disease appearing in their children. The parental awareness about the Thalassemia carrier test and pre-natal diagnosis were inadequate. It is need of time to realize the density of problem and inform the general public and make awareness among the Thalassemic families about preventive aspects of Thalassemia to decrease the load of Thalassemia in Pakistan (pp.218-21).

2.4.3 The Perception of Thalassemia Patients and Their Families toward Thalassemia Disease

Wahab et al (2011) stated that in Malaysia Thalassemia arise in Malay and China. Almost 150 to 350 children were affected by Thalassemia every year. Till August 4,541 Thalassemic children were recorded in Malaysia. This study occupied the Thalassemia patients and their families attending Paediatric Clinic Department of Pediatrics, Tengku Ampuan Afzan Hospital, Kuantan, Pahang, Malaysia. The study was made after the approval of ethical committee. The focus groups were applied as this study let the members share their own views, the commonalities and differences regarding Thalassemia. Both the Thalassemic children and their parents were called to take part in the study via phone through a research assistant. Focus group

discussions were arranged for the agreed participants. On the scheduled focus group discussion the written agreement was taken from the participants. The tour repayment and refreshments were provided to the enrolled participants. The registered Thalassemic children were divided into five focus groups regarding their age groups. Group 1- male and female patients from ages 7 to 12 years; group 2- male patients aged from 18 to 22. 17 years; group 3- female patients aged from 13 to17; Group 4- female participants aged from 18 to 22 and group 5 to male patients aged from 18 to 22. The parents were also divided into five groups. Pilot study was carried out with pre-identified Thalassemia patients to process the question line and the way of questioning the facilitator. Ten sessions of focus group discussions involving diverse groups were conducted from February 2009 to August 2009. The participants, of each group, who were aged 3 to 9 were facilitated by the two researchers. The sessions were arranged in Malay. The duration of every interview session was of one hour and the recordings were also verified later. Most of the parents were apprehensive regarding their Thalassemia patients who were getting higher education. Major Thalassemia patients were afraid of being criticized by the other students and even by the teachers if they mixed with them in hostels or institutions. Both the patients and parents supposed that sickness had influenced the academic performance, due to which they felt stress, anxiety and even accepted that they felt insulted. Thalassemic patient's face also contributed to the significantly negative body reflection. The parents of the Thalassemic children had to face great trouble in their jobs as they had to get time off to be with their children for the cure specially those who worked in private companies. Almost all the parents accepted the load of financial matters. Some patients had complaints that due to their dark skin color, short stature and low educational achievement they were ignored even by their own family members. Even parents felt the illness of their child as a hurdle for them to assimilate socially. This first rate

method let the researcher's contact the parents and the family members to get their responses for follow up questions and probing the answers. The major finding was the psychological problems of the Thalassemic children and their families. Psychological support is necessary to help them so that they may decrease the mental distress and make a proper strategy. It will help them to better the treatment of their patients. Moreover a perfect strategy should be made that is a multidisciplinary approach to the management of Thalassemia (pp.326-34).

2.4.4 Knowledge of disease in Thalassemic Major Patients and their Families

Lee, Lin and Tsai (2008) mentioned that there are three aims of study, to observe the knowledge of disease in major Thalassemia patients and their families, to investigate the importance of chosen issue in expecting patients' awareness Thalassemia major and to know the relationship between the knowledge of the disease and its treatment. The purposive sampling was applied and a cross sectional correlation survey was made. Total number of 32 Thalassemic major children and the same number of mothers were recruited. The data was collected through a three division prepared self account questionnaire based on individual information form, an evaluation of the awareness of disease regarding Thalassemia major and a question regarding DFO infusion observance. Besides it, chart reviews were exercised to get data about observance to the fixed appointments of patients on the basis of the recommendations from two pediatric hematologists. The questions were written and transform into English. To assess the questionnaire the content validity and face validity were used. The objects were developed in Mandarin and translated in English. The content validity and face validity were used to assess the questionnaire. Statistical Package for Social Sciences (SPSS) was used to analyze the data. Descriptive statistical method was employed. Pearson correlation was used to check the

relationships between the patients' DKTM and treatment adherence, some demographic and disease variables and parents' knowledge. One-way ANOVA and T test were employed to test the differences in patients' DKTM according to other demographic and disease variables. The regression analyses were carried out to differentiate the relative importance of selected factors in predicting patients' DKTM. The knowledge of the patients was limited that does not guarantee the proper treatment. So knowledge of the patient regarding Thalassemia is required. The study vividly shows that medical professionals enhancement of the patient care quality, strengthening of medical education and improved struggle for staff on clinics regarding the disease can considerably better the treatment.

Hajeri and Arrayed (2012) concluded in their study that the people of Bahrain knew very well about Beta Thalassemia although the ratio of patients with Beta Thalassemia was very low. In this research many respondents agreed about the importance of pre-marital checking, and also that proper awareness of health education could reduce the incident of both Beta Thalassemia and blood disorders as SCD (Sickle Cell Disease). The researchers also observed that the females had far more knowledge than the males and these results got through hemoglobinopathies, results also suggested that different education programs should be helpful for the awareness of Beta Thalassemia and its consequences on the people. It was observed that the knowledge of married people was much better than the unmarried because the married people got awareness through the law and it had great impact on their knowledge capabilities. The researchers emphasized the need to focus more on unmarried people and also to make sure that their counseling begins at school level including awareness through educational information in the educational curriculum specially targeting the males. It was suggested to launch the awareness through educational

programs by using different media channels i.e. TV shows, live lectures and also by means of seminars, workshops etc.

2.4.5 Parental Knowledge about Thalassemia Major Disease

Shukr, Ali and Yasmin (2011) find out the knowledge and attitude of mothers of Thalassemia major children. Thalassemia major was explained first time in early 1920s by Detroit Pediatrician Dr. Denton Cooley. The signs of disease incorporated anemia, a large spleen, and the characteristic of bone deformities. From the end of 1950s transfusions were provided to symptomatic patients when their hemoglobin touched extremely low levels. However, these transfusions required lifelong for several years before the patients expired of infection of cardiac failure. The look of Thalassemia children in later years is well known: small noses, large heads, distended abdomens and thin limbs. These patients have reduced the life expectancy, and required the frequent blood transfusions, regular medicine, retardation in the growth and sexual maturation. These are huge challenges for the patients suffering from Thalassemia and also confrontations for the families of patients. For example there are 3500 patients suffering from Beta Thalassemia major in Greece, and they use one quarter of the country's total blood supply. Iron chelation therapy expenditure for them is seven million dollars a year. Enormous lessons can be learned through experiences of other industrial countries. The major success story is of Cyprus. It was projected that if Major Thalassemia was not forbidden, by the year 2000 the cost of treatment of these children would consume the whole health care budget of Cyprus and need all of the blood that the island's population could supply. Due to the compulsory pre-marital screening and the optional pre-natal testing, form 2000 to 2007 there were no Major Thalassemia births. Whereas the other countries with the disease like Pakistan did

not focus on the practicability of pre-marital screening. The study is aimed to assess the knowledge about inheritance of disease and complications of multiple transfusions. The research was conducted at the Thalassemia centre situated in department of Pediatric Military hospital Rawalpindi form 1st to 30th August, 2011. In addition 201 patients were registered for the transfusion at centre and many other approached regarding treatment. Approximately averages of 6-7 transfusions were done daily in the centre. Thalassemia Children between the ages of 2-21 years were included in the study. Patients less than 2 years and those undergoing the transfusion for other disorders like hemophilia and anemia were excluded. These Thalassemia patients were being treated with regular transfusion and long term iron chelation therapy. After gaining authorization from the hospital's ethical committee, clinical data was gathered through comprehensive interviews of the mothers with preformed questionnaires. Questions were asked to the Mothers regarding the knowledge that the pre-marital counseling could have averted the disease and that antenatal testing could have diagnosed the illness earlier. Their view was also sought regarding compulsory pre-marital testing. The knowledge regarding inheritance and hazard of transfusion were assessed as nil, fair and good on a scale of three and its correlation with social status and educational status of mother were analyzed. Statistical Package for Social Sciences (SPSS) was used to analyze the data. The Chi-square tests of significance were employed to see the significance of association among knowledge, educational status and socio-economic status. Greater part (52%) had stunted growth. Majority of the mothers were uneducated 35(70 %). About 58 % of the mothers were aware that pre-marital testing could be preventive to the disease. About 60 % were aware that the antenatal tests available and 40 % had undergone CVS for antenatal investigation. Respondents agreed that the pre-marital counseling should be mandatory and same percentage felt that the antenatal testing was a reasonable option.

Consequently such videos and audio lectures should be formed in local language to complete fliers and written material should already be available. And to improve patient awareness among uneducated patients, instructional and the audio lectures should be added to pamphlets already in circulation. Additional facilities for pre-marital screening and counseling should be made accessible (pp.703-08).

Wong, George and Anne (2011) conducted a study on the public behavior towards the Thalassemia affecting facts in any multi racial population. Thalassemia major is a widespread key problem in Malaysia. In Malay and China almost 4.5 to 6 % population are carriers of the disease. In Malaysia first nation wise survey was held, the major aim was to find out what differences could be found in the behavior of multiracial population towards Thalassemia. A cross sectional computerized interview survey of a Malaysians aged 18 years and the above were started between July to December 2009. The study illustrates the screening was very useful and acceptable method in decreasing the Thalassemia. The results presented a positive change in the behavior of the people towards prevention of Thalassemia. The pre-natal diagnosis had noticeably decreased the effect of Thalassemia. The study showed that the attitudes and perceptions toward pre-natal screening were different. For example the Muslim couple opposes the pre-natal screening on the basis of religion. This survey aims to find out such dissimilarities among the people. It was suggested that this kind of community based educational programs could bring fruitful results in a multiethnic country (pp.1-9).

2.4.6 The Effect of Public Awareness Programs

Dehkordi and Heydarnejad (2008) have studied to evaluate the impact of booklet and the methods (video, lecture, etc) on the awareness of Thalassemia major patients' parents. The two

groups of the parents were randomly chosen. Besides educational programme one group used booklet and the other used combined method. The questionnaire had an aim to collect the data, regarding disease, from both of the groups. The both methods of education (lecture and combined) helped significantly increase the knowledge of the parents about Thalassemia and had a great effect on the awareness of the parents. It was suggested that the parent's level of awareness could reduce the problem of Thalassemia.

Family has a key role in caring for the Thalassemic child. It is must that the family knows proper knowledge of the disease and its treatment. This research study was to locate how much level of knowledge the Thalassemia children's' parents need. The descriptive study was done on 300 parents of the patients. The data was gathered with the help of research based questionnaire by taking interviews from the parents and the data was examined by using the SPSS, ANOVA, T-Tests and Spearman correlation coefficient. The knowledge of the parents was less than 50 percents in all items and they obtained only 37 percent of the total score. Positive correlation between the knowledge and the parent's level of education was made. Education needs of mothers were more than that of fathers. Generally the parents of the patients have no proper information about the disease and they need authentic level of education. (Ghazanfari, Arab, Forouzi, & Pouraboli, 2010).

2.5 Impact of Thalassemia Major on Parents

Caro, et al (2002) find out the effects of major Thalassemia on the patients and their families direct and indirect expenditures paid by the patients, mental suffering, physical and social problems faced by the affects are the areas of interest of this study. According to this

study, Thalassemia Major can be managed through consistent blood transfusions and iron chelation therapy. Its management also demands lifelong access. Direct costs include visits to physicians and other indirect costs consist of days missed from school or paid employment. Data shows that Thalassemia or its treatment restricts the social activities of the patient and his care givers. As far as irons over load related complications are concerned, it is determined that heart, lever, diabetes, thyroid or hormone problems are found much common. Finally, it is suggested that management process of Thalassemia needs to be improved. Improvement regarding management will prove very conducive to the patients suffering from iron related complications (pp.150-57).

2.5.1. Socio-Cultural and Socio-Economic Challenges and Risk Factors

Liem et al (2011) conducted a study on the effects of Thalassemia on Asian Indian and Southeast Asian families in America. The main purpose was to depict the challenges, including the socio-economic and socio-cultural problems which these families were facing due to Thalassemia major. It was clear that the Thalassemia had devastating their emotions and social well-being. So the individuals affected by the Thalassemia had to undergo hardships to tackle the problems there. A specific struggle is required to locate the factors especially socio- economic and socio-cultural. The study firstly observe the distinctive aspects of Thalassemia by using interviews with parents and the Thalassemic children to explain the challenges including socio-economic and socio-cultural risk factors faced by the families affected by Thalassemia. The analysis was made in comprehensive program at Children's Memorial Hospital. The collected interviews were divided equally into two groups 1. Southeast Asian and Asian (Cambodian, Lao, Chaines, Vietnamese) and 2. Asian Indian (Indian, Pakistani). The interviews gathered a good

effect on the parents and Thalassemic children especially on the parental emotional well-being was the most commonly functional code for the transcripts and emerged as the major theme. In the study, disappointment, helplessness and worry of parents about their Thalassemic children were observed. The disease also had a great impact on the performance of the Thalassemic children in schools because blood transfusion in hospitals led them to the school absenteeism. The parent's complaints about knowledge gaps are a source of frustration. It was the first effective study to find out the challenges, barriers, and socio-cultural concerns significant to the Thalassemic affected families in America (pp.361-69).

2.5.2 The Financial and Social Impact of Thalassemia

Sattari et al (2012) carried out a study on the financial and social impact of Thalassemia and its treatment in Iran. The entire beta-Thalassemic patients attending two hematology clinics were involved to the study. The following two Thalassemia centers cover patients from the East Azerbaijan province and neighborhood provinces. Information were provided to the patients and those who consented, were incorporated in the study. The questionnaire were consisted of 3 sections; the demographic information, treatments and cost of the treatment. Patients' record provided information on number of physician visits and prescription used. The cost of the medications, physician visits, laboratory tests and blood preparations were obtained from the pharmacies, physicians, laboratories and blood banks, respectively. The history of the illness and the side effects were collected by the questionnaire completed from the patients. This information was draw on to estimate direct and indirect expenditure of Thalassemia treatment. Thalassemia is a disease which required lifelong treatment. Thalassemia treatment includes regular blood, management of several medications such as iron chelating agents and other associated medications. The cost of treatment in these patients as well as any other disease does

not only cover the medication cost. These extra costs include the cost of medical consultation, diagnostic tests, laboratory tests, expenditure of preventative or treatments of side effects of therapies and many other indirect costs. About 25,000 registered Thalassemia patients in Iran and their diseases are in need of special attention about their treatments, preventions or prevalence. Patients are economically supported by the government. Almost all the medications in Iran are subsidized by the government and a small fraction of total cost of treatment is paid by patients such as the iron chelating therapies (ICTs) in Thalassemia treatment. There is also insurance coverage for these kinds of patients. In present study the researcher tried to study the economic burden of Thalassemia treatment on government, insurance companies and the Thalassemia children. The major purpose of this research study is to examine the economic burden of Thalassemia treatment in Iran. Those who were consented (100 patients) fulfilled a simple questionnaire. The study revealed that a large sum of money is paid for Thalassemia treatment by government and Thalassemia patients. When income of an average Iranian is considered, the magnitudes of problems come out (pp.171-76).

Loukopoulos (2013) discussed that Thalassemia is caused by a variety of remarkable molecular mechanisms, has a dense path physiology, constitutes a comprehensive medical problem with pain and melancholy for the patients and unhappiness for their families, creates several investigative and healing questions for their physicians, and has a vast social and economic impact crosswise countries where it occurs in high frequencies. The systematic study of Thalassemia developed rapidly after the Second World War at three levels: Understanding the molecular and cellular path physiology of the disease including, improving the quality as well as the expectancy of life of the patients, and alleviating the pressure of the disease on the Public Health System of each country. Adequate transfusions did not solve the problem of Thalassemia;

they may have worsened it in a way. As the iron contained in the transfused erythrocytes could not be excreted, it was gradually deposited in various organs and caused damage through the abundant production of free oxygen radicals. The noxious potential of transfusion iron was noticed very early. In 1995, British authors have reported an additional reason for the iron overload; increased erythropoietin, be it effective or non effective, increased the absorbance of dietary iron and could well be a factor aggravating the effects of transfusion iron. Attempts to remove iron from the body have started in the fifties, when CIBA GEIGY in Basel reported that a siderophore extracted from a bacterial species, known as streptomyces pillosus, had an extremely strong affinity for iron and could be administered to humans, bind the iron which was not bound to transferring, and be excreted in the urine. The chemical name of the compound was desferioxamine. In parallel, the need for an iron cheater which would be administered orally became more pressing. Patients demanded it; if parental therapy was so effective, then an equivalent oral agent had to be produced. Over the ensuing years, various iron chelating agents have appeared and vanished. DTPA, rhodotorulic acid, HBED, PIH and several others reached the point of uncontrolled medical trials. However, none of them prove efficient enough. In the early eighties emerges the L1. This compound, chemically known as defer prone has an unbelievable controversial story. It was synthesized in by Dr. Hider in the UK; then, Dr. Kontoghiorgis, a Cypriot chemist working with Dr Hider and later with Professor Hoff brand gave it to iron laden, heavily transfused patients. The study was simple and had no clear cut criteria of effectiveness beyond iron excretion in the urine. However, the result was considered as important and was published in the British Medical Journal in 1987. During the last years other equally important interventions have taken place. In addition to removing the toxic effects of iron on the endocrine system, a series of careful studies of the levels and rhythm of secretion

of a number of sex hormones led to sophisticated ingenious replacement therapies, which have allowed a better growth, sexual development and, above all, child bearing, a blessing for the couples where one or both partners had thalassemia. Antonio Cao has significantly contributed in all these fields. As Professor of Pediatrics in Cagliari was involved in Thalassemia already in 1974, when he organized and directed the Institute of Clinica e Biologia dell'Età Evolutiva which, in association with the Primary Regional Hospital for Microcytemia provided high level care to hundreds of Sardinian Thalassemic children.

2.6 Economic Impact of Disease on Patients' Families

Riewpaiboon et al (2010) ascertained that Beta Thalassemia is common inherited disorder of blood worldwide. The Hemoglobin E/b-Thalassemia is particularly widespread in Southeast Asia and Indian subcontinent, coastal North America, where the Southeast Asian immigrants represent a substantial percentage of the population. With the population of 65 million, 7% with a beta Thalassemia trait and 17% with HbE trait, an estimated 35,000 patients are alive with beta thalassemia syndrome in Thailand. Different Studies on the economic burden of beta Thalassemia have been reported from United Kingdom, Taiwan, Canada, Israel, Sri Lanka, and Myanmar. The study hospitals were chosen on the basis of data convenience and cooperation (personal relationship amongst researchers). The study was composed of children aged between 2-18 years with beta Thalassemia/Hb E and major thalassemia during the financial year 2005 (1st October 2004 to 30th September 2005). In this study, the patients were classified as "severe" if they met at least one of following criteria (1) children whose onset of anemia were before 2 years of age, and those whose first transfusion arise before 4 years of age (2) the patients who were analyzed with homozygous beta Thalassemia and (3) patients whose pre-trans fusion Hb level were less than 7 g/dL. The demographic and clinical characteristics were Two

hundred and one patients included in the study and interview response rate was 100%. The compositions of hospitals were 36% from the Saraburi Hospital, 43% were from the Chulalongkorn Hospital and 21% from the Phramongkutklao Hospital. In the researcher knowledge, this was the first time a complete cost-of-illness study regarding Thalassemia has been performed in Thailand. The results provided cost of taking care of the child patients in a societal perspective, covering the direct medical cost, the direct non-medical cost, and indirect cost. In the present study 201 patients with beta thalassemia/Hb E (91%) and homozygous b-thalassemia (9%) were enrolled for this study. The ninety-two (46%) was severe Thalassemia and 109 (54%) was mild to moderate severity. Annual average costs of treatment were US$950, 59% were direct medical cost, 17% direct non-medical cost, and 24% the indirect cost. The costs were differentiated by a few potential predictors. The significant predictor variables were the hospital, blood transfusion pattern, health insurance scheme and iron chelation drug used. Average annual costs per patient were calculated, and the cost model was estimated. These would be the applied for national planning, budget, economic evaluation of treatment, prevention interventions, and Impact analysis (pp.1-7).

Fung et al (2008) stated that the people having Thalassemia are mostly distressed due to their illness and their deteriorating health. The researchers observed that the patients who have Thalassemia major do not seem to be satisfied with their treatment procedure. In their daily life routine their self-improvement and development status are much better. Many patients having the disorder for more than 5 years are mentally affected and their coping capabilities are also less as compared to other normal peers. They always remain conscious in finding the views of other people of how they think about their social status. The patients having Thalassemia always remain worried about their illness and its treatment. Many Thalassemic patients felt that due to

their disease they are mentally disturbed and this disturbance also affected their decision making power for their future and careers. Due to this disease the patients and their families faced financial problems; their survival was a challenge with a dark future ahead. Teenage patients were found more vulnerable than the old age patients and they seemed to be more mentally disturbed because the old patients knew very well the consequences of the disease and had become accustomed to it and learned to live with it. The older patients tried to keep themselves happy which was helpful for their coping ability and indulged themselves in such activities that prevented them from thinking about the deleterious consequences of this disease. This study also found that the different age groups of Thalassemic patients had different coping abilities. There is need to focus on the psychosocial status of the patients and remain conscious about their personality development process, while the teenagers require more psychosocial interventions due to their intense reactions towards the illness, enduring disease, and the necessity to struggle for a better, normal and independent life.

2.6.1 Treatment Expenditures

Mallik et al (2010) conducted a study on the Expenditure to treat Thalassemia, an experience at a tertiary care Hospital in India. A cross-sectional descriptive study was carried out in the Institute of Hematology and Transfusion Medicine situated in Medical College, Kolkata, India. The main objective was to assess the socio-demographic profile, clinical presentation, expenditure for treatment of Thalassemia patients and awareness about cause and prevention of the disease. Thalassemic patients attended the Government setting was mostly from the lower socioeconomic status with low rank of literacy. Thalassemia disease is one of the most difficult being faced by the mankind with virtually no permanent treatment. Each year approximately

100,000 children are born worldwide among Thalassemia major, of which 10,000 are born in India. Once a child is diagnosed to have disorders of Thalassemia he or she has to take lifetime treatment. The management includes frequent filtered packed red cell transfusions, chelation therapy regarding iron overload and regular transfusions. According to the World Health Organization, an annual average consumption of 27 units of blood and the $ 8658 worth of drug are desired to manage every patient according to recommended principles. The only stem cell transplantation is a treatment but is out of reach for majority of the patients. As a result the emphasis has shifted from treatment to the prevention of birth of such kids in future, which can be only achieved by the prenatal diagnosis and genetic counseling of carriers of the gene. The current study has been carried out through the following objectives. To study the socio-demographic profile and the clinical presentation of Thalassemia patients attending the Institution of Hematology & Transfusion Medicine located in Medical College, Kolkata. To assess annual costs for treatment of these Thalassemia children and to assess how much load it incurred to family, to study the level of awareness of patients and their families concerning the cause and prevention of the illness. The current cross-sectional and observational study was carried out in the Thalassemia OPD of the Institute of Hematology & Transfusion Medicine located in Medical College, Kolkata, India. The study population was the diagnosed Thalassemia children attending to Out Patient Department, who fulfilled the inclusion and exclusion standard. Thalassemia who had history of blood transfusion from the at least 1 year were included in the study and all new thalassemia registered patients were not considered. According to the statistics available by the institute of the year 2007-08 that total number of Thalassemia patients registered were 682. Twenty percent of registered patients were considered the sample, which came as 136. Usually thalassemia patients were being advised to come for a three weekly follow up in

Thalassemia Out Patient Department which is run on the every Monday. The data were composed about socio-demographic variables, information of treatment adopted by Thalassemia patients and the number of units of blood transfused in last 1 year (1st June 2007 to the 31st May 2008). Sooner than conducting study the ethical clearance from Ethical Committee of the college and informed consent from patients were taken. In the present study 70% of families had to spend up to the 20% of their yearly income used for treatment of thalassemia. The present study observed that the 68.9% were aware about cause and the 60.7% about prevention. Fifty two percent of the families had implemented some form of family planning way. In conclusion, study found that the scope still exists about improvement of the awareness about disease and how to prevent it and recommends necessary premarital screening for thalassemia. Decentralization of blood transfusion and carrier screening services at the district level should be planned to decrease the costs for treatment, alleviate the harassment of families and also to improve the extended carrier screening for relatives of the affected families. The folate and calcium tablets, hepatitis B vaccination can be made accessible at the government setting free of cost (pp.78-84).

2.7 Emotional Impact of Thalassemia Major

Mazzone et al (2009) described that Cognitive-Behavioral Family Therapy (CBFT) can be an effective psychological approach for the patients of β-thalassemia major, rising fulfillment the treatment, lessening the emotional burden of disease, and improving the quality of life of caregivers. Twenty-eight β-thalassemic major patients that followed CBFT for one year were compared with the twenty-eight age-matched healthy children, focusing particularly on behavioral, mood, and temperamental characteristics as compliance with chelation, assessed using the Child Behavior Checklist (CBCL), Children's Depression Inventory (CDI),

Multidimensional Anxiety Scale for Children (MASC), and Emotionality, Activity, Sociability and Shyness Scale (EAS). Ninety percent of β-Thalassemic children illustrated the good compliance with chelation therapy; though they had considerably increased somatic complains, physical symptoms and the separation panic. Thalassemia children feel dissimilar from their peers and complex negative thoughts regarding their life, guilt senses, increased nervousness and low self-esteem; their behavioral report is similar to normal subjects, but many of them can manifest rigorous psychosocial harms due to complexities in complying with painful chelation; male patients, in particular, show oppositional defiant disorder. This study proposed that CBFT can be an additional tool to move to the difficulty of a chronic disease such as β-Thalassemia major. The choice of CBFT can be justified to get better compliance to the chelation therapy, though certain psychological results, such as somatic complaints, physical symptoms, and separation panic in β-Thalassemia major children are investigative of persistent emotional burden, probably related to fear for future complications. CBFT can be a suitable tool to enhance the fulfillment with chelation therapy in β- Thalassemic children; though, treated children continue to show an important emotional burden; furthermore. CBFT therapy seems not to have any helpful impact on the quality of life of care giving mothers, who may therefore require additional psychological support. In children, particularly, β-Thalassemia major and its complications carry an important psychological impact, causing emotional burden, hopelessness, and complexity with social integration (pp.1-6).

Liem et al (2011) have studied to illustrate challenges, including socio-economic and socio-cultural barriers faced by an urban immigrant population in the United States affected by thalassemia major. The ethnographic, semi-structured, 1-on-1 interviews using an interview schedule were developed for this study. The digital recordings were transcribed and the data

were analyzed by using constant comparative method. The participants were fourteen Southeast Asian and the Asian Indian parents of children with transfusion Thalassemia dependent. The Thalassemia has the greatest impact on the emotional and the social well-being of affected patients and their parents. Impact of Thalassemia is tremendous for affected patients and their parents and is due to more factors that were either disease-specific or common to other chronic disease models rather than influenced by culture. The unmet needs of these families require the additional examination to facilitate the development of initiatives aimed at improving the quality of life and decrease overall impact of Thalassemia.

2.7.1 Depression in Mothers of Children with Thalassemia Major

Sharghi et al (2006) discussed the overall impact of depression on people and how common it has become in every society and considered it to be a "psychological flu." Depression in women is noted to be two times more as compared to men due to their anatomical, physiological, psychological and socio-economic reasons and also due to their dual roles and heavy responsibilities with hardly any appreciation in return. This study was carried out by taking 294 mothers as sample and concluded that mother's level of depression was significantly higher whose children suffered from thalassemia or any type of blood malignancies. The depression level of the mothers increase due to their child's disease as they tend to indulge more in caring and looking after their sick child as compared to the fathers. This study revealed that the mothers who were educated were less vulnerable from those who were uneducated. Education increases the information level which minimizes the depression level of the women because they can understand that their depression would not ameliorate the condition of their children. Similarly, educated women had knowledge regarding coping with the disease in which

her child is involved. The study also observed that the disease along with the social status of the women also caused higher level of depression, like divorced women were more depressed as they lacked social support of a partner leading to severe depression which can be more precarious for the psychological development of their children. The screening test for depression was suggested by the researchers for the depressed mother's in order to receive help on time, in the form of psychiatric counseling and support groups so the mother can face the challenge of her child's disease in a more determined and optimistic manner.

2.7.2. Dreadful Disease of Thalassemia Turned to a Chronic Condition

Loukopoulos (2013) reported that Thalassemia is a disease with a lot of challenging aspects. Its reason, by a variety of the interesting molecular mechanisms, has a complicated pathophysiology, constitutes a multifaceted medical problem by pain and misery for patients and sadness for their families, creates the several diagnostic and therapeutic questions for their physicians, and has a vast social and economic impact across the countries where it occurs in high frequencies. The first formal explanation of Thalassemia is from Thomas Cooley, a physician from Detroit in the US, who reported a series of cases of spleen omegaly in children with peculiar bone changes in 1925. The term thalassemia was coined by Whipple and Bradford. Later, several authors all over the world added various explanations concerning clinical and laboratory aspects of disease, while Caminopetros pointed out conclusively in 1936 that this was a familial condition inherited in an autosomal recessive disorder. The systematic study of Thalassemia developed rapidly after Second World War at three levels: (a) understanding molecular and the cellular pathophysiology of disease including; (b) improving the quality as

well as the expectancy of life of the patients, and (c) alleviating pressure of the disease on the Public Health System of each country harboring high numbers of patients.

2.8 Psychosocial Burden

Khurana, Katyal and Marwaha (2006) summarized as Thalassemia has an impact on the different psychosocial life characteristic of the teenagers, it is very necessary to give psychosocial support, including support of a clear understanding of the illness. Thalassemia support groups are very significant as they not only educate the patients and their families about the disease but also give patients with a chance to meet their peers and contribute in social activities. Psychosocial help may consist of link with teachers or school administration who should be informed about the disease. The adolescents must be permissible to get concerned in normal activities with healthy peers to permit the expansion of adequate self-image. The need for psychosocial support is higher in a developing country like India where the normal and expensive treatment can pose a financial load as well for the families of the Thalassemic. It is vital to focus our concentration on psychosocial life aspects of Thalassemic and start intervention programs with a view to incorporate Thalassemic into the social mainstream and help them in important healthy, imaginative and fulfilling lives. In this study mostly thalassemia patients were not satisfied because of their body image. All the respondents felt that the Thalassemia disease did not affect their social relationship and family. Greater part of the subjects did not discuss their illness and related problems with their friends. They directly depended on their parents for financial and emotional help. Thalassemia children take one to three days off from school in the every month because of the regular red cells transfusions. Due to the regular blood their

performance becomes poor. Most of the patients not satisfied with their body images (pp. 877-80).

2.8.1 Psychosocial Problems of Parents

Aziz, Safad and Kanwal (2012) conducted the cross sectional study among parents of Thalassemia children attending the Thalassemia centre of Bahawalpur Victoria Hospital, Bahawalpur, Pakistan during March 2011 to August 2011. Non probability convenient sampling techniques were used. An ethical consent was given by the hospital ethical committee. A questionnaire was used contained on psychological and social aspects. Patient Health Questions were used to assess the depression of parents of thalassemia children. Total 100 parents were interviewed and significant numbers of parents have psychological problems due to the illness of their babies. The counseling of parents is needed on the regular basis. The present study designed to simplify the psychological problems experienced by Pakistani parents of Thalassemia children. Out of 100 parents 71 were mothers and only 29 were fathers. Out of one hundred, 56 percent reported that this Thalassemia disease affected their economic status, 27 percent were unable to go in social gatherings. Only 8 percent of parents reported that the Thalassemia disease of their children had not affected their routine work. More rigorous depression was found in the mothers as compared to the fathers. Lack of education among the parents and general public leads to many social problems. To address these problems holistic approach must be used. Awareness of this disease should be raised through different health education program. It is important that counseling facilities should be on regular basis.

2.8.2 Psychological Problems and Quality of Life of Thalassemia Children

Shaligram, Girimaji and Chaturvedi (2007) examined a study to evaluate the psychological problems and the quality of life in children with Thalassemia. This study was conducted from the Department of Psychiatry of National Institute of Mental Health & Neurosciences, Bangalore, intended to assess the psychological problems and the Quality of life (QOL) in thalassemia children. The sample was thirty nine children under the age group (8-16year). Thalassemia transfusion dependent were assessed for the psychological problem using childhood psychopathology measurement schedule and the quality of life was assessed by using the EQ-5D. Those with the mental retardation and other chronic illness were excluded from this study. Various authors have been reported that up to the 80 % children with Thalassemia are more likely to have the psychological problems e.g. defiant disorder, anxiety disorder, depression. Even though children with all types of blood disorders are bare to similar stressors, those with the Thalassemia are unique in that they have to attend the hospital on a regular basis for blood transfusions. The demographic and clinical details of children were collected by using the semi structured Performa that were constructed for study. For assessing psychological problems the childhood psychopathology Measurement Schedule (CPMS), were used. The following factors were assessed psychotic symptoms, depression, anxiety, conduct disorder and low intelligence with behavior problems, somatization and physical illness with emotional problems. The quality of life were assessed by using the EQ-5D as an instrument that depicted quality of life in the five dimensions, anxiety, pain / discomfort, usual activities, self care and mobility. The children dependent on the regular transfusion were taken up for study by using the convenience sampling technique. Forty children fulfilled the criteria and one was refused consent. In the present study data were analyzed by using the Statistical Package for Social

Sciences (SPSS) version 10. The test Chi square was applied to find significant association between demographic and clinical data and outcomes. Forty four percent of children had psychological problems and seventy four percent had a poor quality of life (QOL). Emotional problems, particularly depression were sixty two percent and conduct problems were forty nine percent. The children were the majority, likely to impaired quality of life due to rigorous difficulties in pain and discomfort. Also psychological problems were the significant predictor of the impaired quality of life (pp.727-30).

Matsaniotis and Kattamis (1969) mentioned that prevalence of Thalassemia in the Greece makes many problems for the pediatricians who were responsible for care of those patients. The major facilities for proper treatment and follow up for patients of beta Thalassemia were urgently required in the all rural hospitals, even which hospitals have no facilities of paediatric departments. The same were also true of the facilities of diagnosis of beta Thalassemia all over the country. Emotional problems of the Thalassemia patients' families required the special consideration and handling. The genetic counseling was the highly recommended, especially in the areas of a high prevalence of the beta Thalassemia traits and believed that it will help in reducing the maximum number of patients with Thalassemia major (pp.223-30).

2.8.3 Psychological Distress and Coping Strategies among Parents of Thalassemia Major Children

Ali et al (2012) conducted a study on psychological well being of the parents of Thalassemic patients. According to World Health Organization (WHO) "State of complete social, physical and mental well-being of a person" not just the nonappearance of disease. On the parent's perspective it is frightening and troublesome incident in which they have to cope up

with psychosocial aspects of Thalassemia along with regular visits to Thalassemia centers for blood investigations and blood transfusion with an iron chelation therapy and their determination to fulfill the cure. The Parents of beta Thalassemic patients experience a significant psychological impact, causing the emotional burden, difficulty, hopelessness with social integration. They faced the negative feelings about their life, increased anxiety, guilt, and low self-esteem. They have cruel psychosocial problems due to their incapability to cope up with throbbing situation which leads to decline of relationship amongst the family members, increased marginalization and isolation. The present study was focused on psychological well being of parents of Thalassemia children. The parents of Thalassemia patients highly structured a painful perception of the disease and show destruction in domains involved in the physical health, psychological health and quality of life. The Poor quality of life (QOL) of parents is able to explain by a sense of blame for having generated a child with genetically determined illness. The cross sectional study was carried out on the parents of Beta Thalassemia Major Children attending thalassemia department in Rawalpindi, from May 2010 to April 2011. Total Forty parents including 17 Fathers, 23 mothers were recruited in this study. After gaining the informed consent, the parents coming for frequent treatment of their children were asked to complete the questionnaire in Department. Psychological distresses were assessed by using Parental Stress Scale (PSS) and the General Health Questionnaire (GHQ) and coping strategies were evaluated using COPE Inventory. Parental Stress scale (PSS) is 19-item self-report measure of parental stress which was developed by the Berry & Jones (1995). Parents were asked to the sign disagree or agree with items in terms of their usual relationship with their child and to rate each item on five-point scale: 1) strongly disagree 2) disagree 3) undecided 4) agree 5) strongly agree. The scores on the scale range between the 18-90. The higher scores on the scale point out the greater

stress and the lower score show lesser stress. Parental Stress Scale demonstrated suitable levels of inside reliability (.83), and the test-retest reliability (.81). The General Health Questionnaire (GHQ-12) was used to measure the psychological distress. It was initially developed by the Goldberg in 1970 and is a broadly used tool in the primary care to monitor for psychological distress and the psychiatric morbidity. Every question has the four possible responses, i.e. less than usual, rather more than usual, no more than usual or much more than usual. The data were analyzed by the software Statistical Package for Social Sciences, SPSS-14. Descriptive statistics was used for describe the data. Independent Samples t-test was used to evaluate scores between different groups. P-value < 0.05 was considered as the significant. Total of 40 parents, 17 were fathers and 23 were mothers included in the study. Age of the parents was ranged from 30-50 years. All parents (40/40) were found to have the severe parental stress. This never-ending illness is a source of stress for parents and the rest of family. Such condition results in the survival of various types of emotional reactions and the behavioral patterns in family, which affects the associations of family members amongst the each other and with their settings. The chronic illness of child special effects the parents at: emotional level, cognitive levels, and their daily routine. In the current study psychological distress and the coping strategies amongst parents of beta thalassemic patients showed that all parents of these thalassemia patients experienced cruel parental stress however, psychological distress were reported by the 27 (67.5%) parents. Beta thalassemia is continuous illness that can lead to the excessive psychological burden to patients and their families. It was reported by the Deepika Shaligram, that fifty seven percent of caregivers have psychiatric problems and Quality of Life were affected in 50 percent. They have to face the many concerns like psychosocial adjustment of child, provision of treatment, financial problems, traveling and the other social problems. Further goal of present study were to evaluate

coping strategies of the parents. For the said purpose COPE Inventory were used which has the fourteen types of coping strategies. Different coping strategies were employed by parents. The most frequently used coping strategies were the Active coping (97.5%), Religion (92.5%), Planning (95%), Acceptance (92.5%), self-blame (92.5), and Self-Distraction (82.5%). Others include Use of emotional support (73%), Venting (70%), Use of instrumental support (90%), Positive reframing (87.5%), Behavioral disengagement (62.5%) and Denial (60%). Least used coping strategies were humor (15%), and substance use (7.5%). Significant differences was found on the coping strategies of Denial ($p<0.01$) and the behavioral disengagement ($p<0.05$). Both coping strategies were more prevalent in the fathers. As fathers were initiate to have difficulty in accepting their child's illness and denied it completely. This behavior made fathers to be the overprotected about their child which intern effected psychosocial development of child. The Coping strategies of denial were associated with guilt of the parents, and any of negative remarks from the environment played the significant role to enhance such behaviors. The psycho social support intended at falling emotional distress of parents, and strengthening their coping strategies for the better addition in daily life is therefore much necessary(pp.124-28).

The study was to evaluate the knowledge regarding depression in Thalassemia detailing in children, adolescents, adults. The technique of this study included bibliographic review of the literature, mainly in the PubMed data base, which referred to the depression in Thalassemia patients, adolescents, adults. The search of the literature was conducted from 2001 to 2012 by using the following key search terms: "depression", "Thalassemia in children-adolescents-adults". Progress of therapeutic regimen has significantly increased life expectancy of Thalassemia patients but at same time has created important ongoing health care needs.

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According to the literature, depression involved in surviving Thalassemia is increasingly recognized, globally. The main factors triggering the onset of depression are personal, family, social or hereditary. Depressed Thalassemia children, adolescents and adults faced many difficulties in all facets of life. More in detail, depression in Thalassemia is the mainly related with low school or job performance, social isolation, failure of independence, maladaptive coping strategies, compromised physical ability and limited life opportunities. Provision of accurate information to Thalassemia individuals about the therapeutic regimen by expertise health professionals is a key-factor that plays a vital role on the outcome of depression. Standard screening for depressive symptoms is necessary to identify at-risk individuals so as to provide proper psychological support with ultimate goal to develop both emotional and physical health (Koutelekos & Haliasos, 2013).

2.8.4 Coping and Adjustment of Patients with Thalassemia Major

Fung et al (2008) conducted a study on the psychological vulnerability and resilience in Thalassemic major children and adolescence. This study aims to map a pattern how to cope and adjust Thalassemic patients and to identify the issues regarding the living with Thalassemia major. Seventy three patients, receiving the treatment, were assessed with the set of semi-structured interview and the questionnaires instruments with children's insight of the quality of life, illness and its treatment. Procedure on life satisfaction, extent and nature were the source of evaluating their psychological adjustment. The result declared that the patients were not satisfied with their disease, treatment and health condition. It was very clear that the patients showed different reactions as the older patients were highly exhausted with the illness. It indicated that psychological intervention was necessary at all stages especially for the older patients.

2.8.5 Life Experience of Families with Thalassemia Children

Prasomsuk and Jetsrisuparp (2002) conducted a qualitative study on the life experience of Thai families with Thalassemic children. The main purpose of the research was to discover the life experiences of rural Thai families having Thalassemia children. An exploratory design was used to investigate the life experiences of Thalassemia families, how they feel and think regarding their lives, Thalassemia major and its impact on their life. Qualitative method was adopted in this study as it is a helpful method in this situation. Fifteen mothers and fifteen Thalassemia children aged 2-14 years were invited to take part in this study. They were thoroughly interviewed by the interviewer, and signed the consent forms. The patients who were diagnosed from 2-10 years of age were interviewed. At the paediatric ward at the Udorn Thai Centre Hospital in Thailand. The faculty of medicine Khon Kaen University gave its ethical approval. In a developed interview guide which includes a) questions regarding the experience of families in caring for the diagnosed Thalassemic children, b) the feeling of the families in caring for the Thalassemia children, c) the information of the disease they collected, d) how useful the information was, e) after child finding their life experience and f) the causes affecting their quality of life. In the semi structured conversational interviews the participants took part in a proper way and all the interviews were recorded, transcribed and translated. All the 15 married mothers, with major thalassemia children, aged from 24-27 participated in this study. The researcher made major six categories including psychological problem, lack of thalassemia knowledge, financial difficulties, future concern and social support and health care services. Thalassemia is a major health problem in the South East Asia, and especially Northeast Thailand. Almost one percent of Thai people is suffering from the disease. Approximately 600,000 cases of Thalassemia have been found and about forty percent population is carrier of Thalassemia. This

study traces the psychological problems of the family such as fears about the imagination of it, sickness, treatment and child's life. These problems affect their whole life and they desire that the other families should not face the horrible problem of Thalassemia. Psychosocial care was the other issue which stressed that every member of the family must be saved. The health care professionals should educate the people about the effects of thalassemia and the skilled personals and the standard guidelines must be made in the whole country to achieve the goals.

Borhani et al (2011) stated that the study was done to evaluate the effect of family-centered empowerment model on quality of life of the children aged 6-12 years among thalassemia in the Kerman Thalassemia Center. The present experimental study was carried out on the eighty six Thalassemia children aged 6-12 years who were divided randomly into case and control groups. The tools for data collection were consisted on demographic and the general quality of life questionnaires in children that included social, physical and emotional aspects in addition to school functions. Questionnaires were used after the determination of content validity and the reliability through internal correlation method. This model was performed in test group according to four steps problem solving, threat perception, educational participation and evaluation. Quality of life was calculated 1.5 months after intervention. The results revealed that average quality of life of Thalassemia children before intervention were 26.23 in test group and 27.62 in the control group and they were not significantly different ($p > 0.05$).On the other hand after performing the model, average quality of life in test group reached 35.19 while it was 28.02 in control group and observed difference were statistically significant ($p < 0.05$). In the current study, it was pointed out that school aged children with thalassemia had lower quality of life in the physical dimensions. Such a result might be due to the difficulties followed by Thalassemia. These patients generally experience from many physical symptoms and side effects. Thus,

essential of addressing physical requirements in these children is determined extra than ever and training and attention to these patients also must be done even in small communities. According to the results of this study, it was indicated that the quality of life of children with Thalassemia were in a low level. This pointed to the importance of education and the participation of patients and their families in healthcare affair. Family-centered empowerment model, due to contribution of the families in education and learning and taking care of their ill children, would be a suitable model for further researches (pp.292-98).

2.9 Parents Opinion of Quality of Life

Ahmad et al (2011) concluded that parents of the Thalassemic children are worried about the physical, social and psychological life aspects of their children. The main reason of the study was to evaluate parent's opinion of the quality of life in Pakistani Thalassemic children. Moreover, it aimed to evaluate the physical, social and psychological life aspects of the thalassemic patients. Thalassemic is found in all parts of Pakistan. The number of thalassemic babies amounts to 5000 yearly and the number of suffers is five out of one hundred and about eight million people are the carriers of the disease. Dependence on blood transfusions, as the only treatment available has created burden on health system. Thalassemic has badly affected the diseased children life as well as his family system. A Thalassemic child cannot perform his normal activities properly and his parental have to face various difficulties in looking after their baby. This study brings to light the fact that male children are preferred over female ones in connection with treatment and care provided by the parents. It is reported by the study that the quality of life of such children is significantly poor. The studies have recommended that health care professionals should be involved to impart the health education. Parents should be educated

about their responsibilities so that they may seek best possible treatment for their children. Moreover, this study invites the policy makers and stakeholders to come forward and provide social and financial support for family members of the diseased children. Such support will enable them to improve the quality of life in thalassemic children (pp.470-73).

2.9.1 Quality of Life Issues in Caregivers

Shaligram, Girimaji and Chaturverdi (2006) find out that major objective were to evaluate the contribution about psychological problems regarding the illness to the Quality of Life (QOL) in the family. In the study forty four percent of the family was clinically interviewed for the qualifying GHQ cases. The study was done by the Psychiatry Department of National Institute of Mental Health and Neuroscience India, a caregiver was involved to provide thalassemic youngster. Demographic and clinical information from youngster and his caregiver were gathered with the help of semi structured interview. The majorities caregivers were low educated and from urban areas. The social disadvantage (the lower educational attainment with the lower socio-economic status) describes the critical condition in psychiatric problems of male care givers. While the female caregivers who were job holding mothers had severe psychiatric problems perhaps due to pressure of workplaces and home chores. Lower educational attainment among the fathers creates problems in understanding the nature of the disease. Sixteen female caregivers had not as good quality of life. The study shows that the psychiatric issues and the concerns of the caregivers about thalassemia create problems in the quality of life. In order o optimize the outcomes, education, psychological intervention, medication should be provided to the caregivers to manage the problems of Thalassemia (pp.275-77).

2.9.2 Factors Affecting the Health Related Quality of Life (HRQL)

Thavorncharoensap et al (2010) concluded that in Thailand, with the population of 65 million, about forty percent have Thalassemia traits or carriers, whereas one percent of population afflicted through this disease. The cross sectional study was done among children and adolescents of Thalassemia who received outpatient treatment at the three participating hospitals namely Phramongkutklao Hospital, Saraburi Hospital, King Chulalongkorn Memorial Hospital from June to November 2006. Participants in the study were chosen based on inclusion and exclusion criteria. All the suitable patients and their parents were approached as they visit for the routine follow-ups at Thalassemia Paediatric Thalassemia Department of each three hospitals for the time of data collection. Written informed consent was done through parents and the child's assents were received prior to the participating in this study. At the time of interview, all the respondents were aware of the objectives of the study and were confident that all the responses would remain confidential. For Health Related Quality of Life assessment, the Paeds Quality of Life (QL) questionnaires were completed independently through children with a minimum age of eight years. The Children aged from 5-7 years were interviewed by the trained interviewers. The study was accepted by the ethical committee of each participating hospital namely, the Institutional Review Board of the Faculty of Medicine, Royal Thai Army of Medical Department, Chulalongkorn University, and Institutional the Review Board of Saraburi hospital. The data were examined by Microsoft Excel 2003 and SPSS package version 13.0. The General characteristics of patients were obtained in terms of percentage, mean, and standard deviation. It was found that about 51 percent of the participants were male. About 42 percent of the patients had received blood transfusion during the three months prior to interview, while only 27 percent of them had received iron chelation therapy. The following factors significantly affected the

Health Related Quality of Life (HRQOL) of the patients age at onset of anemia and the age at first transfusion. For the improvement of Health Related Quality of Life (HRQOL) of thalassemia patients, the suitable programs designed for providing psychosocial support and link between the patient, school officials, family and the physician are important, especially in terms of improving school functioning scores. The findings are also confirmed that the importance of maintaining pre transfusion Hb level of at least 9-10.5 g/dL (pp.1-10).

2.9.3 Implications for the Control and Management of Thalassemia

Premawardhena et al (2004) concluded that Thalassemia pose an increasing the burden for health-care services in many of the Asian countries. In order to preserve rare resources, it is necessary to establish the reasons for the remarkable phenotypic heterogeneity and natural history of these disorders so that most cost-effective methods for their control and management can be adopted. A long-term observational study of patients with different types of Thalassemia in Sri Lanka proposed that in addition to the well-defined primary, secondary and the tertiary genetic modifiers, particularly malaria, environmental factors and variation in the ability to adapt to the profound anemia which characterizes these conditions, may play a important role in determining their clinical severity. Before conducting the study, ethical approval were obtained from the Central Oxford Research Ethics Committee University of Colombo and the Ministry of Health, Sri Lanka. The population survey of children were carried out to assess the approximate frequency and distribution of Thalassemia, The highest frequency were found in the Kurunegala State and in a small region on the south coast, areas which are, historically, those with the highest frequency of malaria. Though it has taken a long period of detailed observation, it has been possible clearly to define both mild and severe phenotypes of Hb E b Thalassemia in the Sri

Lankan population. It is also clear that psychological aspects of serious genetic disease require the immediate urgent attention, particularly as they affect communities of the developing patient management (pp.203-06).

2.9.4 The Life of School Aged Thalassemia Children

Dakhakhny et al (2011) studied on the Quality of School Age Thalassemic Children at Zagazig City. The main aim of the study was to evaluate the quality of life of school age children with thalassemia. A descriptive study was carried out to assess the quality of life of school-age children with Thalassemia major. The study was performed at the Out Patient Department of Hematology Clinic at Zagazig University Hospitals in Sharkia Governorate. The study was based on sample of 100 school aged children who were completed the following criteria 1) Confirmed diagnosis of Thalassemia major. 2) Age from 6 years old to 12 years old 3) both sexes. 4) Free from any other chronic diseases. Two tools were used to gather the necessary data. First is structured interview questionnaire sheet. Structured interview questionnaire sheet were developed by the investigator to gather the following necessary data, A- Biosocial data of the child as, child's age, sex, birth date, and education level. Information about illness history, any similar conditions in the family, quantity of blood transfusions per month, compliance with blood transfusion and conformity with chelation therapy. Socio-demographic data of child's parents, such as the age, educational level, occupation, family income, crowding index. The written consent was gain from parents of children. A pilot study were carried out on 10% of children and their parents to check the clarity of the questions and to guess the time required for filling the sheet and no modification was done. Every child and his/her mother were individually interviewed to collect the essential data using tool I and tool II. The time was consumed to

answer the questionnaire sheet ranged from 25 to 30 minutes. The average number of children and their mothers/day were 6 children. The data were assembled during 10 months, starting from the July 2008 to April 2009. The collected data were coded and entered in a data base file using, FoxPro for windows program. After complete entry, data were moved to SPSS version 14.0 program by which analysis were carried out applying frequency tables with percentages and the cross tabulations. The chi-square test was used to locate the significant associations between demographic and clinical data and outcome measures. The present study originated that most families reported inadequate family income. This may explain that only poor families are more likely to take their children to the general hospitals, or may reflect that the rich families have enough money to make premarital and prenatal screening tests when they are knowledgeable about it. Based on the results of present study, it was concluded that the Thalassemia as a chronic disease had a negative impact on the perceived physical, emotional, social and school functioning of school age children resulting in impaired quality of life. The study imitated that the emotional functioning were the most affected from the point of view of both children and the parents. The study were also demonstrated an association between the compliance with treatment regimen and quality of life. On the basis of recent findings it may be recommended that a psychologist should be deputed in the hematology ward and the Out Patient Department to help in providing a link between patients, school administration, families and physicians (pp.186-97).

Ismail et al (2013) concluded that according to this study, Thalassemia disease have spread negative impact on quality of life (QOL) of the caregivers and Thalassemic children in Malaysia. In this study a cross-sectional study was conducted among children and adolescents, aged 7 and 18 years old with beta Thalassemia major, HbE beta Thalassemia and Thalassemia intermediate who received regular blood transfusion treatment (1 to 3 times monthly). So the

quality of life view of patients' caregivers was performed using EQ 5 Descriptive system which consists of five dimensions as follows: mobility, self care, usual activity, pain/discomfort and worry/depression. If we talk about the total number of respondents then a total of 75 Thalassemic patients from Hospital Kuala Lumpur (HKL) and UKM Medical Centre (UKMMC) and 64 caregivers were approached. The majority of patients were Malays (69%), followed by Chinese (25%) and other ethnic groups (5%) In this study, we found that the mean total summary scores among Thalassemia children (65.35±10.57) were lower than parents' proxy reports (67.20±11.36); *p* value was however 0.136 (Table 2), while physical functioning score for patients' self report (69.67±12.51) was higher than the parents' proxy report (67.25±14.28), but with *p* value 0.337. In this study, the score for emotional functioning subscale was lower compared with previous studies. Mean emotional function score was reported to be 68.14±17.22. Pre-transfusion haemoglobin (Hb) level, frequency of transfusion and frequency of chelation therapy were found to be significant predictors of HRQOL scores. The study exposed that patients whose Hb level was higher than 9 g/dL had a significantly higher (p=0.02) total summary score (68.41±7.69) than those with Hb levels of 7-9 g/dL (66.00±8.98) or less than 7 g/dL (46.30±17.53) in patients' self report. This result is supported by Dahlui et al. (2009) in his study on Thalassemia patients and also consistent with the findings from several studies conducted on other diseases that also address the association between Hb concentration and quality of life. As reported in previous studies, we found that there was a significant relationship between frequency of blood transfusion and HRQOL (p=0.034), with patients receiving more frequent blood transfusion having lower psychosocial health score when compared with patients receiving less frequent blood transfusion. The patients typically have to undergo for blood transfusions at least once a month depending on the severity of the illness. This means attendance for an entire day at the hospital

which leads to school absenteeism and might impaired HRQOL indirectly. Our study also showed that frequency of iron chelation treatment was significantly related to HRQOL. (pp 373–380).

2.9.5 Dimensions of Quality of Life, Physical, Emotional, Social and Role Functioning

Torcharus and Pankaew (2011) conducted a study on the four dimensions of quality of life-Tphysical, social, emotional and role (school) functioning-using the Peds QLTM 4.0 Generic Core Scale to evaluate the patients' HRQoL. This study objective was to evaluate the quality of life in Thalassemia patients treated through three iron-chelating agents. The cross-sectional study was conducted with children and adolescents of thalassemia at Phramongkutklao Hospital from December 2006 to November 2007. The written parental informed consent were obtained prior to their participating in the study. The study was approved by the Hospital Ethics Committee. Inclusion criteria were thalassemia patients 6-18 years of age, who regularly received the blood transfusion, had serum ferritin > 1,000 ng/mL, and were being treated along with iron chelation. The data was analyzed through SPSS (Statistical Package for the Social Sciences) program version 13.0. The assessment of HRQOL of Thalassemia patients showed that psychosocial health had a high score than physical health, especially emotional functioning, which were different from the findings in an earlier study. It was concluded that the medical therapy of these patients should be supported with the psychological aid and psychiatric treatment. The credit and management of psychological problems that accompany chronic physical sickness including thalassemia would optimize treatment outcomes and HRQOL. In the present study forty-nine thalassemia patients were enrolled and treated by iron-chelating agents. The Quality of Life showed no significant differences in age, gender, type of thalassemia, and the serum ferritin. The multivariate regression analysis showed that there are no significant differences in clinical severity, age onset, and the pre-transfusion hematocrit level. The quality of life in thTalassemia

children illustrate improvement of psychosocial health, especially social functioning. These three iron-chelating agents had no distinction in impact on health-related quality of life. The study aims to assess the HRQOL of Thalassemia children who were receiving blood transfusion and iron chelation. The quality of life in Thalassemia children showed an improvement of psychosocial health, especially social functioning. The three iron-chelating agents have no significant difference in impact on health-related quality of life.

2.9.6 Thalassemia Major: A Public Health Problem

Prasomsuk et al (2007) conducted a study on the lived experiences of mothers caring for children with Thalassemia major in Thailand. The Thalassemic patients should be given continuous cure throughout their lives due to physical and the psychological effects of this disorder, their families are also impacted. The qualitative study discovers the lived experiences of 15 mothers of children with Thalassemia major by conducting the semi structured interviews; the data were analyzed by utilizing content analysis. The study identified six themes: psycho social problems, lack of knowledge about thalassemia and concerns for the future, financial difficulty, social support systems and the effectiveness of health care services. The findings suggest that a holistic, culturally sensitive nursing approach must be considered when caring for children with thalassemia.

2.10 Familial Aspects of Thalassemia

Najafi et al (2001) concluded that Thalassemia is one of the most widespread human genetic blood disorder in the world and its provides many harms for patients, families and the health care system. This model helped the families with sick children to empower to face the disease and its complications. For the said purpose knowledge and attitude of patients and their families regarding the disease should be updated. This study evaluated the effects of empowering family centered model on the knowledge and attitude of mothers who have children's with Thalassemia referred to the Thalassemia Center of Kerman. This study was designed to determine the effectiveness of family centered empowerment model on mothers' knowledge and the attitudes about thalassemia disorder. The major objective of this study was too assessing the effect of family-centered empowerment model on mothers' knowledge and attitudes about disorder of Thalassemia in children with Thalassemia. The semi-experimental study was done on 86 children among Thalassemia that were randomly divided into the two groups. The questionnaire was filled with demographic information and the knowledge and attitude of mothers about the disease. A questionnaire was tested for the content validity and reliability (internal correlation). Information was given to the first group and second group did not obtain any more information. After the intervention final assessment was performed one and half month later. The data examination showed that before intervention, average awareness and the attitude of mothers in test group were no significantly different with the control group ($p>0.05$). Though, after performing the model in test group, this averages was significantly higher in test group than the control ($p<0.05$). The results of the present study indicated that implementation of family centered empowerment model are useful on knowledge and attitudes of mothers of children with thalassemia. The study was a quasi-experimental study and eighty six mothers of children from 6

to 12 years old with Thalassemia referred to the Thalassemia Center of Kerman entered of this study after inform consent and explaining plans and goals. The subjects randomly were divided into two groups control and intervention. The knowledge and the attitudes of all parents were evaluated through questionnaire before intervention. Questionnaires included the demographic information, and knowledge and attitudes regarding parents about Thalassemia. They commence in the group sessions and discussed use of the pamphlets and slides about disease. According to the model first, knowledge and awareness of parents and patients about disease were increasing. In the next step or decoding phase problem, their self-belief should be improved. Then they accomplished that they could contribute in programs of care. In the third step, educational broachers and other handouts and CD audio tracks were given to the family members, which increased awareness about disease and improved the attitude of children in care procedure. Then evaluations were performed one and half month after the intervention for both groups. Results of this evaluation were analyzed throughout statistical software Statistical Package for Social Sciences (SPSS) version. Study has been discussed the impact of family centered empowerment model on knowledge and the attitudes of parents with Thalassemia children. Fortunately, the knowledge and attitude of parents regarding their children disease were significantly enlarged after intervention. The results showed that implementing family centered of empowerment can increase the awareness and attitudes of mothers of thalassemia children. They could deal with the better and easier with more awareness and the better attitude (pp.98-102).

2.11 Reproductive Behavior of Mothers of Children

Habibzadeh et al (2012) conducted a study on the reproductive behavior of mothers of children with beta-Thalassemia major. It was revealed that Thalassemia is one of the most widespread monogenic autosomal hereditary diseases throughout the world. The cross-sectional

questionnaire based study was done at the reproductive behavior of one hundred and fifty six (156) mothers of affected children with beta Thalassemia major in Fars province, southern Islamic Republic of Iran. The results indicated that reproductive compensation occurs in the families with a child with Cooley anemia in this province. The genetic counseling, either before marriage or after birth of the first affected child, had a major effect on lowering the number of children born. The study was conducted to know the reproductive behavior of mothers of children with beta-Thalassemia major in Fars province, southern Islamic Republic of Iran. The study was done in the first week in July 2005; the mothers of all Thalassemia major patients who attended the hospital Dastgheib affiliated to Shiraz University of Medical Sciences were interviewed through a trained nurse or a general practitioner. The major objectives of study were described to the participants and consent was taken before enrolment of the study. Every mother was asked whether she had had genetic counseling before the marriage or after birth of her first affected child. The only 7 (4.5%) mothers had received genetic counseling before marriage. Genetic counseling, either before marriage or after the birth of the 1st affected child had the significant effect on lowering the number of children born. Therefore, in countries where the Thalassemia is prevalent, one of most effective way to control the birth of Thalassemia patients, it is necessary to establish a good counseling system. It was observed that the only 4.5% of mothers had received premarital counseling, but that after birth of their 1st affected child, many of them (23.1%), although not all sought medical counseling. In our knowledge, no such kind of study was previously conducted in the Islamic Republic of Iran. The numbers of mothers interviewed were also higher than the sample size of many other studies reported worldwide. Genetic counseling, both before and after marriage, has a considerable effect on this compensatory mechanism. The Islamic Republic of Iran has established a combination of carrier

screening and genetic counseling to be the most suitable approach to preventing the birth of children with Thalassemia.

2.12 Adjustment of Children with Beta Thalassemia and Their Families

Tsiantis et al (1996) conducted a cross national research study including various countries such as Italy, Cyprus and Greece to measure the psychological problems of families because of having a Thalassemic patient aged between 6 to 14 years. He collected a sample size of 188 Thalassemic patients who met the inclusion criteria of the study. By using semi structure interview he collected the data from these patients and then measure the psychological problems faced by the parents of Thalassemic patients in these countries. He revealed that in Greece, majority of mothers are being blamed as a major reason of having a Thalassemic child as compared to other countries. Results of the study revealed the negative relationship between psychological burden and the treatment. It means if a good a quality of treatment are provided to patients, psychological burden go down but as quality of treatment compromised, psychological burden go up. Therefore, researcher recommended that concentration should be given on the treatment and prevention method and techniques. It keeps a dual benefits, quality of treatment will help in decreasing the psychological burden on patients' families. Similarly, prevention programs will help families to know about Thalassemia and will assist them to adopt coping mechanism to avoid Thalassemia in subsequent child. He also recommended the key role of teachers, doctors, and close relative in the social bindings of Thalassemic patients, this will not only help to fight against the disease but also will avoid them to get psychological effect of disease and its continually treatment (pp.193-203).

2.13 Prevention of Thalassemia

Bejaoui and Guirat (2013) carried out a study to understand the epidemiological profile and clinical characteristics associated with Thalassemia major patients in Tunisia. Retrospective and descriptive observation was the major feature in the study. Various medical centers and institutions were included in this study and questionnaire was sent to 33 various institutions providing a blood transfusion and treatment facilities to Thalassemia patients. The questionnaire gathered clinical and demographic data. The inferential statistics were applied to assess the inter group significance among categorical variables, and t- test was employed to decide the difference among categorical variables. Statistical Package for Social Sciences (SPSS) version 11.5, p value<0.05 was considered statistical significance. Health education and screenings are the best way to reduce the incidence of these diseases, which might be shown in social and health benefits and financial saving. Study revealed that majority of the Thalassemic patients were from the area north west region of Tunisia and in clinical characteristic associated with Thalassemia major patients revealed that one of the major reason associated to death of the half of the Thalassemic patient were heart failure.

Dhamcharee, Romyanan and Ninlagarn (2001) carried out a study to identify the problems associated with genetic counseling in Thailand because genetic counseling has proved a very useful strategy to control the birth of Thalassemic patients. Therefore, researchers aimed to identify the problems relating to genetic counseling in various hospitals and places of Thailand to make it more effective and useful. Study reported that a large numbers of the hospitals were supporting genetic counseling with the help of other organizations but there were a few hospitals which were continuing genetic counseling by their own resources. Researchers recommended

that there was a need to adopt a standardize genetic counseling guideline to provide awareness to the parents of the Thalassemia patients effectively and also to general public as well (pp.413-18).

Ghotbi and Tsukatani (2002) explored various prevention mechanisms that can be useful in Iran to prevent Thalassemia and to avoid the economic burden that expend on the treatment and management of the Thalassemic patients. Researchers' explored prenatal diagnosis of Thalassemic disease is the most successful method to prevent from Thalassemia disease. Many countries have practically exhibit this method, which help them to reduce the rate of Thalassemia birth. Screening of the couple before marriage found a practical way with significant results in this study to prevent from Thalassemia. Researchers reported that Thalassemia is the common and increasingly disease day by day in Iran. According to an estimation about 8, 000 pregnancies every year are at risk. Moreover, in Iran 25,000 major Thalassemic patients are getting treatment in Iran. These numbers of patients are increasing every year because in Iran it is prohibited to abortion after 4 months of pregnancy due to Islamic teachings and beliefs. Therefore, if an infant diagnosed a victim of Thalassemia in pregnancy, it gets impossible for parents to get abortion in Iran. This is found another reason in increasing of Thalassemia. Though the blood transfusion organization (BTO) and Thalassemia Patients Supporting Society (TPSS) decided to collaboratively run a program in which school going children will be screened for beta Thalassemia. This will help in reducing the Thalassemia in Iran by its spreading (pp.1-15).

Vang et al (2000) declared that Thalassemia is an inherited disease and the study was to locate the feasibility of screening programmes in Hmong population. Its first aim was to examine this program. The second aim was to know the prevalence of Thalassemia and to educate the

Hmong people. Thalassemic major has been a serious public health concern. So effective education and screening can decrease the prevalence of Thalassemic major. Third aim was to establish the reliability of the two different methods of screening in Hmong population. Studies show that in Southern Asia, Thalassemia is in a high frequency. A successful module was developed by the Health Research, Chulalongkorn University to monitor Thalassemia among the Thai people. This study highlighted the feasibility of the educational and Thalassemia screening programme among the Hmong people. A pre-test and post- test design was applied; the participants (N=12) were living in Thailand and they could read English and were between the ages 18-50. All the participants had two meetings with the researchers. In the first meeting their knowledge about Thalassemia was judged, the second meeting consisted of evaluating the knowledge and providing counseling and written report of individual blood sample. Almost (82%) of participants did not know about the Thalassemia major before participation. This programme gave them easy understanding. After screening out of eleven participants two were the carriers of Thalassemia. To decrease the ratio of Thalassemia it was necessary to be the part of risk diminution of health services. Screening can examine a large number of Hmong people to find out and verify the prevalence of Thalassemia. The researchers can understand easily the status of prevalence of Thalassemia in order to better health condition. The new programme could be copied in other marginal group samples in Thailand. It could also be copied among English speaking Hmong people in the America.

2.14 Premarital Screening and Termination of Pregnancy

Karimi et al (2008) this study was to focus the opinions of the physicians about termination of pregnancy due to Thalassemic major, Hemophilia and Down's syndrome. The

questionnaire was designed for preferred physicians with the help of stratified random sampling to decide following: gender, age, knowledge of prenatal diagnosis, recommended age for abortion, agreement in abortion. Mostly physician agreed to abortion with Thalassemia major and Down's syndrome while for hemophilia they opposed abortion. The study was started to know the opinion of the Physician of Iran about termination of pregnancy due to Thalassemic major, Hemophilia and Down's syndrome. With the help of cross-sectional and descriptive study of three months in the Shiraz University of Medical Sciences in Shiraz all the physicians agreed to the abortion due to three genetic diseases (Hemophilia, Down's syndrome and Thalassemia major). This study was also accepted by the Medical ethics Committee of Shiraz University of Medical Sciences. All the physicians gave their consents in written forms. About 384 out of 770 physicians were for this research anonymously with the help of stratified random sampling. Just 323 physicians took part in this study. These were the students of Shiraz University of Medical Sciences. Questionnaire took 20-30 minutes for completion and it exposed opinions of the physician about their view on abortion for Down's syndrome, hemophilia and Thalassemia major. Statistical Package for Social Sciences (SPSS) version 11.5 was used for data analysis and Chi square were done for inferential statistic. The P value less than 0.05 were consider ed significant. The results showed that 91.3 percent physicians gave their consents to abortion due to the fetal diseases like Thalassemia major and also because of the fact that in Iran Fatwa by Ayatollahs has been declared in favor of abortion due to the genetic disorder before 16th week of growth. To the abortion for Thalassemia major and Down's syndrome 78.6% physicians agreed and to hemophilia 40.6% physicians recorded their consents. Thus majority of the physicians accepted abortions in cases of Down's syndrome Thalassemia major (pp.1-4).

Amooee et al (2011) analyzed in their study the maternal and fetal effects and the risk factors linked with patients with β-Thalassemia minor during pregnancy. The researchers closely studied it in two universities affiliated with hospitals in Shiraz, a city in Iran between the time span of 2006-2008. They mentioned that β-thalassemia is very common in Iran; its carriers exceeded two million in the country. Approximately 110 mutant genes had been identified around the globe of which 21 were present in Iran. It was recognized that women with Thalassemia minor during their pregnancy would have possibly severe anemia between the end of their second and beginning of third trimester, due to which vigilant maternal and fetal monitoring during pregnancy is vital by fetal medicine, genetic councilors and hematology specialists. The researchers performed case-control study; both groups were based on 510 β-Thalassemia minor participants and 512 healthy participants, all with single pregnancy. Results revealed that no major diversity between the both groups in the terms of baseline characteristics, pregnancy hypertension and gestational diabetes neither visible difference among the groups score, ICU admissions and placental abruption, on the contrary caesarean delivery was more frequent in case group in comparison with the control group. It was concluded that overall β-Thalassemia minor had no adverse effects on the pregnancy (pp. 9-14).

This study was started to see the possibilities of screening in an extended family and to review the consents of parents to exchange information of their Thalassemic children with the relatives. The second objective was to see the behavior and response of relatives toward the screening of the extended family and to find the difficulties in its acceptance. The study was conducted in the Department of Medical Genetics, Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow, India, during 1998-1999. Thalassemia is one of the most alarming diseases and its control is possible by screening. The purpose of the study was to explore the

feasibility of the screening in the extended family to locate the carriers and to stop the birth of Thalassemic child and to find out the barriers in its acceptance. By using the pre-designed questionnaire, just 100 parents were interviewed. The results exposed that ninety six parents were ready to share the information regarding Thalassemic children with friends and relatives. Fourteen families were screened while relatives of sixty two parents showed their fear of being carriers. Another thirty four families could not be screened due to the lack of screening services in the town and tests expenditure, and lack of inadequate motivation. It is found that the parents have no fear in sharing information regarding their Thalassemia children with their relatives. Anyhow communication need be improved for the families to accept the risk of having a Thalassemic child. Moreover screening must be available to motivate high risk groups through awareness increasing workshop (Saxena & Phadke, 2011).

2.15 Genetic counseling for Thalassemia

In Bangkok and Thailand a survey was conducted for the Thalassemia services by using a designed questionnaire. The study objectives were to examine the healthcare system, genetic counseling methods, attitudes and knowledge of counselors. The basic problems in genetic counseling were subsequent: the problem of Thalassemia being neglected by the administrators, there are irregular services and team work, need of Thalassemia support group, awareness and inadequate number of counselors. The possible solutions were offered. The study was to locate the hidden obstacles and problems. So genetic counseling that is the critical components for the successful prevention of Thalassemia has taken important position to tackle the difficulties and problems. If the counselees are in a large number they should be divided into different groups (Dhamcharee, Romyanan, & Ninlagarn, 2001).

The study was conducted to reduce the births of Thalassemic children with immediate effect. The strategy were adopted for screening of Thalassemia carriers was to target the population of pregnant women attending the hospitals/ health care centers so that antenatal diagnosis and counseling could be offered in the current pregnancy itself. The wife was tested first, and then husband was asked to be tested if the wife was found to be a carrier. This reduces the screening load to fifty percent. If both the wife and husband are found carriers the couples at risk were offered for the prenatal diagnosis. Thus a total of twenty couples opted for prenatal diagnosis by DNA analysis. Twenty six pregnancies from twenty couples were investigated (one parent came twice). Prenatal diagnosis by DNA analysis showed 30.77% affected fetus having Thalassemia mutations in homozygous or double heterozygous state while 69.23% were unaffected (Gajra, Chakraborti, & Sengupta, 2002).

Overall, the literature demonstrated that Thalassemia is a disease of blood disorder, but has strong associations with psychological burdens, economic condition and social impact on the patients and their families. The literature also indicated that Thalassemia is an inherited deadly disease but it is 100% preventable. Many countries have successfully controlled the disease by spreading, through running public awareness programs at national level, and by making a mandatory pre-marital screening. It is also evident from the literature that preventing from disease is far easier than in its control once it hits to a child. It is found that currently in Pakistan; over 120,000 children are suffering from a Thalassemia. The number of Thalassemia patients is increasing day by day due to lack of awareness of the disease, cousin marriages, lack of knowledge of pre-marital screening, and to non-availability of public awareness programs at a wider level. Limited studies have been conducted in Pakistan to explore the perceptions of parents regarding Thalassemia disease; its social, economic and psychological impact on patients

and their families. Although, literature on preventing mechanism of Thalassemia is easily available on the internet, but it is mainly in English language and the majority of the parents in Pakistan are computer illiterate. Overall, the literature indicated a wide gap of lack of studies on the perception of Thalassemia patients and their families regarding, its social, economic, and psychological impact on patients' families. The prevention of Thalassemia disease through awareness programs at national level, covering pre-marital screening, and counseling of individuals need to be launched. The literature also indicated the need for legislation on Thalassemia screening before marriage which can produce the positive results and can help the prevention of Thalassemia in Pakistan.

Chapter No 3

Research Methodology

3.1 Material and Method

This study is designed with an aim to identify the Impact of Thalassemia Major on Patients' Families in Pakistan. This chapter is distributed into two sections. First section describes the material and methods adopted for quantitative approach and second section explains the methods used for qualitative approach. This chapter also explains population of the study, selection of sample size and the way respondents have been selected, the method with which they have been approached and their responses have also been secured. Data analysis procedure, statistical techniques and methods which have been used to present results of this study as well as coding and themes which have been drawn from Focus Group Discussions have also been explained. Overall, this chapter explains the methods and the procedures which have been applied by a researcher to carry out this study.

The researcher has used mixed method to carry out this study; which includes quantitative and qualitative methods. Quantitative approach is employed to gather numerical data to give details predict and manage phenomenon under study. Through quantitative methodology, the researcher has found cause-effect relationships between variables while qualitative research methodology is used to gain insights of the problem which is not possible otherwise. In qualitative approach, researcher preferred FGDs, for two reasons (i) to validate the results which have been gathered through quantitative approach (ii) to understand the new dimensions or area of the problem. Interview schedule is conducted to gather data from respondents. Interview

schedule is more useable and acceptable method for research in social sciences particularly in sociology (Gay, 2000; 622).

3.2 Research Method for Quantitative Approach

Choosing research methods depend on the research problem as well as the aim, audience, resource limitations and the personal experiences of the researcher (Creswell 2003; Pickard 2007). It has been ascertained that various methods of research have been used in various studies in Social Sciences for example Torre et al (2003) and Change (2004) used Quantitative Methods, but on the other hand, Deshpande et al (2003) and Bryant (2004) used mixed methods approach which includes qualitative and quantitative methods.

As for interview is concerned this method is likely to be managed through oral swap (Gillham, 2000; Ritchie and Lewis, 2003) and as such its usefulness thorough based on statement ability of the interviewer (Clough and Nutbrown, 2007), which takes account of the aptitude of the interviewer to clearly questions structure (Cohen et al., 2007); listen attentively (Clough and Nut-brown, 2007); basis, prompt, probe appropriately (Ritchie and Lewis, 2003); This type of interviews provide variety through which the researcher fulfills his requirements by using the methods like 'unstructured' and 'structured'. Through 'Structured' interview he can observe the interviewee with in structured questions and through 'Unstructured' he also can judge the respondents closer.

3.3 Population of the Study

The population of this study comprises of registered Thalassemia Major Patients at four Thalassemic c enters; (1) The Children's Hospital and the Institute of Child Health Multan (CH&ICH), (2) Fatimid Blood Foundation (FBF), (3) Minhaj-ul-Quran (MUQ), and (4) Amina Blood Foundation Multan (ABF) (Table 3.1).

A total, 2500 of children were registered in above mentioned Thalassemia Centers (Appendix A). Parents (Mothers and Fathers) of these registered children were the population of this study.

Table 3.1 Distribution of the Registered Patient in Thalassemia Centers

Thalassemia Centers	No of Thalassemia registered patients
Thalassemia / Hemophilia Centre, The Children's Hospital & the Institute of child health Multan	500
Fatimeed Foundation	1500
Minhaj Al-Quran	250
Amina Blood Foundation	250
Total number of Thalassemia registered patients	2500

3.4 Sample Size and Sampling Procedure

Proportion allocation method of Sampling (n1= N1/Ni x ni: A.L.Bowley: 1920) was used to draw a sample for this study (Table 3.2).

The detail is given below:

Table 3.2 Distribution of proportion allocation

Hospitals / Health Centers	No of Thalassemia registered patients /Children	Total Number of Parents (Mothers and Fathers)	Sample Size
Thalassemia/ Hemophilia Center, The Children's Hospital & the Institute of Child Health Multan	500	1000	100
Fatimeed Foundation	1500	3000	300
Minhaj Al-Quran	250	500	50
Amina Blood Foundation	250	500	50
Total	2500	5000	500

Researcher has used Bowley (1920) sampling method in (table 3.2) to draw a sample. A total sample for this study is drawn was 500 (N).

3.5 Instrument

Interview schedule was developed after accessing the situation of Thalassemia Centers and population in Multan and also conducting a detailed relevant literature review. The Interview schedule was discussed with two senior doctors (>8 years' experience) working at Thalassemia Centers. It was revised to incorporate the recommended improvements. A five and four point Likert scale was used to procure the opinion of respondents about every statement that asked in the questionnaire. A Likert scale measures the level of agreement and frequency of use, i.e. it shows the opinion of a person that up to what extent he agrees or disagrees with the question. The most common scale which are 5=Very Often, 4= Often, 3= Sometimes, 2= Seldom, 1= Never and 4= To a Great Extent, 3= To Some extent, 2= Very Little, 1= Not at all, was used in this study by the researcher.

3.5.1 Question Wording

The questions wording were also the key considerations. Allen Edwards (1957) was recognized for his work on the attitude scales and stated that "avoid the use of words that may not be understood by those who are given to complete the scale" (P. 13). Therefore, the researcher has kept with care the general principle of question wording while developing a questionnaire. Wordings were kept simple and understandable to the respondents; so that they could easily able to understand the question and answer it accordingly. If in case respondents were asked the same questions again, their answers were the same. So wording of questions was evaluated in terms that they could provide reliable information, while Jargons, abbreviations and short forms of the terms were avoided.

3.5.2 Question Order

The researcher gave significant attention to the ordering of the questions. According to Bradburn, Sudman, and Wansink (2004) the researcher should keep in view the significance of combination items "into coherent categories so that all items flow smoothly from one to the next". Therefore, Questions grouping and ordering were particularly kept in logical sequence. Homogenous questions were ordered together in sub-scales while heterogeneous questions were ordered separately. Bradburn, Sudman, and Wansink (2004) concluded that questions should be in such a sequence as to reduce the result of respondents' respond to following questions.

The questions were divided into 5 sections. Section 'A' comprised on questions relating to demographic information such as gender, age, relationship with patients, residential area, education status of the respondents, occupation and monthly income. The 'B' Part related to questions regarding the general information of the respondents. Questions relating to awareness of a Thalassemic disease were included in Part 'C' of the structured interview. The Part 'D' was related to questions regarding social impact of disease on patients' families. The Part 'E' of the Questionnaire was related to questions about economic impact of disease on patient's families.

3.6 Pilot Study

A Pilot study was carried out at the completion of 15 questionnaires, to check the validity and reliability of the interview guide. Response of first 15 respondents was discussed with an expert panel that included one subject specialist from the field of Sociology and two Senior Doctors (>8years' experience) working in Thalassemia Centers.

According to Burns (2000) there are two incredible types of validity; (i) Face validity and (ii) Content validity (P.585). Face validity can be measured by asking subject specialist of

the field. Subject specialist examines the questions' statement and tells whether the statements are appropriate and tend to gain the required results or it is inappropriate and required information cannot be obtained. In other words, researcher can ask about what he is intended to ask, while content validity can be measured by using a particular statistical formula to judge the response of the panelists, who are asked to assess the questions whether statements used in Interview guide is relevant, useful and essential or useful but not needed in the content of the study.

3.7 Data Collection Procedure

The quantitative data collection process was started from February15, 2012 to October10, 2012. Before starting the data collection process, the researcher had taken an appointment with the In-charges of all Thalassemia Centers which include (i) CHC&ICH, (ii) FBF, (iii) MULQ and (iv) ABF Multan. The purpose of this appointment was to give them briefing regarding the objectives of the study and obtain consents to provide a researcher to access to the subjects, in order to gather data from respondents. The In-charges of Thalassemia centers were requested to provide prescribed lists of registered Thalassemic children in their respective centers. After gaining permission from respective In-charge, data collection process was carried out. Nurses of the participating Thalassemic centers worked as study facilitator. The major role of facilitators was to lend support to the study within their Thalassemic centers. They also helped in getting the responses from the participants of this study.

All the respondents participated voluntarily in this study and there were no restriction for respondents to participate in this study. Respondents were requested to participate in interview schedule. Respondents were explained the duration of the structure interview and were briefed

about the study. They were also informed that they could leave the process of interview at any time. All the process of quantitative data collection was done in Thalassemic centers before or after the blood transfusion of the children. It was specifically taken with care that during blood transfusion interview process should be avoided.

Information gained from the participants of the study through Interview guide (Appendix B). Participants were requested to cooperate and answer the questions honestly. Participants' anonymity and confidentiality of the information was made assured.

3.8 Data Analysis

Data was analyzed statistically by means of Portable IBM SPSS Statistics (Statistical Package for the Social Sciences) version 19. The researcher used descriptive statistics which include frequency, percent, mean and standard deviation as well as Inferential Statistics which includes Frequency Distribution, Percentages, Bar Charts, Mean, Standard Deviation, One Way ANOVA, Independent sample t-test, Pearson Correlation, Cross Tabulation. The findings were presented in tables and interpretation of the finding was given in the text.

The variables studied were: age, gender, relationship with patients, residential area, education status, occupation of the respondents and monthly income of the respondents were independent. awareness of disease, social impact of the disease and economic impact of the disease were dependent. Comparison of different variables was made by applying Independent sample t-test which includes respondents' gender and social impact of the disease, residential area and social impacts of the disease, family structure and social impact of the disease, residential area and their awareness to disease, Education status and awareness toward disease. One way ANOVA test was employed to compare the level of education and awareness of

disease, similarly level of education and economic impact of the disease, level of education and social impact of disease, respondents' occupation and economic impact of the disease, blood transfusion and economic impact of the disease. Cross tabulation was used to compare the type of marriage and number of affected Thalassemia children. Relationships of various variables, such as economic and social impact of the diseases were found by applying Pearson Correlations and coefficient.

3. 9 Research Method for Qualitative Approach

Qualitative approach permits the researcher to study social issues in detail and in depth. A focus group discussion comprises a discussion on a specific topic with a small group of people. Groups should consist of 4-12 members that participate in an interview for at least 90 to 120 minutes (Quinn, 1990). In qualitative approach, focus group discussion method is the best to collect qualitative data and there are some principles to recruit the participants and to conduct a focus group discussion (Goldsman et al. and Greenbaum, 1987, 1988) and Burgess (1986) suggested that quantitative and qualitative data should be collected to complement and validate each other findings.

The researcher relied on purposive sampling; only those participants were included in this research who met the established criterion. Criteria include (1) Thalassemia affected child's parents, who require the support of blood transfusion (2) Child who is registered in one of these centers (i) The Children's Hospital & the Institute of Child Health Multan, (ii) Fatimid Foundation, (iii) Minhaj Ul Quran, (iv) Amina Blood Foundation. A total of (N=64) sample was drawn and participants were divided equally (n=16) from 04 blood transfusion centers. We conducted 08 focus group discussions (FGDs) divided equally into 08 groups comprising (n=2) participants from each blood transfusion centers. Mothers rather than their affected children were

chosen as participants because we trust that mothers can demonstrate the impact of Thalassemia on both their children and the family in a better way. A structure FGDs moderator's guide was developed for correspondence of research questions. To gain deep understanding, we divided questions in four major domains which were (i) Belief about child disease, (ii) Awareness and knowledge about Thalassemia, (iii) Thalassemia impact on child and family, and (iv) Prevention and future concerns. Participants voluntarily participated in FGDs, which were carried out from August, 2013 to October, 2013 after completing the quantitative data analysis. Before conducting FGDs, the participants filled a written questionnaire to give information about their demographic backgrounds. (Table. III). Majority 35(54.6%) of the participants were illiterate, therefore, keeping in view the convenience of the participants, FGDs were conducted in Urdu and other regional languages such as Saraiki and Punjabi. All participants provided written consent forms.

The moderators read a brief passage regarding Thalassemia. The passage that is stated tells that Thalassemia is an inherited disorder of blood with low numbers of red blood cells and deficiency of blood. Thalassemia is a disorder of blood that passes from parents to their children. Alpha and Beta are the two types of Thalassemia. When the couples have the same Thalassemia minor trait they are likely to have 25% children with Thalassemia major, and 50 % children with a minor Thalassemia and a 25% children (normal). For every one Focus Group Discussion was continued until the data dissemination was obtained to the required level or there was no information but obtained. Coding and categorizing were made by using the QSR NVivo-7. According to the research themes transcripts were thematically coded that is got from the negotiations, and the themes were further divided into sub theme. The research was accepted by the Medical Ethics Committees of all the Thalassemic Centers chosen for the research.

Focus group discussions were recorded in two ways (i) taking notes and (ii) tape recording. Key phrases were the source of notes; and the lists of the major points made by the participants were noted down. Words or key terms exposed in quotations mark capture the participant's own language. The main purpose of the written notes was to collect high quality data. Moderator made short notes quickly without intervening ongoing discussion. Besides increasing the exactness of data collection, tape recorder was also used which permitted the moderator to remain more attentive to the participant. The researchers themselves acted as moderators. The comfortable and neutral places were selected for participants in group discussion. The chairs were arranged in 'U' shape pattern with equal distance around the table. Before starting the each FGDs, a purposeful small talk was conducted in order to create an excited, comfortable and conducive environment. The effort was made to control the discussion group with proper techniques. Aggressive and dominants participants were controlled and introverted participants were encouraged to participate in the discussion. After discussion, tape recorder was turned off and a word of thanks was given to the participants. Then it was again asked if something is missing in the discussion to be told.

3.10 Focus Group Discussions (FGDs)

Focus group discussion is actually made to get recognition in social context because most of the people make decision in social context. People belonging to homogeneous group are invited to ponder on the questions. This type of discussion is usually comfortable and people enjoy during the discussion. They comfortably share their ideas; make additional comments, in spite of their own ideas they also listen to the ideas of other people and make major and minor premises. It is not requisite for a group to reach at some consensus. The session normally starts with a particular question in order to focus the discussion in a particular dimension. In all the

process of FGDs moderator plays an impartial role to make a conversation healthy and giving every participant an equal chance to put forward his/her opinion about a particular problem and highlight the related issue. A good moderator needs few pre-requisites in terms of professional approach and for the smooth running of discussion e.g. maintaining the situation and having the ability to get maximum information he requires patience, ability to control and professional approach. In addition, moderator must have ability to give equal space and time to each member of the focus group to avoid the dominance of one or two participants. The data from participants is their words and views. It is necessary to be sure what a person means when using a common language, because sometimes same words keep different meanings in various cultures. With small group of people in an hour, it is normally not possible to ask more than four to five major issues.

3.11 Advantages of Focus Group Discussion

Focus group discussion has the several advantages. It is highly efficient qualitative data collection technique. In limited time moderator can collect the maximum information from group of people instead of one person. Focus group discussion also provides some quality control on data information as participants tend to provide check and balance on information provided by one another other, exonerate fake or insignificant ideas. The people participating in the discussion contribute openly by targeting the most significant issues and topics included in discussion. Focus group discussions, when conducted properly and used carefully, promise to provide a rich and new way of gathering qualitative information (Krueger, 1988; AED, 1989).

3.12 Selection Process of Participants and Location

Different questions arise at the time of selection of the participants. How should the members be involved in discussion? How different groups of discussion are managed? At first,

which one should be invited? Composition of the group should be considered and there is always a concern about the size of the group and number of the groups. Normally, focus group is of four to twelve members but researcher can enhance the number of participant to check the maximum variation in responses. As for as, the location is concerned as to where the discussion should be conducted, a room of any house is the best place. Before, the selection of location, it should be ensured that the place may be neutral and approachable for every participant. Sitting arrangement may be a round table and all participants be in eye contacts with one another. Moderator should select conspicuous space to have an overview of all participants.

3.13 Precession of Focus Group Discussion

First of all, assistant moderator received the entire participants with good gesture. He introduced all the participants with one another. Before starting the discussion small talk was encouraged by the moderator to create an excitement, comfortable and friendly environment and keep the participants at ease. Precession of focus group discussion helped to understand the feeling of the participants to avoid controversy.

3.14 Recording the Focus Group Discussion and Written Notes

Focus group discussion was mainly recorded by the moderator in two ways (i) taking notes and (ii) tape recording. Notes were principally consisted on key phrases; lists of important points given by the participants were noted down on the paper. Key terms or words given in the quotation mark show the participant's own language. First and foremost aim of the research was to collect data and not to change the views of people. The main purpose of the written notes was to collect high quality data. Moderator tried to make short notes quickly without interrupting the ongoing discussion. Notes were taken depending upon the nature of study. Tape recorder was the part of the most important equipment of a researcher using qualitative methods. Besides it

improving the correctness of data collection, the tape recorder lets the interviewer be more attentive to the participants. The use of tape recorder also permits the need for taking notes. Notes in writing keep at least have two reasons. Notes taking interview helps the moderator to formulate new questions as the interview progresses. Taking notes is necessary to check the observation from the taped quotations.

3.15 Measures Adopted to Improve the Quality of Data

The following steps are adopted to collect the enriched information from the participants.

1- The researcher himself acted as a moderator.

2- The comfortable and neutral places were selected for female participants in group discussion. It was taken care that the selected places were peaceful and without disturbance.

3- The chairs were arranged in U shape pattern with equal distance around the table. The main motive behind it was that participants would be able to maintain eye contact with one another and listen to one another as they were sitting.

4- During tape recording prior tests were conducted to check the performance of instrument. In addition through rewinding and listening respondents were provided a check to listen whether he/she was speaking distinctly. In vice versa condition they were asked to improve their conversation.

5- A mechanism was developed for indicating interpretations, thought and ideas that might come to mind during interview.

6- The questions were arranged in a sequence and were kept on track.

7- Open ended questions were asked in order to allow the participation to answer from a variety of dimensions. Close ended question were avoided as such questions are against the essence of qualitative study.

8- Before starting the questions a purposeful small talk was conducted in order to create an excited, comfortable and conducive environment.

9- Sound background knowledge to each participant about the purpose of the study was provided to minimize strategy assumptions.

10- The effort was made to control the discussion group with proper techniques. Aggressive and dominants participants were also controlled and introverted participants were encouraged to participate in the discussion.

13- After discussion tape recorder was turned off and a word of thanks was given to the participants. Then it was again asked if something was missing in the discussion, once it was satisfactory in the view of participants, moderator thanked once again for co-operation.

3.16 Ethical Consideration

Respondents' anonymity and confidentiality were ensured. Informed consent was obtained from participants. During data collection process, purpose of the study was explained to respondents in detail. In case of their questions, they were answered calmly. Respondents voluntarily participated in this study. There was no compensation for responding nor was any known risk in participating in a study. Approximate duration of interview completion was also explained to respondents. Respondents were also briefed and encouraged to ask for the additional information or questions. In case they were not satisfied with the manner in which this study was being carried out, participants were provided the contact number and address of the researcher.

Chapter No 4

4.1 Data Analysis and Interpretation

This chapter keeps two portions; one portion consists on quantitative data analysis and second portion comprises on qualitative data analysis. A data which has been collected through focus group discussion has been analyzed qualitatively by using NVIVO-9 and a data collected through interview schedule has been analyzed statistically, through Statistical Package of Social Science (SPSS) 19 version. The statistics includes Frequency Distribution, Percentages, Bar Charts, Mean, Standard deviation, and One Way ANOVA, Independent sample t-test, Cross Tabulation and Pearson Correlation. This chapter deals with data analysis and interpretation of the results. The tables are according to the demographic profile of the respondents, education status of respondents, occupation of respondents, monthly income of the respondents, family size, number of other Thalassemia patient in the family, family structure, patients frequency of blood and source of blood, other complication associated with Thalassemia major child, types of marriage, age of diagnosis, management of medical expense, relationship between the couples, awareness of parents towards Thalassemia, emotional aspects in Thalassemia, social participation of the parents and the liaison of the parents with the non Thalassemic child. Analysis is to show the relationship between the number of Thalassemic persons and the socio demographic profile of Thalassemia child.

The analysis has been carried out to see the relationship between the socio demographic profile-gender of Thalassemia child and the number of persons with Thalassemia, treatment cost per month, respondents believe on some rituals regarding treatment, parents knowledge about test, respondents reaction from in-laws after diagnosis of child disease, respondents social

activities affected, respondents participation in different family gathering, respondents hesitation while talking about the disease of child with others, financial expenditures for treatment, financial burden because of child disease.

4.2 Quantitative Data Analysis

Table 4.1

The Distribution of respondent's by their age

Age	Frequency	Percent
15-20	25	5.0
21-25	107	21.4
26-30	111	22.2
31-35	134	26.8
36-40	53	10.6
41-45	40	8.0
46-50	14	2.8
51-55	9	1.8
56-60	7	1.4
Total	500	100.0

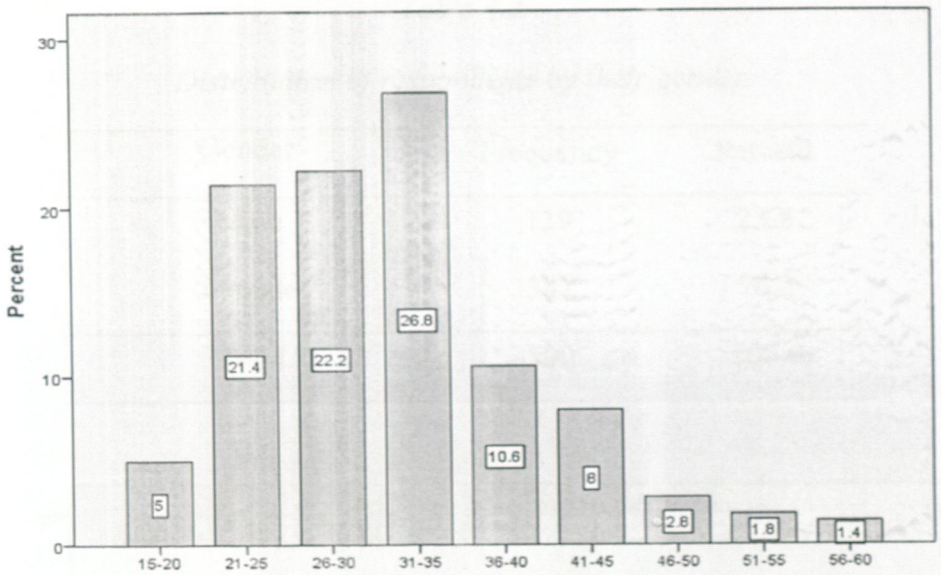


FIGURE 4.1 RESPONDENT'S AGE

Table No: 4.1 shows the distribution of respondents by their age. Respondents age was broad, with 25(5.0%) between 15- 20 years, 107(21.4%) from 21-25 years, 111(22.2%) from 26-30 years, 134(26.8%) from 31-35 years, 53(10.6%) from 36-40 years, 40(8.0%) from 41-45 years, 14(2.8%) from 46-50 years, 9(1.8%) from 51-55 years and 7(1.4%) between 56-60 years.

Table shows that most of the respondents 134(26.8%) were from the age group ranging 31-35 years followed by 111(22.2%) respondents from age group 26-30. While less number of respondents 7(1.4%) were from the age group 56-60 years.

Table 4.2

Distribution of respondents by their gender

Gender	Frequency	Percent
Male	119	23.8
Female	381	76.2
Total	500	100.0

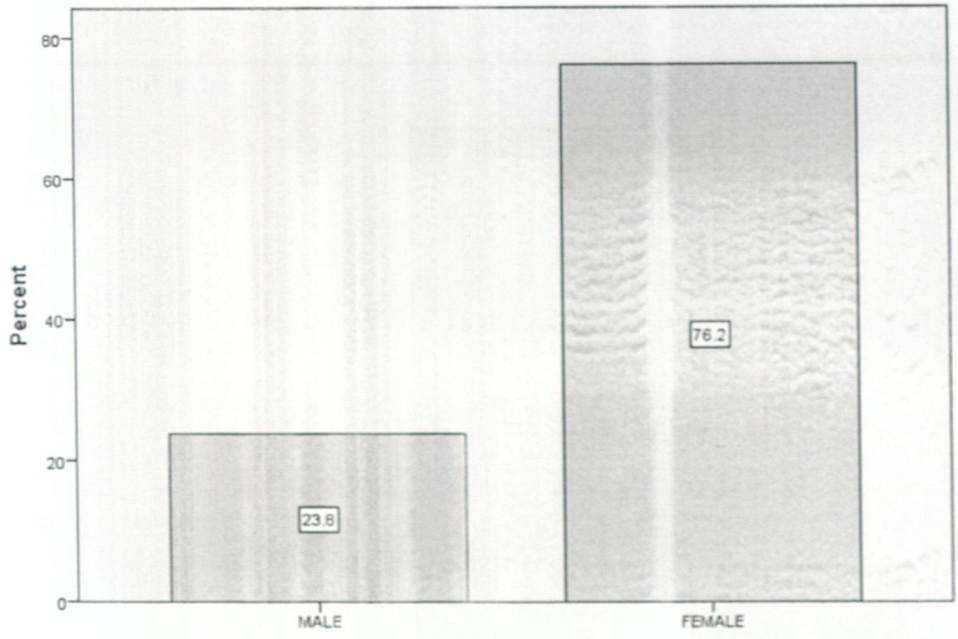


FIGURE 4.2. GENDER

Table No: 4.2 shows distribution of respondents by their gender. Demographic information shows that 119(23.8%) were male and 381(76.2%) were female.

Table 4.3

Distribution of respondents by their relationship with patient

Relationship Nature	Frequency	Percent
Father	100	20.0
Mother	329	65.8
Close relatives	71	14.2
Total	500	100.0

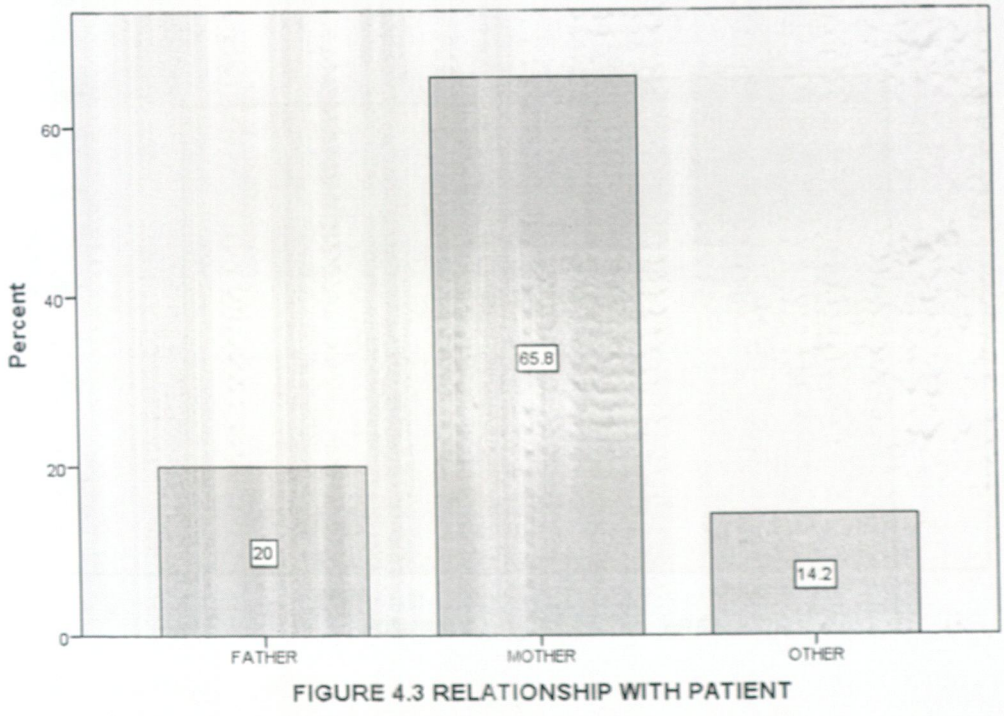


FIGURE 4.3 RELATIONSHIP WITH PATIENT

Table No: 4.3 indicates the distributions' of respondent's relationship with patients. Data indicated that 100(20.0%) respondents were patients' father while 329(65.8%) were mothers and 71(14.2%) were close relatives.

Table 4.4

Distribution of respondents by their residential area

Residential Area	Frequency	Percent
Rural	244	48.8
Urban	256	51.2
Total	500	100.0

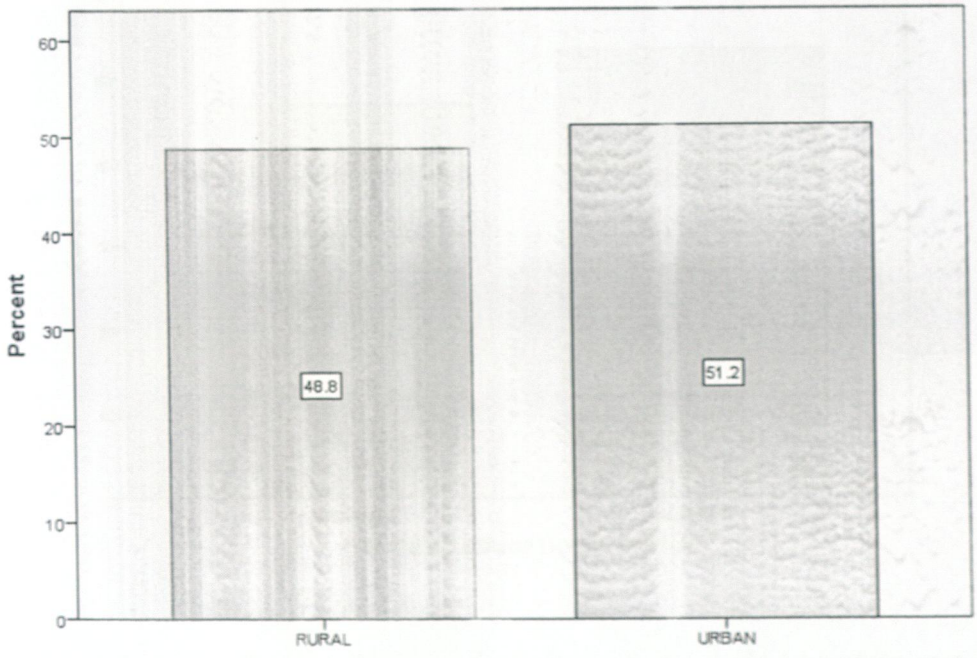


FIGURE 4.4 RESIDENTIAL AREA

Table No: 4.4 pointed out the distribution of respondents by their residential area. Above table reveals that 224(48.8%) respondents were from rural areas and 256(51.2%) respondents were from the urban areas.

Table 4.5

Distribution of respondents by their educational status

Education Status	Frequency	Percent
Literate	234	46.8
Illiterate	266	53.2
Total	500	100.0

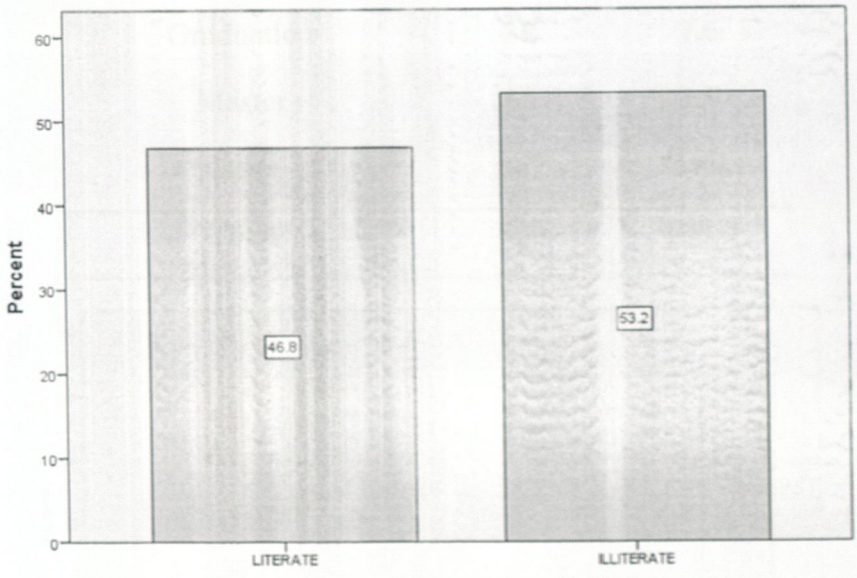


FIGURE 4.5 EDUCATIONAL STATUS

Table No: 4.5 shows the distribution of respondents by their education status. Analysis shows that 234(46.8%) respondents were literate and 266(53.2%) were illiterate. The above table depicts that illiterate respondents were more in numbers. Illiteracy among the families might stress on understanding and awareness of the chronic disease like Thalassemia.

Table 4.6

Distribution of respondents by their education level

Level of Education	Frequency	Percent
Primary	53	10.6
Middle	53	10.6
Matriculation	59	11.8
Intermediate	25	5.0
Graduation	38	7.6
Master	15	3.0
Other	257	51.4
Total	500	100.0

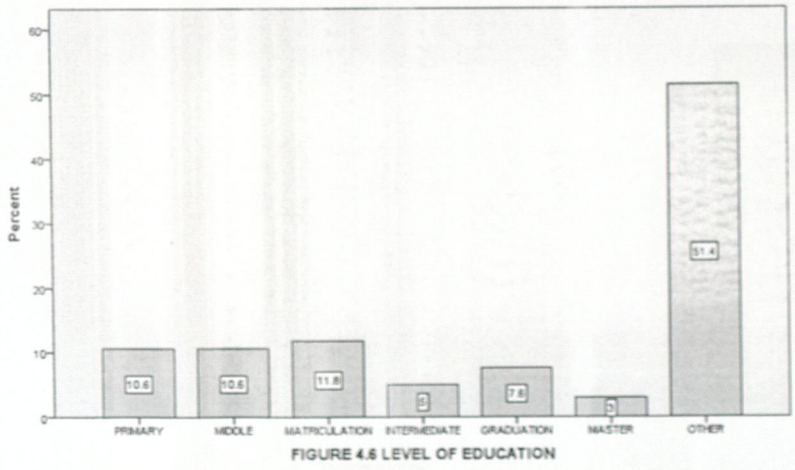


FIGURE 4.6 LEVEL OF EDUCATION

Table No: 4.6 reveals distribution of the respondents by their level of education. The data shows that 53(10.6%) respondents were of primary level 53(10.6%) were of middle level, 59(11.8%) were matriculates, 25(5.0%) were intermediate, 38(7.6%) were graduate, 15(3.0%) were Master and 257(51.4%) were illiterate. It was concluded that majority of the participants were not educated adequately.

Table 4.7

Distribution of respondents by their occupation

Occupation	Frequency	Percent
Unemployed	5	1.0
Business	12	2.4
Private	47	9.4
Govt	4	.8
Laborer	79	15.8
Unemployed	353	70.6
Total	500	100.0

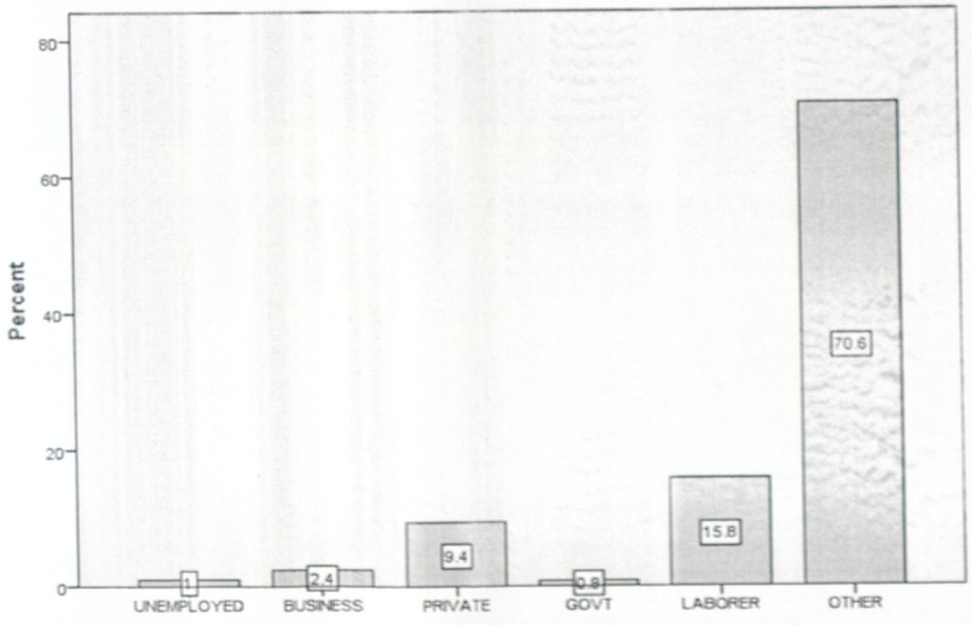


FIGURE 4.7 OCCUPATION OF THE RESPONDENT

Table No: 4.7 shows distribution of the respondents by their occupation. Of the total respondents, 5(1.0%) were unemployed, 12(2.4%) were working in the business sector, 47(9.4%) were doing private work, 4(.8%) were government employees, 79(15.8%) were laborers, and

353(70.6%) were unemployed. From the above table it is examined that, greater part of the respondents (70.6%) was unemployed. The lower level of education can be a cause of unemployment. Of the 500 respondents, 9.4% were working in the private sector and .8% in the government sector. To some extent the people in government sector get some assistance to meet the medical expenses. The minority, (15.8%) were laborers the most vulnerable because of costly medical cure for Thalassemia. Therefore they are unable to bear the medical expensive. It is observed that they only get a schedule work and are not capable to afford the medical costs.

Table 4.8

Distribution of respondents by their family monthly income

Monthly Income	Frequency	Percent
1000-3000	34	6.8
3100-5000	99	19.8
5100-7000	168	33.6
7100-9000	106	21.2
Above 9000	93	18.6
Total	500	100.0

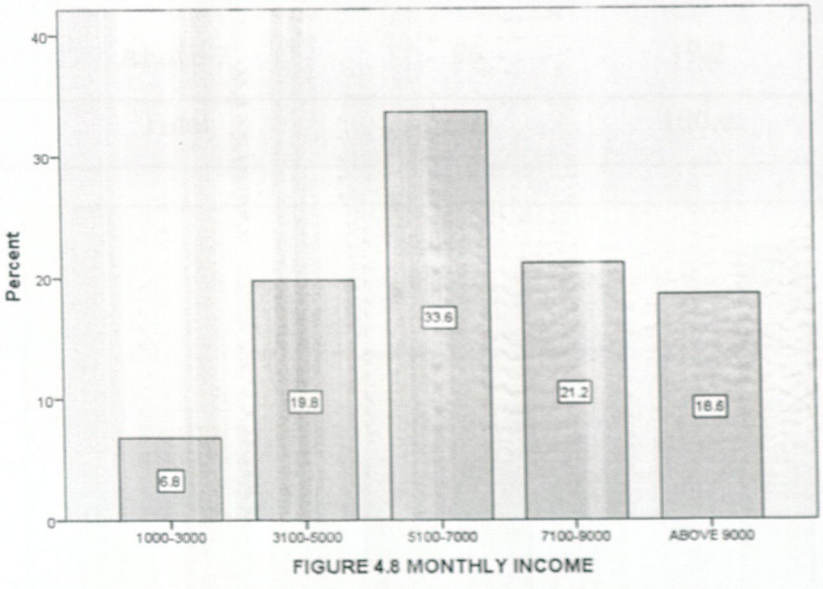


FIGURE 4.8 MONTHLY INCOME

Table No: 4.8 describes the distribution of respondents by their family monthly income. Amongst the total respondents 34(6.8%) respondents have the monthly family income Rs.1000-3000 while 99(19.8%) have the family monthly income Rs. 3100-5000, 168(33.6%) have the monthly family income Rs. 5100-7000, 106(21.2%) have the monthly income 7100-9000 and 93(18.6%) respondents have the monthly income above Rs. 9000.

Table 4.9

Distribution of respondents by their family size

Family Size	Frequency	Percent
1	38	7.6
2	58	11.6
3	83	16.6
4	74	14.8
5	88	17.6
6	46	9.2
7	17	3.4
Above 7	96	19.2
Total	500	100.0

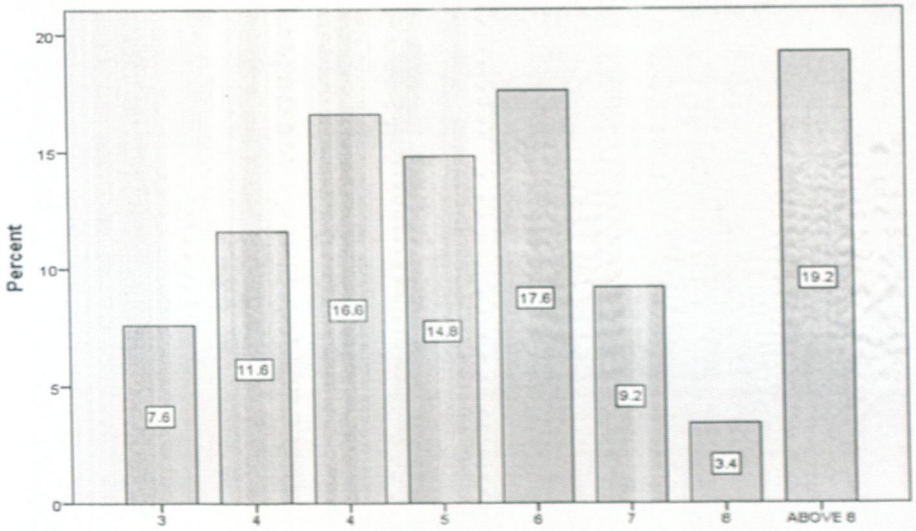


FIGURE 4.9 FAMILY SIZE

Table No: 4.9 indicates the distribution of respondents by their size of family. Among the total participants, 38(7.6%) have a single child, 58(11.6%) of the respondents have two children

and the 83(16.6%) of the respondents have three children, 74(14.8%) of respondents have four children, 88(17.6%) of the respondents had five children, 46(9.2%) of the respondents have six children, 17(3.4%) of the respondents have seven children and 96(19.2%) of the respondents have more than seven children. It is detected that the commonly, 88 respondents keep five Children.

Table 4.10

Distribution of respondents by their any other thalassemia patient in family

Response	Frequency	Percent
Yes	152	30.4
No	348	69.6
Total	500	100.0

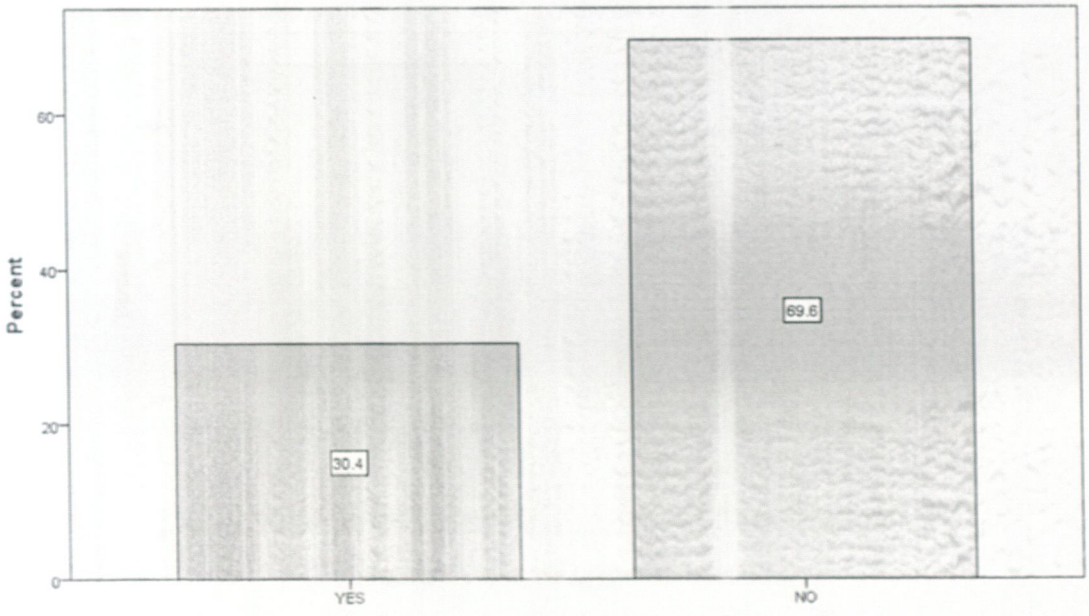


FIGURE 4.10 ANY OTHER THALASSEMIC PATIENT IN FAMILY

Table: 4.10 shows the distribution of respondents by their any other Thalassemia patients in the family. The data shows that 152(30.4%) respondents have more than one Thalassemia major child in the family while 348(69.6%) of the respondents were not have more than one Thalassemia child in the family.

Table 4.11

Distribution of respondents by their number of affected thalassemia children

Affected Children	Frequency	Percent
1	345	69.0
2	155	31.0
Total	500	100.0

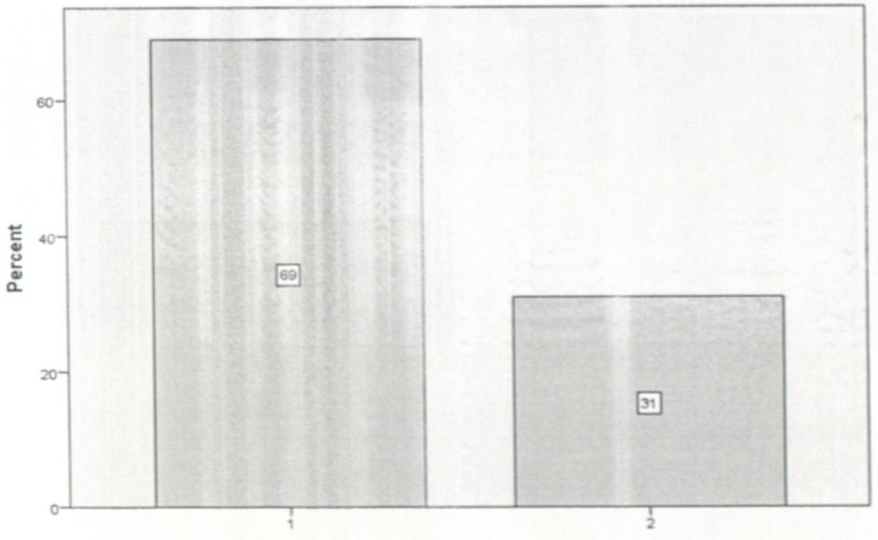


FIGURE 4.11 NO. OF AFFECTED CHILDREN

Table: 4.11 indicates the distribution of the respondents by their affected number of Thalassemia patients. Of the total respondents 345(69.0%) respondents have a single Thalassemia major child and while 155(31.0%) of the respondents have two Thalassemia Major affected children in their family. Almost the parents who had taken a Thalassemia child major they knew about Thalassemia and its nature. The chart shows that the majority (69.0%) have one Thalassemic child. It convinced them to accept the decision of preventing the birth of another Thalassemic child.

Table 4.12

Distribution of respondents by their family structure

Family Structure	Frequency	Percent
Joint	201	40.2
Nuclear	299	59.8
Total	500	100.0

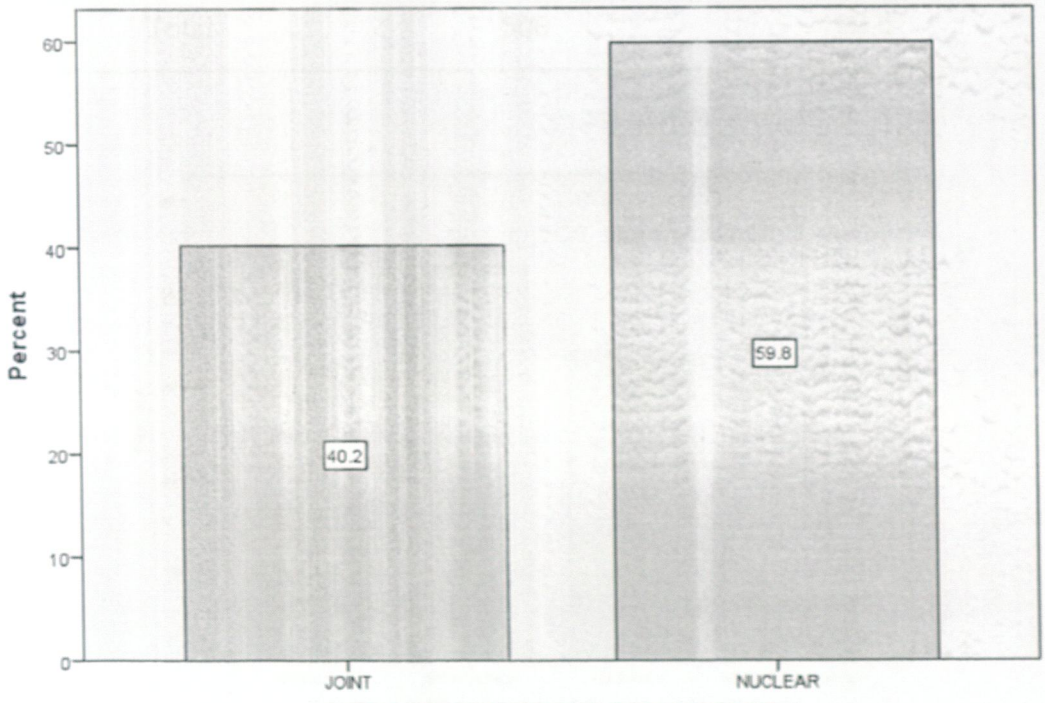


FIGURE 4.12 FAMILY STRUCTURE

Table No: 4.12 indicates the distribution of the respondents by their family structure. Of the total respondents 201(40.2%) living under the joint family system and 299(59.8%) were living under the nuclear family system. From the above table it is observed that the majority (59.8%) families were residing under the nuclear family system.

Table 4.13

Distribution of respondents by their children frequency of blood transfusion

Blood Transfusion	Frequency	Percent
Weekly	83	16.6
Bio monthly	214	42.8
Monthly	168	33.6
More than monthly	35	7.0
Total	500	100.0

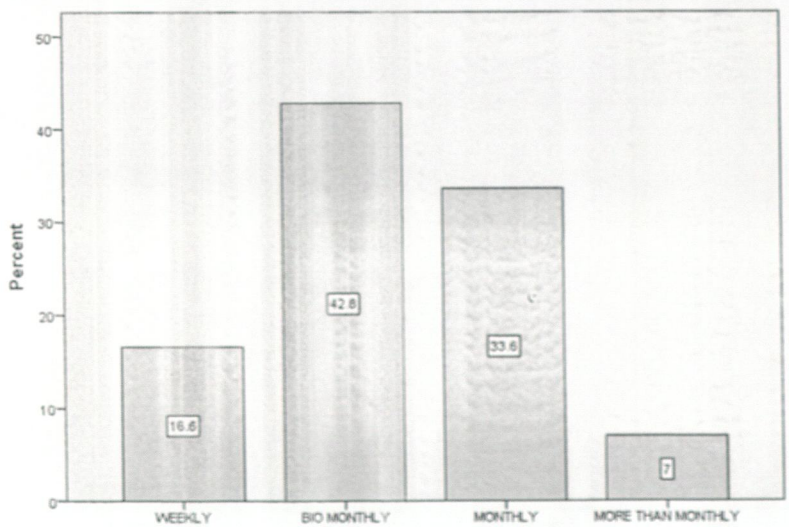


FIGURE 4.13 FREQUENCY OF BLOOD TRANSFUSION

Table No: 4.13 shows the distribution of respondents by their children frequency of blood transfusion. Among the total respondents, 83(16.6%) of the respondents weekly visited to the Thalassemia Centers for the purpose of their children transfusion while 214(42.8%) of the respondents visit Thalassemia centers after fifteen days. 168(33.6%) of the respondents visit for their children transfusion on monthly basis. Only 35(7.0%) respondents visited to the Thalassemia centers more than monthly.

Table 4.14

Distribution of respondents by their source of blood

Source of Blood	Frequency	Percent
Government	18	3.6
Both	40	8.0
Relatives	59	11.8
Friends	383	76.6
Total	500	100.0

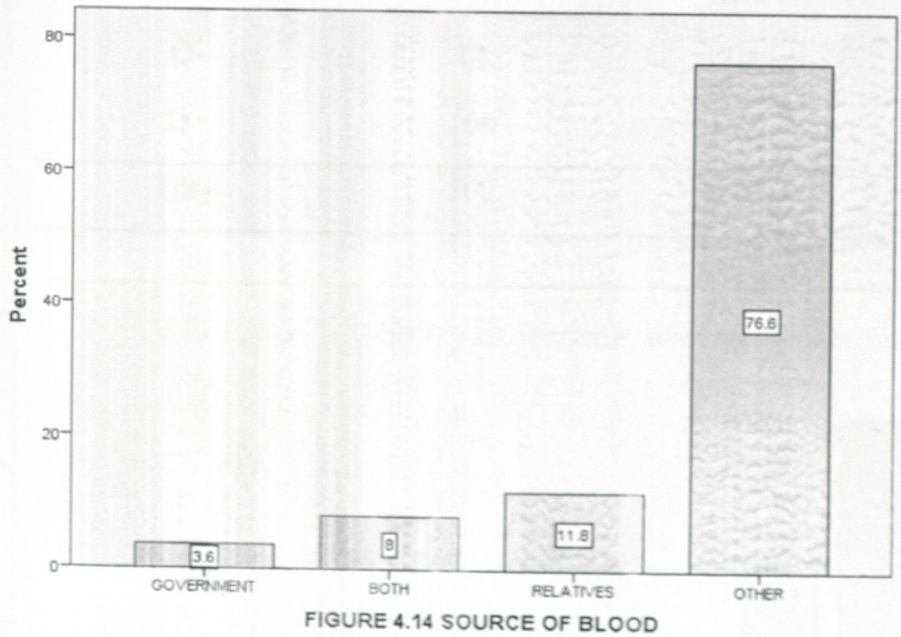


FIGURE 4.14 SOURCE OF BLOOD

Table No: 4.14 indicates the distribution of respondents by their source of blood. Among them, 18(3.6%) of the respondents received blood for their Thalassemia children through Government Health Institutions, 40(8.0%) of the respondents get help through both private and government hospitals while 59(11.8%) received blood with the support of their relatives and majority 383(76.6%) of the respondents have the only source of their friends.

Table 4.15

Distribution of respondents by their children blood groups

Blood Group	Frequency	Percent
A-	11	2.2
A+	86	17.2
AB-	9	1.8
AB+	42	8.4
B-	10	2.0
B+	160	32.0
O-	14	2.8
O+	168	33.6
Total	500	100.0

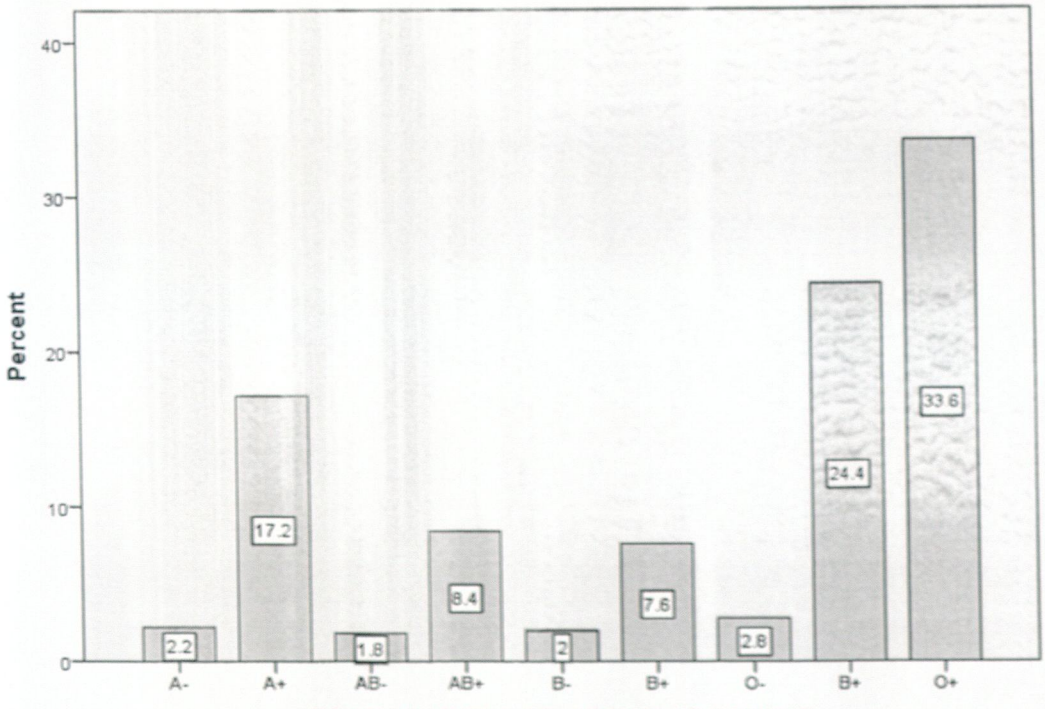


FIGURE 1.15 BLOOD GROUP OF PATIENT

Table No-4.15 shows the distribution of respondents by their Thalassemia Major Children's blood groups. Of the 500 respondents, 11(2.2%) of the respondents Thalassemia Children's blood group was A-ve, 86(17.2%) of the respondent's children blood group was A+ve, 9(1.8%) respondent's children blood group was AB-ve, 42(8.4%) were AB+, 10(2.0%) of the respondent's Thalassemia children's blood group was B-ve, 160(32.0%) respondents Thalassemia affected children's blood group was B+ve, 14(2.8%) of the respondent's children blood group was O-ve, while majority 168(33.6%) of the respondent's Thalassemia children's blood group was O+ve.

Table 4.16

Distribution of respondents by their other complications associated with their children

Complications	Frequency	Percent
Heart	9	1.8
Liver	13	2.6
Diabetes	5	1.0
Thyroid	7	1.4
Hormone	17	3.4
No	449	89.8
Total	500	100.0

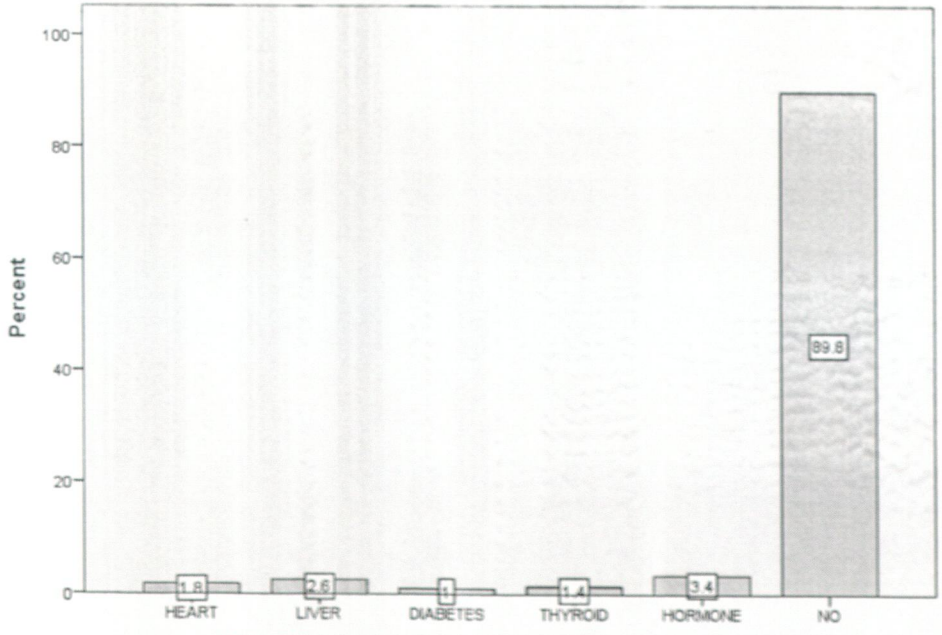


FIGURE 4.16 OTHER COMPLICATIONS ASSOCIATED

Table No: 4.16 shows the distribution of respondent's children by their other complications associated with their Thalassemia major. Among the total respondent's children, 9(1.8%) suffered from other complications of heart, 13(2.6%) of the respondent's children suffer from liver disease, 5(1.0%) of the respondents children had diabetes problems, 7(1.4%) of the respondents had undergone with thyroid problems, 17(3.4%) of the respondent's Thalassemia Major children were suffering from other complication associated with growth hormones and 449(89.8%) respondent's children were not having any other complication associated with Thalassemia Major.

Table 4.17

Distribution of respondents by their marriage type

Type of Marriage	Frequency	Percent
1st Cousin	306	61.2
2nd Cousin	91	18.2
Distance relatives	34	6.8
Out of family	69	13.8
Total	500	100.0

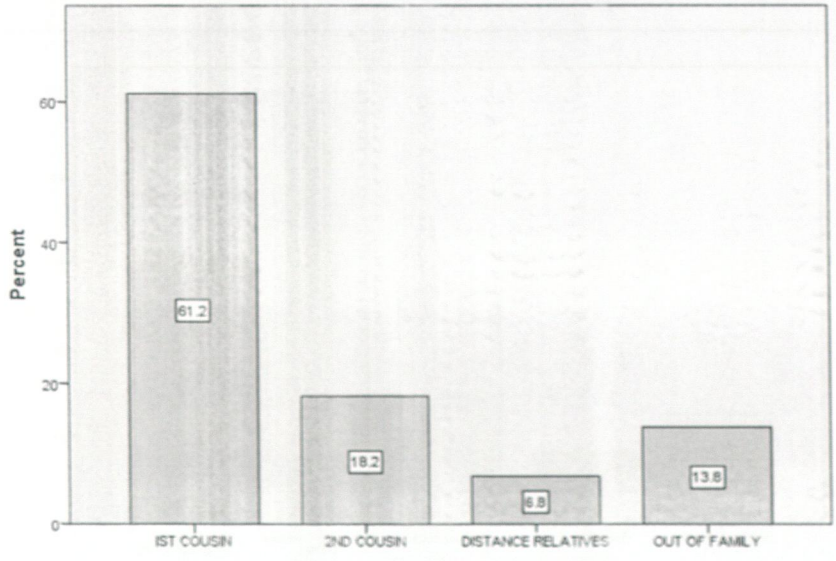


FIGURE 4.17 TYPE OF MARRIAGE

Table No: 4.17 describes the distribution of respondents by their marriage type. Of the total respondents, 306(61.2%) were married to their first cousins, 91(18.2%) of the respondents were married to their second cousins, 34(6.8%) of the respondents married in distance relatives and 69(13.8%) of the respondents married out of family. From the above table it is observed that 306(61.2%) couples married endogamous with 1st cousins. It further shows that mostly the marriage with the first cousin leads to the Thalassemia Major in the family.

Table 4.18

Distribution of respondents by their children age of diagnosis

Age of Diagnosis	Frequency	Percent
During pregnancy	14	2.8
4 months after birth	249	49.8
4-8 months	134	26.8
9-12 months	40	8.0
After a year	63	12.6
Total	500	100.0

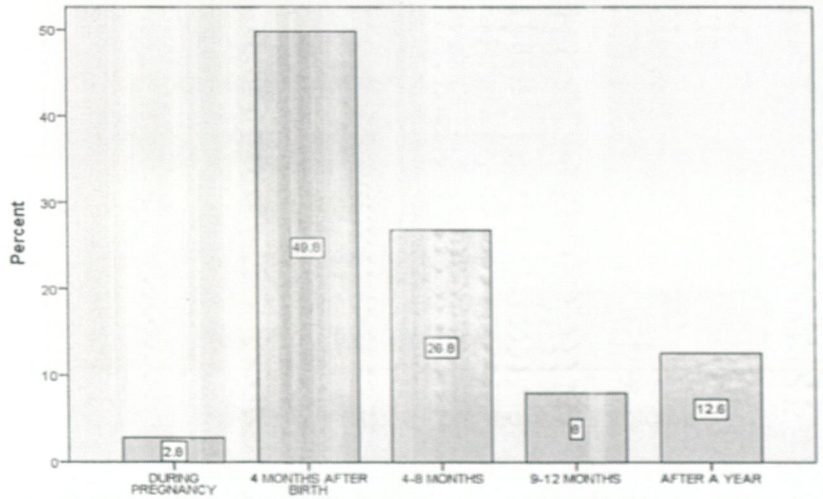


FIGURE 4.18 AGE OF DIAGNOSIS

Table No 4.18 shows the distribution of respondents by their children age of diagnosis. Among the total respondents, 14(2.8%) respondent's children were diagnosed during pregnancy, 249(49.8%) of the respondent's children were diagnosed at the age of four month after birth, 134(26.8%) of the respondent's children were diagnosed Thalassemia Major during four to eight months of the age and 63(12.6%) of respondent's children were diagnosed after a year. From the table it is observed that majority of the children were diagnosed during the age of four months.

Table 4.19

Distribution of respondents by their patient on regular medicine

Medication	Frequency	Percent
Yes	427	85.4
No	73	14.6
Total	500	100.0

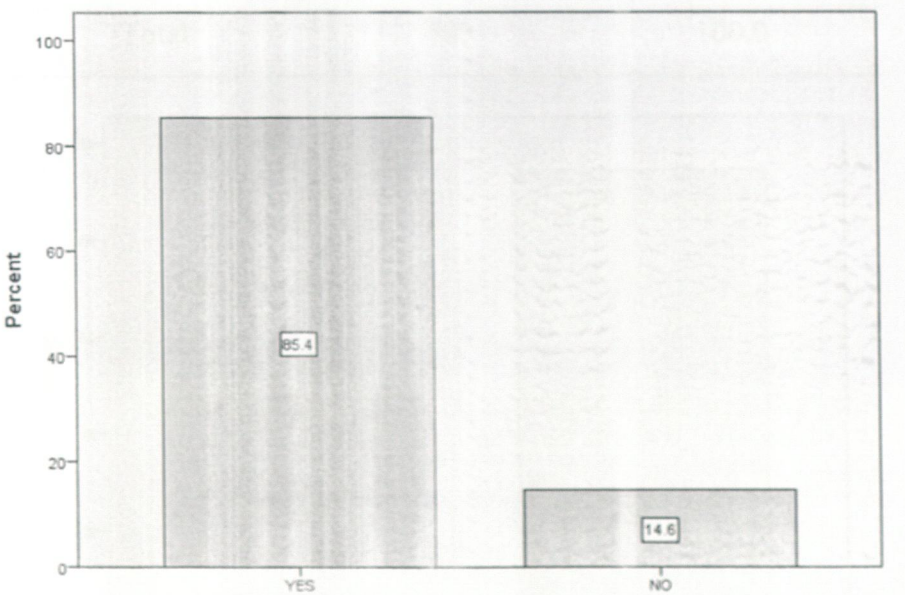


FIGURE 4.19 PATIENT ON REGULAR MEDICINE

Table No: 4.19 describes the distribution of respondents by their patients on regular medicines. Among the total respondents, 427(85.4%) were giving the regular medicines to their children and 73(14.6 %) of the respondents were not able to purchase and give regular medicines for their Thalassemia Major children because of the poor socio economic status. From the above table it is examined that majority of the respondents (85.4%) give regular medicines to their children with the support of relatives, philanthropists, Zakat Funds and Pakistan Bait ul Mal funds.

Table 4.20

Distribution of respondents by their knowledge about thalassemia is inherited disease

Is thalassemia inherited disease?	Frequency	Percent
Yes	29	5.8
No	471	94.2
Total	500	100.0

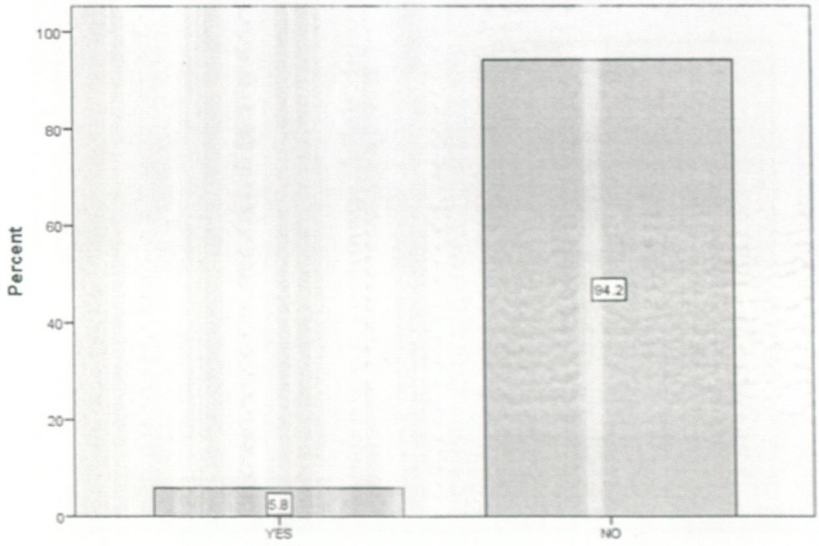


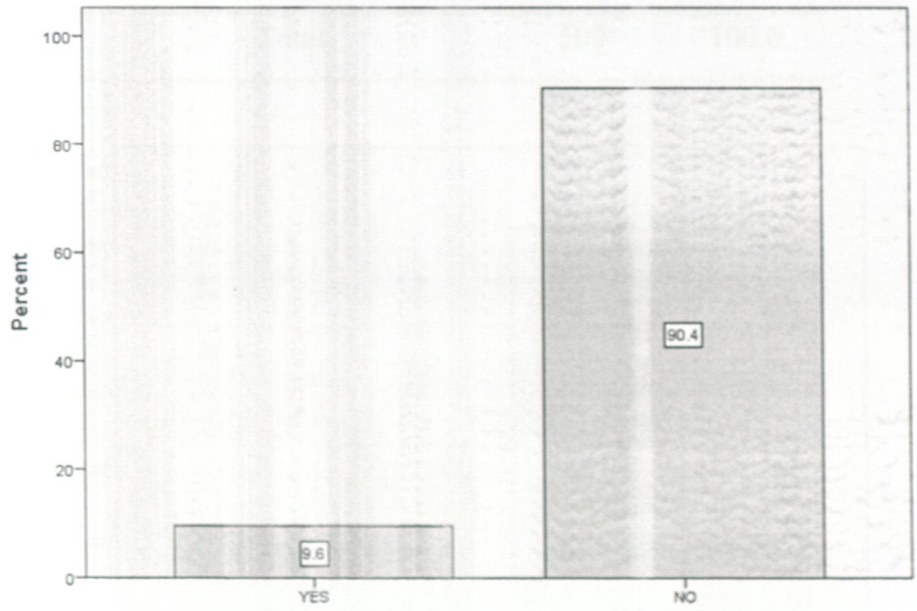
FIGURE 4.20 THALASSEMIA IS INHERITED DISEASE

Table No: 4.20 shows the distribution of respondents by their knowledge about Thalassemia is inherited disease. Among the total respondents, 29(5.8%) have the knowledge that Thalassemia is inherited disease while majority 471(94.2%) respondents were not having the knowledge that thalassemia is inherited disease. Pakistani Society is based one male dominant society and male always blame to their wives because they do not understand that Thalassemia is inherited and comes from both sides.

Table 4.21

Conduction of Thalassemia carrier test by parents

Carrier Test Under taken	Frequency	Percent
Yes	48	9.6
No	452	90.4
Total	500	100.0



FIGONURE 4.21 CONDUCTION OF CARRIER TEST BY PARENTS

Table No: 4.21 indicates whether the carrier test under taken by the parents. Among the total respondents 48(9.6%) of the respondents under took the carrier test and 452(90.4%) of the respondents did not take carrier test. From the above table it is examined that (90.4%) of the respondents did not undertake the test because of lack of knowledge about test.

Table 4.22

Role of education of parents and the diagnosis of children disease

Scale	Frequency	Percent
To a great extent	65	13.0
Somewhat	262	52.4
Very little	115	23.0
Not at all	58	11.6
Total	500	100.0

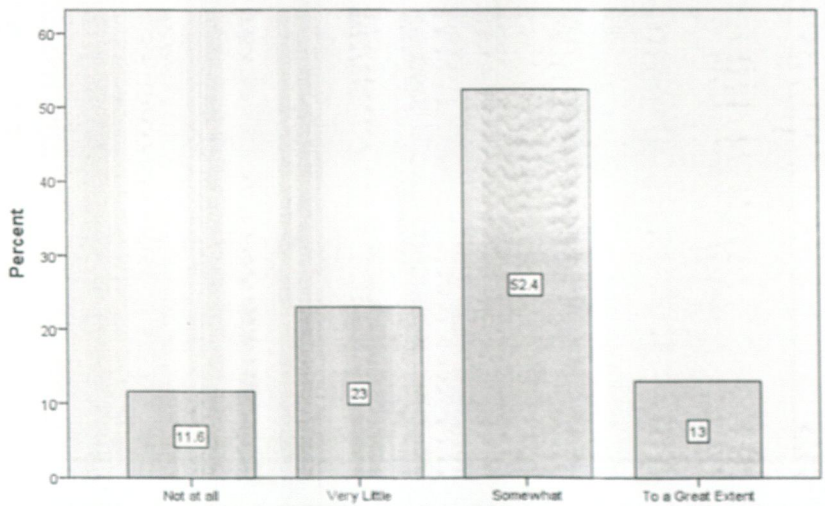


FIGURE 4.22 EDUCATION OF PARENTS PLAY AN IMPORTANT ROLE IN DIAGNOSE OF CHILD DISEASE

In Table 4.22 the respondents were asked if the education of parents plays an important role in diagnoses of child's disease. 65(13.0%) of the respondents reply was 'to a great extent' while 262(52.4%) of the respondents reply was 'somewhat' agreed that education of parents plays an important role to diagnosis of child disease and 115(23.0%) of the respondents replied that 'very little' and 58(11.6%) of the respondent's answer was 'not at all'.

Table 4.23

Distribution of respondents awareness about the disease before diagnosis

Response	Frequency	Percent
Yes	20	4.0
No	480	96.0
Total	500	100.0

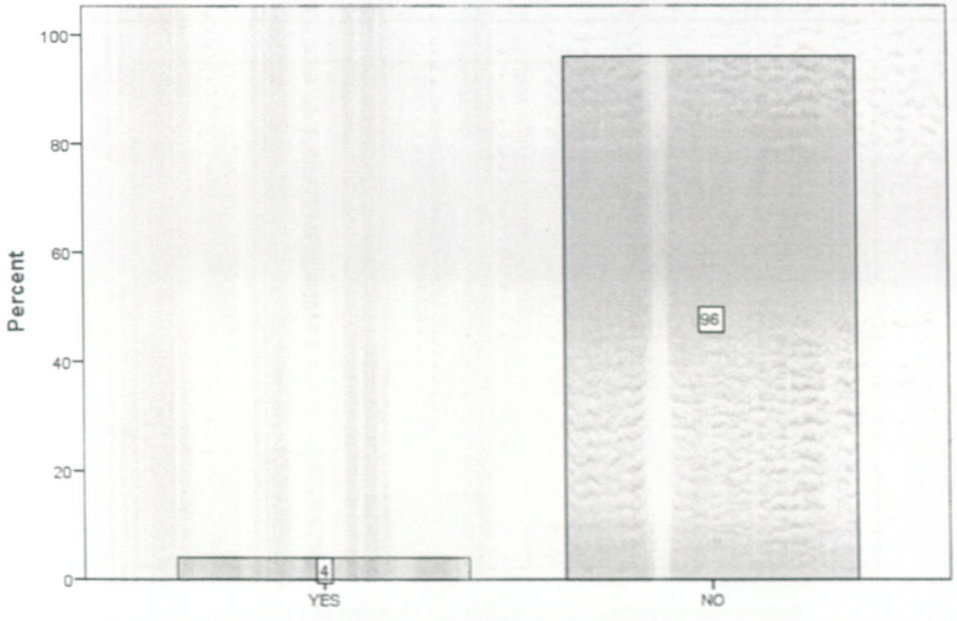


FIGURE 4.23 RESPONDENTS AWARENESS ABOUT THE DISEASE BEFORE DIAGNOSIS

Table No: 4.23 shows the distribution of respondent's awareness regarding the disease before diagnosis. Among the total respondents, 20(4.0%) respondents were aware of the disease before diagnosis and majority 480(96.0%) of the respondents did not have the awareness about the disease before diagnosis.

Table 4.24

Distribution of respondents by their believes on rituals regarding treatment

Scale	Frequency	Percent
To a great extent	330	66.0
Somewhat	32	6.4
Very little	53	10.6
Not at all	85	17.0
Total	500	100.0

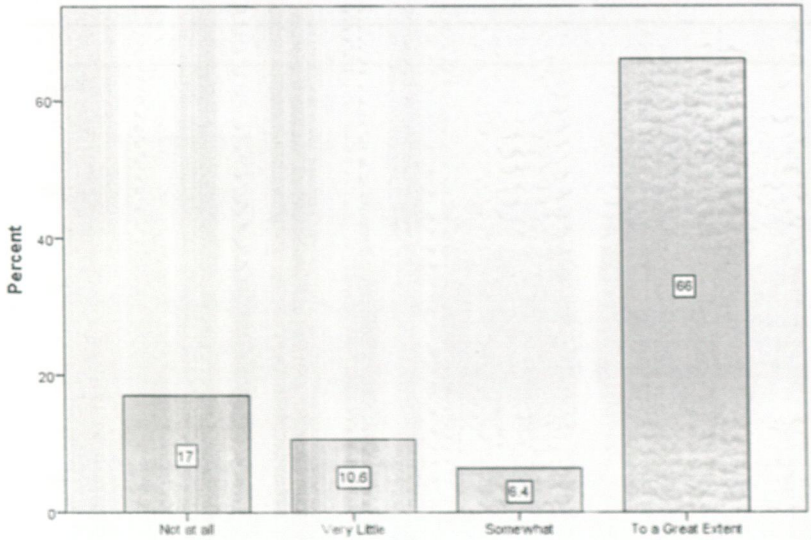


FIGURE 4.24 BELIEFS ON RITUALS REGARDING TREATMENT

Table: 4.24 indicates the respondents beliefs on rituals regarding the Thalassemia child's treatment. As the results study shows that the majority 330(66.0%) of the respondents believe on rituals regarding their child's treatment 'to a great extent' while 32(6.4%) of the respondents believe on rituals regarding their child's treatment 'somewhat' and 53(10.6%) of the respondents believe on rituals regarding their child's treatment 'very little' and 85(17.0%) do not believe on rituals and response 'not at all'.

Table 4.25

Distribution of respondents by their level of knowledge about test

Scale	Frequency	Percent
To a great extent	1	.2
Somewhat	16	3.2
Very little	31	6.2
Not at all	452	90.4
Total	500	100.0

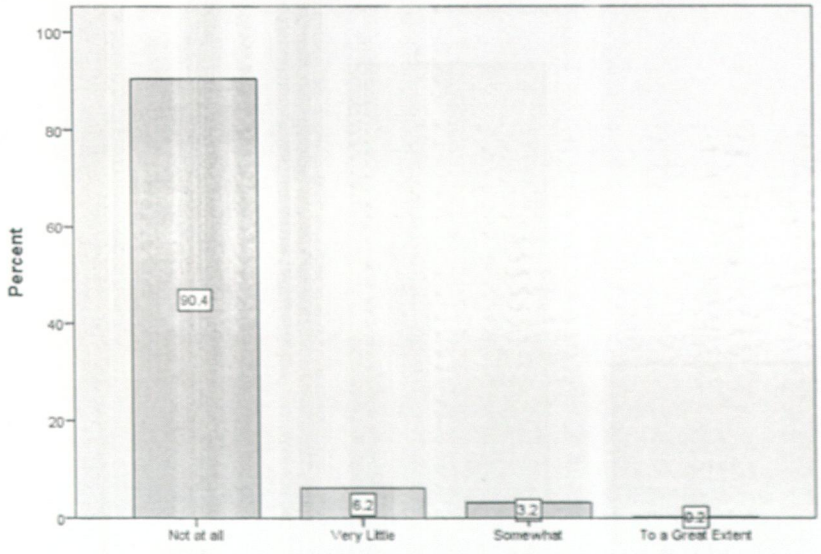


FIGURE 4.25 LEVEL OF PARENTS KNOWLEDGE ABOUT TEST

Table: No 4.25 shows distribution of respondent's by their level of knowledge about Thalassemia test. Of 500 respondents, 452(90.4%) respondents knowledge was 'not at all' about the Thalassemia tests while 31(6.2%) were having 'very little' knowledge and 16(3.2%) respondent's knowledge was 'somewhat' about Thalassemic Test. On the other hand, 1(.2%) of the respondent's knowledge was 'to a great extent' about the Thalassemia test.

Table 4.26

Distribution of respondents by their tendency towards family planning

Scale	Frequency	Percent
To a great extent	143	28.6
Somewhat	353	70.6
Very little	4	.8
Total	500	100.0

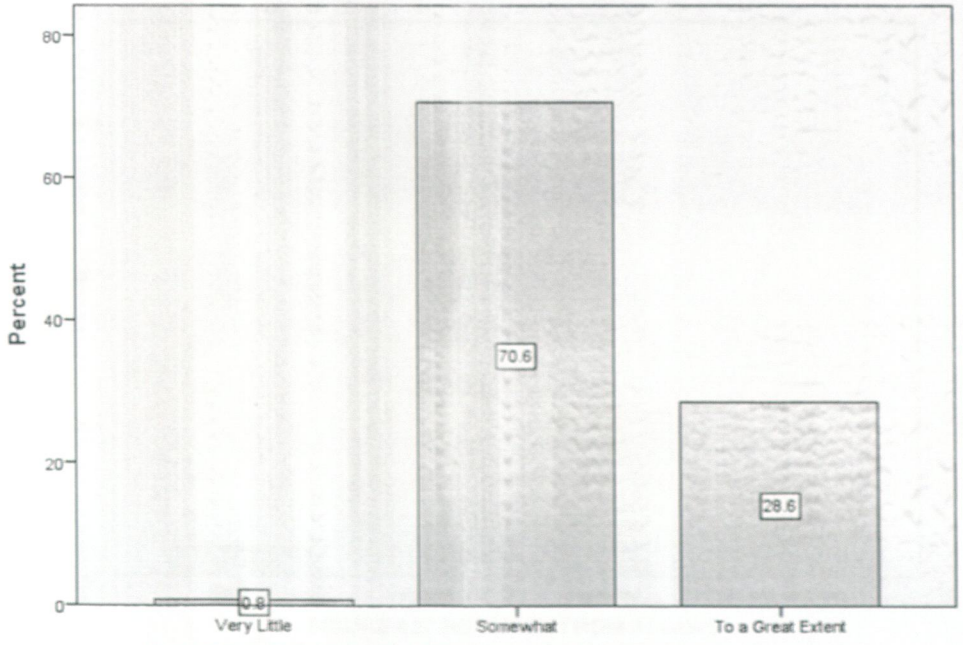


FIGURE 4.26 PARENTS TENDENCY TOWARDS FAMILY PLANNING

Table 4.26 indicates the results of parent's tendency towards family planning. Of 500 respondents, 143(28.6%) respondents tendency towards family planning was 'to a great extent' while 353(70.6%) respondents tendency was to 'somewhat' and 4(.8%) respondents tendency was 'very little' tendency towards family planning.

Table 4.27

Distribution of respondents by their reaction from in-laws

Scale	Frequency	Percent
To a great extent	65	13.0
Somewhat	109	21.8
Very little	307	61.4
Not at all	19	3.8
Total	500	100.0

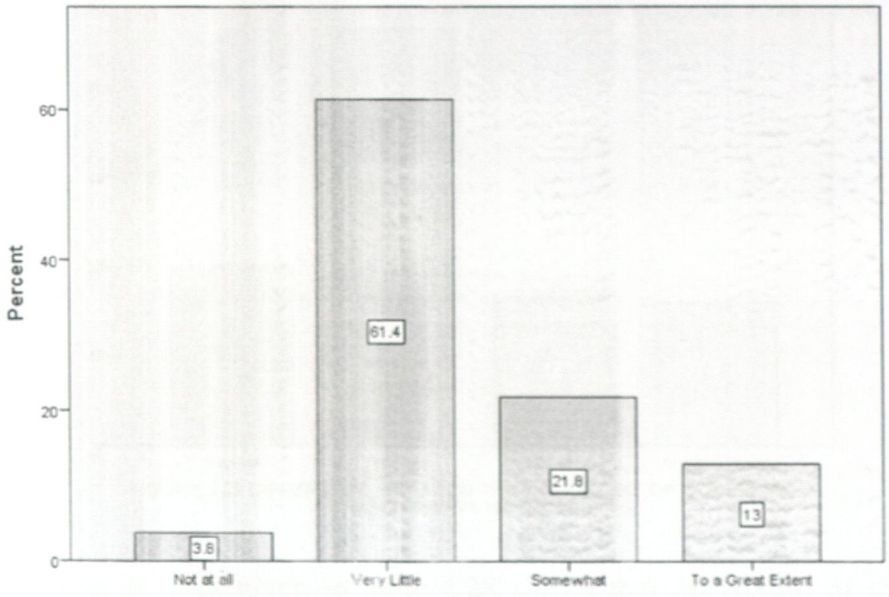


FIGURE 4.27 REACTION FROM IN-LAWS

Table 4.27 indicates the result of in-laws reaction faced by respondents. As the table shows that 65(13.0%) respondents faced the reaction 'to a great extent' from in-laws while 109(21.8%) of the respondents faced the reaction 'somewhat' and 307(61.4%) of the respondents faced reaction from in-laws 'very little'. On the other hand 19(3.8%) of the respondents faced the reaction from in-laws 'not at all'.

Table 4.28

Difference between the treatments of government. and private hospitals

Scale	Frequency	Percent
To a great extent	80	16.0
Somewhat	87	17.4
Very little	233	46.6
Not at all	100	20.0
Total	500	100.0

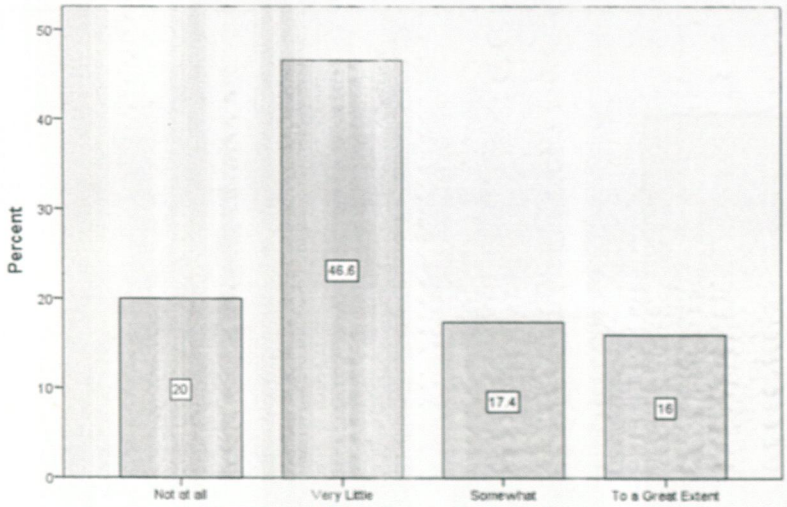


FIGURE 4.28 DIFFERENCE BETWEEN THE TREATMENT OF GOVERNMENT AND PRIVATE HOSPITALS

The description of data given in table 4.28 shows that 80(16.0%) of the respondents found difference between the treatment of government and private hospitals 'to a great extent' while 87(17.4%) of the respondents found difference 'somewhat' and majority 233(46.6%) of the respondents reported 'very little' difference between the government and private hospitals treatment. On the other hand, 100(20.0%) of the respondents found the difference in government and private hospitals 'not at all'.

Table 4.29

Cooperation of paramedical staff

Scale	Frequency	Percent
To a great extent	259	51.8
Somewhat	149	29.8
Very little	73	14.6
Not at all	19	3.8
Total	500	100.0

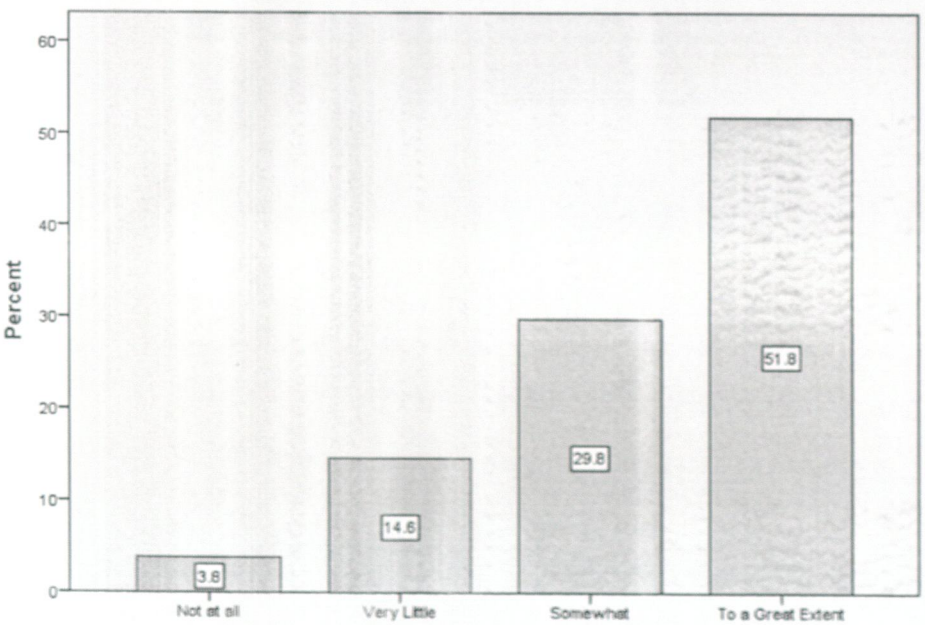


FIGURE 4.29 COOPERATION OF PARAMEDICAL STAFF

In Table 4.29 Respondents were asked a question regarding the cooperation of paramedical staff during the blood transfusion of their child. Is it useful in releasing the mental stress regarding the treatment process? Of 500 respondents, majority 259(51.8%) of the respondents indicated that cooperation of paramedical staff was useful 'to a great extent' in releasing the mental stress regarding the child's treatment process while 149(29.8%) of the

respondents found paramedical staff cooperation useful 'somewhat' and 73(14.6%) of the respondents reported the usefulness of cooperation of paramedical staff 'very little'. On the other hand 19(3.8%) of the respondents reported the cooperation of paramedical staff was 'not at all' useful in releasing the mental stress regarding the treatment process of the Thalassemic child.

Table 4.30

Do you feel that your life is a successful

Scale	Frequency	Percent
To a great extent	24	4.8
Somewhat	89	17.8
Very little	201	40.2
Not at all	186	37.2
Total	500	100.0

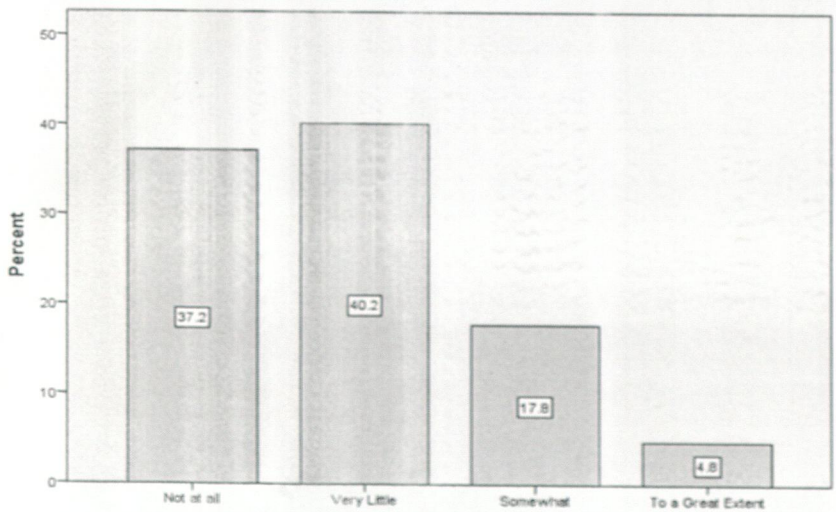


FIGURE 4.30 SUCCESSFUL LIFE OF PARENTS

Table 4.30 Respondents were asked the question regarding success of their life. The results reveal that of 500 respondents, 24(4.8%) respondents reported that they thought their life was successful 'to a great extent' while 89(17.8%) respondents were of the view that 'somewhat' and 201(40.2%) respondents were mentioned that 'very little'. On the other hand 186(37.2%) respondents pointed out that the success in their life was 'not at all'.

Table 4.31

Mental stress because of a disease of a child

Scale	Frequency	Percent
To a great extent	479	95.8
Somewhat	18	3.6
Very little	3	0.6
Total	500	100.0



FIGURE 4.31 MENTAL STRESS BECAUSE OF A DISEASE OF A CHILD

Table 4.31 illustrated the results of mental stress because of a Thalassemic child. As the results of the table show that majority 479(95.8%) of the respondents were under mental stress because of the child' disease 'to a great extent' while 18(3.6%) of the respondents were under mental stress 'somewhat' and 3(.6%) of the respondents were under mental stress 'very little'.

Table 4.32

Supportive behavior of hospital staff

Scale	Frequency	Percent
To a great extent	287	57.4
Somewhat	172	34.4
Very little	36	7.2
Not at all	5	1.0
Total	500	100.0

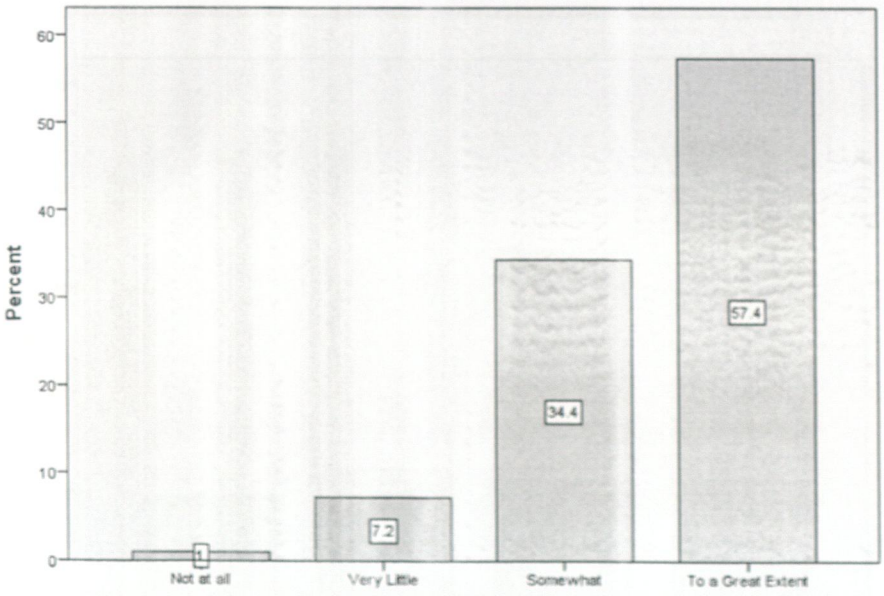


FIGURE 4.32 SUPPORTIVE BEHAVIOR OF HOSPITAL STAFF

Tables 4.32 demonstrated the results of supportive behavior of hospital staff. Of 500 respondents, 287(57.4%) reported that behavior of the hospital staff was supportive 'to a great extent' while 172(34.4%) respondents indicated that hospital staff's behavior was supportive 'somewhat' and 36(7.2%) respondents found hospital staff's behavior was supportive 'very little'. On the other 5(1.0%) respondents found hospital staff's behavior was supportive 'not at all'.

Table 4.33

Aggression because of child disease

Scale	Frequency	Percent
To a great extent	221	44.2
Somewhat	169	33.8
Very little	62	12.4
Not at all	48	9.6
Total	500	100.0

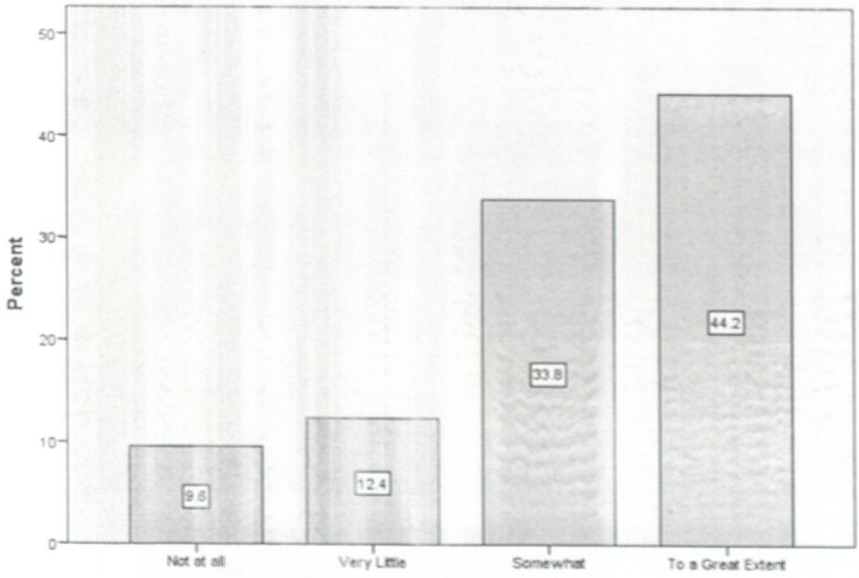


FIGURE 4.33 AGRESSION BECAUSE OF YOURS CHILD DISEASE

Table 4.33 indicates the results of respondents' aggression because of their child's disease. As the results of the table shows that majority 221(44.2%) of the respondents were aggressive 'to a great extent' because of the child disease while 169(33.8%) respondents were 'somewhat' aggressive because of child's disease and 62(12.4%) respondents were 'very little' aggressive regarding their child's disease. On the other hand 48(9.6%) respondents were 'not at all' aggressive because of their child's disease.

Table 4.34

Balance between the normal and affected children

Scale	Frequency	Percent
To a great extent	274	54.8
Somewhat	99	19.8
Very little	62	12.4
Not at all	65	13.0
Total	500	100.0

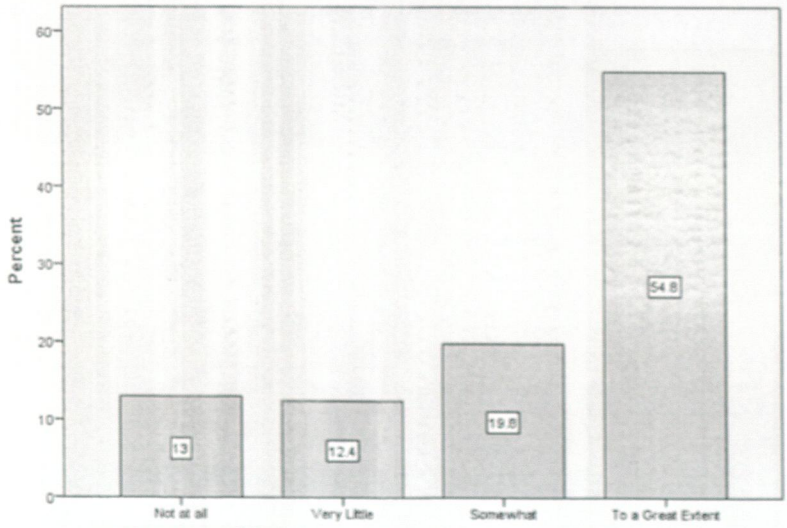


FIGURE 4.34 BALANCE BETWEEN NORMAL & AFFECTED CHILDREN

Table 4.34 describes the results of respondents balance between normal and Thalassemic children. Results show that majority 274(54.8%) of the respondents were keeping balance 'to a great extent' between thalassemic children and normal children while 99(19.8%) respondents were keeping balance 'somewhat' and 62(12.4%) respondents reported balance between normal and Thalassemic children 'very little'. On the other hand 65(13.0%) of the respondents reported balance between normal and Thalassemic children 'not at all'.

Table 4.35

Distribution of respondents by their division of time between Children

Response	Frequency	Percent
Equally	20	4.0
More attention to normal children	9	1.8
More attention to sick children	471	94.2
Total	500	100.0

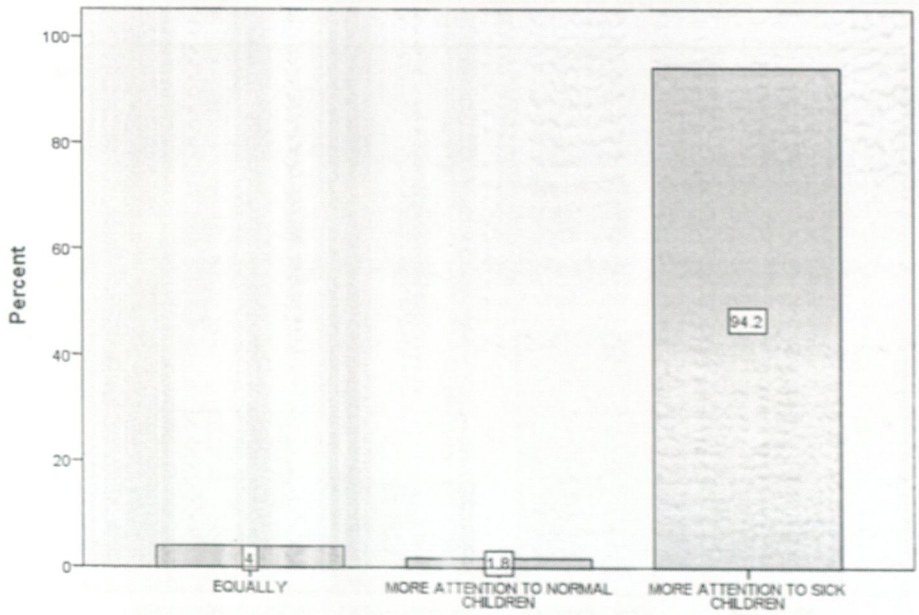


FIGURE 4.35 DIVISION OF TIME BETWEEN CHILDREN

Table No: 4.35 shows the distribution of respondents by their division of time among children. Of the total respondents, 20(4.0%) respondents give equal time to their children, 9(1.8%) respondents give more attention to their normal children and majority 471(94.2%) respondents give more attention to their sick Thalassemia children.

Table 4.36

The Distribution of respondents by their reaction in depression

What do You do In time of Depression	Frequency	Percent
Medication solution	87	17.4
Catharsis with husband	53	10.6
Catharsis with family members	126	25.2
Not discussed with any one	234	46.8
Total	500	100.0

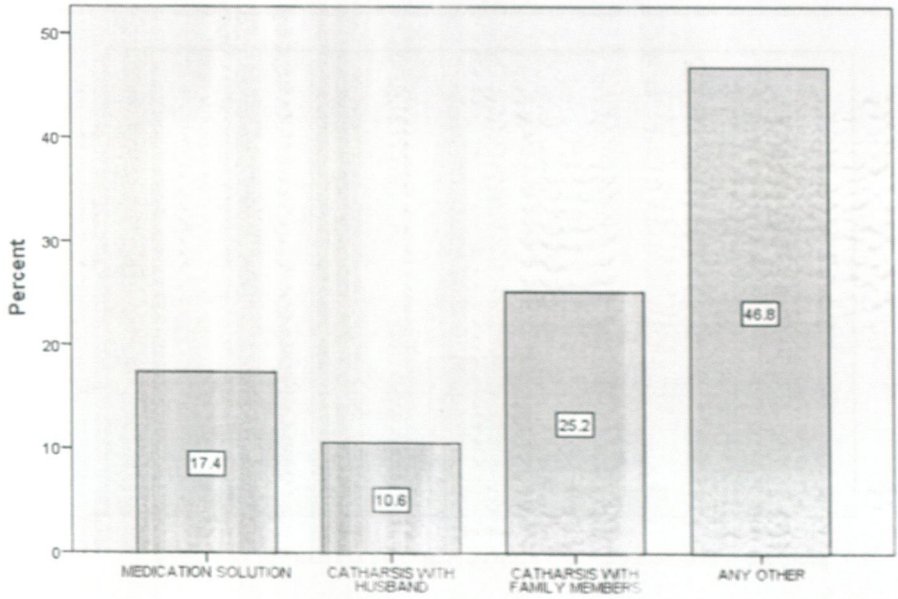


FIGURE 4.36 IN TIME OF DEPRESSION

Table No: 4.36 Shows the result of respondent's reaction in time of depression. 87(17.4%) respondents take the medicine solutions, in case of depression 53(10.6%) of the respondents do their catharses with their husbands, 126(25.2%) respondents at the time of depression do their catharsis with family members and 234(46.8%) respondents remain silent in the time of depression.

Table 4.37

Respondents' affected social activities because of child disease

Scale	Frequency	Percent
Very often	323	64.6
Often	22	4.4
Some times	126	25.2
Seldom	22	4.4
Never	7	1.4
Total	500	100.0

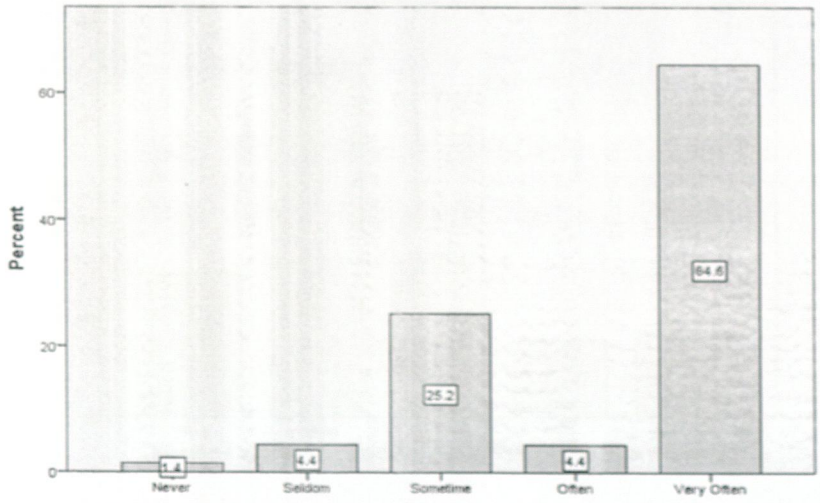


FIGURE 4.37 AFFECTED SOCIAL ACITIVIES BECAUSE OFCHILD DISEASE

In table 4.37 the respondents were inquired how often parent's social activities were affected because of their child's disease. Majority 323(64.6%) of the respondents reported that their social activities 'very often' affected because of their child's disease while 22(4.4%) of the respondents reported their social activities 'often' affected and 126(25.2%) of the respondents reported their social activities were 'sometimes' affected. On the other hand 22(4.4%) respondents reported their activities affected 'seldom' followed by 7(1.4%) respondents reported their social activities 'never' affected because of child's disease.

Table 4.38

Respondents' participation in different family gathering

Scale	Frequency	Percent
Very often	44	8.8
Often	39	7.8
Some times	165	33.0
Seldom	180	36.0
Never	72	14.4
Total	500	100.0

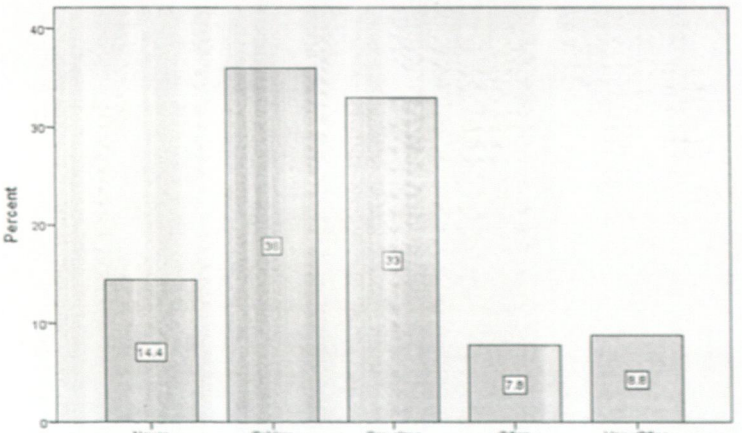


FIGURE 4.38 PARTICIPATION IN DEIFFERENT FAMILY GATHERING

Table 4.38 indicates the results of respondent's participation in different family gathering. Of 500 respondents, 44(8.8%) respondents participate 'very often' in different family gathering while 39(7.8%) respondents participate 'often' in the different family gathering and 165(33.0%) respondents report that they participate 'some times' in different family gathering. On the other hand 180(36.0%) respondents 'seldom' participate in family gathering and 72(14.4%) respondents 'never' participate in any family gathering owing to a Thalassemic child.

Table 4.39

Respondents' hesitation while talking about the disease with others

Scale	Frequency	Percent
To a great extent	49	9.8
Somewhat	200	40.0
Very little	103	20.6
Not at all	148	29.6
Total	500	100.0

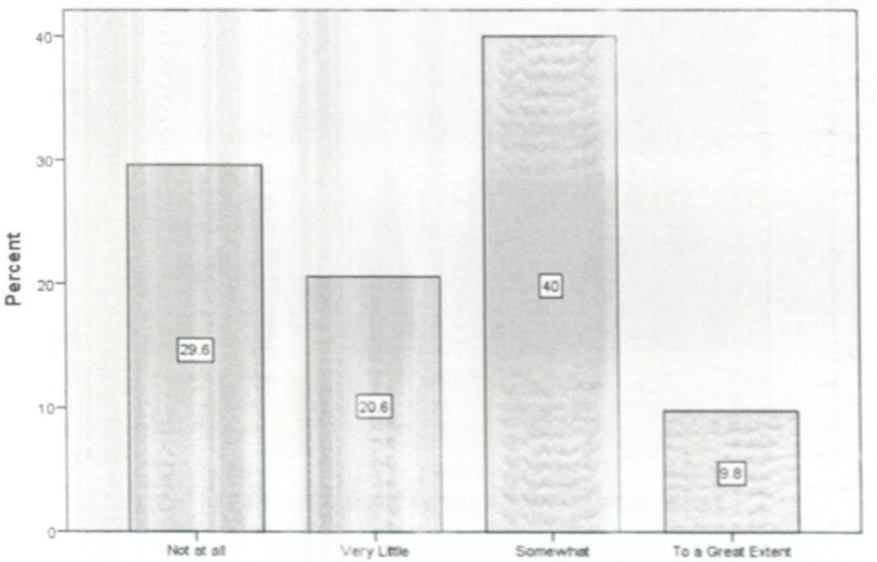


FIGURE 4.39 HESITATION WHILE TALKING ABOUT THE DISEASE WITH OTHERS

Table 4.39 describes the results of respondent's hesitation while talking about the child's disease with others. 49(9.8%) respondents felt hesitation 'to a great extent' while 200(40.0%) respondents felt hesitation 'somewhat' and 103(20.6%) respondents felt hesitation 'very little'. On the other hand 148(29.6%) respondents felt hesitation while talking about the disease with others 'not at all'.

Table 4.40

Distribution of respondents by their nature of relationship with family

Nature of relationship	Frequency	Percent
Strong	65	13.0
Weak	70	14.0
Normal	365	73.0
Total	500	100.0

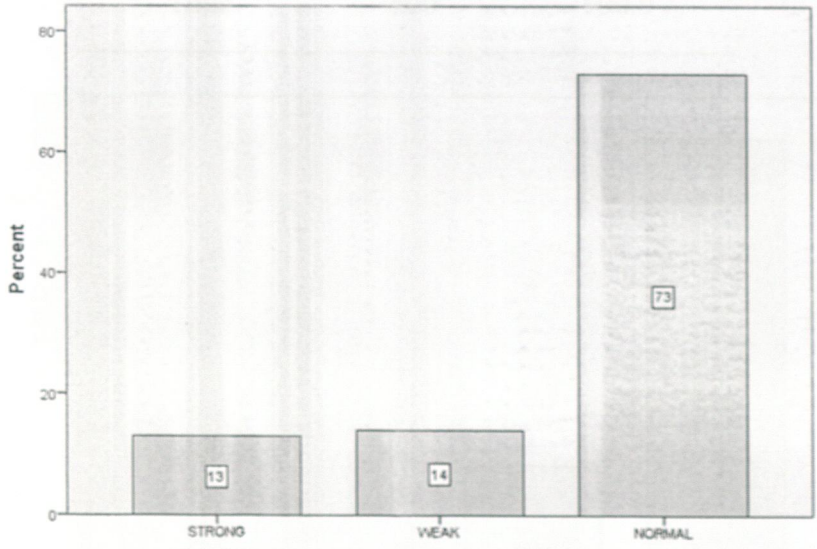


FIGURE 4.40 NATURE OF RELATIONSHIP WITH FAMILY

Table No: 4.40 Shows the results of respondents' relationship with family. Among the total respondents 65(13.0%) respondents nature of relation was 'strong' while 70(14.0%) of the respondents reported that their relationship was 'week' with family and 365(73.0%) respondents remark their relationship 'normal' with their family members.

Table 4.41

Homelessness feelings because of Childs disease

Scale	Frequency	Percent
To a great extent	341	68.2
Somewhat	123	24.6
Very little	20	4.0
Not at all	16	3.2
Total	500	100.0

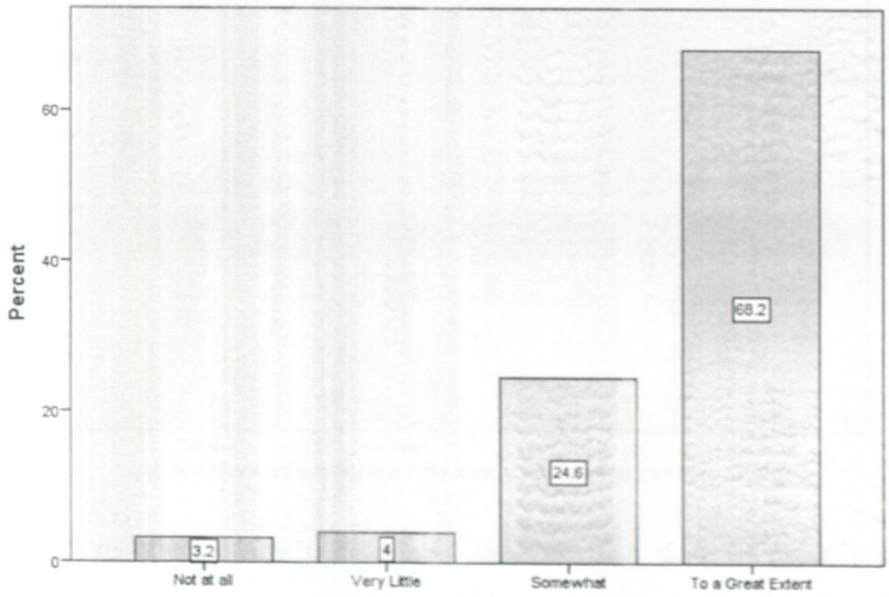


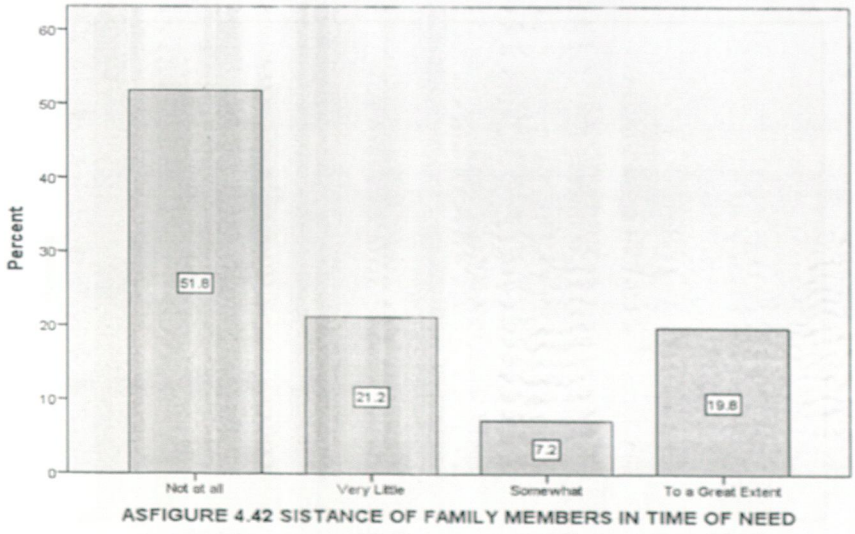
FIGURE 4.41 HOMELESSNESS FEELINGS BECAUSE OF CHILDS DISEASE

Table 4.41 indicates the results of respondent's feeling regarding their loneliness. 341(68.2%) of the respondents were having lonesome feeling 'to a great extent', 123(24.6%) of the respondents were feeling 'somewhat' loneliness and 20(4.0%) respondents were feeling homelessness 'very little'. On the other hand 16(3.2%) respondents were 'not at all' feeling homelessness.

Table 4.42

Assistance of family members in time of need

Scale	Frequency	Percent
To a great extent	99	19.8
Somewhat	36	7.2
Very little	106	21.2
Not at all	259	51.8
Total	500	100.0



ASFIGURE 4.42 SISTANCE OF FAMILY MEMBERS IN TIME OF NEED

In table 4.42 results of family members' assistance in time of need is shown. Of 500 respondents, 99(19.8%) of the respondents indicate the assistance of family members was provided 'to a great extent' in time of need, 36(7.2%) respondents indicate that family members' assistance was provided 'somewhat' in time of need, 106(21.2%) respondents were provided assistance from family members 'very little'. On the other hand majority 259(51.8%) respondents reported that they were given 'not at all' assistance by family members in time of need.

Table 4.43

Assistance of relatives in time of need

Scale	Frequency	Percent
To a great extent	26	5.2
Somewhat	40	8.0
Very little	113	22.6
Not at all	321	64.2
Total	500	100.0

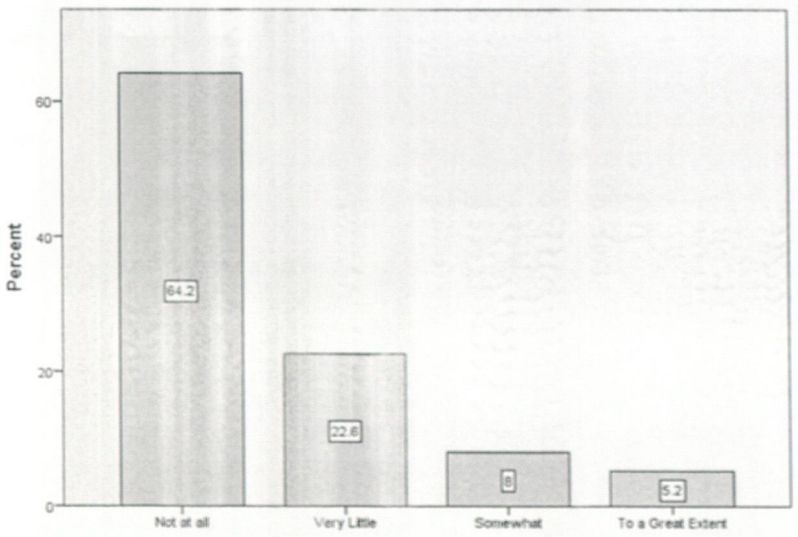


FIGURE 4.43 ASSISTANCE OF OF RELATIVES IN TIME OF NEED

In table 4.43 the respondents were asked the question regarding relative's assistance in time of needs. The results of the study reveal that 26(5.2%) respondents indicate that they were provided assistance 'to a great extent' from relatives, 40(8.0%) respondents reveal that assist stance of relative was 'somewhat' in time of needs and 113(22.6%) of the respondents reported relatives assistance 'very little'. On the other hand majority 321(64.2%) respondents were 'not at all' provided assistance from relatives in time of need.

Table 4.44

Assistance of friends in time of need

Scale	Frequency	Percent
To a great extent	55	11.0
Somewhat	60	12.0
Very little	135	27.0
Not at all	250	50.0
Total	500	100.0

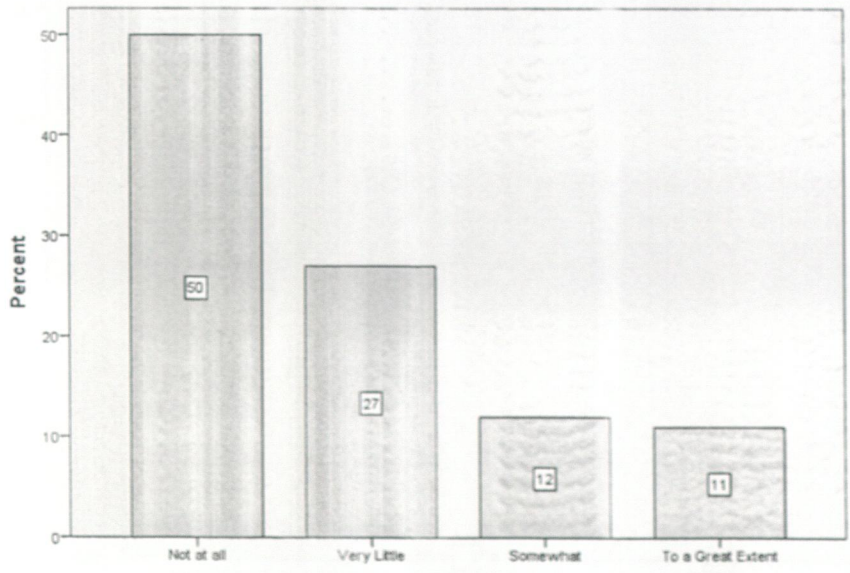


FIGURE 4.44 ASSISTANCE OF FRIENDS IN TIME OF NEED

Table 4.44 indicates the result of assistance of friends in time of need. Of the 500 respondents, 55(11.0%) respondents receive assistance from their friends 'to a great extent' while 60(12.0%) respondents receive 'somewhat' assistance by friends in time of need and 135(27.0%) respondents reported 'very little' assistance from their friend. On the other hand majority 250(50.0%) respondents receive assistance 'not at all' from friends.

Table 4.45

Distribution of respondents financial expenditure for treatment

Financial Expenditure	Frequency	Percent
Personally	492	98.4
Government	6	1.2
Others	2	.4
Total	500	100.0

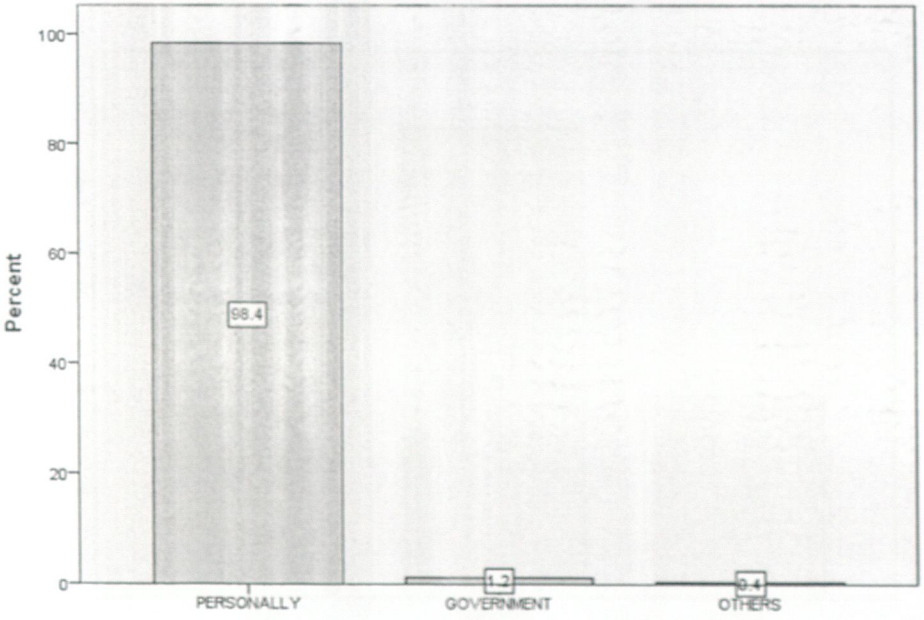


FIGURE 4.45 FINANCIAL EXPENDITURE FOR TREATMENT

Table No: 4.45 indicate the distribution of respondents who meet the financial expenditure for treatment. Among the total respondents, majority 492(98.4%) of the respondents personally meet the financial expenditure of their Thalassemia children, 6(1.2%) respondents get the financial assistance through government and 2(.4%) respondents received financial expenditure through other sources like donations by the friends and relatives.

Table 4.46

Distribution of respondents' average monthly expenditure on treatment

Monthly Expenditure	Frequency	Percent
< 5000	177	35.4
5000-10000	226	45.2
> 10000	97	19.4
Total	500	100.0

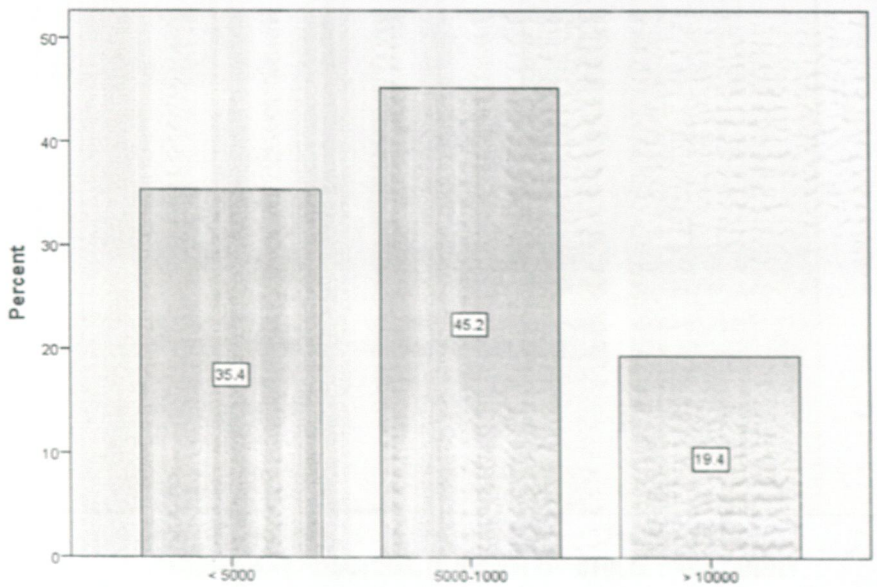


FIGURE 4.46 AVERAGE MONTHLY EXPENDITURE ON TREATMENT

Table 4.46 describes the distribution of respondents by their monthly expenditure on child's treatment. Above table shows that 117(35.4%) respondents' child monthly expenditure was <5000 while majority 226(45.2%) of the respondents monthly expenditure was 5000-10000 and 97(19.4%) respondents' child monthly expenditure was more than ten thousand.

Table 4.47

Financial burden of child treatment

Scale	Frequency	Percent
To a great extent	497	99.4
Very little	3	.6
Total	500	100.0

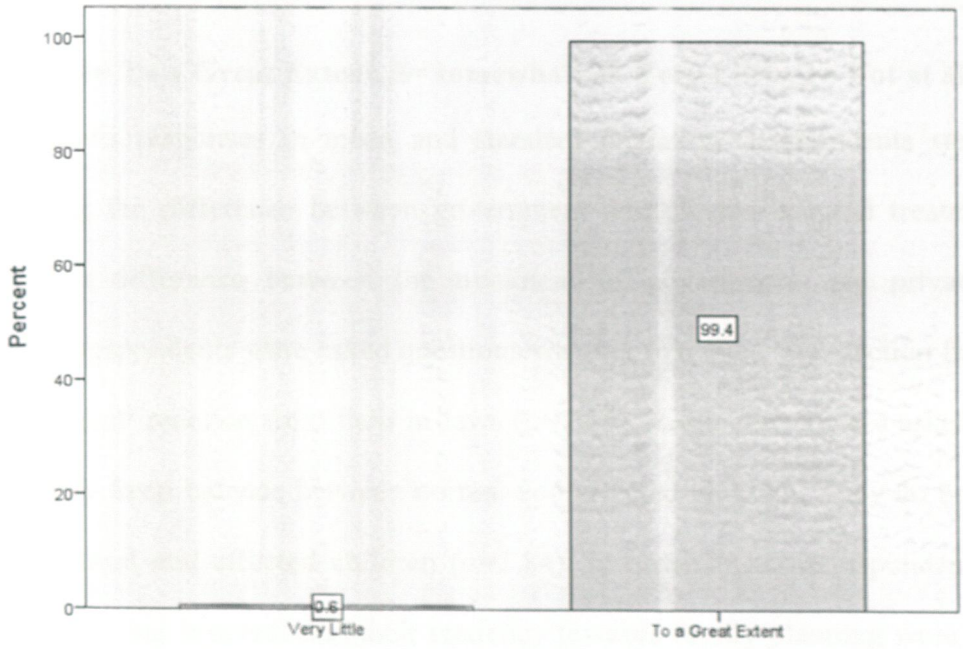


FIGURE 4.47 FINANCIAL BURDEN OF CHILD TREATMENT

Table 4.47 indicates the distribution of respondents by their financial burden because of thalassemia disease. The above data shows that majority 497(99.4%) respondents faced the financial burden because of their child's disease while 3(.6%) respondents face 'very little' financial burden of thalassemia major child treatment.

Table 4.48
Parent's perception about general questions

Ranks	Statements	N	Mean	Std. Deviation
1	Difference between the treatment of Govt. and private hospitals	500	2.71	.964
2	Reaction from in-laws	500	2.56	.764
3	Balance between normal & affected children	500	1.84	1.080
4	Parents tendency towards family planning	500	1.72	.466

Score: 4= To a Great Extent, 3= somewhat, 2= Very Little, 1= Not at all

Table shows responses in mean and standard deviation. Respondents were asked a question regarding the difference between government and private hospital treatments. They 'somewhat' see a difference between the treatment of government and private hospitals (μ=2.71). Female respondents were asked questions whether they face any reaction from in-laws. They face 'somewhat' reaction from their in-laws (μ=2.56). Respondents were asked a question regarding how they keep balance between normal and affected children. They do balance 'very little' between normal and effected children (μ=1.84). In order to know respondents tendency towards family planning it reveal that their tendency towards family planning were 'very little' (μ=1.72).

Table 4.49
Parent's knowledge towards thalassemia disease

Ranks	Statements	N	Mean	Std. Deviation
1	Level of parents knowledge about test	500	3.87	.437
2	Education of parents play an important role in diagnose of child disease	500	2.67	.846
3	Believe on rituals regarding treatment	500	1.79	1.184

Score: 4= To a Great Extent, 3= Somewhat, 2= Very Little, 1= Not at all

The respondents were asked questions related their knowledge and treatments of the thalassemic child. They were asked about their level of knowledge regarding Thalassemic test, Table 4.51 shows that they were having knowledge 'to a great extent' about thalassemic test (μ=3.87). In response to a question, respondents 'somewhat' agree that education of parents plays an important role in diagnosis a thalassemic disease in child (μ=2.67). While they believe on rituals regarding child treatment is 'very litter' (μ=1.79).

Table 4.50
Distribution of respondent's general questions

Ranks	Statements	N	Mean	Std. Deviation
1	Life is unsuccessful & messed-up because of child disease	500	3.10	.857
2	Hesitation while talking about the disease with others	500	2.70	1.000
3	Aggression because of child disease	500	1.87	.967
4	Homelessness feelings because of Childs disease	500	1.42	.719
5	Mental stress because of child disease	500	1.05	.240
6	Financial burden of child treatment	500	1.01	.155

Score: 4= To a Great Extent, 3= Somewhat, 2= Very Little, 1= Not at all

Respondents were asked multiple statements regarding their social life. Respondents 'somewhat' feel that their life is successful and messed-up because of child's disease (μ=3.10). They 'somewhat' feel hesitation while talking about the disease with others (μ=2.70). Respondent's feel 'very little' aggression because of child's disease (μ=1.87). They feel homelessness and mental stress because of child's disease with a mean score 1.42 and 1.05 respectively (Table 4.50).

Table 4.51
Distribution of respondent's level of satisfaction

Ranks	Statements	N	Mean	Std. Deviation
1	Supportive behavior of hospital staff in releasing parents' mental stress	500	2.03	.865
2	Cooperation of paramedical staff	500	1.70	.854
3	Supportive behavior of hospital staff	500	1.52	.674

Score: 4= To a Great Extent, 3= Somewhat, 2= Very Little, 1= Not at all

Respondents' reported that supportive behavior of hospital staff play a 'very little' role in releasing mental stress (μ=2.03) and respondents' found cooperation of paramedical staff and supportive behavior of hospital staff 'very little' with a mean value 1.70 and 1.52 respectively.

Table 4.52
Distribution of respondent assistance

Ranks	Assistance in Time of Need	N	Mean	Std. Deviation
1	Assistance of relatives in time of need	500	3.46	.850
2	Assistance of friends in time of need	500	3.16	1.018
3	Assistance of family in time of need	500	3.05	1.176

Score: 4= To a Great Extent, 3= somewhat, 2= Very Little, 1= Not at all

Respondents were asked questions regarding relatives, friends and family assistance in time of need. Most of the respondents reported that they received 'somewhat' assistance of relatives, friends and family members in time of need with a mean score of 3.46, 3.16 and 3.05 respectively (Table 4.52).

Table 4.53

Distribution of respondent's relationship with family

Ranks	Statements	N	Mean	Std. Deviation
1	To what extent do you think a child disease effects your conjugal relationship	500	3.50	1.170
2	How often do you participate in different family gathering	500	3.39	1.101
3	How often your social activities affected because of child disease	500	1.74	1.064

Score: 5=Very Often, 4= Often, 3= Sometimes, 2= Seldom, 1= Never

Table 4.53 showed the results of multiple statements which were asked to respondents. Respondents felt a child disease 'often' affect their conjugal relationship (μ=3.50). While they participate 'sometimes' in different family gathering (μ=3.39) and they reported that their social activities disturbed 'seldom' (μ=1.74).

Table 4.54

Table Comparison between awareness towards disease and residential area (Independent sample t-test)

Residential area	N	Mean	Std. Deviation	T	df	P
Rural	244	6.6475	1.83439	-4.726	498	.000*
Urban	256	7.3633	1.54566			

P<0.05

Table 4.54 describes that statistically there is significant difference among residential area of affected families and their awareness level towards disease as p-value is less than 0.05. It can be seen from the table 4.54 that residents of urban areas (M=7.363, SD=1.54566) have higher level of awareness as compared to residents of rural areas (M=6, 6475, SD=1.834).

Table 4.55

Comparison between education status and awareness towards disease (independent sample t-test)

Educational status	N	Mean	Std. Deviation	t	Df	P
Literate	234	6.6838	1.86290	-4.069	498	.000**
Illiterate	266	7.3045	1.54716			

** P<0.05

Table 4.55 showed the results of comparison between education status and awareness towards disease. There is a significance level of difference found in awareness level towards disease of literate and illiterate respondents.

Table 4.56

Comparison between level of education and awareness to disease (One way ANOVA)

Source of variation	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	91.380	6	15.230	5.365	.000**
Within Groups	1399.522	493	2.839		
Total	1490.902	499			

****P<0.05**

Table 4.56 showed significant difference between the level of education and awareness to disease as F(6,493)=5.536 and p-value is less than 0.05. Level of education categories was broad, which include primary, middle, matriculation, intermediate, graduation, master and other education if any.

Table 4.57

Comparison between level of education and economic impact of the disease (One way ANOVA)

Source of variation	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	13.257	6	2.209	3.217	.004**
Within Groups	338.551	493	.687		
Total	351.808	499			

**P<0.05

Significant difference found between level of education and economic impact of the disease as F(6,493)=3.217, P<0.05 (Table 4.57). Level of education was broad which includes categories of Primary, Middle, Matriculation, Intermediate, Graduation, Master and other if any.

Table 4.58

Comparison between level of education and social impact of the disease (One way ANOVA)

Source of variation	Sum of Squares	df	Mean Square	F	P
Between Groups	503.430	6			
Within Groups	5689.808	493	83.905	7.270	.000**
Total	6193.238	499			

****P<0.05**

In table 4.58 comparisons between level of education and social impact of the disease is made. Significant difference is found on social impact of the disease and level of education as $F(6,493)=7.270$, $^{**}p<0.05$.

Table 4.59
Cross tabulation of type of marriage and affected thalassemic children

Type of Marriage	Affected Patients in Family		Total
	Two	One	
1st Cousin	105	201	306
2nd Cousin	21	70	91
Distance relatives	9	25	34
Out of family	17	52	69
Total	152	348	500

Table 4.59 showed a cross tabulation results of type of marriage and affected thalassemic children. Result shows that 105 families were having two children affected with thalassemic major and 201 families were having one child each with thalassemia major disease. On the other hand in second cousin marriage of parents had two children affected in 21 families and 70 families had one children affected. Parents of thalassemic children married in distance relatives had two children affected with disease of nine families and 25 families had one children affected similarly parents of the sick patients got married out of family had two children affected with thalassemia major in 17 families and one child affected had 52 families.

Table 4.60

Comparison of education level of parents with economic impact of the disease on parents (One way ANOVA)

Source of variation	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	13.257	6	2.209	3.217	.004**
Within Groups	338.551	493			
Total	351.808	499			

**P<0.05

Table 4.6o showed the result of comparison between the two groups, educational level of parents and economic impact of the disease on parents. Statistically significant difference is found between educational levels of parents and economic impact of the disease on patients' families as F(6,493)=3.217,**p<0.05.

Table 4.61

Comparison of parents' occupation and economic impact of the disease on patients' families (One way ANOVA)

Source of variation	Sum of Squares	df	Mean Square	F	P
Between Groups	19.328	5	3.866	5.743	.000**
Within Groups	332.480	494			
Total	351.808	499			

****P<0.05**

One way ANOVA test applied to learn the comparison between parents' occupation and economic impact of the disease. Table 4.61 shows that significant difference between parents' occupation and economic impact of the disease as F(5,494)=5.743,**p<0.05.

Table 4.62

Comparison of parents' monthly income with economic impact of the disease on patients' families (One way ANOVA)

Source of variation	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	28.573	4	7.143	10.939	.000**
Within Groups	323.235	495			
Total	351.808	499			

****P<0.05**

Researcher applied the one way ANOVA test to find out the significant difference between parents' monthly income and economic impact of the disease of patients' families. Statistically significant difference found between respondents monthly incomes and economic impact of the disease as F(4,495)=10.939,**p<0.05.

Table 4.63

Comparison between frequency of blood transfusion and economic impact of the disease (One way ANOVA)

Source of variation	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	1.025	3	.342	.483	.694
Within Groups	350.783	496			
Total	351.808	499			

P<0.05

Researcher applied one way ANOVA test to find out significance between frequencies of blood transfusion and economic impact of the disease on patients' families. Table 4.63 shows that no significant difference found between the frequencies of blood transfusion and economic impact of the disease as F(3,496)=.483, P>0.05.

Table 4.64

Relationship between economic and social impact of the disease (Pearson correlations)

Pearson Correlations	
	SIOD
Pearson Correlation	.008**
Sig. (2-tailed)	.857
N	500

P<0.05

Table shows relationship between economic and social impact of the disease. It can be seen in table 4.64 that here is a direct

Table 4.65
Social impact of the disease with gender distribution (Independent samples t-test)

Gender	N	Mean	Std. Deviation	T	df	P
Male	119	29.0924	3.45428	3.129	498	.002*
Female	381	27.9449	3.50407			

****P<0.05**

Comparison between social impacts of the disease with gender distribution has been made in this table in order to find out the significance. Table 4.65 describes that there is a significant difference between gender and social impact of the disease. Table shows that social impact of disease is more on male (M=29.0924, SD=3.45428) as compared to female (M=27.9449, SD=3.50407).

Table 4.66

Comparison between social impacts of the disease with residential area (Independent samples t-test)

Residential area	N	Mean	Std. Deviation	t	df	P
Rural	244	28.3033	3.58297	.528	498	.294
Urban	256	28.1367	3.46988			

P>0.05

Comparison between social impacts of the disease with residential area is drawn in table 4.66. Table describes that there is no significant difference between social impact of disease and residential area of the respondents.

Table 4.67

Comparison between monthly income group and social impact of the disease (One way ANOVA)

Source of variation	Sum of Squares	df	Mean Square	F	P
Between Groups	259.623	4	64.906	5.415	.000**
Within Groups	5933.615	495			
Total	6193.238	499			

****P<0.05**

Table showed that there is significant different between respondents' monthly income group and social impact of the disease as F(4,495)=5.415, **p<0.05.

Table 4.68

Comparison between family sizes with social impact of the disease (One way ANOVA)

Source of variation	Sum of Squares	df	Mean Square	F	P
Between Groups	259.623	4	64.906	5.415	.000**
Within Groups	5933.615	495			
Total	6193.238	499			

****P<0.05**

Table showed comparison between family size and social impact of the disease. Results indicates that there is a significant difference among the two variables as F(4,495)=5.415, **P<0.05.

Table 4.69

Comparison of social impact of the disease with type of the Marriage (One way ANOVA)

Source of variation	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	130.908	3	43.636	3.570	.014
Within Groups	6062.330	496			
Total	6193.238	499			

P<0.05

Table showed comparison between social impact of the disease and type of the marriage. Results shows that there is a significant different between type of marriage and social impact of the disease as $F(3,496)=3.570$, $p<0.05$.

Table 4.70

Comparison between family structures with social impact of the disease (Independent samples t-test)

Family structure	N	Mean	Std. Deviation	t	df	p
Joint	201	28.9801	3.75894	4.026	498	.000**
Nuclear	299	27.7057	3.26261			

P<0.05

Table showed comparison between family structure and social impact of the disease. Result indicates that there is a significant difference among family structure and social impact of the disease. Social impact of the disease on joint family in more (M=28.9801, SD=3.75894) as compare to nuclear family (M=27.7057, SD=3.26261).

Table 4.71

Comparison between frequency of blood transfusion and social impact of disease (One way ANOVA)

Source of variation	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	145.435	3	48.478	3.976	.008**
Within Groups	6047.803	496			
Total	6193.238	499			

****P<0.05**

Table 4.71 showed the comparison between frequency of blood transfusion and social impact of the disease. Result shows that there is a significance difference between frequency of blood transfusion and social impact of the disease as F(3,496)=3.976, **p<0.05.

4.3 Qualitative Data Analysis

4.3.1 Beginning of the Focus Group Discussion

Following points were considered for the beginning of focus group discussion, an overview of the topic, ethics of discussion and first question. In start the purpose of the discussion was made clear to all participants so that they may easily comprehend the concept and express their views freely. The participants were told that they had been selected randomly. It was made clear to all participants that there was no opinion to be wrong but they were allowed to express their views either for or against the topic. They were told to feel free and have some rules in their mind.

1. This is just a research study.
2. Speak but merely one at a time.
3. During dialogue, do not try to mention name of any particular person and place that is going to attach with any issue.
4. During conversation kindly keep in mind that responses are going to be recorded on tape due to fear of missing the important responses.
5. The session will continue about 90 minutes and there will be no formal break. General to specific approach (funnel approach) was established to explore the participants' views starting from general discussion leading towards specific topic. The following questions were asked by the researcher in given domain.

Table I. Focus Group Questions and Domains of Discussion

Domain	Questions
Belief about child disease.	What is your belief, as a mother, to have a child with thalassemia?
Awareness and knowledge about thalassemia.	What do you know, as a mother of affected child, about thalassemia?
	What do you know, as a mother, about your child's disease?
	What do you know, as a mother, about the choices of treatment for your child's disease?
Thalassemia impact on child and parents	How has thalassemia affected your child and family?
Prevention and future concerns	What can be the possible preventive mechanism to stop thalassemia?
	What is your future concerns regarding thalassemia?

4.3.2 **Analysis of Focus Group Discussions**

For the data analysis of FGDs, content analysis technique was used, which is defined as "A research technique for the systematic, objective, and quantitative description of overt content of communications" (Berlson, 1974). This technique is used to estimate the occurrence of certain concept or views within texts or sets of texts. Three moderators were involved to code the data into classification and results of coding were compared and discussed.

Table II. Codes and Sub codes from Focus Group Discussions

Domains	Final Codes and Sub codes
Belief about child disease	Belief of Disease (BD) - BD- Religious Faith - BD- Cousin Marriage - BD- Childhood Illness - BD- Mother responsible
Awareness and knowledge about Thalassemia	Awareness and Knowledge to Disease (AKD) - AKD- Inherited Disease - AKD- Blood Transfusion and Medicines - AKD- Knowledge Gaps
Thalassemia impact on child and parents	Child Impact (CI) - CI- Chronic Ailment - CI- Disease Treatment - CI- Social and Emotional Parental Impact (PI) - PI- Financial - PI- Emotional and Social - PI- Weakness in Parental relationship
Prevention and future concerns	Preventive Mechanism (PM) - PM- Premarital Screening - PM –Educational Program Future Concerns (FC) - FC- Hope for Cure - FC- Availability of Blood

Table III. Demographic Characteristics of Respondents (N=64)

Demographic variables	Total sample N	%
Gender		
Female	64	100
Marital status		
Married	60	93.7
Divorced	2	3.1
Widow	2	3.1
Type of Marriage		
Cousin marriage	52	81.2
Marriage with relative	9	14.0
Out of family	3	4.6
Age		
<20	4	6.2
21-30	46	71.8
31-40	8	12.5
41-50	5	7.8
>50	1	1.5
Highest Education Attainment		
Illiterate	35	54.6
Primary School	15	23.4
Secondary School	8	12.5
Matriculation	2	3.1
Graduation	4	6.2
Occupation		
Unemployed	18	28.1
Business	9	14
Private Employee	10	15.6
Government Employee	13	20.3
Laborer	6	9.3
Other	8	12.5
Monthly income in PKR		
< 5000	13	20.3
5000-7500	18	28.1
7501-10000	16	25
10001-12500	6	9.3
>12500	11	17.1
Residential Area		
Rural	22	34.3
Urban	42	65.6

Theme 1: Belief about Child's Disease

Data elements related to this theme were identified by questioning from mothers to discuss their beliefs about their children suffering from Thalassemia. Mothers demonstrated various beliefs about their children's disease but religious faith was the most frequently applied code to our transcripts and emerged as a dominant theme. Mothers expressed their thorough belief in the will of God and they considered it a trial from Allah because it is a part of their religion that everything whether good or bad comes from heaven. It shows their solid faith that how firm they are in religious beliefs and how do they thank to the blessing of Allah even in times of adversity. One of the mothers said,

"Humans do not have power to do anything without the will of Allah, it's all planned and written that what is going to be happen; we are the puppets in the hands of heaven and cannot do anything without the will of divinity, this disease was written in the fate of my child so we have to bear it with endurance and fortitude. Everything in this world is fragile and everything has to come to its eternal end, the real world is hereafter".

In our transcript, cousin marriage emerged as an important secondary theme. Mothers blamed and cursed their marriages with their cousins; to them this was a reason for their child's disease.

'I really did not know before that a cousin marriage gives birth to so many diseases until I found my child's disease. I wish I could know it before, I had option then, but now I got no option except to take care of my child and get him treated rest of his whole life'.

Mothers also discussed their belief about child's disease in these other areas, 'childhood illness' was another reason for Thalassemia that due to constant illness in early months became a reason for a child's disease, mothers were also disappointed from the behavior of society and

they discussed that society considered them responsible for child's disease because it's a male dominant society and women are always considered responsible for every wrong.

'when she was born, she used to remain sick most of the time and we used to get her treated from Hakeem (quack) available in village but after few months she fell seriously ill for weeks with fever and when she got so weak, we were told by a neighbor that we should take her to city and get her treated from hospital and that was the first time when we were told by a doctor that amount of blood in her body was so less and we had to arrange blood for transfusion, that was a first time she received blood transfusion and until now even right after 8 years we are compelled to get her a blood transfusion every month and sometimes after 20 days if she gets fever and ill meanwhile'.

Theme II: Awareness and Knowledge about Thalassemia

In the group discussion when the mothers were asked about the nature of Thalassemia only some of them defined that it is an inherited blood disorder. Some of the mothers misunderstood the Thalassemia as a blood cancer. When it was asked whether Thalassemia was a infectious disease and if it could be passed on from one person to other, most of the mothers could not give the answers.

'Blood transfusion is the treatment of my child because his body does not produce enough blood. Every month when my child is transfused, I do hope and believe that this is the last time and now after this blood transfusion my child will get alright and his body will start producing blood'

In our transcripts, lack of knowledge was emerged as another related theme. Mothers demonstrated lack of awareness and knowledge about Thalassemia, its treatment and management.

Mostly the mothers did not know about the difference between Thalassemia major and carrier and that they had the wrong opinion that major Thalassemia patients are physically and psychologically abnormal and abnormal to do their daily activities and even they had the view that Thalassemia carrier also need blood transfusion. They had the poor Information about the genetics of Thalassemia. Majority of the parents were unaware of the fact that both parents might be carriers and could give birth to a Thalassemic major, carrier or normal child. Even they had misconception that only one parent who is carrier may produce an affected child. Lack of understanding to Medical Terminology emerged as a related theme. Mothers discussed that due to complex medical jargons and terminologies which are used by doctors, nurses and paramedical staff to explain something regarding child disease makes it difficult to understand about child's disease.

'I have been visiting to Thalassemic center for the blood transfusion of my daughter every month for the last seven years. Blood transfusion process takes 5 to 6 hours which includes blood test, cross match and blood transfusion. But I never acquire any knowledge about Thalassemia from doctors or nurses. Because I am uneducated and I cannot understand their words'

'I want to know all about my child's disease, what actually the disease is and what is its treatment, but no one ever told me about my child's disease and its treatment in detail'

Mothers perceived Thalassemia as, less serious and less dangerous and uncommon disease. They were not aware of the severity of the disease and complications associated with it. When asked that what was the treatment of their child's disease. Blood transfusion and

medicines reply emerged as a major theme and mothers believed that blood transfusion and proper medication was the only treatment of their child.

'I do not know that Thalassemia is connected with other diseases. I believe that blood transfusion is the real treatment of Thalassemia'

Only (n=4) mothers believed that bone marrow transplantation could save the lives of their children. Majority (n=60) of the mothers were not aware with the process of bone marrow transplantation. Mother's lack of information and awareness was one of the major causes of inadequate knowledge about Thalassemia. Due to the inherited complexity of the illness, mothers asked for educational material that should be simple and understandable for a lay man..

Theme III: Impact of Thalassemia on Child and Family

To know the impact of Thalassemia on child and family, mothers were asked to give examples of specific factors that had affected the child and their parental lives. Separate codes for child and parental impact were used to identify the impact on specific areas including psychological, emotional, and financial state. Our Focus Group Discussions (FGDs) found a considerable impact of Thalassemia on affected children and their parents. Child chronic ailment emerged as a major theme and it has more commonly impacted child. Mothers discussed that their children frequently caught fever and their growth was also delayed which was affecting child's overall activities and most of time they could not take part in games with other children and if they took part in any game, they became fatigued.

'I want my child to live a normal life like other children; I want him to go to school, to participate in routine activities, I want him to stay strong and face the world. I cannot see him suffering with this disease; I want him to fight with the disease'

In impact of Thalassemia transcripts, disease treatment was emerged as an important secondary theme, mothers discussed the difficulties and miseries a child faced while getting blood transfusion and treatment every month which directly affected child's emotions and his school regularity.

'It's always hard for him to get pricked repeatedly for blood transfusion. He always forces me after every blood transfusion that now he will not go to hospital for blood transfusion, it's so painful. It's always hard for me to bring him to hospital for blood transfusion. He always comes to hospital weeping and asks me questions why do i always take him to hospital; and that he will not get the blood'.

Impacts of Thalassemia on parental lives were significant. The impact of Thalassemia on financial state was the most applied code to our transcripts and emerged as a dominant theme. Mothers expressed their financial expenditures on medicines, blood transfusion and treatment of their child; mothers voiced a financial constraint in order to provide a better treatment to their child including the financial expenditures, transportation, visits to doctors and hospital, blood tests, blood transfusion and purchase of medicines. Impact of Thalassemia on emotional well being was emerged as a related sub theme. Mothers expressed frustration, sadness and helplessness regarding the disease of their child. Another related theme that emerged from code was restricted social activities of the parents because of an affected child. Mothers discussed that due to the frequent illness of their child, most of time they were unable to participate in social activities such as family gathering and functions, related sub theme was financial constraint because they spent most of the money on child's treatment and they was not able to save enough money to participate in family functions and social activities.

'People predict different things about my child's disease that makes me sad'.

In our transcripts, weakness in parental relationship emerged as a related sub theme. Mothers expressed that their lives would have been better and their relationship with their husbands would have been strong, if their child was normal.

I am not responsible for my child's disease, but my husband believes that it is because of me. Now my life is not the same as it was before, I want my husband to talk to me about our child's disease and want him to go to doctors with me, stay with me at the time of blood transfusion but it never happened and he put all the responsibility related to child's treatment and hospital visits on me'.

Theme IV: Prevention and Future Concerns

Data relevant to preventive mechanism was investigated using questions that asked mothers to discuss the possible preventive measures to stop Thalassemia. Pre-marital screening was the most frequent applied code to our transcript related to preventive mechanism and emerged as a major theme. The majority of affected child's mothers have not at all been tested for Thalassemia, and the reason was unawareness. Mothers discussed that pre-marital screening should be made mandatory for couples before marriage and it should be implemented by force through law.

'In the context of our culture, where most of the marriages are performed between cousins and close relatives, pre-marital screening should be made compulsory for every couple. I do not want any other couple to become the victim of this disease and give birth to a thalassic child'.

A related sub theme was pregnancy test for Thalassemia, few mothers discussed that testing for Thalassemia during pregnancy was helpful for mothers who already had a Thalassemic child. Few mothers showed their concern that majority of mothers were not aware of this test. When probed further, whether test for detection of Thalassemia should be carried out during pregnancy, and in case test comes positive, will the pregnancy be terminated? There were combined views about the termination of pregnancy having major Thalassemia if test indicates a Thalassemic child during pregnancy. Women voiced that abortion was against Islam and should be seen in conventions of Islam on abortion, it should clearly be known whether this was against Islamic teaching or not.

Educational programs emerged as a second major theme relating to preventive mechanism, mothers did not know the prevalence of Thalassemia in Pakistan.

Mothers recommend the several suggestions, together with dissemination of educational materials in the form of pamphlets and posters at open places such as markets shopping malls and in marriage registries. Mothers also suggested that special educational sessions should be conducted for the parents of affected children, where parents should be educated about Thalassemia, its preventive mechanism, and treatment of Thalassemia and how to educate relatives and other family members in order to prevent them from Thalassemic child. One of the mothers explained her concerns;

'I want to prevent my family members and relatives from this disease but I really do not know what exactly to tell relatives that what this disease is and what are the preventive measures to this disease'.

Mothers discussed their fears and future concerns about their child's disease. In our transcript mothers' hope for a child's cure emerged as a theme. Mothers were deeply concerned about the well being of their children. They were desperately hoping to see their children healthy and normal. Mothers discussed their concern about treatment because currently, it had caused pain for both parents and children. Mothers specked regarding their hopes for new treatments and the opportunity of having healthy children in the future. Some mothers also showed their helplessness that children by this disease could not live a lengthy life. Non-availability of blood emerged as another related sub theme. Mothers expressed their concern on the arrangement of blood for affected child every month and discussed that it was the most difficult job to arrange blood.

'How can we manage blood every month, neither anyone donates nor we can buy it. It is very hard to arrange blood every month. Earlier, hospital used to provide blood for transfusion and treatment was also free but now hospital does not provide it anymore and we do not have links to arrange blood'.

4.3.3 Summary

The results demonstrated the mothers' belief regarding Thalassemia, their awareness to disease; its impact on patients and families and future concerns of the 64 mothers of affected children. The primary themes that emerged from our analysis were (i) belief about child's disease, (ii) awareness and knowledge about Thalassemia, (iii) impact of Thalassemia on child and families, (iv) prevention and future measure. Our coding scheme led to the recognition of several important secondary themes. The findings of this study demonstrate that mothers' belief about their child disease is firm and they all have taken their child's disease as a 'will of Allah'.

Chapter No 5

Summary, Conclusions and Recommendations

The present chapter describes a brief summary of the study, its findings, conclusions and provides recommendations. It also provides recommendations for future studies.

5.1 Summary

The study was carried out to explore the impact of Thalassemia major on patients' families in Pakistan. The researcher used interview guide and focus group discussion method to achieve the objectives of this study. The research study was done in four Thalassemia Centers of the Southern Punjab. Which include (i) Thalassemia / Hemophilia Centre of the Children's Hospital & the Institute of Child Health Multan, (ii) Minhaj-ul-Quran, (iii) Amina blood Foundation and (iv) Fatimid Foundation Multan. The researcher reviewed the literature to explore the relevant topics and to become aware of the findings of the relevant studies conducted before in Pakistan and abroad. The researcher also observed the situation in order to construct the questions for interview guide of this study. Nurses of the participating Thalassemic centers worked as study facilitator and obtained the information on designed questionnaire from parents of the Thalassemia major patients through convenient sampling. The researcher had taken this step of gathering data from respondents to ensure the reliability and validity of the data collection tool and another reason was during pre-assessment of the population, researcher found out that majority of the individuals from population were illiterate. The data for the study was collected through interview schedule and 500 respondents were interviewed. Statistical Package for Social Sciences (SPSS) 19 version was uses for the data analysis. Descriptive and inferential

statistics was applied to analyze the data included: frequency distribution, percentages, bar charts, mean, standard deviation, one way ANOVA independent sample t-test, , cross tabulation and Pearson correlation and FGDs. Demographic information showed that 119(23.8%) were male and 381(76.2%) were female. Of 500 respondents, 224(48.8%) respondents were from the rural areas and 256(51.2%) respondents were from the urban areas. Among the total respondents, 234(46.8%) were literate and 266(53.2%) were illiterate.

The results of the study showed that the parents understanding to disease was of very low level; they explained that cousin marriage was the root cause of this disease but they were reluctant to have pre-marital screening and pre-natal diagnosis. The findings of this study correlate with other studies conducted by (Liem et al, 2011; Prasomsuk & Jetsrisuparp, 2007; Wong et al, 2011; Zaman & Salahuddin, 2006; & Arif, Fiaz & Hamid, 2008) that inadequate knowledge, lack of pre-marital screening practices; illiteracy and unawareness were the main reasons in prevalence of the disease. Findings showed that majority of the Thalassemic children's parents were first cousins. Majority of mothers were illiterate. They were unfamiliar with any preventive measure during or before Thalassemia. Zaman and Salahuddin (2006) concluded in their study that educated parents were taking preventive measures if a disease was presented in their families. But on the other hand, due to the high rate of illiteracy majority was not aware of the preventive measures. The study also addressed some deep misconceptions which comprise Thalassemia is a blood cancer and blood transfusions is the only treatment for this disease. Such misconceptions obviously show the way to unnecessary anxieties. The disease was affecting parental financial state very badly, majority of the affected children's families were poor and unable to afford the costly treatment. Sattari et al, (2012) found a similar finding that disease causes financial impact on patient's families. The average cost for treatment of a

Thalassemic patient is around 10,000 PKR (100 USD) per month apart from blood arrangements, which is too high for a poor family (Khattak, 2006). Though, Government is providing blood transfusion facilities; subsidize and free medicines in public teaching hospitals which are only limited to big cities. Similarly, many philanthropists and NGO's are working together for the treatment of the disease but this is not enough because the miseries of the poor patients are greater than the efforts made so far. If Thalassemic children are not treated in time, they can die between the ages of 1-8 years (Saif, 2002). Therefore, proper and timely treatment is essential for the survival of affected children.

Thalassemia is a preventable disease and across all focus group discussions, there is a need for anti Thalassemic educational exhibits and awareness programs. The only effective way to overcome the prevalence of Thalassemia is to stop the birth of Thalassemic children by making pre-marital screening compulsory for general public and counseling with the affected families. Thalassemia has already been addressed successfully in many countries like Iran, Greece, Italy, and Cyprus by running educational campaigns; making people aware of the disease and highlighting its preventive measures to get rid of the disease. (Ishaq, Abid, Kokab, Akhtar & Mehmood, 2012). Prenatal diagnosis and carrier detection facility is available in Pakistan over a decade, but its use is still limited due to the lack of public knowledge and awareness. It is the need of time to realize the density of the disease and practical steps should be taken to reduce the prevalence of the disease. Therefore, it is important to make people aware of the disease, its complications and preventive measures.

In an empirical study, an association between parents' education and Thalassemia was assessed. It was found that educated parents were more worried and tended to cure the disease

during pregnancy. But the majority of the parents in Pakistan are illiterate and they have little awareness about the disease. Moreover, cousin marriages are in vogue which tends to be a causative factor of the disease (Zaman and Salahuddin, 2006). When the symptoms of the disease are treated, the social activities of the affected family members are restricted due to regular transfusion. Usually the patients cannot continue their studies and let off schools. In addition, the patients suffer from other complications such as heart, liver, diabetes, thyroid and hormones (Jaimes, 2002). The association between the education and Thalassemia assessed that parents' education is strongly linked to cure the disease especially that test during pregnancy. Because the majority of the parent's are illiterate and the cousin marriage is another major factor. Mostly the population is illiterate and without proper health education it is impossible to know the exact nature of this deadly disease (Salahuddin, 2006). Thalassemia major is a genetic disorder which causes a great genetic problem throughout the world (Imran, 2006). According to World Health Organization (WHO) in more than 60 Countries the number of the thalassemic careers patients reaches to 150 million (Galanello, 2002).

In many countries screening has been made an integral part regarding the maternal and child health programs. It has helped in decreasing the incidence of Thalassemia effectively. In Italian city Sardinia in 1975 screening program were started. In 1995 it decreased the cases of beta Thalassemia from 1:250 to 1:4000. In Montreal, Canada, screening had caused the 95% decrease in the incidence of Thalassemia. The same results were observed in the region of France, Marseille, where 86% carrier partners were located some years before in a screening program in high school and later on all carriers couples were advised to get pre-natal diagnosis (Alswaidi, Sarah, 2009).

In Cyprus also screening had helped decrease the Thalassemia cases from 1974 to 1978. In the early 1980s screening was made essential due to this only five affected births were occurred between 1991 and 2001. And between 2002 to 2007 there was no Thalassemia case was observed. In Cyprus, before the screening parents faced the difficulties to arrange the blood supply and expensive medicines for the affected patients. So if the Thalassemic not had been controlled the blood supply would have been the larger problem (Cousens, Gaff, Metcalfe and Delatycki, 2010). In Taiwan the screening programme resulted a noteworthy reduction in the incidence of beta Thalassemia. Every year 20 Thalassemia children were born before the screening but after screening this number comes down from three to six. In, Chinese city Guangdong, after screening only one child was born with beta Thalassemia and it happened due to a misdiagnosis. In many major countries of the world pre-natal diagnosis is accessible and abortion is a impediment approach (Alswaidi, Sarah, 2009).

The current socio-economic condition of the country reveals that Pakistan cannot adequately treat all of its Thalassemic. So, considering the gravity of the issue, Government of Punjab has initiated Thalassemia Prevention Programme, which has been implemented in the 18 districts of Punjab. In Pakistan the preventive measures are highly required to stop Thalassemia because almost 10 million people are told to be the carriers of Thalassemia disease. About 5-8 percent population are suffering from Thalassemia in Pakistan. The diagnosis of the disease is easier than the treatment. Only blood transfusion is required to sustain the patient's life but due to improper screening of blood about 30,000 patients is affected with hepatitis during injecting blood. The Government must make it a law to stop Thalassemia by conducting seminars for awareness (Tahir, 2013).

5.2 Findings related to Research Questions (RQ)

To achieve the objectives of the study, researcher set the research questions in chapter 1. Research questions were asked accordingly to the respondents through interview guide and focus group discussion to gather the data from respondents and to achieve the objectives of the study.

Major findings related to research questions are as under.

5.2.1. RQ 1. What are the beliefs of Thalassemic child's parents about their child's disease?

The respondents described their belief to have a child with Thalassemia and reasons of child disease. Respondents demonstrated various beliefs about their child disease. Respondents expressed that it was the will of God and a trial from God to their faith that how firm they were in religious teachings and how they thanked to the blessing of Allah even in the times of adversity. One of the respondent said 'humans do not have power to do anything without the will of Allah, it's all planned and written that what is going to be happen; we just act accordingly so do the disease of my child was written. Everything in this world is fragile and everything has to come to its eternal end, the real world is hereafter'. Respondents were blaming and cursing their marriages with their cousins, to them this was a reason for their child disease. They really did not know before that a cousin marriage gives birth to so many diseases until they found their child disease. Respondents also discussed their belief about child disease in these other areas, 'childhood illness' was another reason for Thalassemia that due to constant illness in early months became a reason for a child disease. Child mothers were disappointed from the behavior of society and they discussed that society considered them responsible for child disease because it's a male dominant society and women are always considered responsible for every bad.

5.2.2. RQ 2. What are the awareness and the knowledge of Thalassemic patients' parents regarding pre-marital screening and pre-natal diagnosis?

Findings of this study showed that majority 471(94.2%) of the respondents had no knowledge regarding Thalassemia is an inherited disease. Majority of the respondents (90.4%) were not undertaken the Thalassemic carrier test due to lack of awareness. Majority 480(96.0%) of the respondents were not aware about Thalassemia disease before its diagnosis. Therefore, majority (49.8%) of the patients was diagnosed as Thalassemia major at the age of four month. Overall, study reported very poor level of awareness and knowledge among respondents.

5.2.3. RQ 3. What is the status of carriers screening and genetic counseling regarding Thalassemia?

Majority of the respondents were un-aware about carriers screening and this has made them to produce a Thalassemia child. Respondents identified that general public should be provided awareness regarding carriers screening test so that spread of Thalassemia may be controlled. Greater parts of the respondents were not aware about genetic counseling before the birth of Thalassemic child. After having a Thalassemic child still few respondents were having some basic knowledge regarding genetic counseling but majority of them were still not aware about genetic counseling and carrier screening.

5.2.4. RQ 4. What is the frequency of blood transfusions and socio-economic impact it brings on patients and their families?

The findings revealed that 17% of respondents' visited weekly to the Thalassemia centers for blood transfusion of Thalassemic children while 43% respondents visit to Thalassemia

centers after fifteen days, 34% of the respondents visit for blood transfusion on monthly basis. Majority 76.6% of the respondents' major blood source was their friends. Findings of this study reported that poor families were facing the difficulties in arranging blood donors for frequently blood transfusion.

5.2.5. RQ 5. What are the financial constraints that patients' families face?

Despite of lower income and high amount of patients' treatment most of the patients' parents were bearing a financial difficulty in the treatment of child. Majority of the respondents' 168(33%) were earning between the range of 5100-7000 rupees per month while 93(18.6%) respondents were earning more than Rs. 9000/- . Majority of the parents were spending 5-10 thousand rupees on monthly basis for the treatment of their Thalassemia child in terms of blood transfusion, investigations and medications. But it is noted that majority 492(98.4%) of the respondents personally meet the financial expenditure of their Thalassemia children while 6(1.2%) of the respondents were getting the financial assistance by government hospital and 2(.4%) of the respondents financial expenditure over a child treatment were being met by further another sources like donation by relatives and friends. So therefore it is concluded that treatment of the Thalassemia major is very expensive, parents monthly income is very low and cannot afford the expensive treatment. Overall results demonstrated great economic impact of patient's families in term of frequent visit to Thalassemia centers, medicines, investigations and blood transfusion. Findings showed that most of the time parents get engaged in the treatment of the child that cause them absent from work which is another reason for a financial burden because their child disease cannot allow them to work at the best and full capacity. Eighty five percent respondents' kids were on regular medicines but fifteen percent of the respondents were not able

to purchase and give regular medicines to their thalassemia major children because of poor socio-economic status. Majority of the respondents were receiving regular medicines for their children with the support of relatives, philanthropists, Zakat Funds and Pakistan Bait ul Mal donations.

5.2.6. RQ 6. What is the social impact of disease on patients' families?

Majority of the respondents reported that they face anxiety and stress because of children disease which has badly affected their social life. Mothers expressed that they spent maximum time and attention to their sick children. Their societal activities are affected because of having thalassemia major child. The study findings showed negative impact of disease on the life of patients' families in many ways. Family social activities were limited because of the sick child. Majority of the respondents find isolate in time of depression. Few of the patients' mothers were facing reactions and abusive words form their in-laws. Many mothers were declared as a responsible for the birth of Thalassemic major child. Majority 186(37.2%) of the respondents were considering that their life is unsuccessful. On the other hand, majority of the respondents were found hopeful that sooner their child will get out of this disease. Therefore, majority 471(94.2%) of the respondents were giving more attention to their sick Thalassemic child as compare to their normal child. Parents suggested that supporting behavior of hospital staff is very necessary to minimize the miseries.

5.2.7. RQ 7. What are the major barriers patients' families face in treatment of Thalassemia child?

Findings showed that due to poor socioeconomic condition, increased expenses related to treatment, transportation, and hospital admissions, blood arrangement, lack of understanding

about the disease were among the major barriers patients' families were facing. Respondents expressed that Thalassemia is a big burden because it has badly affected the quality of life of Thalassemia child; which caused repeated absences from schools, worried during the transfusions of blood, physical restrictions and other associated complications resulting from the sickness itself.

5.3 Conclusion

Following conclusions are based on the finding of the study:

Majority of the respondents' age range was between 31 to 35 years. And majority of them were females. Respondents were mixed and had equal representation from urban and rural areas but majority 53% of the respondents were illiterate and their income were between the ranges from 5100-7000 PKR. On the other hand their family size consisted on 8 > eight members and their family structure were nuclear. Majority 345(69.0%) of the respondents had one Thalassemic child in the family and 155(31.0%) of the respondents had two thalassemic child. Majority of the mothers (65.8%) visit to the Thalassemia / Hemophilia centers for the transfusion of their Thalassemia child while only (20.0%) of fathers use to visit to Thalassemia centers for purpose of blood transfusion. And their major source of blood collection was from friends and relatives. Greater part of the respondents visit Thalassemia center for blood transfusion after every 15 days. Majority (94.2%) respondents were not aware that Thalassemia is an inherited disease while only (5.8%) of the respondents were aware that Thalassemia is inherited disease. Results showed that majority of the respondent were not carried out Thalassemic test in order to diagnose a Thalassemic disease.

The respondents believed that education of the parents play somewhat an important role to diagnose child disease. Majority of the respondents were not aware about the disease before diagnosis and 90.4% of the respondents were not having the knowledge about test. When their child diagnosed as Thalassemic, their belief on rituals for treatment of their child were found to a great extent. 85.4% children were on regular medicine. However 14.6% of the parents were not able to purchase expensive medicines so they were not giving medicines to their Thalassemia child. They were considering the cost of treatment for Thalassemic child as a burden. Results showed that they were giving more attention to their sick Thalassemia children as compared to other normal child and they were reluctant to talk about their child disease to other people. Majority of the respondents were satisfied with the cooperative behavior of paramedical staff of the Thalassemia centers. The majority of them were not happy with the behavior of their relatives but the mothers of thalassemic child were facing reaction and abusive words from their in-laws.

Majority of the children's parents were cousins but they have not been screened for Thalassemia before marriage and despite of the birth of thalassemic child, they were unaware about prenatal diagnosis. Inter family marriages was also one of the main reason of the disease among these patient's. The majority of the cases of Thalassemia are due to avoiding Thalassemia tests and the awareness of parents is also not proper and the result is so horrible.

In the social factors, their family income was very less as compared to the family members and the expenditure of the treatment. Parents shared their sympathetic condition about their affected children, disease management and also the education problems of the children. It also has affected parents economic and even for their jobs and even they have to face

transportation problems due the distance from the centers for Thalassemia treatment. The parents showed lack of medical terminologies with the health care team members during conversation. But at the end they agreed to Thalassemia screening. Majority of the respondents were under mental stress because of thalassemic child. Majority of the parents social activities were affected due to the Thalassemic major child.

5.4 Recommendations

The following recommendations are made on the basis of the conclusion.

- General awareness and health education about the causes, precautionary measures and remedial steps should be spread through print and electronic media.
- Initiatives of Thalassemia eradication program should be taken and involvement of social volunteer and community should be made available and the control of Thalassemia requires treatment of the individual patient as well as a community based educational effort to increase awareness of the problems.
- School-based carrier screening should be launched and made necessary because it may lead to positive outcomes.
- The education thorough booklet and combined method shows affirmative impact on enhancing knowledge of the people and it is useful to decrease the burden of Thalassemia.
- Implementation of medical education and struggle of medical professionals in giving practical information about Thalassemia can make the patient be adhere to the cure.
- Majority of patients' parents belong to remote areas and they travel miles to approach the Thalassemic centers. It is recommended that necessary medical equipments for

Thalassemic transfusion and screening facilities should be provided at every basic health unit with required trained staff.

- Use easy-to-understand media and language for communication and financial support from Government in high risk population. Education on Thalassemia should be included into high school and college curriculum.
- Anti Thalassemic public educational campaigns and programs should be arranged and carried out according to local cultural, educational status and religious beliefs.
- The social disgrace regarding the finding of Thalassemia required to be tackled to increase the awareness of public so that they may be screened for Thalassemia.
- The doctors, social workers and family counselors should put more stress upon the screening of all the relatives of Thalassemic children in Pakistan, and the individual counseling of prospective couples before marriage, these steps will gradually decrease the number of marriages at risk of producing a Thalassemic child.
- The Public health message ought to target to clarify all misunderstanding and support the carrier screening and prenatal diagnosis that shall finally reduce the Thalassemic major births.
- It should be necessary to put more stress upon the careening of all the relatives of Thalassemia children in Pakistan, and the individual counseling of prospective couple before marriage. These steps will gradually decrease the number of marriages at risk of producing a Thalassemia child.
- Couples should be advised to go for blood tests and follow the guideline regarding family planning. They should be considering the importance of genetic counseling.

- Parental knowledge about the Thalassemia carrier screening and prenatal diagnosis is inadequate. It is the need of time to understand the density of problem and educate the general public and create awareness among Thalassemic families about preventive aspects of Thalassemia in order to reduce the burden of disease in Pakistan.
- Additional facilities for premarital screening and counseling should be available at every Government teaching Institutions, District Head quarters and THQ, BHQ levels.
- Commonly, due to different religious translations and complicated culture people do not favor abortion in Pakistan. Therefore pre-marital screening, antenatal diagnosis and abortion before four months ought to be suggested.
- Knowledge regarding disease among mothers should be enhanced and health care professionals must educate the mother's education regarding Thalassemia major relating to carrier, premarital screening and prenatal diagnosis.
- Cousin marriages are in vogue in Pakistani context, which tends to be a causative factor of the disease. Therefore, it is important implication if premarital screening may be made mandatory before marriages.
- The findings of the present study also stress the need of applying successful public educational programs and making premarital screening compulsory for general public to reduce the prevalence rate of the disease. Moreover, additional facilities for premarital screening and counseling should be made accessible and available to general public.
- Administration of hospitals should take measures for the maintenance of proper records and cooperation for data collection of the Thalassemic patients and their families. Such data will be helpful in making and implementing the policies for reduction of Thalassemia.

- People awareness through seminars, media, debates, health training, symposia, local and general practitioners, pediatricians, obstetricians, social workers, staff nurses, generalists may be effective tool for the prevention of Thalassemia.
- There is need of further research to explore the related aspects of the disease, its consequences on a child and family lives, people awareness and knowledge to disease, and preventive measures in different context.
- In order to get deep understanding of this issue and to fill the knowledge gaps which will help policy makers to address the issue in an effective way.
- The researchers here recognized the role of library and information centers for providing information to the parents with Thalassemic child i.e. awareness about cousin marriage, premarital screening, future complications, home care and normal health conditions. The health centre/hospital library or mobile library can provide books, pamphlets, newsletters, video or audio tapes about Thalassemia, flip-charts, and diagrams etc.

Quality of life of children

APPENDICES

(A) List of Thalassemia Centers

Sr No	Name of Thalassemia Centers
1	Thalassemia Centre / The Children's Hospital & the Institute of Child Health Multan, Pakistan
2	Fatimid Foundation Multan, Pakistan
3	Amina Blood Foundation, Multan, Pakistan
4	Minhaj Al Quran, Blood Banking Multan, Pakistan

(B) INTERVIEW SCHEDULE

IMPACT OF THALASSEMIA MAJOR ON PATIENTS' FAMILIES IN PAKISTAN

This research is the part of the award of PhD degree which focuses on "Impact of Thalassemia Major on Patients' Families in Pakistan". Your response will be kept confidential and will be applied for the research purposes only.

Demographical Data:

1. **Name**:_____**Age**:_____
2. **Gender:** □ Male □ female
3. **Relationship with Patient:**

   □ Father □ Mother □ If other (please specify) _____
4. **Residential Area:** □ Rural □ Urban
5. **Education Status**

   □ Literate □ Illiterate
6. **Education status of the respondent?**

□ Primary

□ Middle

□ Matriculation

□ Intermediate

□ Graduation

□ Master

□ Other _____

7. Occupation of the respondent?

□ Unemployed

□ Business

□ Private

□ Govt

□ Laborer

□ Other

8. Monthly income : □ 1000 – 3000 □ 3100 – 5000 □ 5100 – 7000

□ 7100 – 9000 □ Above 9000

General Information:

9. Family size _____

10. Is there any other thalassemic patient in your family? □ Yes □ No

11. No. of affected children? □ Male ____ □ female_____

12. Family structure? □ Joint □ Nuclear

13. What is the frequency of blood transfusion?

□ Weekly □ Bio monthly (15teen days) □ Monthly □ more than monthly

14. What is the source of blood?

□ only government □ private organization □ both private and govt. blood bank

□ Relatives □ If other (please specify)_____

15. **What is the Blood Group of the Patient?**

□A- □A+ □AB- □AB+

□B- □ B+ □O- □B+

16. **Which type of other complication if your children have?**

□ Heart □ Liver □ Diabetes □ Thyroid □ Hormone

17. **Type of marriage**

□1st Cousin □2nd Cousin □ Far relatives □Out of family

18. **Age of Diagnosis**

□ During pregnancy □ Within 4 months after birth □ 4-8 months

□ 9months- 1 year □ After a year.

19. **Is Patient on Regular Medicine**

□Yes □ No

Awareness to Disease:

20. **Do you know that thalassemia is inherited disease?** □ yes □ no

21. **Does the carrier test under taken by parents?** □ yes □ no

22. **To what extent do you feel that education of parents play an important role in diagnose of child disease?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

23. **Do you aware about disease before diagnosis?** □ Yes □ No

24. **To what extent do you believe on some rituals and regarding the treatment?**

□To a Great Extent □ Somewhat □Very Little □ Not at All

25. **What is the level of parent's knowledge about test?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

26. **Parents tendency toward family planning to stop them?** □Yes □No

Social Impact of Disease on Patients Families:

27. **What type of reactions you have to face from your in laws after the diagnosis of disease?**

□ harsh □ ignoring □ normal □ supportive □ polite

28. **To what extent do you feel differences between the attitude of Govt. and private hospital?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

29. **To what extent do you think that paramedical staff is cooperative with you?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

30. **To what extent do you feel that your life is a successful?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

31. **To what extent do you have mental stress because of disease of your child?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

32. **How do you find the behavior of hospital staff?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

33. **To what extent do you feel that supportive behavior of hospital staff play a great role in releasing mental stress?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

34. **To what extent do you feel aggression because of disease of your child?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

35. **To what extent do you feel any problem to make a balance between normal and affected children?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

36. **How do you divide time between children?**

□ Equally □ more attention to normal children □ more attention to sick children

37. **What do you do in time of depression because of child illness?**

□ medication solution □ catharsis with husband

□ catharsis with family members □ any other _____

38. **How often your social activities are affected because of your child disease?**

□ very often □ often □ sometimes □ seldom □ never

39. **How often do you participate in different family gathering?**

□ very often □ often □ sometimes □ seldom □ never

40. **In what extent your conjugal relationship is affected by disease of your child with other people?**

□ very often □ often □ sometimes □ seldom □ never

41. **To what extent do you feel hesitation while talking about the disease of your child?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

42. **What is your nature of relationship with your family?**

□ strong □ weak □ normal

43. **To what extent you have a feeling of homelessness due to disease of your child?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

44. **To what extent your family members help you in time of need?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

45. **To what extent your relatives help you in time of need?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

46. **To what extent your friends help you in time of need?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

Economic Impact of Disease on Patients Families:

47. **Who meets the financial expenditure for treatment?**

□ Personally □ NGO □ Government □ Philanthropist □ relative

□ if any other_____

48. **What is average monthly expenditure on treatment?**

□ < 5000 □ between 5000 to 10000 □ > 10000

49. **To what extent do you feel financial burden of your child's disease treatment?**

□ To a Great Extent □ Somewhat □ Very Little □ Not at All

50. **Respondent's suggestion**

_____

_____

(C) FOCUS GROUP DISCUSSION

1) **Name:**_____

2) **Gender:**

☐ Male ☐ Female

3) **Marital Status:**

☐ Single

☐ Married

☐ Widow

☐ Divorced

4) **Age:**

☐ <20

☐ 21-30

☐ 31-40

☐ 41-50

☐ >50

5) **Highest education attainment**

☐ Low education

☐ Primary school

☐ Secondary school

☐ High education

☐ University

6) Occupation of the respondent:

□ Unemployed

□ Business

□ Private

□ Govt

□ Laborer

□ Other

8) Monthly income: □ 1000 – 3000 □ 3100 – 5000 □ 5100 – 7000

□ 7100 – 9000 □ Above 9000

9) Residential Area:

Occupation of the respondent?

□ Unemployed

□ Business

□ Private

□ Govt

□ Laborer

□ Other

8. Monthly income: □ 1000 – 3000 □ 3100 – 5000 □ 5100 – 7000

□ 7100 – 9000 □ Above 9000

9) Residential area:

□ Rural □ Urban

Questions

1. What are the beliefs of Thalassemic child parents about their child disease?
2. What is the awareness and knowledge of Thalassemic patients' parents regarding pre-marital screening and pre-natal diagnosis?
3. What is the status of carriers screening and genetic counseling regarding Thalassemia?
4. What is the frequency of blood transfusions and the social and economic impact it brings on patients and their families?
5. What are the financial constraints that patients' families face?
6. What is the social impact of the disease on patients' families?
7. What are the major barriers patients' families face in treatment of Thalassemia child?
8. Is there any Thalassemia centre near to your home?
9. How much distance you traveled for the transfusion of your child?
10. In your knowledge what is the treatment for thalassemic child?
11. Before marriage you ever been tested for Thalassemia?
12. What prevention measure you have taken to avoid Thalassemia major in future?

REFERENCES

Arif, F., Fayyaz, J., & Hamid, A. (2008). Awareness Among Parents of Children with Thalassemia Major. *Journal of Pakistan Medical Association, 58* (11), 621-623.

Ammad, S. A., Mubeen, S. M., Shah, S.F.U.H., & Mansoor, S. (2011). Parents' Opinion of Quality of Life (QOL) in Pakistani Thalassemic children. *Journal of Pakistan Medical Association, 61*(5), 470-73.

Alswaidi, F.M., Sarah, J. (2009). Premarital screening programmes for haemoglobinopathies, HIV and hepatitis viruses: review and factors affecting their success, *Journal of Medical Screening 16*(1), 22-28, DOI: 10.1258/jms.2008.008029.

Aziz, K., Sadaf, B., & Kanwal. S. (2012). Psychosocial Problems of Pakistani Parents of Thalassemic children: A Cross Sectional Study done in Bahawalpur, Pakistan. Bio Psycho Social Medicine, 6(15). Doi. 10.1186/1751-0759-6-15.

Ali, Sabih, Jehan, Anwar and Javed .(2012). Psychological Distress and Coping Strategies among Parents of Beta Thalassemia Major Patients. International Conference on Clean and Green Energy IPCBEE, Vol.27 IACSIT Press, Singapore.

Ansari, S.H., Shamsi, T.S. (2010). Thalassemia Prevention Program. Haematology Updates, 23-28.

Amooee, S., Samsami, A., Jahanbakhsh, J., & Karimi, M. (2011).The Pregnancy Outcome in Patients with Minor β-thalassemia. *Iranian Journal of Reproductive Medicine, 9*(1), 9-14.

Academy for Educational Development (AED). (1989). *Hand Book for Excellence in Focus Group Research*, Washington DC.

Ahmed, S., Atkin, K., Hewison, J., Green, J. (2006a) The Influence of Faith and Religion and the Role of Religious and Community Leaders in Prenatal Decisions for Sickle Cell Disorders and Thalassemia Major. *Journal of Prenatal Diagnosis,* 26(9), 801–809.

Alkuraya, F.S., Kilani, R.A. (2001). Attitude of Saudi Families Affected with Hemoglobinopathies towards Prenatal Screening and Abortion and the Influence of Religious Ruling (Fatwa). *Journal of Prenatal Diagnosis, 21*(6), 448–451.

Atkin, K., Ahmad, W.I., Anionwu, E.N. (1998). Screening and Counseling for Sickle Cell Disorders and Thalassemia: The Experience of Parents and Health Professionals. *Social Science and Medicine, 47*(11), 1639–1651.

Alessia Marcon, Laura Zanaboni, Marina Baldini, and Maria Domenica Cappellini (2008) Pregnant Women Affected by Thalassemia Major: A Controlled study of traits and personality. Journal of Research in Medical Sciences, 15(2): 100–106.

Ahmad A. (2006). Assessment of Level of Awareness and Utilization of Treatment Options in Thalassemic Children. *Pakistan Paediatric Journal.* 30, 188-92.

Ahmed, S., Green, J.M., Hewison, J. (2006) Attitudes towards Prenatal Diagnosis and Termination of Pregnancy for Thalassemia in Pregnant Pakistani Women in the North of England. *Prenat Diagn.* 26, 248-57.

Ahmad, S., Saleem, M., Model, B., Petrou, M.(2002). Screening extended families for genetic hemoglobin disorders in Pakistan. *New England Journal of Medicine, 347*(15), 1162-1168.

Burgess, R.G. (1986). Analysing Qualitative Data, *The Law Book Company*, London: Rutledge.

Borhani,F., Najafi, M.K., Rabori, E.D., Sabzevari, S. (2011), The Effect of Family-Centered Empowerment Model on Quality of Life of School–Aged Children With Thalassemia Major. *Indian Journal of Medical Research, 16*(4), 292-298.

Bills.S. (2001). Congenital Disorders of Blood Cells. *Medical International, Pakistan edition*.pp.20-27.

Babbi, E.R. (1990) Survey Research Methods 2nd Ed. Belmont, CA; Wadsworth.

Bhushan, B. (1992). Dictionary of Sociology. Mc Graw-Hill, Inc. New York.

Bejaoui M., Guirat N. (2013). Beta Thalassemia Major in a Developing Country: Epidemiological, Clinical and Evolutionary Aspects. *Mediterranean Journal of Hematology and Infectious Disease,5* (I). DOI.10.4084/MJHID.2013.002.

Cohen, Bruce J. (1979). Introduction to Sociology. Mc Graw-Hill, Inc. New York.

Cohen, L., Manion, L., & Morrison, K., 6th Edition (2007) *Research Methods in Education* London: RoutledgeFalmer.

Caro, J.J., Ward, A., Green, T.C., Huybrechts, K., Arana, A., Wait, S., & Eleftheriou, A. (2002). Impact of Thalassemia Major on Patients and their Families. *Acta Hematological 107*, 150-157.

Chattopadhyay, S. (2006). Rakter dosh-corrupting blood: the Challenges of Preventing Thalassemia in Bengal, India. *Social Science Medicine, 63*(10), 2661–2673.

Cappellini, N., Cohen, A., Eleftherion, A., Piga, A., & Porter, J. (Eds.). (2000). *Guidelines for the Clinical Management of Thalassemia.* Nicosia, Cyprus: Thalassemia International Federation.

Cazzola, M., De Stefano, P., Ponchio, L., Locatelli, F., Beguin, Y., Dessi, C., et al. (1995). Relationship between Transfusion Regimen and Suppression of Erythropoiesis in Beta-Thalassemia Major. *British Journal of Haematology , 89*,473–478.

Cazzola, M., Borgan-Pignatti, C., Locatelli, F., Ponchio, L., Beguin, Y., & De Stefano, P. (1997). A Moderate Transfusion Regimen may reduce Iron Loading in β - thalassemia major without producing excessive expansion of erythropoiesis. *Transfusion, 37,* 135–140.

Cooper, H.M. (1988). The Structure of Knowledge Synthesis - *Knowledge in Society, 1*, 104-126.

Cousens, N.E., Gaff, C.L., Metcalfe, S.A., and Delatycki, M, B.(2010). Carrier screening for Beta-thalassaemia: a review of international practice, *European Journal of Human Genetics, 18*, 1077–1083

Dakhakhny, A.M.EI., Hesham, M.A., Mohammad, S.E., Mohammad, F.N. (2011) Quality of Life of School Age Thalassemic Children at Zagazig City. *Journal of American Sciences, 7*(1), 186-197.

Dhamcharee, V., Romyanan, O., & Ninlagarn, T. (2001). Genetic Counseling for Thalassemia in Thailand: Problems and Solutions. *South Asian J Trop Med Public Health, 32*(2), 413-418.

Dehkordi, A. H., Heydarnejad, M.S. (2008). Effect of Booklet and Combined Method on Parents' Awareness of Children with b-Thalassemia Major Disorder. *Journal of Pakistan Medical Association, 58*(9), 485-87.

Dhamcharee, V., Romyanan, O., & Ninlagarn, T. (2001). Genetic counseling for thalassemia in Thailand: problems and solutions.

Fung, Low, Ha, Lee (2008) Psychological Vulnerability and Resistance in Children and Adolescents with Thalassemia Major, Department of Clinical Psychology, Queen Mary Hospital, 102 Pokfulam Road, Hong Kong, China.

Fung, A., Low, L., Ha, S., & Lee, P. (2008). Psychological Vulnerability and Resilience in Children and Adolescents with Thalassemia Major. *HK J Paediatr, 13,* 239-252.

Ghotbi, N., Tsukatani, T. (2002). An Economic Review of the National Screening Policy to Prevent Thalassemia Major in Iran. Kyoto Institute of Economic Research Kyoto University, Japan.

Guha, P., Talukdar, A., De, A., Bhattacharya, R., Pal, S., Dasgupta, G., & Ghosal, M. K. (2013).Behavioral Profile and School Performance of Thalassaemic Children in Eastern India. *Asian Journal of Pharmaceutical and Clinical Research, 6*(2), *49-52.*

Goldman, A.E. and S.S. Mc Donald. (1987). The Group Depth Interview: Principles and Practice, Englewood Cliffs, NJ Prentice Hall.

Greenbaum, T.(1988). The Practical Handbook and Guide to Focus Group Research Lexington.

Goldbeck, L., Baving, A., & Kohne, E. (2000). Psychosocial Aspects of Beta- Thalassemia: Distress, Coping and Adherence. *Klinische Padiatrie , 212* (5), 254–259.

Gajra, B., Chakraborti, S., & Sengupta, B. (2002). Prenatal diagnosis of thalassaemias. *Int J Hum Genet, 2*(3), 173-178.

Ghazanfari, Z., Arab, M., Forouzi, M., & Pouraboli, B. (2010). Knowledge level and education needs of thalassemic childern's parents of Kerman city. *Journal of Critical Care Nursing, 3*(3), 3-4.

Hajeri, A.A., Arrayed, S.A (2012) Public awareness of beta thalassemia in Bahrain. *Bahrain Medical Bulletin, 34*(1), 1-7.

Habibzadeh, F., Yadollahie, M., Roshanipoor, M., and Haghshenas, M. (2012). Reproductive Behavior of Mothers of Children with beta-thalassaemia Major. *Eastern Mediterranean Health Journal, 18*(3), 246-49.

Hajeri, A., & Arrayed, S. (2012). Public Awareness of Beta Thalassemia in Bahrain. *Bahrai Medical Bulletin, 34(1)*, 220-29.

Hafeez, M., Aslam, M., Rashid, Y., Jafri, H.(2007). Regional and ethnic distribution of beta thalassemia mutations and effect of consanguinity in patients referred for prenatal diagnosis. *Journal of College of Physicians & Surgeons Pakistan, 17*(3), 144-47.

Iqbal, M., (2009). Prevention of Thalassemia, *Nishtar Medical Journal*, 1(2), 1-3.

Ishaq, F., Abid, H., Kokab, F., Akhtar, A., & Mehmood, S. (2012). Awareness Among Parents of ß-Thalassemia Major Patients, Regarding Prenatal Diagnosis and Premarital Screening. *Journal of College of Physicians and Surgeons Pakistan, 22*(4), 218-221.

Ismail, M., Chun, C.Y., Yusoff, N.A.M., Shahar, S., Manaf, Z.A., Rajikan, R., Latiff, Z.A., Ibrahim, H.M. & Jamal, A.R.A. (2013). Quality of Life Among Thalassemia Children, Adolescent and Their Caregivers. *Sains Malaysiana 42,*(3), 373–380.

Karimi, M., Bonyadi, M., Galehdari, M. R., & Zareifar, S. (2008). Termination of pregnancy due to Thalassemia major, Hemophilia, and Down's syndrome: the views of Iranian physicians. *Bio Medical Central,* 9(19). 1-4 DOI: 10.1186/1472-6939/9/19.

Kuo, H.T., M.Y. Tsai, C.T. Peng and K.H. Wu. (2006). Pilot study on the "quality of life" as reflected by psychosocial adjustment of children with thalassemia major undergoing iron - chelating treatment in western Taiwan. Hemoglobin. 30(2), 291 - 299.

Khurana, A., Katyal, S., & Marwaha, R. K. (2006). Psychosocial burden in Thalassemia. *Indian Journal of Pediatrics*, *73*(10), 877-80.

Krueger, Richard, A. 1988. Focus Group Interviews: A Practical Guide for Applied Research Newburry Park, CA:Sage.

Koutelekos, J., & Haliasos, N. (2013). Depression and Thalassemia in children, adolescents and adults. *Health Science Journal, 7*(4).

Liem, R.I., Gilgour, B., Pelligra, S.A., Mason, M., Thompson, A.A. (2011). The Impact of Thalassemia on Southeast Asian and Asian Indian Families in the United States: A Qualitative Study. *Ethnicity & Disease, 21* (3), 361-369.

Loukopoulos, D. (2013). Thalassemia: A Dreadful Disease Turned to a Chronic condition. *Thalassemia Reports, 3*(s1) e2, 3-6.

Lee, Y.L., Lin, D. T., Tsai, S.F. (2008). Disease Knowledge and Treatment Adherence Among Patients with Thalassemia Major And their Mothers In Taiwan. *Journal of Clinical Nursing, 18*, 529–38, doi: 10.1111/j.1365-2702.2007.02150.x.

Loukopoulos, D, Thalassemia: A Dreadful Disease Turned to Chronic Condition. *Thalassemia Reports, 3*(s1), 3-6.

Matsaniotis, N., Kattamis, C. (1969). Thalassemia, a Social Problem in Greece. *Ann. Soc. Belge Med. Trop. 49*(3), 223-232.

Mallik, S., Chatterjee, C., Mandal, P. K., Sardar, J.C., Ghosh, P., & Manna, M. (2010). Expenditure to Treat Thalassemia: An Experience at a Tertiary Care Hospital in India. *Indian Journal Public Health, 39, (*1), 78-84.

Mazzone, L., Battaglia, L., Andreozzi, F., Romeo, M.A., and Mazzone, D. (2009). Emotional impact in β-thalassaemia major children following cognitive- behavioral family therapy and quality of life of caregiving mothers. *Clinical Practice and Epidemiology in Mental Health, 5*(5), 1-6.

Mishal, A.A. (2003). Human life before birth: Contemporary Biomedical Issues in the light of Islam. *Federation of Islamic Medical Associations*, 1-14.

Najafi, K., Borhani, F., Rabari, D., Sabzevari, S. (2001). The Effect of Family-Centered Empowerment Model on the Mothers' Knowledge and Attitudes about Thalassemia Disorder. *Iranian Journal of Pediatric Hematology Oncology, 1*. (3) 98-102.

Tahir, N. (2013). Punjab Thalassemia Prevention Program, Progress report, Punjab, Pakistan.

Nikam S. V., Dama S. B., Patil S.S. (2012). Literacy Status in Thalassemic Patients From Solapur District, Maharashtra, India: A Statistical Study, *DAMA International 1*(1), 22-24.

Prasomsuk, S., Jetsrisuparp, A. (2002). Life Experience of Thai Families with Thalassemic Children: A Qualitative Approach, *Department of Pediatric, Faculty of Medicine, Khon Kaen University Thailand.*

Premawardhena, A., Silva, S.D., Arambepola, M., Olivieri, N., Merson,L., Muraco, J., Allen, A,. Fisher, C., Peto, T., Vichinsky, E., and Weatherall, D .(2004). Thalassemia in Sri Lanka: *A Progress Report. Human Molecular Genetics,13*(2),203–206, doi:10.1093/hmg/ddh250.

Prasomsuk,S., Jetsrisuparp, A., Ratanasiri, T., and Ratanasiri, A. (2007). Lived Experiences of Mothers Caring for Children with Thalassemia Major in Thailand. *Journal forr Specialists in Pediatric Nursing, 12*(1), 13-23.

Politis, C. (1998). The Psychosocial Impact of Chronic Illness. *Annals of the New York Academy of Sciences, 850*, 349–354.

Quinn, P. M. (1990). Qualitative Evaluation and Research Methods, 2nd Ed. Newbury Park, CA: Sage.

Qasmi, M. U. (2001). *The sharia resolutions for complicated problems of present day (urdu).* Idaratul Quran wal uloom Islamia, Karachi. Pakistan, 2(3), 245-49.

Robert I. Liem, Brynnan Gilgour, Stephanie A. Pelligra, Maryann Mason, Alexis A. Thompson (2011) The Impact of Thalassemia on Southeast Asian and Asian Indian Families in the United States: A Qualitative Study, Health Research Program, Children's Memorial Research Centre, Chicago, 4(2), 432-38.

Riewpaiboon, A., Nuchprayoon, I., Torcharus, K., Indaratna, K., Thavorncharoensap, M., & Ubol, B. (2010). Economic burden of beta- thalassemia/Hb E and beta- thalassemia major in Thai children. *Bio Medical Central 3* (29), 1-7.

Rehman, S.U., Batool, S., Qadir, R. (2002) Socio-Economic Status of Impact Thalassemia Child on Families of Faisalabad District. *Pakistan Journal of Applied Sciences, 2* (2), 202-205.

Rizwan, F., Memon, F., & Memon, A. (2011). Frequency of thalassemia trait in pregnant women. *Medical Channel, 17*(1).

Ritchie, J. and J. Lewis (2003). *Qualitative research practice : a guide for social science students and researchers*. London: SAGE.

Ratip, S., & Modell, B. (1996). Psychological and Sociological Aspects of Thalassemia. *Seminars in Hematology, 33* , 53–65.

Shaligram, D., Girimaji, S.C., & Chaturvedi, S.K. (2006) Quality of Life Issues in Caregivers of Youngsters with Thalassemia. *India Journal of Pediatrics, 74*(3), 278-78.

Shaligram, D., Girimanji, S.C., &Chaturvedi, S.K. (2007). Psychological Problems and Quality of Life in Children with Thalassemia. *Indian Journal of Pediatrics 74* (8), 727-30.

Shamsi, T.S.(2009). β-Thalassemia- A major Health Problem in Pakistan. Bismillah Taqee Institute of Health Sciences and Blood Disease Centre Karachi, *Pakistan, Editorial, 1*(1), 11-14.

Shukr, F., Ali, S., Yasmin, A.(2011). Attitude and Knowledge of Mothers with Thalassemia Major Children. *Professional Medical Journal, 18*(4), 703-708.

Saini A, Chandra J, Goswami U, Singh V, Dutta AK .(2007). Case Control Study of Psychosocial Morbidity in Beta Thalassemia Major. J Pediatr. May;150(5):516- 20.

Sattari, M., Sheykhi, D., Nikanfar, A., Pourfeizi, A..H., Nazari, M., Dolatkhah, R., and Mashayekhi, M. (2012). The Financial and Social Impact of Thalassemia and Its Treatment in Iran. *Pharmaceutical Sciences 18*(3), 171-176.

Sharghi, A., Karbakhsh, M., Nabaei, B., Meysamie, A., & Farrokhi, A.(2006). Depression in Mothers of Children with Thalassemia or Blood Malignancies: A Study from Iran. *Clinical Practice and Epidemiology in Mental Health, 2(*27).doi: 10.1 186/1745- 0179-2.

Sands., Deborah, M. (1986). Farming Systems Research Clarification of Terms and Concepts. Exploring Agriculture, Farming System Series. *Cambridge University Press 22*:87- 104.

Samavat, A., Modell, B. (2004). Iranian National Thalassemia Screening Program. *British Medical Journal*, 329:1135–1137.

Saxena, A., Phadke, S.R. (2002). Thalassemia Control by Carrier Screening: The Indian Scenario. *Current Science, 83*(3), 291–295.

Shamsi, T.S. (2004). Beta Thalassemia a major health problem in Pakistan, *Journal of Pakistan Medical Association, 54*(10), 498.

Saxena, A., & Phadke, S. R. (2011). Feasibility of thalassaemia control by extended family screening in Indian context. *Journal of Health, Population and Nutrition (JHPN), 20*(1), 31-35.

Tsianitis, J., Dragonas, T., Richardson, C., Anastasopoulos, D., Masera, G., & Spinetta, J. (1996). Psychosocial Problems and Adjustment of Children with B-thalassemia and their families. *European Child & Adolescent Psychiatry,5*(4),193-99.

Thavorncharoensap, M., Torcharus, , K., Nuchprayoon, I., Riewppaiboon, A., Indaratna, K., & Ubol, B. (2010). Factors Affecting Health Related Quality of Life in Thai Children with Thalassemia. BMC disorders, 10(1), 1-10.

Torcharus, K., Pankaew, T. (2011). Health-related Quality of Life in Thalassemia Treated with Iron Chelation. *Royal Thai Army Medical Journal, 64(*1), 3-10.

Vang, P., Zongrum, O., Sindhuphak, R., Dusiksin, N. (2000). Priliminary Study on Thalassemia Screening and Genetic Counseling in Selective Hmong People in Saraburi Province. Thailand, *Hmong Studies Journal, 8*, 1-19.

Wahab, J.A., Naznin, M., Nora, M.Z., Suzanah, A.R., Zulaiha, M., Faszrul, A.R.A., and Kamaruzaman, W.S. (2011). Thalassemia: A Study on the Perception of Patients and Family Members. *Medical Journal Malaysia, 66*(4),326-334.

Wong, L.P., George, E., & Tan, J.A.M.A.(2011). A holistic approach to education programs in thalassemia for a multi-ethnic population: consideration of perspectives,

attitudes, and perceived needs. *Journal of Community Genet, 2*, 71-97,DOI 10.1007/s12687-011-011-0039-z.

Wong, L.P., George, E., Tan, J.A.M.N.(2011). Public Perceptions and Attitudes Toward Thalassemia: Influencing Factors In a Multi-Racial Population. *Bio Medical Central, Public Health*, 11(193), 11-193.

Zaman, Q., Salahuddin. (2006). Association between the Education and Thalassemia: A Statistical study. *Pakistan Journal of Statistics, II*(2),103-110.

Zahed, L., Bou-Dames, J. (1997). Acceptance of First-Trimester Prenatal Diagnosis for the Haemoglobinopathies in Lebanon. Journal of Prenatal Diagnosis,17(5),423–428.