Society, Consanguineous Marriage and Genetic Abnormalities with special emphasis on Thalassemia

A case Study of Fatimid Foundation, Peshawar

By

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Thesis submission to the department of anthropology,

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Final Approval of Thesis

This is to certify that we have read the thesis submitted by Ms. Shabnam Sarzamin Khan. It is our judgment that this thesis is of sufficient standard to warrant its acceptance by the Quaid-i-Azam University, Islamabad for the award of the Degree of M.Sc in Anthropology.

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Shabnam Sarzamin Khan

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Dedication

I dedicate this work to my beloved

MOM

Who has always been a source of inspiration for me because her prayers, encouragement and assistance is a constant source of inspiration.

Abstract

This research is based on qualitative aspects of child illness and inter cousin marriages in the Peshawar region. The study focuses on the objectives, to explore the social placement of thalassemia patients in society (recognition in terms of productivity, non-productivity, and also lack of recognition as accepted member of society). To study the reasons behind thalassemia patients influencing the total welfare of the family. To know the local perception about consanguineous marriage and its relationship with thalassemia illness among kids. To investigate how thalassemia patients found social recognition in the social melie, particularly in the peer groups. The study has collected primary data, which is collected from the Fatimid foundation Peshawar, the study has used in-depth interviews. The interviews were conducted with patients and family of the patients. The study found that there are many cases of such illness, when the nature of marriages is consanguineous and this type of marriage is evident to cause genetic abnormalities, especially thalassemia among children. This study found that inter-family or inter-cousin marriages are good for relationships across larger size families but it has a cost to the couple with abnormalities in their kids. The study concluded that a Society with frequently consanguineous marriage have faced high frequency genetic abnormalities. In this case thalassemia is center of debate and it is quite plausible to manage social norms and medical precaution of these marriages.

Keywords: Society, consanguineous marriage, genetic abnormalities and thalassemia.

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CHAPTER 1

Introduction

The South Asian region is considered to be one of the most diverse regions in the world. There exist several ethnicities, divided into ethnolinguistic and socio-cultural, and religious lines. The caste system is very much prevalent in the societies and there exist sub-caste systems as well. These structures validate the class structure in the society for the people. Pakistan is no exception to this type of society discussed earlier. It gets its strengths from a similar societal structure. It is divided into four provinces and two administered areas of Gilgit and Kashmir. All these units have a very distinct attribute that they possess a strong pride in their language and cultural heritage. Moreover, all of these units are accustomed to their societal norms, beliefs, and values systems. All of these attributes are beneficial for society as a whole, they help to retain diversity and inclusiveness in the society. Even though there are several benefits that we get from this type of societal structure, there are some perils as well which are affecting society's core.

These societal structures result in a very strong interlinguistic, inter-caste, inter-faith, inter-family bond, and much more. In addition, people perceive people from other cultures and languages as interesting yet untrustworthy. This gives rise to a very strong Baradari system. Ian Talbot in his book, A New History of Pakistan, highlights the importance of understanding baradari to have a grip on Pakistan's societal landscape. The core concept of baradari comes from the idea of having one ancestor at a point in time. This intra-caste norm has come to the point where the family as a basic unit of society declines trusting other families for marriages and tries to be self-dependent and rely on

cousin marriages. These marriages are common and considered a norm in almost all ethnicities of Pakistan.

Trust is one of the reasons for inter-family marriages. However, one can find as many as they want. These marriages may be a result of the patriarchal norms, or to have the lands and money within the family or any other sane reason. In the past, the availability of data was not much, and it was difficult to calculate the impact of these widespread inter-family marriages on the overall health of societal structures. Nevertheless, the availability of data has made it easy to calculate the overall impact. To date, thousands of researches have been conducted, and most of these researches have warned people and societies about the dangerous impacts of consanguineous marriages on the health of offspring. Due to these marriages, the children often face genetic abnormalities. These genetic abnormalities could be mild to severe such as dizziness problems, height issues, eyesight deficiencies, hypertension, heart diseases, body part deformity, etc. Thalassemia is one of those genetic abnormalities that arise from inter-family marriages.

1.1. Problem

Thalassemia is a genetic disease, and specifically a blood disorder where the number of red blood cells is so low that they cannot fulfill the body's hemoglobin demand which carries oxygen to all the cells of the body (Zaheer, Waheed, Abdella, & Konings, 2020). This is an inherited disease, any of the parents could be carriers of the disease. Depending on the severity of the disease, it could be minor thalassemia or major thalassemia or alpha thalassemia, or beta-thalassemia (Vichinsky, 2005). A parent with minor thalassemia could be a potential carrier if it marries another thalassemia minor, and could end up in the more severe form of thalassemia. However, the chances reduce drastically when a

minor thalassemia person marries one who is normal and has no thalassemia stains. Thalassemia major is the most severe among all and requires regular blood transfusions in the patient's body which help them survive. A condition Hydrops details are so severe that it affects the baby inside the mother's womb; this baby is either stillborn or lives shortly after birth. According to the National Human Genome Research Institute, of all the children that are born with thalassemia worldwide, almost 100,000 of them are born with the severeness of the disease and start exhibiting the symptoms within the first two years.

Thalassemia, from the information, seems like a dangerous disease. The chances of getting this disease increase in areas where consanguineous marriages are widespread. Unfortunately, Asia's region is one of the regions where this disease is common (Ebrahim, et al., 2019). Considering the severity of these diseases, the purpose of this research is to understand the social problems that are being faced by the thalassemia patients such as recognition for the productivity and none productivity of thalassemia patients, and non-recognition to accept them as members of society.

Another aspect of conducting this research is to determine the influence of thalassemia patients on the overall welfare of the family. This disease takes parents' time to the child that has thalassemia; therefore, neglect other children or do not have the money to bear the education and health expenses of normal children which affects the overall family's welfare very badly. In addition, the disease is common, the research purpose is to understand people's understanding of consanguineous marriages in perspective of this thalassemia disease. One of the research studies proposed that, as the severity of the

disease rises the age of thalassemia patients with all the possible medical procedures, their life rarely extends after 30.

Therefore, keeping this in mind, the research is conducted to explore the sensitive understanding of recognition of thalassemia patients among their peer group. The research is more qualitative and less quantitative. All of the objectives of conducting this research are very sensitive and require a study to help society understand the perils of consanguineous marriages. For this research purpose, a questionnaire was prepared, and with the help of Peshawar Fatimid Foundation primary data is collected. Based on the objectives of the research a total of forty questions are asked from each patient. With asking basic information of the respondent, all other questions were interlinked with the objectives of the research such as social recognition issues, impacts on family's welfare, local perception of inter-family marriages, and acceptance in peer groups. With the results of this research, we would be able to spread more awareness among people regarding the consequences of inter-family marriages. To help people to take precautionary measures before entering into any marriages against thalassemia. Understanding the cost of bearing a thalassemia child and much more. All of this detail will help in the future to curb this long-standing, long-prevailing disease in our country.

1.2. Problem statement

Pakistan is a culturally rich society, where relationships are important and family bonds are quite helpful for the survival. Culturally rich society has a family value system and social norms of the society. Some norms and social values are scientifically alarming causing as significant level of medical issues. Inter –cousin marriages are said to be dangerous for kids birth with abnormalities. The study explores this issue to come up

with some policy oriented findings to help the basics of societies in rural and urban settlements of Pakistan.

1.3. Objectives of the study

The basic objectives of the study are to,

1. Explore the social placement of thalassemia patients in society (recognition in terms of productivity, non-productivity and also lack of recognition as an accepted member of society).

2. Explore the relationship between inter cousin marriages and existence of thalassemia disease in children.

3. Study the reasons behind thalassemia patients influencing the total welfare of the family.

4. How thalassemia patients found social recognition in the society particularly in the peer groups.

1.4 Significance and limitation of the study

The issue of inter-cousin marriages has extensively debated but none of the policy debate has yet highlighted this issue in policy meetings in Pakistan. It is very important to study this issue for further policy making in Pakistan. The significance of this study will remain breathing unless until the inter cousin marriages are channelized to process, where the test of blood or other diseases can be done before the marriages.

The study has following limitations, where first is the time and resources allocation, as student the author has limited time and funds to conduct as type of study. There are several other limitations, where some female is from a background that they even do not wanted to share their issue, however the study focus only on Peshawar region.

CHAPTER 2

Reviews of Relevant Literature

Beta thalassemia trait is present in about 60–80 million persons worldwide. Thalassemia minor and thalassemia major are two of the most common types of the disease. In most cases, people who have thalassemia minor due to an error in one of their -globin genes are not at risk of dying. In most cases, the moderate anemia caused by this condition does not need any therapy. However, if both parents are carriers of the thalassemia minor trait, their children are more likely to be carriers of the thalassemia major trait as well. Beta thalassemia major often occurs in a person who has both genes (encoding the b-subunit) affected. Such babies are born with severe anemia and have larger bone marrow cavities as a result of the excessive synthesis of hemoglobin. Bone anomalies, particularly in the facial bones, are the result of this scenario. As a result, these people have aberrant hemoglobin that is unable to adequately carry oxygen. The bone marrow, liver, and spleen are put under stress when hemoglobin's become unstable, and this may be harmful to the body. Splenomegaly is often seen as a side effect of efforts to remove aberrant blood cells from circulation. The only way to keep patients alive is to provide them with regular blood transfusions. Thalassemia patients have a higher iron level because of the constant blood flow, the destruction of diseased blood cells, and the unstable hemoglobin. Chelation treatment may alleviate this iron deficiency.

Among those at risk for beta-thalassemia, several comparable mutations and some unusual mutations have been found. Strong linkage disequilibrium and specific configurations of the restriction fragment length polymorphism inside the cluster of -globin are assumed to be connected with every mutation. Approximately 80% of

mutations are linked to twenty distinct restriction fragment length polymorphisms, according to subsequent research. In light of this, it may be concluded that there are distinct populations with beta-thalassemia. Differing regions of the globe have different rates of this illness. India, China, Central Asia, South Europe (also known as the North Mediterranean), and the Arab Region have thalassemia carrier rates of 1 percent – 40 percent each; India, China and the Central Asian subcontinent each have rates of 10 percent; South Europe has rates of 1 percent, and the Arab Region has a carrier rate of 3 percent. However, in Australia, North Europe, South Africa, and the United States, the prevalence of thalassemia carriers is quite low. Among all countries in the Eastern Mediterranean, Pakistan has the greatest yearly number of beta-thalassemia newborns (Waheed, Saba , Wazeer, & Ahmed, 2021; Elhence , Solanki, & Verma, 2013).

Sex education is often avoided in educational institutions such as schools and universities. Pakistan has a greater percentage of people marrying cousins and family members than other North African Muslim nations. In most Asian nations, parents have a major role in determining the outcome of a couple's marriage. Teaching students and their parents about the risks of consanguineous marriage would be a good first step in preventing genetic disorders in future generations. Consent and privacy protections are essential for premarital screening programs to be successful. Pakistani culture and public conduct overwhelmingly reject premarital screening. These difficulties must be addressed in the premarital screening process. Premarital screening for hemoglobinopathies, HIV, hepatitis B, and hepatitis C (HBV and HCV) in young couples is very difficult owing to a lack of awareness, the negative effect of culture, and insufficient genetic counseling. More than half of all marriages in Arab regions are said to be consanguineous. Saudi

Arabia's national government began implementing this initiative in 2004. Premarital screening for HBV, HCV, and HIV was made obligatory in Saudi Arabia in the first half of 2008. For free, the government heavily supports counseling and premarital screening. Across the nation, there are more than a hundred health reception centers, 70 blood screening departments, and 20 clinics offering genetic counseling services. Eighty-six percent of female students at King Saud University had a favorable alasstude toward premarital screening. More than 87% of respondents agreed that testing should be mandatory. And 94% of those polled said that genetic counseling and premarital screening are critical measures in preventing blood problems of the hereditary kind.

Italy, Bahrain, Iran, Jordan, Saudi Arabia, United Arab Emirates, Tunisia, Egypt, Spain, Portugal, Turkey, Cyprus, Canada, Greece, United Kingdom, USA, China, Taiwan, Brazil, Palestine, Malaysia, India, Indonesia, Maldives, Singapore, and Thailand are some of the countries with appropriate premarital screening programs in place at the national level. The Committee of Islamic Fiqh Academy in Makkah holds that a pregnancy may be terminated only if it is less than 120 days old at the time of the decision. After 120 days, however, it is considered sinful to end a pregnancy. Premature delivery is a harrowing experience for both the mother and the obstetrician. Premarital testing and prenatal identification of genetic abnormalities may help prevent this from happening. Thalassemia prevalence in Pakistani cities has only been studied in small numbers. Approximately 62% of the population lives in rural regions with a low degree of understanding of the dangers posed by viral infections. In high-risk groups like thalassemia, epidemiological patterns of HBV and HCV are urgently needed. Shortly, hepatitis viruses are expected to become the most lethal viral infection. Helpful for the

application of blood-safety rules in many public health sectors, these studies will be. According to previous research, 34.8 percent to 60.0 percent of the thalassemia population in metropolitan regions had HCV prevalence (Ehsan, Wahab, Anwer, Iftikhar, & Yousaf, 2020; Akhtar, Abdul Nasir, Shah, & Hinde, 2019). Thalassemia patients may get hepatitis C by receiving unscreened blood from donors during the donor window period, which is well-known. The seroprevalence of HCV infection in thalassemia patients varies widely over the globe. There was a seroprevalence of 2.350 percent for the hepatitis B virus surface antigen, 3.260 percent for HCV, and 0.017 percent for HIV among 160 376 blood donors from Pakistan's capital twin cities in our earlier research. There was a 0.084 percent chance of having both HBV and HCV at the same time. According to Iranian and Indian studies, 63.8 and 16.7 percent of individuals with thalassemia were found to have HCV, respectively (Ansar & Kooloobandi, 2002). Pakistani research found that 60 percent of thalassemia patients had HCV, and this was in Rawalpindi Region. The frequency of HCV infection in thalassemia children in Karachi has been estimated to be 20.5 percent (Ahmed, et al., 2021). The entire people must be educated on how to avoid contracting viral and genetic disorders. There was a pressing need for both preventative and therapeutic vaccines to be used promptly to save healthy persons from becoming ill. Nature provides numerous undiscovered cures for a wide range of ailments, as is widely known (cancer, cardiovascular diseases, metabolic disorders, chronic inflammation, and many others). These natural compounds' medicinal potentials must be discovered, and this is a top priority. Increased activation of numerous cellular proteins has been documented to induce cancer growth, which may be further prevented by possible inhibitors. However, hereditary illnesses like thalassemia are

difficult to cure. Consanguineous marriage should be discouraged in society as the most effective method of preventing such genetic illnesses within families. Consanguineous marriages and thalassemia go hand in hand. In Pakistan, it's not uncommon for people to get married to one other's relatives. This is one of the primary reasons why the prevalence of genetic illnesses has grown in many families. Patients with thalassemia need blood frequently to ensure their survival. Blood transfusions for patients with thalassemia may raise the chance of infection with HBV, HCV, and HIV, on average, by 25 per year. If Pakistan wants to avert a future epidemic of dangerous illnesses, it is imperative to avoid marrying people with close family ties (Saeed & Piracha, 2016).

In clinical genetics, consanguineous marriage is defined as a union between two individuals who are related as second cousins or closer, with the inbreeding coefficient (*F*) equal or higher than 0.0156 (Bittles A. , 2001), where (*F*) represents a measure of the proportion of loci at which the offspring of a consanguineous union is expected to inherit identical gene copies from both parents. This includes unions termed first cousins, first cousins once removed, and second cousins. In some communities, the highest inbreeding coefficients are reached with unions between double first cousins practiced among Arabs and uncle-niece marriages practiced in South India where (*F*) reaches 0.125 (Hamamy, et al., 2011).

In highly consanguineous populations, pedigrees with complex consanguinity loops arising from cousin marriages in successive generations are encountered leading to higher inbreeding coefficients. Reports on consanguinity rates may sometimes include marriages between third cousins or more distantly related individuals. Although this discrepancy affects the total consanguinity rate, the lower coefficients of inbreeding in more remote

unions limit a marked alteration of the mean inbreeding coefficient (α) . To report and compare consanguinity rates among different populations, the two parameters best used are the mean inbreeding coefficient and the rates of marriages between first cousins. In populations of North Africa, West Asia, and South India, consanguineous marriages are culturally and socially favored and constitute 20–50% of all marriages, with first cousins unions accounting for almost one-third of all marriages (Bittles & Black , 2010; Tadmouri, et al., 2009). The prevalence of consanguinity and rates of first-cousin marriage vary widely within and between populations and communities, depending on ethnicity, religion, culture, and geography. Consanguineous marriages are also practiced among emigrant communities from highly consanguineous countries and regions, such as Pakistan, Turkey, North Africa and Lebanon, now resident in Europe, North America and Australia (Hamamy, et al., 2011; Schulpen, et al., 2006).

The high consanguinity rates, coupled by the large family size in some communities, could induce the expression of autosomal recessive diseases, including very rare or new syndromes which increase the public awareness of the risks associated with consanguineous marriages. Currently, many young consanguineous couples planning to have children seek preconception genetic counseling for fear of the consequences of consanguinity on their offspring. In communities with high consanguinity rates, sociological studies indicate that consanguineous marriage could enforce the couples' stability due to higher compatibility between husband and wife who share the same social relationships after marriage as before marriage, as well as the compatibility between the couple and other family members. Consanguineous marriage may be more favorable for the women's status, including the wife's better relationship with her in-laws who could

support her in time of need. There is a general belief that marrying within the family reduces the possibilities of hidden uncertainties in health and financial issues. It is believed that consanguinity strengthens family ties and enforces family solidarity, with cousin marriage providing excellent opportunities for the transmission of cultural values and cultural continuity (Sandridge, Takeddin, Al-Kaabi, & France, 2010). Premarital negotiations regarding financial matters of marriage are more easily conducted and sometimes less costly. Wife's parents prefer to have their daughter living near them and to enjoy the presence of their grandchildren. Moreover, wealthy landlords may prefer to keep their property within the family (Bittles A., 2001; Hamamy & Bittles, 2009). Health care providers and genetics specialists could consider both the negative impact of consanguineous marriage in terms of increased genetic risks to the offspring, as opposed to the potential social and economic benefits (Hamamy, et al., 2011). The reproductive health criteria related to consanguinity show that in first cousin marriages as opposed to non-consanguineous marriages, fertility rate is slightly higher, abortion rate is not different, stillbirths and infant mortality rates are slightly higher and birth defects frequency is estimated to be around 2–3% points more than the background rate among newborns in the general population (around 2–3%). Furthermore, consanguineous unions lead to increased expression of autosomal recessive disorders (Bittles, et al., 2014; Bittles & Black , 2010; Hamamy, et al., 2011; Tadmouri, et al., 2009). The offspring of consanguineous unions may be at increased risk for recessive disorders because of the expression of autosomal recessive gene mutations inherited from a common ancestor. The closer the biological relationship between parents, the greater is the probability that their offspring will inherit identical copies of one or more detrimental recessive genes.

For example, first cousins are predicted to share 12.5% (1/8) of their genes. Thus, on average, their progeny will be homozygous at 6.25% (1/16) of gene loci ((Bennett, et al., 2002).

In general, consanguinity does not increase the risk for autosomal dominant conditions in offspring when one of the parents is affected, nor for X-linked recessive conditions if neither parent is affected (Hamamy, Masri, Al-Hadidy, & Ajlouni, 2007). Most of the literature studying the association of Down syndrome with parental consanguinity concluded that no such association existed. The association of consanguineous marriages with late onset complex diseases such as diabetes, cardiovascular disorders, schizophrenia and cancer requires further studies to precise any existing risks because currently unambiguous evidence-based conclusions are difficult to establish (Hamamy, et al., 2011). Preconception genetic counseling for consanguinity is considered one of the important pillars amongst the community genetic services in highly consanguineous populations. Premarital counseling is another increasingly demanded service in some countries and communities where consanguinity rates are still high and selective abortion of affected fetus is not feasible and/or not acceptable. Marriage in many such countries is regarded as a family decision and not just the couple's decision, although the frequency of "arranged marriages" may be declining in recent years due to the increasing number of females reaching university level education which gives them a broader choice of marriage partner. Many marriages, whether both interfamilial and intrafamilial (consanguineous), are however still considered arranged marriages in some communities. The term "arranged marriage" does not mean that the marriage is planned against the will or acceptance of either partner, but it basically implies that a certain suitable couple is

given the option of getting married under the family supervision. Among marriages contracted from 1969 to 1979 in Jordan, 73.3% of 1983 marriages were arranged through parents' agreement first and then couples' consent, while in 18.6%, the marriage was through the couples' agreement first then the parents' consent (Khoury & Massad, 1992).

In populations with high consanguinity rates and common inherited blood disorders, community programs for premarital screening to detect carriers of hemoglobinopathies such as thalassemia and sickle cell anemia are in progress as for example in Jordan (Hamamy, Al-Hait, Alwan, & Ajlouni, 2007), Saudi Arabia (Memish & Saeedi, 2011), Iran ((Fallah, Samavat, & Zeinali, 2009), Iraq (Al-Allawi & Al-Dousky, 2010), Bahrain (Al Arrayed, 2005) and Turkey (Mendilcioglu, et al., 2011). Carrier detection and genetic counseling programs have been very successful in reducing the birth prevalence of inherited disorders in some populations, such as in Iran (Khorasani, Kosaryan , Vahidshahi, Shakeri, & Nasehi, 2008; Samavat & Modell, 2004). These programs are most successful when they are sensitive to the cultural backgrounds of populations in which they are applied. In Saudi society, although premarital screening to identify carrier status and the provision of appropriate counseling has tremendous potential to prevent inherited disease (Meyer , 2005), results from a screening program for sickle cell disease and β-thalassemia indicated that about 90% of couples in Saudi Arabia at risk of having affected children still decided to marry because of fear of social stigmatization and/or because wedding plans could not be cancelled, which emphasizes the need to conduct premarital screening well in advance of the wedding. One option to be explored is the introduction of screening during secondary school (Alswaidi, et al., 2012).

In addition to their primary goals, premarital screening programs in some communities have helped in raising the public's awareness of genetic diseases in general, their prevention possibilities and the fear that consanguinity is a risk factor for expression of recessive disorders, which has led to an increase in numbers of couples seeking premarital and preconception counseling for consanguinity.

In countries such as Tunisia, premarital genetic counseling is obligatory for all couples with a history of genetic complications and in cases of consanguinity (Chaabouni-Bouhamed, 2008). Premarital counseling is also frequent in some countries offering population-based genetic counseling. For example, in Shiraz, southern Iran, among 2,686 couples presenting for genetic counseling during a 4-year period, data files revealed that 85% had consanguineous relationships (74% were first cousins). Most prevalent reasons for referral were premarital counseling (80%), with 89% consanguinity. Premarital genetic counseling poses unique challenges and opportunities in such countries where the tradition of consanguinity is likely to persist (Fathzadeh, et al., 2008).

Preconception carrier screening for hemoglobinopathies is debated in the Netherlands, a country with immigrants from populations known to have high rates of hemoglobinopathies and high consanguinity rates. A study assessing the intentions to participate in preconception carrier screening for hemoglobinopathies among Turkish female immigrants reported that of the 109 women enrolled in the study, 83.5% would participate in preconception carrier screening, if it was offered. Although the acceptability of preconception carrier screening was high, the degree of acceptability of prenatal testing and termination of affected pregnancies was relatively low (van Elderen, et al., 2010). In offering preconception counseling for consanguinity, it is crucial to

distinguish between families with a known genetic or inherited disorder and those with no known such disorder by taking a detailed family history and constructing a four-generation pedigree (including offspring, siblings, parents, grandparents, aunts, uncles, nieces, nephews and first cousins of the consultand or proband) (Bennett, et al., 2002). Reports have shown that in certain clinical settings, practice guidelines regarding collecting information on consanguinity as part of family history are not available, despite the relevance of such history in identifying at-risk pregnancies (Bishop, Metcalfe, & Gaff, 2008). Specific questions addressed to the couple could help in eliciting the presence of a genetic or hereditary disorder in the extended family. These could include inquiry about the presence of any of the following in blood relatives:

CHAPTER 3

Research Methodology

In order to collect information for objectives, following methods were used.

3.1. Preparing Reports

With the help of my key information as well as my observations in the society I prepared reports. I am permanent resident of Peshawar and I have observed lot of things about cousin marriages and thalassemia in my locality. Most of the participants were those whom I know from the beginning and others I observed during my research duration. I spent time with them before the start of my work and gained their trust and obtained information. On the basis of these information I built reports. All of them were informed about my research and I obtained their consent. I clearly made them understand that my purpose is not to defame them neither to use the information for other purposes except research.

Reports were established because this is necessary for observations. Also the informations are helpful in obtaining data related to research.

3.2. Observations

For observations I visited different places which were mostly close to my home. I visited patient's homes and spent time with the patient and their parents as well ass their siblings. I also visited the schools of some of the patients and spent time there with the tha patients as well as their peers and teachers. I visited some of the patients in the parks and observed their behavior as well as behavior of the people towards the patient. on the basis

of these observations as well as interviews which I conducted randomly in the society I was able to construct my report.

3.3. Interview guide

The topic of my research was different as I was dealing with patients and their families as well as common people and relatives to the patient family. They were wondering about the research I am doing. For this reason I used interview guide to get data from my respondents because of its suitability according to my research topic. I have included questions related to my objectives in my interview guide. Interview guide has helped me to ask different questions from my respondent according to the time, situation and even sometimes according to the place, mood and age of my respondent. I have also attached my interview guide in the end of thesis.

3.4. In depth interviews

An in depth interview is a conversation with an individual conducted by trained researchers that usually collect specific information about one person. It leads a person to go inside of the real happening what is experienced and so observed by the respondent. It is taken out when one wants to know more and more until all the doubts are not removed. During my field work I have conducted in depth interviews from different age group. I have used informal/unstructured interviews owning to the flexibility of this form.

I have conducted in depth interviews with patients and their parents and common people randomly in order to get the data. In depth interviews helped me to get the data in a very good way because during in depth interviews certain respondents have given me the data which was otherwise impossible for me to get.

3.5. Field notes

I have also used field notes during my research. They have helped me a lot in my research and in gathering true information. Field notes are broadly endorsed in qualitative research as a means of documenting wished contextual statistics. With developing use of records sharing, secondary analysis, and met synthesis, area notes ensure wealthy context persists past the original research crew.

3.6. Case studies

In order to get true information and to clarify the objectivs of the research case studies were included in the research which can help in inquiring and getting data within real life context. It helps in getting into depth of the interview of living persons and two know about the events which are related to the problem. Multiple case studies were included in the research which helped in developing theoretical proposition from qualitative and quantitative data, depending upon multiple sources of evidence. Case studies were included for better understanding of the research.

3.7. Sampling

Random sampling technique was used to obtain unbiased information about the research topic. This method is widely used in the field of research for obtaining accurate information about whole population, as whole population can not be used for the purpose therefore scientist use random sampling technique which involved interviewing individuals from a particular territory. The selection of individuals are totally random and belonged to no specific ethical group or religious group. Individuals interviewed from a population were called samples.

3.8. Participants and data collection

The study is based on primary data which is collected through interviews and formal and informal discussions with parents of the patients and the health experts as well as common people. The data was collected from Fatimid foundation Peshawar, where the patients of thalassemia visits for finding health assistance in terms of bloods recharge and other possible health care. A total of twenty two patients of different age groups were included in the study while 22 parents were interviewed for obtaining the information for the objectives. All the patients and their parents belonged to different parts of the province but most of them were permanent residents of Peshawar. Informed consent was signed from the patients and their parents before interview for the use of the information for research purpose and with the consent that their personal information will not be disclosed in the study and will be used with fake names.

3.9. Tool for data collection

This study has used interviews as tool for data collection. The interviews were conducted in Peshawar Fatimid foundation. The data was collected from parents as well as the patients themselves were taken some time to talk and explore the issue. Some of the patients and their parents as well as their relatives were interviewed by paying visits to the patient home. Teachers of th patients and his peers were also visited and were interviewed. Observations were also made to get every possible information regarding the topic of my research. Random people were also included in the study in order to obtain information related to the topic of my research,

The interview guide included question about the type of disorder patient is suffering, parents occupation, duration of treatment, problems regarding getting blood, economical problems of the parents they face during the period. Relationship of mother and father whether they are cousins or not, awareness about the genetic basis of the disorder. The interview also included questions about the behavior of the people with the patients and the family after being diagnosed with the disorder.

All the information obtained through interview were used to address the objectives of the study which included social placement of thalassemia patients in society and exploring the link between inter cousin marriages and existence of thalassemia disease in children. The interviews were also used to obtain information about the effect of thalassemia patients over welfare of the family as well as the social recognition of the patient and his family in the society particularly in the peer groups.

Besides these information, case studies were also included in the study in order completely understand the scenario in depth.

3.10. Data Analysis

Percentage was used to compared different information obtained through questionnaire and was represented in tables.

CHAPTER 4

4. Area Profile

This research is conducted in the district of Peshawar which is located in the northern region of Khyber Pakhtunkhwa. Peshawar District is a district in Pakistan's Khyber Pakhtunkhwa province's Peshawar Division. It is about 160 kilometers to the west of Pakistan's capital, Islamabad. Peshawar, the district headquarters, is also the capital of Khyber Pakhtunkhwa. Peshawar is bordered by Charsadda, Nowshera, Momand Agency, and Khyber. Peshawar is situated in the broad Valley of Peshawar, which is surrounded on three sides by the mountain ranges, with the fourth opening onto the Punjab plains. The city is situated at the valley's generally level base, known as the Gandhara Plains. Khyber Pakhtunkhwa, (kpk) was formerly known as the North-West Frontier Province.

The Indus River runs through the province on the east, separating it geographically and culturally from the rest of the subcontinent. The province's valleys are fertile subsidiary channels of the Kabul River, which brings water from Afghanistan's mountains. Maize, millet, wheat, sugar cane, cotton, and tobacco are the main crops. The climate is dry and continental, with harsh winters and scorching summers. It is one of Pakistan's five provinces and the country's second-largest province in terms of both population and economy, despite being the smallest of the four provinces geographically. It is home to 17.9 percent of Pakistan's total population, with ethnic Pashtuns and Hindko speakers making up the majority of the province's residents.

Historically, Peshawar's old city was a heavily fortified citadel with high walls. Only the remnants of the walls remain in the twenty-first century, but the houses and havelis

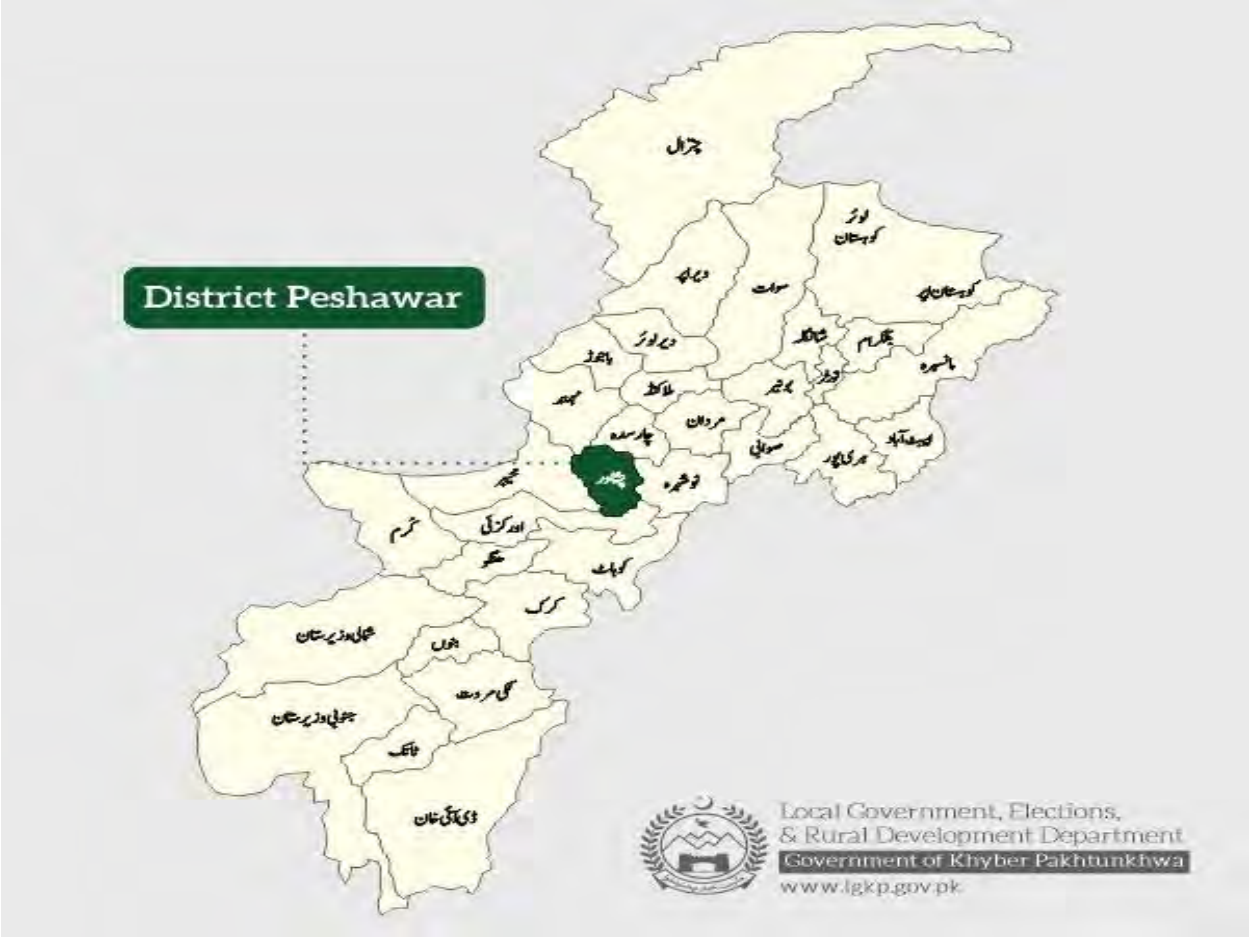
continue to be significant structures. The majority of the houses are made of unbaked bricks, with wooden structures incorporated for earthquake protection, and many are made up of wooden doors and latticed wooden balconies. Many examples of the city's old architecture can still be found in neighborhoods such as Sethi Mohallah. Many historic monuments and bazaars exist in the 21st century in Peshawar's old city, including the Mohabbat Khan Mosque, Kotla Mohsin Khan, Chowk Yadgar, and the Qissa Khawani Bazaar. Due to the damage caused by rapid growth and development, the old walled city has been identified as an area that urgently requires restoration and protection.

The walled city was surrounded by several main gates that served as the main entry points into the city — in January 2012, an announcement was made that the government plans to address the damage that has left the gates largely non-existent over time, with all of the gates targeted for restoration.

4.1. Geography of the Research Locale

The district has a population of 2,026,851, according to 1998 consensus, spread over an area of 3,227 square kilometers (474 sq mi). According to 2017 consensus, the population of Peshawar district is 1,167,892. The city's annual growth rate is estimated at 3.29% per year, and according to 2016 population of Peshawar district is estimated to be 3,405,414. With a population of 1,970,042 according to the 2017 census, Peshawar is the sixth-largest city of Pakistan. and the largest city in Khyber Pakhtunkhwa, with a population five times higher than the second-largest city in the province. The district Peshawar is split into 1 tahsil and 227 union councils Provincial Assembly Seats: 14. There is only one tehsil in the district which is named as Peshawar Tehsil. The district is divided into 4

towns, 279 mouzas (Revenue Villages), out of which 236 are rural, 15 are urban and 28 mouzas are partly urban. There are 30 police stations in the district.



4.2. Climate

With an influence from the local steppe climate, Peshawar features a hot semi-arid climate, with very hot, prolonged summers and brief, mild to cool winters. Winter in Peshawar starts in November and ends in late March, though it sometimes extends into mid-April, while the summer months are from mid-May to mid-September. The mean maximum summer temperature surpasses 40 °C (104 °F) during the hottest month, and

the mean minimum temperature is 25 °C (77 °F). The mean minimum temperature during the coolest month is 4 °C (39 °F), while the maximum is 18.3 °C (64.9 °F).

Peshawar is not a monsoon region, unlike other parts of Pakistan; however, rainfall occurs in both winter and summer. Due to western disturbances, the winter rainfall shows a higher record between the months of February and April.

4.3. Health Infrastructure

Basic health units (BHUs), rural health centers (RHCs), and a referral hospital makes up the health system (DHQ). In every union council of study area, there is a BHU or RHC.

Public sector facilities are composed of hospitals ranging from MTIs to secondary and district-level hospitals (also known as district headquarters [DHQ] hospitals and public hospitals) and supported by RHCs.25 These facility types have inpatient bed capacities and are further supported by a range of un-bedded facilities: BHUs, government rural dispensaries, mother and child health centers, and tuberculosis clinics.

4.4. Medical practitioners.

The government employed 3,644 medical practitioners, 10 radiologists, and an additional 122 dental surgeons in 2016.28 The private sector has 5,075 medical practitioners registered in 2016, 90.8% of whom are males with 466 (9.2%) females. The ratio of government employed doctors to population shows that filled medical posts are relatively well distributed across all districts, except Dera Ismail Khan, Bannu, and Charsadda with a notably lower ratio, and Swat, Karak, and Haripur with a higher ratio. The rate of doctors per 1,000 population for Khyber Pakhtunkhwa is low at 0.3 doctors (in the public and private sector) compared with overall Pakistan at 0.8 doctors in the most recent

countrywide indicators; the rate is 0.3 doctors in Afghanistan and 0.7 doctors in India per 1,000 population.

4.6. Language

The major first language is Pashto (Peshawar language), accounting for 70% of the population while the remaining people speak other languages. The primary native languages spoken in Peshawar are Pashto and Hindko, though English is used in the city's educational institutions, while Urdu is understood throughout the city.

The district of Peshawar is overwhelmingly Pashto-speaking, though the Hindko-speaking minority is concentrated in Peshawar's old city, Hindko speakers in Peshawar increasingly assimilate elements of Pashto and Urdu into their speech.

4.5. Main tribes

Peshawar was an important regional center under the Lodi Empire. The Ghoryakhel Pashtuns Khalil, Muhmands, Daudzai, Chamkani tribes and some Khashi Khel Pashtuns, ancestors of modern-day Yusufzai and Gigyani Pashtuns, began settling rural regions around Peshawar in the late 15th and 16th centuries.

4.6. Travel route of Peshawar

Peshawar's economic importance has historically been linked to its privileged position at the entrance to the Khyber Pass – the ancient travel route by which most trade between Central Asia and the Indian Subcontinent passed. Peshawar's economy also benefited from tourism in the mid-20th century, as the city formed a crucial part of the Hippie trail.

4.7. Major Industry

Cloth weaving, and the manufacture of cotton fabrics, machinery, and equipment are among Peshawar's major industries. Peshawar's Industrial Estate on Jamrud Road is an industrial zone established in the 1960s on 868 acres. The industrial estate hosts furniture, marble industries, and food processing industries, though many of its plots remain underutilized. The Hayatabad Industrial Estate hosts 646 industrial units in Peshawar's western suburbs, though several of the units are no longer in use. As part of the China Pakistan Economic Corridor, 4 special economic zones are to be established in the province, with roads, electricity, gas, water, and security to be provided by the government. The nearby Hattar SEZ is envisioned to provide employment to 30,000 people, and is being developed at a cost of approximately $200 million with completion expected in 2017. Despite the fact that Peshawar is surrounded by rugged and dry mountains, it is a fertile area, and early English visitors referred to it as "paradise." and the city of flowers.

4.8. Roads

Peshawar's east–west growth axis is centered on the historic Grand Trunk Road that connects Peshawar to Islamabad and Lahore. The road is roughly paralleled by the M-1 Motorway between Peshawar and Islamabad, while the M-2 Motorway provides an alternate route to Lahore from Islamabad. The Grand Trunk Road also provides access to the Afghan border via the Khyber Pass, with onwards connections to Kabul and Central Asia via the Salang Pass.

Peshawar is to be completely encircled by the Peshawar Ring Road in order to divert traffic away from the city's congested center. The road is currently under construction, with some portions open to traffic.

The Karakoram Highway provides access between the Peshawar region and western China, and an alternate route to Central Asia via Kashgar in the Chinese region of Xinjiang.

The Indus Highway provides access to points south of Peshawar, with a terminus in the southern port city of Karachi via Dera Ismail Khan and northern Sindh. The 1.9 kilometers (1.2 mi) Kohat Tunnel south of Peshawar provides access to the city of Kohat along the Indus Highway.

4.9. Museums

The Peshawar Museum was founded in 1907 in memory of Queen Victoria. The building features an amalgamation of British, South Asian, Hindu, Buddhist and Mughal Islamic architectural styles. The museum's collection has almost 14,000 items, and is well known for its collection of Greco-Buddhist art. The museum's ancient collection features pieces from the Gandharan, Kushan, Parthian, and Indo-Scythian periods.

4.10. Education

Numerous educational institutes — schools, colleges and universities — are located in Peshawar. 21.6% of children between the ages of 5 and 9 were not enrolled in any school in 2013, while 16.6% of children in the 10 to 14 age range were out of school.

Currently, Peshawar has universities for all major disciplines ranging from Humanities, General Sciences, Sciences, Engineering, Medical, Agriculture and Management Sciences. The first public sector university, University of Peshawar (UOP) was established in October 1950 by the first Prime Minister of Pakistan. University of Engineering and Technology, Peshawar was established in 1980 while Agriculture University Peshawar[160] started working in 1981. The first private sector university CECOS University of IT and Emerging Sciences was established in 1986. Institute of Management Sciences started functioning in 1995, which become degree awarding institution in 2005.

There are currently 9 Medical colleges in Peshawar, 2 in public sector while 7 in private sector. The first Medical College, College, was established in 1954 as part of University of Peshawar. The first Medical University, Khyber Medical University while a women only Medical college, Khyber Girls Medical College was established in 2007.

4.11. Sports

There are hosts of sporting facilities in Peshawar. The most renowned are Arbab Niaz Stadium, which is the International cricket ground of Peshawar and Qayyum Stadium, which is the multi sports facilities located in Peshawar cantonment.

Cricket is the most popular sports in Peshawar with Arbab Niaz Stadium as the main ground coupled with Cricket Academy. There is also small cricket ground, ground, which is located adjacent to Arbab Niaz Stadium, a popular club cricket ground. The oldest international cricket ground in Peshawar however is Peshawar Club Ground, which

hosted the first ever test match between Pakistan and India in 1955. The Peshawar Zalmi represents the city in the Pakistan Super League.

In 1975, the first sports complex, Qayyum Stadium was built in

Peshawar while Hayatabad Sports Complex was built in the early 1990s. Both Qayyum Stadium and Hayatabad Sports Complexes are multiple sports complexes with facilities for all major indoor and outdoor sports such as football, Field Hockey ground, Squash, Swimming, Gymnasium, Board Games

section, Wrestling, Boxing and Badminton. In 1991, Qayyum Stadium hosted Barcelona Olympics Qualifier Football match between Pakistan and Qatar plus it also hosted National Games in 2010. Hockey and squash are also popular in Peshawar.

4.12. HISTORY

Peshawar was founded as the city of Puruṣapura, on the Gandhara Plains in the broad Valley of Peshawar in 100 CE. It may have been named after a Hindu raja who ruled the city who was known as Purush. The city likely first existed as a small village in the 5th century BCE, within the cultural sphere of ancient India.

4.13. Famous places

Chowk Yadgar Known to be one of the most famous places in Peshawar, Chowk Yadgar is located in the heart of the Old City. The monument was originally erected in 1892 in memoriam of General Hastings, but was later dedicated to the victims of the 1930 Qissa Khwani Bazaar Massacre. The Khyber Pass Gate is a famous monument that stands at the entrance to the famous Khyber Pass. The Khyber Pass was an integral part of the Old Silk

Road and connects Pakistan with Afghanistan. And Qissa khwani Bazaar, Peshawar Museum, Jamrud fort, Saddar bazar, Bala hisar fort, Islamia collage.

4.14. Marriages & Social Stratification

Marriage pattern is intra tribal and cases of inter marriage between the two tribes is rare and exceptional. It is preferable to marry within one tribe but cases of inter-tribal marriages are also present. A Yousufzai will marry a Yousufzai and the same is true to kharyan. Chamkani and Daudzi. Social stratification of both the tribes are in complete opposition and One can find caste and class social stratification in pashtun Khalil Peshawar tribe while the same is completely missing in pashtun Khalil tribe.

4.15. Dress Pattern

The men of Peshawar people wear Kameez Shalwar usually with a Waistcoat and a Shawl and the traditional Bannu sandals (much like the national dress of Pakistan). They also prefer the Charsadda/Peshawari chappal and many of them wear a cap of some sort all the time. Generally, in Peshawar, covering head with a cap or Pataki is considering a noble manner.

The women-folk wear colorful clothes at home but go outside only in a full Burqa (also known as a shuttlecock burqa). Strong pardah system exists in Peshawar for females and for females it is consider noble to stay at home. Females can’t visit Bazar without their male relative.

4.16. Music

Peshawar’s traditional music includes Dhol and Rabaab. The men normally dance the ‘Draab' in broad circles in sync to the rhythm of the Dhol. It begins slowly with a few

steps and a slow rhythm, gradually increasing the pace and the number of steps in each round to produce the Attan style dance.

4.17. Fatimid foundation

Fatimid Foundation, a nonprofit charitable organization is the pioneer of voluntary blood transfusion services in Pakistan. It is a symbol of hope for millions of blood disease carriers in Pakistan. Starting with a small center at Karachi in 1981 by Barrister Nazim Jeeva and a handful of volunteers, Fatimid has grown into the largest organization of its kind, now it have four centers at Peshawar, Karachi, Lahore and Multan staffed by a Professional team of physicians and trained workers. Even in terms of quantitative output of blood and blood products, it is the leader of the fraternity of blood transfusion services in Pakistan. The country first regular prenatal diagnostic service for thalassaemia has been started in 1994.

4.18. History

The journey that began in a small room on the pavement of Britto Road, Karachi, Pakistan in 1980 has gradually blossomed into the largest non profit health care and blood transfusion service, providing thousands of units of healthy fully screened blood and blood products each month to Fatimid's thousands of patients (majority are poor and destitute children) suffering from dreadful blood disorders of Thalassaemia and Haemophilia. Fatimid Foundation provides free of cost specialized life saving medical care and diagnostic facilities including transfusion of fully screened safe blood & blood products to Beta Thalassaemia Major and Haemophilia patients. Last year alone Fatimid collected more than 53,000 units of blood and distributed 100,000+ units of blood and

blood products to its more than 14,000 registered patients, through its 9 Centres located in Karachi, Lahore, Peshawar, Multan, Quetta, Hyderabad, Tando Allahyar (Rashidabad), Khairpur and Larkana.

Fatimid is an ISO 9001-2008 certified Organization for its quality management systems and is an approved Charity with the Pakistan Centre for Philanthropy and The i-Care Foundation.

4.19. Facts & Achievements

More than 14,000 registered patients. 9 Centres across Pakistan; Karachi, Lahore, Peshawar, Multan, Quetta, Hyderabad, Tando Allahyar, Khairpur and Larkana.

More than 100 beds and around 200 customized chairs for treatment and blood transfusion of its patients.

Transfuse more than 300 units of blood and blood products to its patients, on a daily basis.

Collects and distributes more than 53,000 units of blood annually, from healthy voluntary donors.

Transfuses more than 100,000 units of screened safe blood and blood products to its patients annually.

Transfused more than 3 million units of screened safe blood and blood products free to its patients, since its inception.

Offers latest physiotherapy, ultrasound and diagnostic facilities to its patients, free of cost.

Provides free of cost Iron chelation treatment and medicines to all its Thalassaemic patients.

Offers free testing and pre-natal diagnostic facilities to Thalassaemia minor parents.

4.20. Donations & Sponsorships

Full treatment cost, including diagnostics, medical care and blood transfusion works out to approximately Rs. 6,500/- per month per child. You can sponsor the treatment of sick children for a period of one month or more.

CHAPTER 5

Results and Discussion

5. Cousin Marriages and place of thalassemia patient in the society

In the present study we evaluated through questionnaire about the status of cousin marriage in Peshawar and its relation with genetic disorders like thalassemia in the population. It was found that cousin marriage is more common in the population and there are several reasons behind this, which are explained in the chapter. Besides this we evaluated the social place of the thalassemia patient in the society how is he/treated and can he/she ne a renowned person of the society.

5.1 Consanguineous marriage is the cause of genetic abnormalities

Cousin weddings may be regarded as marriages between couples who are closely connected, generally as biological kin and commonly as first cousins, although 'cousin' can also imply ancestrally more distant relatives or even a social term instead of a genealogical one. Cousin marriage is commonly characterized in anthropological literature as the 'preferred' kind of relationship in many societies, notably in the Middle East, however, contrary to popular understandings, it is not prescribed by Islam, and may be found in most of the main religion groups. It has now also evolved to be generally perceived by the press and in public health debate as genetically hazardous since cousin marriages are frequently consanguineous to a certain degree. According to the principles of Mendelian genetics, consanguineous wedding provides an enhanced chance that a child would have an autosomal, recessively transmitted genetic disorder. A recessive disorder is one that is created by inheriting two copies – one from each parent – of a gene mutation that in a single copy bears no major health risk. If two individuals possess the

same recessive gene, their likelihood of producing an afflicted kid is 25 per cent. Two biologically unrelated persons have a chance of roughly 2–3 per cent of being both carrier of the same gene mutation, but for first cousins this risk doubles to about 4–6 per cent since they have a grandmother in common from whom they could acquire the same gene mutation.

In the Middle East, North Africa, and Central Asia today, 20–55 percent of marriages are consanguineous. Migrants from various regions of the globe live in Europe, North America, and Australia, where they continue to practice these traditions. Concerns regarding the possible stigmatization of consanguineous couples and immigrant communities in Europe have centered on the genetic risks and the seeming forced nature of cousin weddings among Muslim migrants in recent years in the media and public health discussions. Policy discussions have centered on how minorities' social behaviors are linked to their seeming inability to assimilate into modern European society. Our comparative issue was whether or not this rhetoric of genetic danger in cousin marriage is exclusive to Muslim immigration in Europe. This debate on genetic risk in consanguineous marriage has received little comparative study to far across varied geographical contexts.

As genetic research has progressed since the mid-1980s, and now also thanks to enhanced 'next generation' genomic sequencing tools, new ways to avoid the birth of infants with significant hereditary diseases have been discovered. Genetic research and its social and ethical ramifications have grown in public and academic attention as a result of these technological advancements. Those who oppose genetic risk assessment for people and groups are concerned about the potential benefits and drawbacks of such efforts on

society. Programs focused at avoiding the birth of offspring with hemoglobin abnormalities in European immigrant populations, even those without a specific emphasis on consanguinity, have the potential to curtail reproductive choice and stigmatize carriers. As a disease category, genetic sickness is relatively new compared to, say, viral illness, which raises problems regarding how scientific and local understandings of illness causation may vary. It also raises problems regarding how 'genetic' conceptions might be integrated into local conceptual frameworks about lineage, the structure of kinship ties, inheritance practices, and personal and familial identity

5.2. Demographic characteristics and awareness of the respondents about thalassemia

Table 1 shows the details of demographic characters of the respondents who were included in the study. Data was collected through questionnaire from parents and the respondent patients. The results showed that parents were 55 % illiterate while 45 % were educated. The monthly average income of the parents was 20000 PKR.

In the result it was found that most of the parents were unaware of the disorder named thalassemia before the onset of the disorder in their offspring, only 13 % were having knowledge about the disorder that it is a disorder that effects the blood system. After the onset of the disorder both parents and the patients knew about thalassemia and also knew about different types that prevails in the population.

Table 1: Demographic characteristics of the respondents

		Parents	Childern
Gender	**Male**	**16(81 %)**	**14(66%)**
	Female	**5(19%)**	**7 (34%)**
Education	**Educated**	**45 %**	**20%**
	Illetrate	**55%**	**80%**
Average Monthly income		**20,000 PKR**	**000000**
Awareness about thalassemia	**Before the onset of disorder**	**13%**	**0%**
	After the onset of disorder	**87%**	**100%**

5.3. Cousin Marriages as the main cause of thalassemia

Recessive genes continue to be passed down via marriages between family members, resulting in a rise of noticeable hereditary illnesses. The human genome contains six to eight allelomorphic heterozygotes, each of which is capable of causing one of the several recessive diseases that have been discovered. A genetic abnormality is exposed in a new spread when the recessive alleles that are concealed in heterozygotes come together in the following generation. Autosomal recessive diseases are more likely to have multifactorial causes when married to people of the same sex. The risk of illness increases from 3% to 5% when first-degree relatives marry, since they share 1/8 of their DNA. Phenylketonuria, thalassemia, Landsteiner-syndrome, Fanconi Anderson's haemophilia, neural system defects, and many other illnesses are common in this population. Mortality, morbidity, and fertility are all affected by conjoined marriages. Bad homozygotes have an impact on a population's demographic and genetic structure. The generational impacts of consanguineous marriages are significantly more likely to occur, and that this has a significant impact on prenatal mortality and serious malformations for persons in the same line. As a result of consanguineous marriages, there is an increased risk of congenital deformity, mental impairment, and neonatal and postnatal infant death. Similar findings have been seen in terms of child health indicators when it comes to consanguineous marriage. Congenital abnormalities and mental disorders are becoming more common in families with consanguineous marriages.

In the present investigation we found that most of the thalassemia patients in Peshawar were those who were born to parents who were cousins to one another. Some of them were born to parents who were not cousins but were recessive for the allele. However

main cause of this disorder in Peshawar is cousin marriages. Second cause of this disease is lack of awareness in community because we people don't even know the word of thalassemia but with the passage of time, we come to know that this disease prevails in the society.

Table 2: Roots of Thalassemia in the population

Questions asked	Answer in Yes	Answer in No
1. Have you ever heard about the consequences of cousin marriages?	11%	89%
2. Is thalassemia is caused by consequences of marriage?	37%	63%
3. Is cousin marriage economical?	36%	64%
4. Is cousin marriage provides strength to the family?	47%	53%
5. Are your parents cousins to one another?	88%	12%

6. Is thalassemia is from God side as a consequence of sins?	57%	43%

5.4. Reason behind cousin Marriages in Peshawar

In pashtoon society cousin marriages is usually preferred over marriages outside the family. It is usually because of the fact that the considered that close relatives can be of more advantage in terms of economic benefits as well as strong family bonds that is the soul of pashtoon culture, however, poverty is the main cause of cousin marriages in Peshawar as it is represented in Table 2. The parents can not spend lot of money on wedding there fore they prefer cousin marriages which are economically friendly. Other reasons behind cousin marriages **is** marriages between first-degree cousins are popular because of the general belief that the people outside the family are considered a "stranger." The likelihood of running across individuals who are related is quite high in rural places.

Contrary to popular belief, the practice of intermarriage has a significant role in the perpetuation of poverty. The tight and secluded society becomes the norm in areas where consanguineous marriages are widespread. Even if urbanization increases the chance of distancing the countryside from the city, the market economy fails to foster and the ties to the city are eroded. As a consequence, social life in these areas is very constrained, and the country's structure has created an economic and social dichotomy. It is not uncommon to find large disparities between closed and open areas in terms of wealth, lifestyle, and life expectancy. As a result, the dual structure of the economy causes a

bottleneck. Consanguineous marriages are also more common in areas with historically low levels of investment in human capital. Consanguineous marriage has a significant impact on gene distribution and human capital investment. High cousin marriages in rural areas have led to the development of dual systems in nations where cousin weddings occur often. According to the degree of openness to the outside world, the income, behavioral habits, and living levels of the areas varies. Because of this, the country's dual character is a major impediment to economic growth as long as areas with high percentages of consanguineous marriage remain closed. One thing to keep in mind is that the practice of consanguineous marriage is more prevalent in places with open and sophisticated economies. Investing in people is critical for both economic growth and the prevention of incestuous unions, as we've shown in the previous section. Contrary to this, a lack of human capital investment speeds up the practice of consanguineous marriages and makes it more difficult to cease dual structures and rural reliance, both of which strengthen the stability of consanguineous marriages.

The findings of the above discussion indicate a very strong and positive association between the inter cousin marriages in the families of the thalassemia patients. One of the major reasons is that people in our area prefer marriages inside the families and are not aware of the consequences of it. The engaged the cousin in knot of marriage and ignore this issue which later prove in such kind of disease. Furthermore, the findings of the study further clarifies that many believe that it is a genetic disorder but still they ignore it which is later on carried out in their children and so on. Another respondent defines the same issue in such manner as he and his little sister were the patients of this disease. He elaborates that his parents and his first cousin also have the thalassemia minor which is

transferred to their child in the genes. He further mentioned that his family also prefer marriages in their families. The third respondent of the study defines the disease in such manner as the husband and wife were having this disease and their son was affected as well from the disease. The mother of the child declares that cousin marriage is the root cause of the disease which is transferred to their children. She further elaborates that without knowing the consequences of it her family prefer the cousin marriages and do not take any precautionary measure like doing tests before the wedding. Furthermore, she also stated that this disease is from the God in which the patience of the affected ones is tested. For the above statement of different respondents, it is clarified that the inter cousin marriages is a major cause of the disease.

5.5. Social placement of thalassemia patients in society

Thalassemia is a genetic disease, and specifically a blood disorder where the number of red blood cells is so low that they cannot fulfill the body's hemoglobin demand which carries oxygen to all the cells of the body. Thalassemia major is the most severe among all and requires regular blood transfusions in the patient's body which help them survive. A condition Hydrops details are so severe that it affects the baby inside the mother's womb; this baby is either stillborn or lives shortly after birth. In the present study we investigated about the social status of the patients in the society. In the pashtoon society, patients of thalassemia are treated with sympathy and are much more cared but this cares makes them realize that they are suffering from a disorder that can lead him to death. All the people in the society feel pity for the patient and it makes the patient more uncomfortable when he is present between them. Such sympathetic behavior makes them realize that they are not productive part of the society and they are here for few days.

Table 3: Social status of a patient in the society.

Questions asked	Answer in Yes	Answer in No	Do not Know
Is it hard to live with thalassemia in society?	93%	07%	
Does everyone care for you?	99%	01%	
Does they behave differently as compared to others?	88%	10%	02%
Have you gotten education?	35%	65%	
Do you work?	5%	95%	
Does everyone prefer your words?	77%	23%	
Do you get treatment for free?	13%	87%	
Is it easy to get blood transfusion?	43%	57%	
Has every hospital facility to care for you?	78%		22%

Same is the case with their parents, they care more for their patient kids as compared to healthy ones and siblings too care for the on suffering from thalassemia which is making him alone in the society. Similarly, thalassemia is perceiving to be God curse or punishment but in reality, it is not as it is a natural cause. It is forgotten issue in our society, as not many people pay attention to it and such other diseases. The outcome of the study indicates the recognition of the thalassemia patients in the society such that one respondent mentioned that the patients of this disease is highly deprived and do not have integration with other members of the society depending upon the conditions of the patients which varies from person to person. The patients who are doing well do get the reputation of the other people in the society and just their self while those who are not doing well do not get a high status. Some people says that it is curse and punishment from the God side. Another respondent replied that the parents whose child is having this disease get a very poor image. The parents place them at the top priority but the society place them at the bottom. From the comments of the respondents, it shows that the patients are neglected in the society which makes them hurt and discourage them like they are worthless people in the society.

5.6. Short stature/Growth failure

Not attaining the average height compared to their peers was perceived as a major problem by both parents and patients. This point is frequently raised by both parties. Patients are being called by ‘nick names’ and teased by their peers for their shorter stature. They are also constantly being compared to other siblings at home about their height and thus not respected by younger siblings. As a result of these perceived issues they feel anxious, stressed-up and admit that it lower their self-esteem.

5.7. Education

Majority of the parents are concerned about their thalassaemic children leaving home to further their studies in colleges or higher institutions. Issues raised are related to the well-being of their children and compliance with medication. The patients themselves if given the opportunity would like to be able to leave home to pursue education, but they discouraged by parents due to concerns over health. Although thalassaemic patients wants to be away from home and reside in hostels, they were rather apprehensive about the perception of other students towards them.

5.8. Academic performance and achievement

Both patients and parents believe that the disease influence the academic performance. The patients had performed less well academically, mostly as a result of having to be away from school for follow-up visits, blood transfusion in the day-care centre or admission to the ward. Such absence seem to have an impact on the academic achievement. Periods of absence varied from one day to more than a week per month. Some of the patients expressed their frustration regarding their poor achievement.

In addition many parents attribute the poor academic performance of patients to tiredness and lethargy. These symptoms are more prominent nearer to the time for the subsequent transfusion. There is also general perception among the parents that thalassaemia itself directly cause their children to be slow learners.

5.9. Employment

The difficulty of obtaining a job is expressed mainly by patients who has studied up to only secondary school. Patients who are working admitted to having difficult relationship

with their employers as they had to take time off work frequently for transfusion and other treatment.

The parents of young children also has problems with their own employers mainly related to getting time off to accompany their children for treatment. Parents feel that employers do not understand or refused to understand their predicament.

5.10. Marriage and starting a family

Even though the patients are interested in looking for a life partner, they could not help but express their worry about being rejected by partners because of their illness. All patients agreed however that they should be truthful to their potential spouse about their illness. The parents of adolescence female and male patients also voiced similar concern.

5.11. Relationship and social integration

Although patients have good relationship with siblings and parents, a few problems are highlighted. Some of the patients are teased by family members about their dark-skin colour and short stature. Some patients viewed that because of their low academic achievement they were not treated fairly by parents.

5.12. Peers

Some of the parents claim that their ill children did not have many friends and were virtually housebound. They believed that generally it was the normal children that did not want to befriend the patients. Patients attributed the illness as an obstacle for them to integrate socially.

5.13. Problems of communication

Parents of young adult patients commented that most of their thalassaemic children were not keen on discussing about their disease. The patients themselves felt that discussing about the illness would not change their predicament. Four of the parents suggested that it would be extremely helpful if professional motivation and counseling service for the patients are provided by health

CHAPTER 6

6. Reasons behind thalassemia patients influencing the total welfare of the family

In the present study, influence of a patient on the total welfare of the family was investigated. Parents of the patients, siblings and relatives were interviewed and on the basis of these interviews, different causes were pointed out and discussed here in this chapter.

6.1. Poverty as a main cause due to which a thalassemia patient can influence the welfare of the family

In Peshawar most people are having average income that is hardly enough to support the family with two to three kids. The interview from parents suggested that the average monthly income of the patients family is usually 20000 PKR that is hard enough to support the family The average monthly cost of a thalassemia patient is about 25-30 thousands. This comparison makes the parents unable to support the family and can spend money on other kids. However those having higher monthly income can support their family along with the cost of the patient easily.

These findings can be supported by previous literatures which show that patient with β-thalassemia requires the medication for life of regular blood transfusion and iron chelation therapy, cause social burden and finance is large on patient, family and system of health treatment. Parents often are burdened with treatment cost on child thalassemia is conducted perpetually. It is supported by research is conducted by Saldanha (2015) in her research data points that 82% respondents experience stress cause the finance on the treatment process their children are running perpetually. It can be seen from income section of respondents are discovered the product that most of them namely, 63% of

parents are the worker of semi-skilled, 19% of them is competent and 18% of them are not the competent labour. 65% of them have monthly income between Rs.1,001–5,000; 18% of them Rs.5,001–10,000; 7% between Rs.10,001–15,000 and Rs.15,001–20,000 respectively and 3% of them have income at up Rs.20.000 (Saldanha, 2015). Based on the discovery above, the result of research Shanmugam and Ramachandra (2015), also state that caretakers experience the significant stress on the following domain: stress of daily treatment (DMI) with score of 2,82+1,14 (average ± sd), tension of finance (DM4) 0,90± 0.30, concludes that stress happens significantly amongst of caretakers is stress domain "emotional stress of family", points that family member experiences much more burden give the treatment and need the extra cost to children of thalassemia. From data above, it can be seen that the respondent income very limited to be the medication of thalassemia child is conducted all life perpetually. It becomes the burden to parent in the financing of child for undergoing the treatment process.

The Social Support The treatment of lifetime of thalassemia patient will often cause the hospitalization especially when they have other the health complications. This hospitalization often gives the psychology impact on their parent because they always think about condition their child disease and may not solve because the limited access to obtain support and the accurate information. Therefore, all of this sources will contribute to stressor toward mother and influence their life quality as well.

The parents of the patients are always worried about the economic support they can provide to the patient and thus their life is disturbed as well as their attentions to other kids are also lacking that can effect the life of siblings to the patient.

6.2. Lack of totally free medical facilities as well as education facilities in the province

The respondent parents pointed out the fact that in the province free medical facilities are lacking except some of the foundations like Fatimid foundation that provide health facilities for the patients. Government hospitals are having no such facilities to care for thalassemia patients due to which they are facing economic problems to care for the patients. They are paying for the treatment of the patients and they can not pay school fee of other children. Education business is on its peak in Peshawar and every children has a dream to go to private school or college due to the affections created by the private institutions. But our kids can not go there as we can not pay the fee for school and college.

6.3. Psychology Issue

The parent suffers psychology tension because difficulty cares for child thalassemia. They state that they are pressured and they see their children is sad. They state apprehension toward the child born by thalassemia.. Parent believes that thallasemia diagnosis to their children impacts on mental status and their emotional, family relationship, love and affection amongst the couple. Concern about the born of a child thalassemia, several mothers undergo the operation of tubal ligation is caused separation and divorce in a number of families.

6.4. Other Reasons: Lack of facilities

Government and other institutions are not fulfilling requirements of thalassemia patients and there are no facilities. In Peshawar there were only a few blood banks for thalassemia patients like KTH, LTH and Fatimid foundation. The society also helps in arranging the blood however, the government does not arrange blood for them. Mostly the children

from the start of their birth were affected form thalassemia. Only two specialists were available to treat the disease and they actually helped out. Not only the thalassemic parents carried the genetic abnormalities but others too. There were sacred texts to cure thalassemia. The family members had to face a lot of difficulties specially about the medicines that were too expensive that they sometimes had to borrow money. The total monthly cost of curing the patients was about 10000 out of which one tablet costs 7000 rupees.

6.5. Case studies

The results of the study are presented in the form of transcription of interviews, which are conducted in Peshawar from fatimid foundation. A 26 years old person with, AB+ is suffering from thalassemia major because his both parents are thalassemia minor. According to him consanguineous marriages are very common in society because they prefer marriages within the family and if both cousins happened to be thalassemia minor, then obviously it is consanguineous marriage. He also mentions that thalassemia is a genetic disorder in which one's body is unable to make adequate blood for living. It is not a single disease for those who does not take care of it, it is the mother of all diseases. They are socially deprived and are always left out and does not have integration with others but it depends or varies patient to patient. Some patients are performing well and are on high positions, so they get recognized. In our society, thalassemia is perceiving to be God curse or punishment but in reality, it is not as it is a natural cause. It is forgotten issue in our society, as not many people pay attention to it and such other diseases. He also mentioned that due to this disease their lifestyle is totally changed and on daily basis they have to take vitamins and folic acids. We also face different issues regarding

financial and social in term of different aspects. Total monthly cost of my curing is fifteen to twenty thousand which is not difficult for me to manage but seems like its most probably difficult for other patients. Fortunately, in Pakistan, there are very good hospitals and organizations which arrange blood but these facilities are provided in major cities but other facilities are not provided in any part of the country for free.

Respondent 2: Imad Khan 22 years B+ He told me that he and his little sister is suffering from thalassemia major because his parents are first cousins and also carry thalassemia minor. He says that mostly of marriages in our family are consanguineous marriages because we prefer with in the family. Imad defines thalassemia is a disease in which blood is required after ten days whereas some of them call it as a blood cancer and other severe type of disease because they have no knowledge about it. We are recognized in society to some extent but at some point, we are not like in adventures and other activities. I also got anger issues which is somehow not good behavior with family and also for curing this disease I take different type of vitamins that is C and D and folic acid. He mentions that different type of tests should be done before marriage to reduce the chances of thalassemia disease in coming generation but due to lack of awareness many people ignore this. Also, government provide us good health facilities due to which we can somehow compete this disease to some extent. Total monthly cost of my curing is almost twenty-five thousand to thirty thousand.

Respondent 3: Muhammad Saad 7 years B His mother told me that our child is thalassemia major because we both me and my husband carries thalassemia minor. She defines consanguineous marriage is the major cause of this disease because doctors told us that this disease is carried out from one generation to another. Second cause of this

disease is lack of awareness in community because we people don't even know the word of thalassemia but with the passage of time, we come to know that this disease is between us. She also mentioned that this disease is from the side of God in which our patience is tested. Social recognition is very poor as for parents their children are precious, so they place them at the top but in society they place them at low or bottom. Total monthly cost of curing of thalassemia patient for us is ten thousand in which one tablet cost of seven thousand.

Respondent 4: Kausar 28 years A+ Kausar is a thalassemia major patient and their parents are not even cousins but still they carry minor due to which she is affected with this disease. She tells me that they do not believe in consanguineous marriages and mostly they prefer marriages outside the family. According to her thalassemia is a blood disorder, not a single group of disease. And she sees it very normal because she can afford it. And also clarifies it that consanguineous marriages are not only the cause of thalassemia. She mentions that role of economic class towards thalassemia is encouraging and also there is awareness about this and many seminars are conducted by different NJO'S. At the end she told me that family have accepted them with whole heart but society still not accept them like other normal people. Due to this their parents face a lot of problems like in term of facing the society and also, they have to earn enough.

Respondent 5: Marwa Jan 21 years A+ Marwa told me that both couple parents are not cousins but still carry thalassemia minor which means due to their parents they are affected with thalassemia major. She defines thalassemia is a disease in which there is no making of blood and also highlight the issue of consanguineous marriage that this may be the cause but not really. It is a disorder and should be taken seriously. She also mentioned

that people of society do not accept them whereas in family they are accepted fully by parents but other family members still does not accept it with whole heart. Due to this disease, Hb gets low and also lack of sleep occurs. Doctors are playing a great role in this as they help us in prescribing medicines and other important details which may be helpful in this. Total monthly cost of curing this is round about thirty to thirty-five thousand. Government is not playing a great role in helping us because our daily dose of medicines is too expensive which cannot be fulfilled easily specially for poor families.

A 7 years old boy named Muhammad Saad; file number 3745 was a patient of thalassemia having blood group B-. His parents were asked whether they knew about cousin marriages to which they answered yes. They knew thalassemia as a disease when there is lack of blood. They were not sure whether it was caused by cousin marriage or not. According to them Saad's thalassemia type was major in start however now it's not major. They mentioned that the thalassemia in said was caused due to transfer of genes. His paternal and maternal cousins were also affected with thalassemia. They don't know about the people's perception of thalassemia. It was found that in their culture and society the cousin marriages were very common. Before Saad's diagnosis they didn't know the word 'Thalassemia' but now they knew it very well and told that the community members are also aware about it and the society recognizes them and treats them well. Their view about thalassemia was that it is a disease from God in which the patience is tested. In their opinion the role of economic class was not productive towards thalassemia patients.

Due to thalassemia Saad became Pale, his behavior is arrogant and sometimes he gets upset. The doctor had recommended them tablets and syrup long with good diet. The cousin marriages did not reduce in their families despite the awareness about thalassemia

and the family had accepted thalassemia patients. According to them cousin marriage may not be the only cause of thalassemia and there might be other causes too. During the pregnancy of thalassemia affected mothers the blood gets low and heartbeat gets high. To secure the children from genetic abnormality she said that she got injected with a syringe. According to them it was not a curse trouble or testing case for the family. Parents place the thalassemia patients at top but society puts them at last. The patients arrange or put forward blood donors to blood banks and get their desired blood un exchange for their child. They main cause of this disease is the cousin marriages.

Mujtaba shareef is a student of Quaid e Azam university. He was aware of cousin marriages and knew about the thalassemia as a genetic disorder in which one's body is unable to make adequate amount of blood for living. He said that the disease is caused when one minor marries another thalassemia minor if both cousins happen to be thala minor then obviously it is due to cousin marriage. He also knew about the types of thalassemia and described that there were two major types 1) Alpha Thala 2) Beta Thala in his are the major concern was beta thalassemia which was further divided into two types; major and minor. When he was asked about the perception of society, he said that it is unfortunate that many people in the country do not know about and lack basic information. Most of the marriages in their family were within cousins as it was preferable for the family. The awareness among the community was very limited. The patients of thalassemia are socially deprived they feel left out, do not have integration with others. As far the recognition of the patients is concerned it varies from person to person where some patients who were at high position were recognized while others were not. He said that thalassemia is a forgotten issue in his society and people don't pay

attention to it. The economic class despite being part of the same society do not have basic information about it. He said that it is not a single disease but mother of all diseases. According to him being a thalassemia patient his behaviour was normal. He used vitamins, iron and folic acid. He further told that cousin marriages did not get limited in his family due to lack of awareness. The society didn't accept the patients because their lifestyle is totally changed from normal people. According to him cousin marriage was not the only cause of thalassemia as other people also carry genes. Mostly there were social and financial hurdles for these patients. Disease can be stopped after marriages through proper testing tracing and monitoring. In our society, he said, thalassemia is perceived to be a curse but in reality, is not but a natural cause. These patients have no place in society. They do not affect rather save other siblings. Unfortunately, in our society the perception about the thalassemia is that it is a curse and punishment from the side of God. In Pakistan there are many good hospitals and organizations that help in arranging blood for them. In big cities there are good facilities but there is lack of facilities in other regions of the country. There are no blood banks or facilities provided by the government however, society is very much supportive and mostly students donate blood. The disease is genetic so mostly younger age children were diagnosed to be thalassemic. According to him only one thalassemia specialist doctor was present in his district as majority of the doctors don't want to join this field due to lower incomes/profit generation in this field. It is not necessary that only married couples carry abnormalities. There were no major difficulties faced by family members according to him 15-20000 is the total monthly cost for cure of thalassemia patients.

Muhammad haris knew about cousin marriages. He defined thalassemia as a disorder in which there is lack of blood. He had thalassemia major which he said was transferred from his parents through genes transfer. Most of the people in his family and community knew about the disease many however were unaware of it. According to him the thalassemia patients were not treated well in the society and were discriminated due to their different way of living. They are different from normal people the texture of face is not normal and colour is also pale, they have anger issues over small things which society cannot accept as they are not normal. He said that he uses Amoxil, folic acid, cecon, and hydranilctic. As per his information the mother had severe headache during pregnancy. Such diseases can be cured through proper tests after marriage. They received blood easily from donors. He lives in Islamabad and told that in his city there are good facilities available, and also the medicine is provided for free, however government didn't arrange blood camps. Most of the children have thalassemia at younger age because it is genetic. As far as the role of doctors is concerned, they are playing a vital role. The family members have to go through stress they get upset quite often. There were three specialists in his city to treat thalassemia. According to him the monthly expense to cure a thalassemia patient is 30-35000.

Hamayel was aware of cousin marriages. He defines thalassemia as an anemic disease where body do not make blood and they need blood from outside for their living. He said that 70% of the thalassemia was caused due to cousin marriages while 30% out of family. He himself was thalassemia major case. His both parents were minor cases which resulted in him being major. People don't have much awareness and knowledge. As far the behavior is concerned the people who are not educated don't treat them well while the

educated people show good behavior and are kind towards them. He said that good care of such patients should be done by the members of society as it is a dangerous disease. Economic class in his view played a good role towards the patients. The patients do not have proper growth, they are pale and have an issue of sleeplessness unlike the normal people. They get anger issues and stay upset quite often. He was using disperal, vitamins and iron tablets. He said that proper tests should be carried out in order to save future generations from such a disease. In society, the thalassemia patients get affection. The blood is arranged by donors or though hospitals where they are registered. The main causes of the disease to him were lack of knowledge and cousin marriages. He like many others told that government was not arranging blood for them. He named Hamza and Fatmid Foundation who were arranging blood camps for these patients. He too was of the view that children of younger age were diagnosed with thalassemia. To his knowledge there was no such specialist in his area to treat thalassemia patients. He was not satisfied with the performance of doctors in this field. The family members often become sad and concerned and it costed them nearly 30-400000 rupees on a monthly basis to cure thalassemia patient.

She said that in thalassemia the body could not make blood and the disease was not caused by cousin marriage as her parents were not cousins. She was a patient of Thalassemia major. Her parents were minors from two different families. According to her many people are unaware about the disease and both causes whether it is cousin marriage or outside the family marriage they lack knowledge. The society treats us well she said and do recognize such patients. Thalassemia, she added, is a serious disorder and it should be taken serious by the society. The thalassemia patients have anger issues and

they lose temper easily. Her mother during pregnancy was nervous about upcoming baby due to severely low levels of hemoglobin in her body and lack of sleep. Marqa told that she took onista, vitacex, callipin, lyax, thyroxine and disperal injections. She said that if CVS tests are conducted such diseases can be controlled and future generations can be saved. AS far the place of such patients was in society it was good as well as bad too. The society perceives it to be a test from God. The major causes of Thalasssemia are lack of knowledge and cousin marriages. She said that the governments provided no facilities nor arranged any blood camps for such patients. She named Hamza, Frontier, and Fatimid complex that were blood banks in her city of Peshawar. Society plays a vital role in arrangement of blood s mostly volunteer donate blood. Two specialists were available to treat the disease. Mostly the children at the time of birth are diagnosed with thalassemia. The family had to bear a sum of 100k monthly for the treatment of thalassemia patient.

6.6. Summary/Findings

The above discussion indicates different perceptions about the thalassemia disease. According to most of our respondents' consanguineous marriages are considered one of the major causes of thalassemia. The result indicates that consanguineous marriages are very common in our society because people prefer marriages within the family and if both cousins happened to be thalassemia minor, then obviously it is consanguineous marriage. Moreover, some of the patients do not accept cousin marriages to be the cause of thalassemia and identify that it is a natural and blood disorder. Moreover, patients affected from thalassemia are socially deprived and are always left out and do not have integration with others but the severity of the disease varies from patient to patient. Patients who are affected from this disease is having different status in the society that is

some patients who are performing well and are on high positions, so they get recognized while, those who are not doing well do not get a high status and the society look them at the eye of deprivation. According to some of the patients in our society, thalassemia is perceiving to be God curse or punishment but in reality, it is not as it is a natural cause. According to many others those who do not have enough earning is facing much difficulties to ensure their health and they claim that it cost about 25-30 thousand monthly for curing this disease. To reduce the risk of this disease of this disease the government need to aware the peoples about the consequences of cousin marriages and should enforce that people who are doing marriages in the family should do tests before their marriages. Moreover, the government should provide facilities in the backward areas where cousin marriages are at peak and should make blood centers for the affected patients which will help to reduce the risk of the disease.

Chapter 7

7. Summary and Conclusion

Inter-cousin marriages and genetic abnormalities are quite importantly linked that It has a very serious consequence for societies in the long run. Cousin marriage is commonly characterized in anthropological literature as the 'preferred' kind of relationship in many societies, notably in the Middle East, however, contrary to popular understandings, it is not prescribed by Islam, and may be found in most of the main religion groups. It has now also evolved to be generally perceived by the press and in public health debate as genetically hazardous since cousin marriages are frequently consanguineous to a certain degree. A qualitative study is designed to approach such problems through research for making a policy oriented study. In Pakistan social norms and value system keep us bonded to some very important decision. Some societies are more rigged and some are flexible in terms of choices of marriages. Most regid ones have frequently observed that they marry inside family relationships and most of these are facing abnormalities in their kids. Even though reducing infant mortality has been a top research focus in Pakistan for decades, genetic disorders and inter-family marriages have received little attention. In 2012, the Aga Khan University's Centre of Excellence in Women and Child Health conducted a large survey of rural Pakistani families with children under the age of five to determine the prevalence of impairments. Disabilities were found to be less common than previously thought in children under the age of five, with a frequency of roughly 5.5 per 1000. Over 90% of the married women questioned were found to be related to each other. In Pakistan, a large-scale investigation found a correlation between consanguinity and disability. Thalassemia prevalence was examined in different research from 2007 that

looked at consanguinity. 8 An estimated 5000-9000 children per year are affected by this illness, and the estimated carrier rate is 5-7 percent, compared to a global incidence of 1 percent. 10 At 6%, thalassemia was most prevalent in Punjab, according to the study's findings. Since 2016, thalassemia blood tests have been necessary for all couples wishing to be married in the state. 11 Only a few Pakistani hospitals are willing to do a blood test on the spouses of people who know they have a genetic mutation. This research is based on qualitative aspects of Child illness and inter cousin marriages in the Peshawar region. The study focuses on the objectives, to explore the social placement of thalassemia patients in society (recognition in terms of productivity, non-productivity, and also lack of recognition as accepted member of society). To study the reasons behind thalassemia patients influencing the total welfare of the family. To know the local perception about consanguineous marriage and its relationship with thalassemia illness among kids. To investigate how thalassemia patients found social recognition in the social melie, particularly in the peer groups. The study has collected primary data, which is collected from the Fatimid foundation Peshawar, the study has used in-depth interviews. The interviews were conducted with patients and family of the patients. The study found that there are many cases of such illness, when the nature of marriages is consanguineous and this type of marriage is evident to cause genetic abnormalities, especially, thalassemia among children. This study found that inter-family or inter-cousin marriages are good for relationships across larger size families but it has a cost to the couple with abnormalities in their kids. It was also found that thalassemia is prevailing in the society due to the lack of education as well as due to the poverty that can lead into the increase in the number of patients in the society. The study concluded that a Society with frequently

consanguineous marriage have faced high frequency genetic abnormalities. In this case thalassemia is center of debate and it is quite plausible to manage social norms and medical precaution of these marriages. In this study it was also found that the patients are usually in stress because he is given much attention by the parents as well as he is facing tensions from the siblings and the peers. He requires special attentions which is usually needed but due to th lack of health facilities the patient is always in stress. Due to which he can not get a position in the society as a usefull member. In this study it was also found that due to low economic status of the people, parents are usually in stress for medical care and financial matters that can not only affects their lives but also affects the family. In conclusion the present study suggest that special attention needs to be given to the patients in terms of free health facilities and blood transfusion in every part of the province and special centres should be made for the patients that can guarantee their education as well as well being to make them usefull part of the society.

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Interview guide:

1. Have you ever heard about consanguineous marriage?

2. What is meant by thalassemia?

3. Is thalassemia caused by consanguineous marriages?

4 .What is the perception of people towards thalassemia?

5 . How he or she affected with thalassemia, please give detail?

6 . Which are thalassemia types in your area of inquiry?

7 . What is the ratio of thalassemia in your area?

8 .What is trend of marriages in your cultural and society are they

9. mostlyconsanguineous marriages?

10. What is level of awareness among the community members about the thalassemia?

11. How are patient of thalassemia treated in the society?

12. Thalassemia Patient are recognized in the family and society?

13. What is role of economic class toward thalassemia patient?

14. How you see thalassemia in your society?

15. What are abnormalities/disabilities have happened due to thalassemia?

16. What is place of thalassemia patient in society?

17. what is thalassemia patient’s behavior in the family?

18. Is there is any folk medicine for the thalassemia treatment?

19. Consanguineous marriage pattern restricted due to thalassemia?

20. Society and family have accepted thalassemia patient?

21. Is consanguineous marriage single cause of thalassemia in the area?

22. What do only thalassemia married couple carry genetic abnormalities?

23. Which are or can be hurdles for the thalassemia afflicted parents?

24. How can you safe from the genetic abnormality in children after marriage?

25. Thalassemia patients have affected siblings too?

26.Thalassemia is curse, trouble and anathema or tasting case for the family?

27. Is there any socially construct elements and mind set of people towards thalassemiadisease and patients?

28. How thalassemia patients arrange blood for themselves?

29. How many difficulties faced by family members of a thalassemia patients?

30. What are the main causes behind this disease?

31. What do only thalassemia married couple carry genetic abnormalities?

32. Is there are sacred text and emulation for the curing?

33. What are the health facilities for the thalassemia?

34. Are government and other institutions fulfilling requirement of thalassemia patient?

35. What is the total monthly cost of curing for thalassemia patient?

36. How many blood bank centers are present for the thalassemia patients in Peshawardistrict?

37. What is the role of society in the arrangement of blood for the thalassemia patients?

38. Does government arrange blood camps for thalassemia patients?

39. Which age group mostly hit by thalassemia disease in your surrounding?

40. How many specialist doctors are present here to treat this disease?

41. what is the role of doctors towards this thalassemia disease?