SOCIO ECONOMIC AND PSYCHOLOGICAL PROBLEMS FACED BY THE FAMILIES OF THALASSEMIA PATIENTS

(A case study of district Larkana Sindh).

Samreen

This thesis is submitted to the Department of Anthropology, Quaid-Azam University Islamabad, completion of degree of M.phil In Anthropology.

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Final Approval of Thesis

This is to certify that we have read the thesis submitted by Ms. Samreen 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.Phil in Anthropology.

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Formal declaration

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Islamabad, 1st September 2021.

DEDICATED TO

My Parents Mr. and Mrs.Mukhtiar Ali Soomro and my sibblings.

Abstract

The main objective of this research was to explore the socio economic and psychological problems confronted by the parents of thalassemia major children. This research is mainly focused on the lives of thalassemia patients and their families in which they faced many difficulties to receive blood donors and blood transfusion every month. They faced financial issues as well due to the treatment of thalassemia disease. Due to high expenditure involved in the treatment of thalassemia major children. Many families found it difficult to gather money, and they were forced to take out loans and sacrifice other household requirements.

Qualitative research approach is used to carry out the research. In accordance with the criteria of anthropological research, the qualitative research methodology was used for the purpose of data collection it includes rapport building, Participant observation, key informants, sampling, interviews, focus group discussion, and daily diary etc. the data was collected from the patients and parents from the research locale Lahori Mohalla Larkana city. Regarding the perspective of thalassemia disease, Researcher took sample size of 37 respondents in which 21 were female and 16 were male respondents, who were selected through purposive sampling.

Major findings show that families of thalassemia children with major and minor thalassemia had very little knowledge of the disease and only knew about it when their children were diagnosed with major thalassemia. They had to deal with several childcare issues of thalassemia, including the lack of available early diagnosis and treatment services, and their struggle in arranging regular donors to receive blood transfusions.

Since childbirth parents taking care of thalassemia children when they involved in many economic and time resources, the disease had a devastating effect on her socio-economic and psychological problems of the families. Furthermore, the negative social attitudes associated with the disease, the families are always worried about the future of their children. Due to the disease some families were avoid getting marriage of their children in family because the cousin marriage is one of the main reasons behind thalassemia disease. According to the research the findings of the study, some suggestions are provided requiring the government to develop a comprehensive strategy involving all stakeholders to address the problems of thalassemia patients and their families.

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Contents

CHAPTER ONE

1. INTRODUCTION

Health plays a significant role in human life and the prosperity of society. Health is directly related with human happiness and well-being. It also impacts on economic progress as healthy populations are able to contribute more in production and save more time and resources. Thalassemia is a group of inherited diseases of the blood that affect a person's ability to produce hemoglobin, resulting in anemia. Thalassemia is a red blood cell disorder that may cause a person to feel tired, weak, or short of breath (a condition called anemia) and can lead to organ damage and even death. In the united Asian, Indian and middle eastern communities and among those with ancestry from these areas of the world. A child who inherits two thalassemia trait genes, one from each parent, will have the disease. A child of two carriers has a 25% chance of receiving two trait genes and developing the disease, and a 50% chance of being a thalassemia trait carrier. (Sumairs et al, 2012).

Most individuals with alpha thalassemia have milder forms of the disease, with varying degrees of anemia. The most severe form of alpha thalassemia, which affects mainly individuals of the continent. A child who inherits two copies of the mutated gene for beta thalassemia will have beta thalassemia disease. The child can have a mild form of the disease, known as thalassemia intermedia, which causes milder anemia that rarely requires transfusions. Thalassemia major is a serious disorder. It is the more severe form of the disease which is also called Cooley's anemia. It is a serious disease that requires regular blood transfusions and extensive medical care. (King et al., 2002).

Those with thalassemia major usually show symptoms within the first two years of life. They become pale and listless and have poor appetites. They grow slowly and often develop jaundice. Without treatment, the spleen, liver and heart soon become greatly enlarged. Bones become thin and brittle. Heart failure and infection are the leading causes of death among children with untreated thalassemia major. The use of frequent blood

transfusions and antibiotics has improved the outlook for children with thalassemia major. Frequent transfusions keep their hemoglobin levels near normal and prevent many of the complications of the disease. But the repeated blood transfusions lead to an iron overloaded a buildup of iron in the body- that can damage the heart, liver and other organs. Drugs known as "iron chelators" that can help rid the body of excess iron, preventing or delaying problems related to iron overloaded (George H, 2010).

Thalassemia has been cured to using bone marrow transplants. However, this treatment is possible only for a small minority of patients who have a suitable bone marrow donor. The transplant procedure itself is still risky and can result in death. Scientists are working to develop a gene therapy that may offer a cure for thalassemia. Such a treatment might involve inserting a normal beta globin gene (the gene that is abnormal in this disease) into the patient's stem cells, the immature bone marrow cells that are the precursors of all other cells in the blood. Another form of gene therapy could involve using drugs or other methods to reactivate the patient's genes that produce fetal hemoglobin – the form of hemoglobin found in fetuses and newborn. Scientists hope that spurring production of fetal hemoglobin will compensate for the patient's deficiency of adult hemoglobin (Martin, 2015).

The increase in number of patients with thalassemia highlights the importance of provider knowledge about the thalassemia in order to effectively serve these patients in their communities. Provider education and dissemination of thalassemia treatment standards can not only improve knowledge about the disease, but also increase awareness about the disease, but also increase awareness about the importance of coordinating care among a multidisciplinary team of specialist. Improvement in these areas will help achieve the overarching goal of better outcomes and quality of life for patients with thalassemia. Blood tests and family genetic studies can show whether an individual has thalassemia or is a carrier. If both parents are carriers, they may want to consult with a genetic counselor for the help in deciding whether to conceive or whether to have a fetus tested for thalassemia.

Parental testing can be done around the 11^{th} week of pregnancy using chorionic villi sampling (CVS). This involves removing a tiny piece of the placenta. Or, the fetus can be

tested with amniocentesis around the 16th week of pregnancy. In this procedure, a needle is used to take a sample of the fluid surrounding the baby for testing. Assisted reproductive therapy is also an option for carriers who don't want to risk giving birth to a child with thalassemia. A new technique, pre implantation genetic diagnosis (PGD), used in conjunction with in vitro fertilization, that may enable parents who have thalassemia or carry the traits to give birth to healthy babies. Embryos created in-vitro are tested for the thalassemia gene before being implanted into the mother, allowing only healthy embryos to be selected.

Thalassemia is a prominent hereditary disease that is classified as a genetic blood disorder Thalassemia is a blood disorder in which the body is unable to produce enough Hemoglobin, resulting in severe Anemia. Hemoglobin is a protein that carries oxygen throughout the body and is present in red blood cells. When red blood cells don't have enough Hemoglobin, oxygen can't get to all parts of the body. As a result, essential organs run out of oxygen and become unable to operate correctly (Surapon, 2011).

Word of thalassemia disease is combination of two words from Greek language Thala

ssa and anemia. Thalassa means sea and anemia means weak blood. There is another term found in literature for thalassemia which is called Cooley's anemia. In 1925, Professor Cooley Thomas in USA defined about the clinical features of illness in thalassemia patients on Italian region. Word of thalassemia disease created through the honorable award-winning pathologist George Hoyt Whipple (Hazelwood, 2001).

The symptoms of thalassemia vary from patient to patient, but according to Martin (2015), the most normal symptoms consist bone deformities especially in face, dark urine, excessive tiredness and fatigue, delayed growth, yellow or pale skin. The symptoms usually show up in childhood or adolescence.

The cause of thalassemia is abnormality or mutation in gene which is involved in hemoglobin production. The inheritance of this disease is from parents. If one of the parents has thalassemia, the child may have thalassemia minor. It could occur with minor symptoms or there are chances of no symptoms. However, if both the parents are patients of

thalassemia then then the child would have serious form of thalassemia disease. According to Centre of Disease Control and anticipation, the number of the patients of thalassemia is high in Asia, Africa, Middle East and Mediterranean countries (David J. Weatherall).

Oxygen is transferred from lungs to the other parts of body through blood. Hemoglobin is the substance through which oxygen is carried out in the red blood cells. Here are two kinds of protein in hemoglobin called alpha and beta. These globin proteins are made by genes located on pair of chromosomes. The drop-in production of globin is a result of missing or abnormality of globin producing genes (Shazia et al, 2012).

Alpha thalassemia patients are not able to produce enough alpha globin. Alpha globin has four genes, two on each strands of chromosomes. An individual who has missing of the single or double alpha globin genes has alpha thalassemia attribute. If a person has one abnormal globin genes, he is considered to take silent carrier state. In that situation where one of the four alpha globin genes are missing the person may not have health issues because the deficiency of dominant globin protein is in less quantity than there is certainly not an anemia. The silent carrier is the hard to detect. It is detected when a Person have one or two children with the disease of dominant genes of thalassemia minor and major. It will be detected by DNA testing (Edwards et al, 2004).

Alpha thalassemia minor patients have presence of double abnormal alpha globin genes. In alpha thalassemia minor, the lack of alpha globin protein is rather in largest number. Patients with alpha thalassemia minor have less quantity of the red blood cells and the mild anemia. The patient may not have symptoms due to which physicians usually confuse alpha minor thalassemia with iron deficiency anemia and prescribe supplements which are not effective on anemia (Taheret al, 2006).

1.1 Beta Thalassemia disease

The less quantity in number of beta globin protein is the cause of beta thalassemia minor or beta thalassemia attribute. Beta globin is made of the double genes, each on chromosomes

11. The missing or abnormal beta globin gene leads to beta thalassemia minor. There is only mild anemia in beta thalassemia minor and patients do not experience health issues. As doctors confuse the alpha thalassemia trait for the iron deficiency, here they also do mistake in beta minor. The prescription of supplement does not affect beta minor (Hashemi et al, 2014)

If both parents are patients of beta minor, then there are 25% chances that child will have two abnormal beta globin genes. The missing of two globin genes of beta will lead to beta thalassemia major which is cause of life threating anemia. The child will require blood transfusion and extensive medical care.

In beta thalassemia intermedia, patients can have moderately severe anemia or bone deformities (Weatherall, 1997).

1.2 Thalassemia: A Global Disorder

As thalassemia is the genetic disorder and inherited disease, so its existence is prominent in worldwide. Out of 10000 live-birth world-wide, the percentage of thalassemia is 4.4. Due to autosomal pattern of inheritance, male and female carry gene mutation. Five percent of world population carries alpha or beta thalassemia in which some carry silent trait of thalassemia because of absence of visible symptoms. However,1.7 percentage of population worldwide has clear signs of thalassemia trait. The percentage of thalassemia trait varies from region to region. In some regions, the percentage is up to 30% (Colahet ael, 2010).

In the United States, 5% of the population has the thalassemia trait, while nearly forty percent of the population is a genetic carrier. The thalassemia trait is carried by 2% of the population in the Eastern Mediterranean, with up to 60% of the population being a hereditary carrier. One or two percent of the population in Europe has thalassemia, and roughly 12 percent of the population is a genetic carrier. Thalassemia affects 0 percent of the population in Sub-Saharan Africa, while up to 50 percent of the population may be a genetic carrier. In the Western Pacific, thalassemia affects 0 percent of the population, although up to 60 percent of the population may be a genetic carrier. (Smith, 2015).

In India, 30 million people are carrier of thalassemia different types of trait. Every year, 12000 infants are born with severe disorder. The statistics show that in every 25 Indians, one is carrier of thalassemia trait. There is high percentage of thalassemia in certain tribes and regions (Chattoo, 2018).

In Southeast Asia, one to thirty percent of the population has thalassemia, with up to forty percent of the population being a genetic carrier. The total health care cost of United Kingdom patient with expected 50 years age survival is about 720201 Dolor's (WHO,1994,Hatti, 2015).

1.3 Thalassemia in Pakistan

The blood need for newborns with thalassemia is 90000 units of blood, and the cost of an iron chelator is projected to be $22 million. In Pakistan, around 5000-9000 kids are born with beta thalassemia major each year, and there are approximately 9.8 million thalassemia carriers. Pakistan being the resource constrained state cannot afford the outstanding cost for the treatment of thalassemia patients, so there is dire need to devise the comprehensive strategy to manage the issue (Aysha et al , 2006).

70 percent of that collection is set aside for thalassemia patients while the disease can be prevented by adopting some serious strategies. There is the great risk for thalassemia major patients acquiring various blood infections because they are dependent on blood transfusion. It is common to see the patient dying under the age of 25 because of lack of availability of blood for transfusion or the infection acquired by transfusion(Aysha et al., 2006).The prevalence of beta thalassemia in Pakistan is very high because of norms of inter-marriages among close family relatives or among the same caste or tribe (Darr, 1991).

According to Punjab thalassemia prevention program project director, Dr.Shabnum Bashir, every year seven thousands new cases are identified of thalassemia major patients which are surfacing in country. According to the author, around fourteen to seventeen children are born with thalassemia major and minor in every twenty-four hour which is very alarming situation (Dawn, 23 march 2006).

In August 2017, the Sindh health department sent a summary to the Chief Minister for funding the treatment of 100 thalassemia patients every year, while there are 60000 patients in Sindh alone. This shows that state is not able to tackle the drastic situation. There is dire need of devising the extensive program or strategy with special focus on preventive measures of the disease. There will be requirement of 14 billion rupees every year if the Pakistan starts managing thalassemia patients on international guidelines which is not possible, so the preventive measures of disease are more effective in this regard (Awan, 2017).

The preventive measures include pre-marital test of thalassemia trait of both genders and genetic counseling, awareness campaigns at every district levels of Pakistan. The state must encourage the private organizations to take part in this regard. There must be constitutional obligation to take the test of thalassemia trait before the marriage. Preventive measures are the best strategy to overcome the problem of thalassemia disease. There are examples of states which applied the strategy of pre-marital test, like Iran, Turkey (Awan, 2017).

According to the Minister of National Health Service (NHS), Saira Afzal Tarar, the provincial assemblies of four provinces have passed the legislation regarding pre-marital screening for thalassemia disease. There is still rise in thalassemia patients because government is unable to implement the legislation on practical grounds.
The main reasons behind the lack of implementation is public unawareness of the legislation, unwilling behavior to adopt it and fear of not getting married (Dawn, 2015, May 09).

1.4 Thalassemia Disease in District Larkana

The Larkana city is the located in Sindh Province of Pakistan. Larkana is the fifth-largest city in Pakistan in terms of population. It is the birthplace of the Indus Valley Civilization,

as well as Mohenjo-Daro. The health facilities in main cities of the region are relatively less as compared to major cities of Pakistan. More thalassemia patients registered in larkana. There are only one Thalassemia Centre of Chandka medical college and hospital (CMCH),

The Larkana has the less important facilities meanwhile its formation in the year (2011) in spite of the detailed number of the all recorded list of patients which is frequently increasing and other 4 blood banks of government are located in that city which facilitate the thalassemia patients. The livelihood of most of the residents is dependent on agriculture. The health facilities are pathetic in that cities due to which people many times have to move the patient to cities like Karachi, Rawalpindi and Islamabad for the treatment.

CMCH Medical Superintendent Dr Inayatullah Kandhro had taken an action against the Commissioner of Larkana Division, though it has been informed that the Thalassemia Centre was consecutively at Paeds Medicine Department which were facing a lot of difficulties, especially in lack of accurate proficient staff, providing of the mandatory blood to the affected by thalassemia patients. Dr. Kandhro stated that the commissioner had been asked to inform Fatimid Foundation of the request to care after the CMCH Thalassemia Centre on a charity basis.

Figure 1: Source: field work

Round about the month of April dated 10th 2016, the recorded list of the number of thalassemia patients were almost 847 but currently it has been extended about 853 of the World Thalassemia Day on Monday with the addition of the 6 new cases within twenty nine days. The people in that area belong to poor class and there is only one thalassemia Centre in Larkana. The facility for thalassemia patient in Larkana is not satisfactory because the patient family must arrange the blood donor for transfusion. The blood bank of Larkana is not able to fulfill the need.

The treatment options in Larkana city are very limited that's why the people travelled to another city who can afford their expenses. The blood transfusion is the most uphill task for the patient because the patient has to bring the individual for blood donation. Chelation therapy is very costly and affordable to very few. The expertise of beta thalassemia to manage the issue is not available. The facilities of diagnostic problem of thalassemia disease to deal with the treatment of thalassemia patients are very rare in the number. The thalassemia disease carrier revealing is likewise not available.

Thalassemia disease center lacks the facilities which are essential for thalassemia patients. The total funding in the 2016 annual report was 37400 rupees and thalassemia center provided assistance to 428 children in which only 30 patients were provided blood transfusion by the center, it means the remaining patients had to arrange the blood donor by themselves. In 2017 annual report, 674 patients were assisted by the center. There is no detailed report of patients that how many had blood transfusion arranged by the center (Ali, 2014).

1.5 Anthropology of Thalassemia disease

Thalassemia is a chronic and fatal disease with a very complex genetic and clinic picture. A bio cultural approach to the examination of this disease calls for studying not only its clinical (biological) manifestations as well. In the case of thalassemia, the "normal" lifespan of untreated individuals, before modern medical practices intervened, was generally very short. Most effected persons died in the first years of life. With blood transfusion and

other large scale intervention modalities, individuals often live to their late teens, and in some cases often live longer. It expanded in life expectancy which involves huge costs of social, economic and psychological problems. Anthropological research which focuses on the adaptive styles of effected people by chronic disease in which the parents, siblings and patients of thalassemia contributed in the risk factors of social and psychological complications. Thalassemia is often diagnosed in the age of first two years of life. Usually people lose their weight during their age growth but partially normal weight gain is succeeded by progressive anemia. The thalassemia disease represent several abnormalities, depending on globin component. The facial features of thalassemia patients is usually appears with the large shape of skulls along with exposing teeth which is seen as prominent as other normal children (Weatherall and clegg, 1976).

1.6. Statement of the Problem

According to this study the thalassemia disease is a genetic blood illness and the disease is congenital. The study will focus on the thalassemia patients and their families. The aim of this study is to understand the problems challenged by thalassemia patients and their families and analyze the level of awareness about the thalassemia disease. According to this research which will conduct on the patients of thalassemia and their parents, particularly in rural areas of Sindh mostly people have little knowledge about this disease. The purpose of this study is going to investigate the socio-economic issues challenged by families of thalassemia major and minor children, though the treatment of this disease is not affordable by people belong to middle and lower class. The treatment and blood transfusion for thalassemia children is very costly and they cannot afford every month. The study will dig out the major problems due to thalassemia disease that what will the response of society with thalassemia patients and their families after diagnosed it? The study is going to investigate the diagnosis facilities provide by thalassemia patients at the every stage, The thalassemia is the long term disease of life meanwhile thalassemia major children had often experience blood transfusion because they have need to live along with this critical situation. Moreover, accordingly the less number of the patient's treatment and blood transfusion of facilities and the existence of the thalassemia major and minor patients grow with the main

problem. The purpose of this study is to explore the psychological impacts on thalassemia patients and their families. Regarding the thalassemia disease mostly people got mental illness and suffer from the loneliness. The thalassemia can lead the severe complications among children because the disease is life threatening. The purpose of this study is to investigate according to the chronic thalassemia disease in which children need frequent blood transfusion and to get rid of over loaded iron in their body.

1.7. Objectives of the Study

1. To analyze the level of awareness about the disease among the families of thalassemia children.
2. To examine the socio-economic problems faced by the families of thalassemia major and minor children.
3. To document the existing available services for thalassemia patients.
4. To identify the Psychological issues of thalassemia patients and their families.

1.8. Significance of the study

The significance of this study is to analyze the socio economic problems faced by families of thalassemia patients. The disease is hereditary in nature and the numbers are increasing every year. The disease is life-long and patient is dependent whole life on the treatment unless he/she is treated by bone marrow. The huge cost of medicine and treatment is major problem for poor patients. When a child is diagnosed as a thalassemia major, it is not only the child who suffers but his whole has to face socioeconomic issues associated with the disease, so studying these factors are necessary to design interventions to control thalassemia disease and help the families of thalassemia patients.

CHAPTER TWO

2. RESEARCH METHODOLOGY

While discussing scientific methodology Russell says:

Each scientific subject has created its own set of data collection and processing tools, yet there is a common scientific methodology. The approach is founded on the following assumptions: (a) that reality exists "at this time," (b) that the best way to find it is by direct observation, and (c) that material explanations for observable occurrences are always adequate, and metaphysical explanations are never required (Burnard, 1994).

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The goal of methodology is to uncover truthful and helpful knowledge about a certain domain of phenomena in the universe and to find solutions to problems. There are several strategies and methods for gathering the essential data in every field at any given moment. To obtain data, I utilized qualitative approaches.

2.1 Data collection:

Participant observations and open ended unstructured interviews will be used to obtain data. Standard data collecting methods will be used.

2.2. Raport building

The first stage in research technique is to create a report. Every anthropologist must establish a positive relationship with the local population. Raport building means establishment of a good relation between the collector and the source. Entering in a new community to get information is not so easy. Researcher should keep a friendly atmosphere with the members of the community. If researcher failed to develop a good relation with the society then it becomes difficult for the researcher to collect the data or information relevant to the topic. Researcher developed a friendly relation with the members of the community in the field by meeting with the people and having conversation with them. It was difficult for

the researcher to develop a good rapport or relation with people, but it took not more than two weeks to create a good understanding and develop confidence among them. So, it was not difficult to collect the information from the community.

2.3. Participant observation

Participant observation is one of the most significant data collecting strategies in anthropological study.

According to the Russell:

Participant observation is an approach that is both humanistic and scientific. It provides the type of firsthand experience that allows you to speak clearly and from the heart about what it's like to cultivate a garden in the high Andes or dance all night in a Seattle street party.

By using this approach, I became a member of the community and watched them as such. That was the only way I could have direct communication from them. It aided me in observing and recording information about people's lives by allowing me to get close to them and make them feel comfortable in my company. I was living according to the native's customs, participating in the most activities that they perform in their daily routine. I used to became friendly with them while asking about their issues regarding thalassemia disease. I used to visit thalassemia center where thalassemia patients got blood transfusion after 15 days or every month and observe the performance and services of their health staff. I observed the behavior of the staff with their families and also got knowledge about the disease and treatment. I used to visit at my respondents home and asked about the survival of their children that how could they manage blood for their children.

2.4. Key Informants

A key informant is the one who is well-versed in the community and has a broad understanding of society. They can also be used to double-check data. A key informant is an excellent source of data. The key informants should be carefully chosen from inside the

community. It's crucial because if the key informant comes from the same community as the one being examined, he or she will have access to all of the community's actual data. *Good informants are people you can easily interact with, who understand what you're looking for and are ready to offer or get it for you* (Burnard, 1994).

2.5. Interview

Thoughts and explanations interviews are performed to learn more about one's inner thoughts. An interview is a type of conversation between a responder and a researcher with certain goals in mind. It's a type of communication with a definite goal in mind. There are two sorts of interviews: structured and unstructured. Unstructured interviews are ones that are not based on a predetermined plan and do not follow a regular pattern. Structured interviews are those that have been formed in a pattern. Unstructured interviews were conducted to aid her in gaining a basic understanding of her topic. I also conducted in-depth interviews pertinent to her thesis, which helped her understand more about the socio-economic and psychological difficulties that thalassemia patients face.

2.6. In-depth Interviews

When you need extensive knowledge on a person's thoughts, in-depth interviews are beneficial. It provides qualitative data to the investigator. In order to acquire information, you'll need a strong interview technique. The researcher conducted in-depth interviews with the respondents in order to obtain precise and appropriate data. Using this primary approach of in-depth interviews, the researcher was able to gather basic and hidden information about the respondents. *"In-depth interviews take the form of conversation in which researcher probes deeply to uncover new clues, to open up new dimensions of problems or to secure vivid, accurate and detailed accounts that are based on the personal experience of the subject."* (Qualitative Field Research).

2.7. Focus group discussion

Focus Group discussions are highly useful for gathering diverse perspectives on certain topics in a short amount of time. In this approach, I conduct interviews with a group of individuals in order to get knowledge such that if one person hides data, the other can

disclose it. The group should be diverse in this technique, with the respondents ideally not knowing each other. This approach was utilized in the research as a very genuine instrument for gathering primary data relevant to the research issue.

2.8. Sampling

Sampling is a crucial component of the study since it allows us to choose a certain number of people from the target group. Non-probability sampling was used to choose the sample. Sampling is an anthropological research approach that entails taking a sample from the entire population. Due to covid situation, it is critical to choose a sample size unit. I chose 39 sample size of respondents. Purposive sampling is used for this study. The respondent was selected on judgment basis; interviews were conducted with them for collecting the useful information on this topic.

Purposive Sampling

“In this technique the researchers purposely choose subjects who, in their opinion, are relevant to the project. The choice of respondents was guided the judgment of the investigator. For this reason, it is also known as judgmental sampling. There are no particular procedures involved in the actual choice of subjects.”

2.9. Mapping and Census Taking

A socio-economic survey was conducted in all of the village's homes in order to learn more about the region under study's composition and social status. Mapping and census taking technique will help the researcher a lot to get quantitative data. It helped the researcher to get complete information about the community population, educational ratio, occupation and family structure etc. Through the census form researcher got all necessary information about the village.

2.10. Daily Diary

It was at least helpful in planning the activities and keeping track of the records. The daily diary approach will also be used to record the day-to-day happenings during the study period, which will serve as a note.

2.11. Jotting

There is no question that human memory is weak, and that people cannot remember things for lengthy periods of time; thus, jotting is the greatest method for remembering things since researchers write them down. During my study, I carried a daily journal with me at all times and jotted down notes on the spot.

2.12. Photography

During the field investigation, the researchers utilized photography as a non-verbal mechanical tool to gather and document informal data about the individuals and the area.

2.13. Secondary Sources

In addition to collecting data from primary sources and the study's location, the researcher will also consult secondary sources such as books, journals, and newspapers for pertinent information.

2.14. Field Notes

The researcher employed the fields notes approach, bearing in mind its importance, to jot down every item of information seen throughout the study activity. The research was able to re-call events and modes of communication with the respondents and the general public by creating field notes, which was beneficial in gathering data.

2.15 Audio Recording

When I had an important talk with my main informants and other community members, I employed this method. I can easily obtain the needed quantity of data using this method. During casual interviews, I also employed several techniques.

2.16 Case Study

The case study approach aids in the recording of linked occurrences and is an essential means of delving further into the depths of interviews with real people. A case study is a research technique for gathering data on a research subject in order to verify it, as well as an empirical investigation of a phenomena in its real-life setting. Case study research can refer to single or numerous case studies, quantitative as well as qualitative evidence, various sources of evidence, and theoretical hypotheses that have already been developed.

2.17. Locale

The locale which I chose for my research is lies in district Larkana. It is about 28 km away from Moen-jo-daro. Due to my research topic I have choose to work in Larkana because there were I found most thalassemia cases.

2.18. Justification of locale

The reason why we choose this place is that there is not any Anthropological research on the socio economic and psychological problems faced by families of thalassemia patients that has been done on this area. In this area many cases are found of thalassemia patients who are suffering from many problems.

I have done my complete observation on this area very calmly and I found many reasons and problems of thalassemia patients and their families. The area has not already been investigated by any research anthropologically. There are many cases of thalassemia patients due to the lack of facilities and their families faced many problems.

3.19. Research Ethics

The research ethics that guided my study include:

- Being a researcher, I did obtain verbal knowledge consent from all the respondents who were get participated in my research through their willingness in my study.
- The researcher did not ask names or other identifying information from their respondents who were participate in the research. Further, the participants were assured that the information they provided would be kept confidential.
- Interviews were conducted on one-on-one basis to respect the privacy of the respondents and protect the information.

CHAPTER 3

2. LITERATURE REVIEW

The relevant literature regarding thalassemia disease and its types, management or treatment is mainly taken from previous research studies, online websites, journals, and reports. The major material is available on google scholars, Cooley's foundation, Pakistan thalassemia federation, Pubmed, libgen. Different seminars papers, research papers, reports, articles on newspaper related with thalassemia was consulted to conduct the research material. The material regarding psychological aspect of patients are taken from different articles published in medical journals, annual reports of thalassemia centres (Chattoo, 2018).

The material regarding socio-economic aspects of patient's family are taken from different surveys published in research articles and reports published by different organizations operating in Pakistan. The material on thalassemia disease on its clinical aspects in available online in enormous amount.The literature is usually focused on treatment methods while the disease has significant effect socially and economically. The literature regarding psychological, social and economic aspect is quite less as compared to clinical aspect of disease. The socio-economic aspect requires a great deal to be highlighted by academics (Sumairs et al, 2012).

It is estimated that 60000 babies are born with beta thalassemia every year throughout the world. The percentage is higher is Asia region with the figure of 79% affected birth population. The ratio is greater in Asia, with 79 percent of the population impacted by birth. Pakistan has a prevalence of 5-8 percent, and around 5000 infants are born with beta thalassemia each year. According to the study, twenty-five children were recorded in a 2016 article connected to the Pakistan Thalassemia Federation, but the real figures are over one hundred thousand because the bulk of individuals living in rural areas are not registered with thalassemia institutions (Asif at ki, 2016).

There are multilateral reasons for the spread of thalassemia disease in Pakistan. The lack of awareness, insufficient educational campaigns, as most of the mothers which are

healthy physically but carrying silent carrier thalassemia and they would be source of spreading the disease. People are detrimental in taking the blood test for carrier state due to adverse implications on marriage. Thalassemia disease has various social and psychological effects on children, because they require blood transfusion for their survival in life. (Colahet ael, 2010).

Thalassemia is devastating disease which impacts socially, economically on patient's family. The impacts are emotional burden, hopelessness, disease management, financial constraint, and complexities with social integration. The major factor hindering the better treatment of thalassemia children and prevention of disease are poverty, illiteracy, lack of awareness, endogamous marriages, and lack of anti-thalassemia programs (Mirza lt, 2013).

Treatment of thalassemia is dependent on the type and severity of disease. Patients with alpha minor or beta minor have no symptoms usually, so they need little or no treatment. The standard method of treatment includes blood transfusion, iron chelation therapy, and folic acid supplements for the moderate or severe form of thalassemia (Borgna-Pignatti , 2007).

Blood transfusion is the method to treat the moderate or severe form of thalassemia. Blood transfusion is the process in which patient is infused with red blood cells with normal hemoglobin. The duration of red blood cell is 120 days, so the procedure of maintaining healthy red blood cells needs repetition. The interval of blood transfusion is usually reliant on the severity of patient disease (Klein, al et, 2014).

Blood transfusion had also adverse impacts on the patient, so the blood transfusion is limited to adolescence because of cardiac complication caused by iron toxicity.

The bone marrow is considered the most reliable and enduring process for thalassemia patient. It requires a compatible donor either sibling or matched unrelated donor. The bone marrow treatment method was invented by Professor Guido Lucarelli in 1980. The survival rate for low-risk young children with suitable donors is 89 percent, with no need for blood transfusions, and the mortality risk is 3 percent.

The child has to be admitted in the hospital for 35 days and monitoring duration is three tosix months. The cost of bone marrow in Asian countries is estimated 25000-30000 dollars (Satwani et aed, 2015).

Families of thalassemia patients confront a variety of challenges on different levels, including physical, mental, social, psychological, economic, and familial. The care of Thalassemia children saps family members' energy and puts them at risk of mental, physical, and social isolation, leading to feelings of impotence, despair, shame, and a wish to die.

Parents of thalassemia patients must suffer due to providing regularly and lifelong care. The parents face the psychological tensions due to difficulties in caring of thalassemia child. They are distressed and grieved to see their upset child. There is constant tension for parents of thalassemia patients regarding uncertainty about the future of their children (WHO, 2001).

The educational aspect, job aspect, and marriage aspect of their children cause great stress to parents. The expenditure on treatment, hospitalization, transportation severely disturb the monthly budget of families. The parents of thalassemia children face the psychological problems.The high depression in thalassemia major parents is due to uncertainty about child future, criticism by the relative, and at some point (Blair, 2010).There is lack of awareness about the thalassemia disease in our country. Mostly people don’t know about the disease of thalassemia until their own children become victim of it. In the report presented in the conference which was conducted in 2015 showed that 66.8 percent of parents came to know when their child became victim of thalassemia disease. Majority of the thalassemia patients require blood transfusion twice a month to survive. The arrangement of the blood twice a month is very difficult, and the cost of the blood transfusion and medicines is not bearable for the poor parents (Ishfaq, 2015).

Management of thalassemia disease is the challenging task for the government authorities but not impossible. In several reports, it is clear that government lacks in providing facilities regarding thalassemia. High expenses in hospitalization, transportation, and cost of medicine impose heavy burden on families. According to research article there are more than forty thalassemia centers in Pakistan. The large number of thalassemia centers are giving to them only support of blood transfusion. The administration of Pakistan is not providing the compulsory facilities and the major problem is on the NGO's. The charge of chelation treatment is actual expensive for people which indicates poor parents to non-compliance with treatment (Awoyemi ae, 2015).

Thalassemia is a life-threatening blood disease that affects both people and their families. Parents with the thalassemia trait believe they are responsible for their children's illness, in addition to other problems, shoulder the load of responsibility and impossibility, and are anxious about their children's health and future. This research is conducted to explore the lived experiences of parents of children with thalassemia (Shahraki, 2016).

Thalassemia is the most common chronic hereditary disease that affects people of all races and is handed on from parents to children all around the world.

According to the Thalassemia Global Federation, about 240 million people worldwide are carriers of beta-thalassemia, and 200,000 patients with thalassemia major are treated internationally. Every year, 60,000 new people are diagnosed with thalassemia major. The prevalence rate of thalassemia is above 34% in Iran, where there are more than three million beta-thalassemia carrier genes and over 800 children born with thalassemia are added to this group each year. Thalassemia is a serious and life-threatening illness that creates considerable difficulties in a person's social and educational activities, as well as emotions of inferiority and difference, which leads to low self-esteem among sufferers (firouzkouhi M, 2015).

When a kid is a few months old, he or she is generally diagnosed with thalassemia. The stress of caring for a kid who requires constant monitoring and blood transfusions causes parents to lose their mental equilibrium. Trauma inflicted on a family generates a variety of psychological reactions, and family connections are severely harmed. Academic

difficulties (60 percent), social interaction problems (20 percent), a sense of being different (24 percent), and anxiety (31 percent) were all observed in children with thalassemia in a research.

These patients, like other patients with chronic and painful conditions, require round-the-clock care and face a variety of mental health issues, as well as social and economic issues, all of which obstruct therapeutic principles in some manner. Family members are influenced by one another, and a family member's disease has a direct impact on the entire family. Stress placed on one family member will have an impact on the entire family. Family members' energy levels are depleted, putting them at danger of physical, mental, and social isolation, as well as despair, frustration, helplessness, dread, humiliation, and a wish to die. 9,10 As a result, these patients are often known as "hidden patients" (Widayanti, Ae , 2014)

According to the findings of a study of relatives of thalassemia patients, these families face a variety of psychological and emotional problems. Following additional thought, the essay's author believes that parents of children with thalassemia struggle and suffer in the process of providing daily and lifelong care for their children with thalassemia. In addition, parents of children with thalassemia express wrath, amazement, and regret. Furthermore, social attitudes, stigmas, and perceptions of chronic patients, which are frequently based on a lack of understanding about the condition and seen as one of the family's many problems, are more harmful or damaging than the disease itself (Widayanti, Ae , 2014).

As a result, erroneous impressions and unfavourable attitudes among parents about their child's condition, which are frequently caused by a lack of understanding, may endanger their children's public health. When compared to parents with unfavourable attitudes regarding their child's condition, studies have revealed that more parents with positive and accurate opinions about their child's disease employed patience strategies. A study of research articles on children with thalassemia revealed that these kids' ability to tolerate challenges was enhanced when they had an optimistic outlook about life and the future (chalagae Li, , 2019).

In this regard, the topic of what the experience of having a kid with thalassemia is like for parents emerges. The most acceptable technique for answering this issue is one that depicts the nature of a phenomena in its natural setting, as well as the structure and variables

that influence its creation. In this regard, a phenomenological investigation, among other research methodologies, may illustrate the nature of a phenomena and its development process in the natural setting. Researchers will be able to comprehend the actual world of human labour and living through phenomenological research, which allows them to experience the facts as they are and describe and explain the human social reality.

As a result, researchers sought to understand the perspectives of parents of children with thalassemia in order to emphasise the necessity of parental participation. In addition, the purpose of this qualitative study was to learn about the experiences of parents of children with thalassemia in terms of familial, social, and therapeutic concerns. As a result of the above, the author decided to undertake a research in order to learn more about the experiences of parents of children with thalassemia. (shahraki-vahed A, firouzkouhi M, Abdollahimommad A, Ghalgaie J, 20 jan 2017).

In this paper, I looked at the psychological well-being of children with beta thalassemia and their moms. We investigated almost half of the thalassemia patient population in Sri Lanka in the required age range who appeared in the country's three main thalassemia centres, which are located in three separate regions. Psychological symptoms in the emotional, behaviour, and hyperactivity domains, as well as unique peer connections and social skills, are much more common in children with beta thalassemia in Sri Lanka. This article refers to a prior research of 60 Iranian children with severe thalassemia who had higher rates of emotional, conduct, hyperactivity, peer interactions, social, and overall behavioural problems than healthy children.

The article discussed the prior research as well as a few more restricted investigations. Nonetheless, it is the most important research. Similarly, most previous studies were done at a period when thalassemia treatment was still in its infancy, and patients received iron chelator medications via lengthy medical infusions. Despite considerable advancements in medical care, such as the widespread availability of safe blood products and oral iron chelators, the study's findings demonstrate that only little changes in the psychological aspects of thalassemia patients are produced (Bandara D, et al , 2020).

According to the author of this article, "We discovered poorer health-related quality of life ratings among children with beta thalassemia in a prior report." The Consequences of well-being support the study's findings by demonstrating that the impacts are not restricted

to quality of life but also include psychological indicators. Patients with beta thalassaemia exhibit different behaviour symptoms than those with beta thalassaemia major, according to our findings. We observed that these patients receive suboptimal transfusions, have lower pre-transfusion haemoglobin levels, and have a worse quality of life prior to these findings, according to the author. As a result, one or more of these factors might have a role in the higher prevalence of conduct disorder symptoms in HbE-thalassaemia patients.

Using logistic regression, we discovered that individuals with lower pre-transfusion haemoglobin levels (conduct and peer relationship symptoms) and smaller transfusion volumes had greater prevalences of psychological symptoms (conduct and hyperactivity symptoms). This emphasises the need of receiving enough blood transfusions in individuals with beta thalassemia in order to keep pretransfusion haemoglobin levels above 9 g/dL. Surprisingly, body iron status as evaluated by serum ferritin was not linked to psychiatric symptoms in beta thalassemia patients.

A previous study among presumably physically healthy young Brazilians showed no relationship between peripheral markers of iron status and psychological symptom ratings, according to the paper's author. Short stature and malnutrition, on the other hand, were shown to be linked to abnormal hyperac+ tivity and conduct symptom scores, respectively. (Patherivaraj H,2020).

Another noteworthy element of this study, according to the author, is the connection of depressive symptoms among mothers of beta thalassemia patients. When comparing mothers of thalassemia patients to controls, the author noticed a significant increase in depressed symptoms. More specifically, our findings demonstrate that children with high mother depression symptoms have poor psychological health scores in the affective, behavioural, and peer interactions domains.

In this article, the author discusses the findings, which were based on earlier data from other patient groups and revealed substantial links between maternal depression and behavioural issues in children. All of these findings highlight the necessity of include psychological evaluations, psychotherapy treatments, and, where necessary, antidepressant medication in the care of beta thalassaemia patients.

One significant drawback of our study is that we are unable to apply the findings to all Sri Lankan centres that care for thalassaemia patients. The author previously demonstrated that bigger specialised thalassaemia centres give superior treatment than

smaller centres across the country. As a result, the psychological sickness of children undergoing treatment at smaller thalassaemia centres is likely to be worse than described here.

The author said at the conclusion of this paper that a higher proportion of thalassemia patients exhibited aberrant psychological symptoms in a variety of areas, including emotional, behaviour, and hyperactivity symptoms. Patients with beta thalassemia, those who were poorly transfused, and those who had hypothyroidism and undernutrition were more likely to have abnormal conduct disorder signs. Mothers of beta thalassemia children had considerably greater depressed symptoms, which were related with psychiatric disorders in their children. (Mettananda S, Peiris R, Pathiraja H, Chandradasa M, Bandara D, de Silva U, et al. (2020).

Thalassemia sufferers are particularly prevalent in specific Eastern European ethnicities, according to the author. Deficient beta-globulin thalassemia is more common in people of Mediterranean origin. Cooley's anaemia, or Mediterranean anaemia, is another name for this disease. The prevalence of thalassemia is higher in both Africans and African-Americans. The prevalence of thalassemia varies worldwide; nevertheless, more than 1500 persons in the United States are afflicted, and another 2 million have thalassemia-related genetic characteristics. Thalassemia is an autosomal recessive genetic condition with a life expectancy of 20–30 years for individuals who have it (Bonita E, Broyles, 2006).

The author of this article, Kewnil, stated: Thalassemia newborn infants are deemed normal. When the weaning amalgamation of haemoglobin F is routinely balanced by growing creation of haemoglobin A, the clinical manifestation of Beta thalassemia major begins. In thalassemia, the bone marrow is stunted to compensate for the crippling sickness caused by the early elimination of damaged red platelets. In the second half of the early stages of thalassemia, a child's paleness and failure to thrive are common. In addition, the young individuals exhibit characteristics that are difficult to modify.

Hepatosplenomegaly is normal and infrequently high bounds of hemolysis prompts jaundice .The most recent century had noticed a progressive methodology in administration of thalassemia patients. The convensional the executives of thalassemia depends on a profram of standard blood bonding and iron chelation. This has changed thalassemia from a constantly deadly illness into an ongoing infection allowing a typical life or possibly drawn out endurance with confirmations of bone changes because of marrow development,

inability to flourish and other hypoxic confusions. With hyper transfusion treatment most patients with thalassemia are unconventional from difficulty of iron deficiency and compensatory bone marrow development (Anil Kumar Md, 2018).

The most well-known genetic disease is beta thalassemia. The illness has spread all across the world. Roughly 3% of the world's population has the characteristics for Beta Thalassemia, and it is estimated that around 60000 thalassaemic infants are conceived each year all over the world. Around 79 percent of the impacted newborns are in Asia's population. Pakistan has a beta thalassemia carrier rate of 5-8 percent, and about 5000 children are tested each year. 2 In Pakistan, consanguinity is the major cause of high predominance. There are 25,000 children with thalassemia in Pakistan, according to the Thalassemia Federation of Pakistan. Anyway, the true amount is significantly higher, maybe over one lac, because many people live in areas where there are no thalassemia centers (Asif at ki, 2016).

There are three major components of thalassemia management. 1. Conservative deals with medical consultation, investigations of lab, transfusion of safe blood, chelation treatment, and treatment with HbF expanding augmenting specialists. 2. Curative management is involved/dealing with bone marrow transplantation. 3. Preventive management contributes to thalassemia screening and genetic counselling.

In this article author stated that: Achievement of ideal management in this manner requires multidisciplinary group tending to every one of these perspectives. Despite this, only a few clinics focus on all of these aspects of optimal thalassemia care in one location. Thalassemia management is a serious problem in underdeveloped countries like Pakistan. There are 40 Thalassemia treatment clinics in the United States. The majority of them just provide blood transfusions. The government does not provide the required assistance, and NGOs bear the brunt of the load (Neghmai Aen 2019).

There is hence a critical requirement for devoted thalassemia unit in all huge hospitals that administers all facets of treatment and where patients might be alluded to the experts at whenever required. Thalassemia centers should offer free medical consultation, geniting advising, specific pathology investigations, safe blood transfusion and chelation therapy to the patients.

The author explain that there ought to be multidisciplinary group including Haematologist,,Paediatrician,Cardiologist,Endocrinologist,Psychiatrist/Psychologist, Social Worker trained staff who are dedicated. In nutshell an ideal thalassemia centre ought to have three key units: one managing diagnosis and treatment, having close contact with paediatrician, endocrinologist, cardiologist, psychologists second unit dealing with preventive measures including screening and genetic mentoring program and the third one unit of bone marrow transplant. The thalassemia centre ought to equally coordination efforts with national and international organizations. The centre should target giving most noteworthy conceivable degree of comfort and convenience for patients and their families and guarantee their long and quality life. (Naghmi Asif, Khaild Hassan, 2016).

3.1. Theoretical framework

2.1.1. Social Capital theory

Social capital theory was first defined by Bourdieu in 1985. Social capital theory suggests that interpersonal relations create value for individuals as they provide resources which can be used for the achieving desires outcome. Social connections, according to social capital theory, are resources that may help people grow and build human capital. A stable home environment, for example, can help students achieve academic success and acquire highly valued and rewarded abilities and credentials. In evolutionary terms, social capital may be defined as any element of a social link that benefits reproduction. Social connections, according to social capital theory, are resources that may help people grow and build human capital. For example, a stable home environment may foster academic performance and the development of highly valued and rewarded abilities and credentials. In evolutionary terms, social capital may be defined as any element of a social link that benefits reproduction.

According to Savage and Kanazawa, humans have acquired preferences for companionship in general and specialized preferences for signs that indicate higher levels of social capital (2002, 2004). Since evolved preferences for certain types of social relationships should have been chosen in the EEA, we may expect to find gender differences that mirror the division of labour in foraging groups. Females, for example, are more likely

to value and derive emotional fulfilment from being a part of small social networks made up of close personal ties based on strong social bonds. These kind of collaborations would benefit women by assisting them with foraging and child care. Males are expected to gain more from membership in larger social networks based on weak links, such as hunting groups, political alliances, and combat parties. Males, in particular, would gain from types of social capital that impart wealth and social prestige (Savage and Kanazawa , 2020).

Recasting sociological theories of crime in terms of evolutionary theory, the authors believe, may yield fresh knowledge on crime deterrents. According to choice and social control theories, cultural deviance theories, and strain theories, the threat of losing social ties can be a powerful deterrent to deviant or illegal behaviour. The social relationships and interactions that were most closely connected with reproductive success in the EEA are more likely to have a deterrent effect on deviance and crime, according to evolutionary theory. Women are more vulnerable to conduct that jeopardises deep personal ties, thus the threat of losing such relationships would deter such behaviour. Men appreciate social capital because it provides them with monetary resources and social status, and the fear of losing these resources is likely to discourage them from engaging in deviant or criminal behaviour. This line of reasoning is backed up by actual evidence that shows male sensitivity to status loss or degradation.

2.1.2. Approach of the present study

In families impacted by thalassemia, this theory found distinct characteristics of bonding, bridging, and connecting social capital. These were based on the families' own personal experiences. The phenomena of social capital in the form of intra-familial and intimate bonding, community-level informal bridging, and formal hierarchical connecting was clearly brought out by the analysis of the in-depth interviews

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In families affected by thalassemia, this theory revealed unique features of bonding, bridging, and connecting social capital. The families self-reported these based on their own personal experiences. The phenomena of social capital in the form of intra-familial and

intimate bonding, community-level informal bridging, and formal hierarchical connecting was clearly brought out by the analysis of the in-depth interviews.

Social capital is essential in maintaining the health and well-being of children with thalassemia. The study found that child care relied heavily on intra-familial cohesion and relationships, particularly for children with thalassemia. When children with thalassemia and sickle cell disease have an unified and loving family, it is easier for them to adjust and have a positive body image and characteristics. For those suffering from a chronic disease, the family is the most important source of support, providing practical assistance such as daily care, meal preparation, and medication administration. The family also provides emotional, financial, and social support. Social support generated from intra-community social relationships was clearly seen as an important buffer against thalassemia-related family difficulties by the parents. Social capital for blood donation was also given by close relatives and family members.

Support from extended family and community members was identified as a source of social capital that might be used to bridge gaps. According to the findings of this study, the families of the ill children went to their relatives and neighbours when they were in financial need, to pay travel fees, vent their feelings, and receive information. Our findings show that informal networks between thalassemia-affected families and their communities are the most beneficial in coping with the social, physical, and psychological challenges that thalassemia brings. On the one hand, several studies have discovered a relationship between mental health and dense and strong horizontal bridging networks, and vice versa. When poverty and limited access to official services, such as health care, are present, informal social bonds become increasingly important.

Less intimate and more distant connections, according to chronic disease studies, may give varied forms of support and preferred help. Bridging social capital benefits both individuals and society since it allows them to interact with a variety of groups. Social capital acts as a bridging element, allowing parents to learn about services and resources that are accessible to them. This has an influence on how individuals utilise health care, as well as assisting marginalised communities that lack authority, promoting current and contemporary concepts, and increasing people's awareness of modern health care services.

Parents are compelled to look for resources outside of the family and society due to socioeconomic difficulties and the chronic nature of thalassemia. Because of these conditions, the families questioned were very dependant on thalassemia therapy and medicine from professionals, as well as non-profit and government organizations.

The study discovered that afflicted families were able to diagnose the disease and get better treatment through informal and formal connections with specialists, as well as volunteer and governmental organisations. Social interactions between communities or community members and representatives of formal institutions, such as health professionals and social workers, are essential for leveraging resources, information, and ideas, especially among marginalised groups. This is the social capital that binds the community together.

The study was successful in obtaining the viewpoints and lived experiences of parents who spoke about the bonding, bridging, and connecting social ties among people with thalassemia children. According to the participants, all types of social capital are important in managing with thalassemia, learning about it, and seeking treatment. In the context of the study's location, where accessibility and resources were restricted, this was a key predictor of treatment-seeking behaviour. The identification of various kinds of social capital in this community assists in understanding and, as a result, adopting the best methods of providing care for the children who have been impacted. Families with relatives who have thalassemia require physical, social, and emotional support. Their own awareness of social capital helps them cope with thalassemia's challenges. This is a sign of social capital's emotional and cognitive social capital. To determine social capital, this study employed a phenomenological method that was both realistic and cognitive.

There are several drawbacks to this study. The absence of data triangulation and methodological triangulation is one of the major drawbacks. Because thalassemia is a rare illness, there were only a few people who had it. If there had been a larger number of families accessible for the interviews, different data gathering approaches might have been tried. By adopting several methodological techniques, the sample did not enough for methodological triangulation. Rigid analytical triangulation, on the other hand, was useful in confirming the interpretation of the families' narratives.

Thalassemia is a chronic blood condition that strikes children at a young age, usually between the ages of four and six months. It is a major public health issue among India's indigenous people, and children who are afflicted require long-term therapy, such as blood transfusions and iron chelation medicines. The disease's chronic nature has a physical, emotional, and economic impact on the family. The study found that the physical and intangible resources acquired through intra- and inter-group social relationships were essential in assisting impacted families in coping with the circumstance and maintaining their children's health and well-being.

Chronic diseases, such as thalassemia, need long-term, sustained therapy and frequent access to treatment facilities, necessitating the best possible use of social capital to promote treatment access. Social capital and social support are critical for successful health care delivery in marginalised groups, where a higher proportion of the population is adversely impacted by thalassemia. Families with thalassemia must actively organise themselves into support groups and social groups in order to better utilise the available health resources. This type of formal social organisation can also fight for the provision of accessible services to the underprivileged population. The public local government structure may encourage and assist this. It was discovered that connecting social capital was critical in delivering assistance to thalassemia households.
Informing and creating social security policies, as well as preparing for improved thalassemia care, a full grasp of the phenomena of social capital theory in this community may be quite beneficial.

2.1.3. Conceptual framework

Conceptual framework of social capital theory regarding thalassemia effected children and their families are describe beolow. There are some main features of social capital theory.

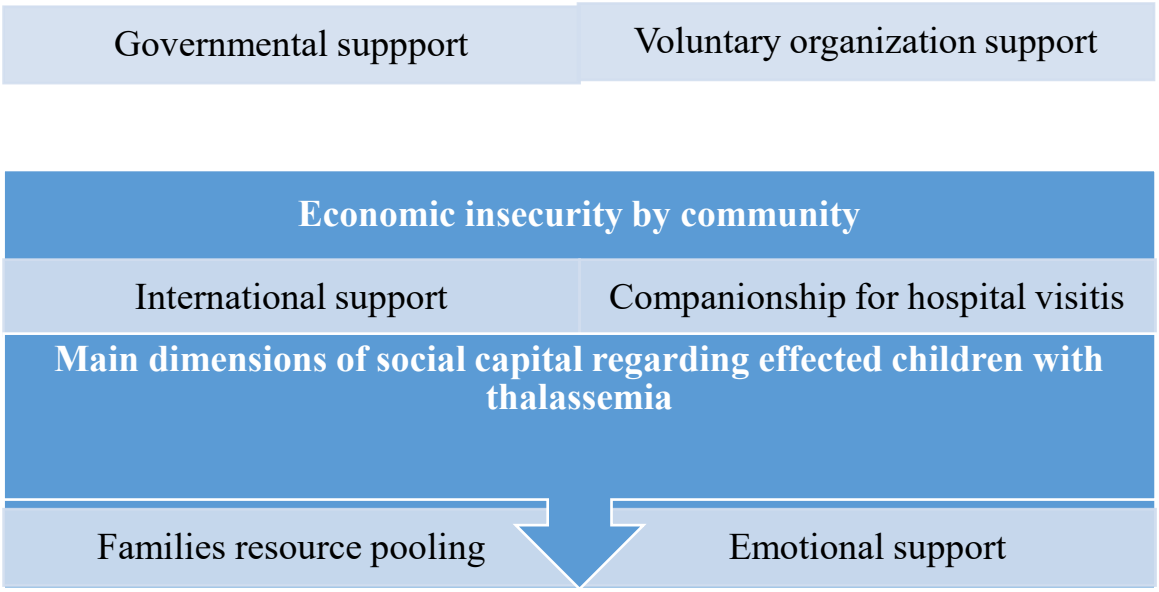


Figure 2 **conceptual framework regarding thalassemia**

The model of social capital theory explain the main dimensions regarding the thalassemia children. Those families which have faced financial problems and they can't afford the opt and treatment of thalassemia patients though they learnt that bone marrow is the permanent solution of disease which is quite difficult for the families to manage expenses than through government they got support by thalassemia welfare association and the voluntary organization plays a vital role in the health management and advocacy through NGO in the indigenous areas. The families have economic insecurities by the community though they get international support through the organizations and interaction with other people which are donating in the organizations.

Families also get companionship for traveling to regular visit at hospital for treatment. Hospital generally put request in front of the families for blood donation at a time of need. Pooling of resources in the extended families is seen as much obligatory and responsibility of one another in the critical situation of thalassemia disease. According to social capital model family members support to maintain the health and well-being with the

parents of of effected children while socialization they also giving emotional support to the parents and effected children when they overwhelmed by the stress of disease.

3.2.1. .Health and Illness

To understand the anthropological approach to health and illness I am defining the short terms below health are imbued with moral, ethical, and political implications. Perhaps the broadest definition of health is that proposed by the World Health Organization (WHO) (Glazier and Hallin , 2010).

Health systems include cultural perceptions and classification of health-related issues, healing practices, diagnosis, prevention, and healers. Illness is a feeling or perception of not being healthy. Illness may be caused by disease, but it can also be caused by psychological or spiritual factors and tied to an individual's worldview (Miller, 2011).

3.2.2. Theoretical Approaches

Anthropologists George Foster and Barbara Anderson, who together with Khwaja Hassan established the field of medical anthropology, associated three approaches of illness describing under:

1. **Personalistic disease theory**: Illness is due to the action of a representative such as a witch, sorcerer, or supernatural entity, e.g., ancestor spirit or ghost. Healers must use supernatural means to learn the cause and to help cure illness.

2. **Emotionalistic disease theory**: As this theory is related to thalassemia disease, in this disease we can understand that illness is due to a negative emotional experience. For many patients, anxiety or fright may cause exhaustion and distraction in thalassemia disease, According to this theory illness called susto. Psychotherapists are interested in the role emotions play in physical health.

3. **Naturalistic theory**: As thalassemia is genetic and chronic disease many people faced multiple diseases in this factors illness is due to an impersonal factor, e.g., pathogen, malnutrition, obstruction (e.g., kidney stone), or organic deterioration (e.g., heart failure). Naturalistic theory has its origins in the work of Hippocrates and dominates the teaching of modern medical schools.

Three theoretical approaches that attempt to understand health systems:

1. **Ecological Approach**: This approach aims to produce data that can be used by public health programs by focusing how the interaction of the natural environment and culture can cause health problems of thalassemia patients and influence their spread through a population.

2. **Interpretivist Approach**: Drawing on the work of Claude Lévi-Strauss, the interpretivist approach examines how community and individual distress is alleviated through healing systems of thalassemia disease and how illness is defined and experienced. The assumption is that the healing system of thalassemia disease provides meaning for suffering.

3. **Critical Medical Anthropology**: Critical medical anthropologists examine how health system of thalassemia disease is impacted by structural elements, e.g., social inequality, political economy, global media and Psychological factors.

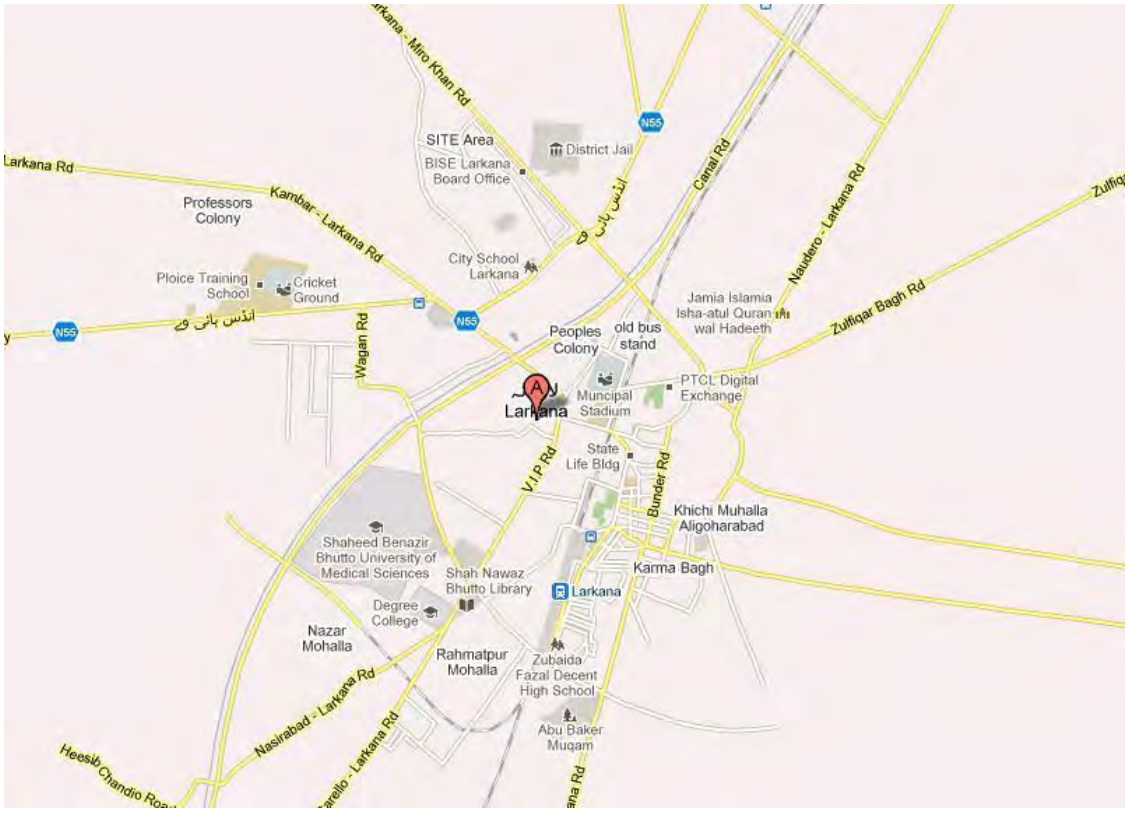
Chapter 4

4. AREA PROFILE

To fully comprehend any place, thorough data must be provided in order to fully comprehend the culture, life patterns, social, economic, and environmental aspects of that area. This chapter gives a thorough explanation of the district and city, as well as an overview of the cultural environment. It includes all of the essential facts about the target district and city, such as its location, geography, population, social structure, religion, and economics, among other things.

The red circle on the map represents the Lahori Muhalla Larkana, which is close to the Rice Canal and where the research was done.

Map: Larkana District



4.1 The Locale

The Larkana city is named for its capital, 'Larkana,' which was once home to the "Lariks" tribe and the lahori Muhalla which is situated near rise canal of Larkana city. It was named by “Lahoris” tribe. The Larkana region covers a total size of l0 square miles. According to the Sindh Handbook, Larkana holds a significant position of importance. After Karachi, it is Sindh's second-largest city on the Indus River's west bank. The city is located on 27° 33' 40.4" North scope and 68° 12' 30.8" East longitude, at a height of roughly 167 feet above mean water level. The city is around 85 kilometres south-west of Sukkur in upper Sindh. In the Larkana region, Dokri and Naudero are two major villages. The Lahori Muhalla of Larkana is near Rise canal of main city where the study was conduct.

4.2. History of Larkana

The area's history stretches back 4000 years, when it served as the foundation for the "Indus Valley Civilisation," the world's oldest human civilization. Relics of this human evolution may be found 18 kilometres from the present-day town of Larkana in Moen-jo-Daro. The Indian subcontinent was conquered by Sultan Mahmud of Ghazni (1019 A.D.). Sindh was governed by a Governor who was only nominally accountable to the caliph. After taking Multan and Kach, Sultan Mahmood Ghazni sent his envoy, Muhammad Abdul Razai, to conquer Sind, but he died in 1026 AD.

This region of the nation was controlled by a Hindu authority prior to the Arab conquest of Sindh. Arore/Alor, which was close to Rohri, was its capital. This kingdom's borders stretched from Kashmir to the north, Mekran to the south, and Kandhar to the west. Rai Siharas was the family's most well-known monarch The Persian armed forces assaulted Sindh during Saharas II's reign, obliterating his kingdom, and Rai Saharas II was murdered as a result. His successor, Rai Sahasi, was a wise ruler. He was beaten by a Brahman called Chach in the year 638 AD.

Raja Chach ruled for a long time before being followed by his brother Chandai, who ruled for a long time until being succeeded by his nephew Dahir, Chach's eldest son, during whose reign the attack of Muhammad-Bin-Qaslm occurred. Muhammad-Bin Qasim conquered the country in 711 A.D., and Raja Dahir was slain. Sindh was ruled by the Umayyad and Abbasid Caliphs till around 908 AD. After the Caliphate fell in 871 A.D., two separate kingdoms formed in this region: Multan and Mansura, which were later incorporated by the final dominion, which had its capital in Bukkar.

Multan's ruler, Ibn e Sumar, eventually joined the nation and established the Sumra line in 1032. The Ghazanavides' authority was only symbolic to the Soomra tradition, which controlled the territory independently. A number of the commanders of Ibn e Somar's line assaulted him. Khafif was a Somra king who made Thatta his capital and expanded his territory from Katch to Nasarpur. Following Khafif's death, the Sumra dynasty began to lose power, culminating in the killing of the last Somra monarch, UrruMehl, by Sammas in 1451 A.D., who placed Jam Umar as the recognised ruler.

The Persian Empire extended to cover all territories west of the Indus River, including Thatta and Shikarpur, after Nadir Shah captured Delhi in 1739. Noor Muhammad ultimately gave up, and the Daudpotras and Afghans took Shikarpur and Sibi from him and handed them over to them.
Noor Muhammad overtook him in southern Sindh in 1746-47, and after Nadir Shah's death, the Kalhora area became a tributary of Ahmed Shah Durrani. In 1768, Ghulam Shah built Hyderabad (then known as Nirankot) and lived there till his death in 1772. The standard of this administration came to an end with the loss of Abdul Nabi Khan Kalhora at Haiani in 1783, and Mir Fateh Ali Khan Taipur gained power.

The Shahdadpur or Hyderabad branch was in charge of central Sindh; the Erpur or Manikanl branch was in charge of Mirpur and Khairpur; and the Sohrabanl branch was in charge of Khalrpur. The Talpurs continued to manage Sindh until 1847, when the British assaulted the Mirs' authority at Miani, and Sindh was abandoned to British administration. Charles Napier became Sindh's principal legislative leader, with complete military, political, and economic authority. Sindh enjoyed the status as a province until 1927, when it was absorbed into the

administration of Bombay 30. Because of the political weights applied by the Muslims of Sindh, it was again divided into a separate area in 1936.

Because of the political weights applied by the Muslims of Sindh, it was again divided into a separate area in 1936.

4.3 Overall Population of Selected Locale

The total population of the Lahori Muhalla Larkana was three thousand three hundred fifty one people. Three hundred twelve household were present there, some of them are made of mud bricks and rest of them are cemented. From three thousand three hundred seventy two populations, Out of total population 49 thalassemia cases were detected. Total population of male were one thousand and sixty four and twelve hundred and forty one were the total population of females. The unmarried was seven hundred and eighteen and the married were three hundred and forty nine.

Total Population and identified cases of thalassemia

Status	Ratio
Males	1064
Females	1241
Married	349
Unmarried	718
Thalassemia major cases	41
Thalassemia minor cases	07

Total House Hold	312
Total Population	3372

Table 1 **Source: Union Council**

4.4. Socio-demographic Profile of the respondents"

Table 2: Socio-demographic Characteristics of participants which were selected through sampling unit.

"Categories"	**"Frequency"**	**"Percentage"**
Parent Respondent		
Father	16	43.2
Mother	21	56.7
Age of the Respondents		
22-27 years	8	21.2
28-33 years	13	35.1
34-39 years	9	24.3
40-45 years	7	18.3

Total Family Members		
4-5	15	40.5
6-7	22	59.4
Total No. of Children		
1-3	20	54.0
4-5	17	45.9
Gender of Thalassemia Children		
Male	16	43.2
Female	21	56.7
Age of Thalassemia Children Male		
4-6years	8	21.6
7-9 years	13	35.1
10-12 years	11	29.7
13-15 years	5	13.5
Age of Thalassemia Children Female		
Upto 6 years	11	29.7
7-10years	13	35.1
11-14 years	8	21.6
15 – 18 years	5	13.5
Family Income		
4000-8000 rupees	11	29.7
8001-12000	12	32.4

rupees		
12001-16000 rupees	8	21.6
Above 16000	6	16.2
Family Structure		
Nuclear	23	62.1
Extended	14	37.8
Father's Occupation		
Private job	13	35.1
Farmer	8	21.6
Laborer	11	29.7
Unemployed	5	13.5
Mother's Occupation		
Housewife	28	75.6
Private teachers	9	24.3
Father's Education		

Uneducated	7	18.9
Primary	5	13.5
Middle	4	10.8
Metric	6	16.
Intermediate	8	21.6
Bachlor	7	18.9
Mother's Education		
Uneducated	4	10.8
Primary	4	10.8
Middle	7	18.9
Matric	9	24.3
Intermediate	5	13.5
Bachelor	8	21.6

In district Larkana Sindh, out of 37 respondents, twentyone were mothers and remaining sixteen were fathers of thalassemia major children. Among the respondents, Eight respondents were in the age category of 22-27 years old, thirteen participants were at the age category of 28- 33 years old, nine respondents were in the category of 34- 39 years and seven respondents were in the age category of 40-45 years. Out of 37 families, fifteen families were consisted of 4-5 members and twenty two families were consisted of 6-7 members. Out of 37 respondents, twenty respondents had 1-3 children, seventeen respondents had 4-5 children. Out of total 37 thalassemia major children, sixteen were boys and twenty one were girls. Regarding the age of male thalassemia children, eight were in the category of 4-6 years, thirteen were in the category of 7-9 years old, eleven were in the category of 10-12 years old, five were in the category of 13-15 years old. Regarding the age of female thalassemia children, eleven were in the category of upto 6 years and thirteen were in the category of 7-10 years old, eight were in the category of 11-14 years old and five were in the category of 15-16 years age. Out of 37 respondents, eleven families had monthly income of 4000-8000 rupees, twelve families had monthly income 8001-12000 rupees, eight families had monthly income of 12001-16000 rupees, whereas six families had income above 16000 rupees. Out of 37 family structures, twenty three families were nucleus, and fourteen families were in extended structure. Regarding the thalassemia children's fathers' occupation, thirteen were in private jobs, eight were farmers, eleven were in labor, and five were unemployed. Almost twenty eight mothers of the thalassemia children were housewives but remaining nine were doing job as a private teacher in school. In fathers' education category, seven were uneducated, five were primary pass, four were middle (8 yearseducation),

six were metric passed, eight were intermediate and remaining seven have done Bachelor (2 years). In mothers' education category, four were uneducated, four were primary educated, seven were middle pass (8 years education), nine were matric pass, and five were intermediate and remaining eight were bachelor graduate.

4.4. Climate of Lahori Muhalla Larkana

Larkana is located in the lower Indus plain, which stretches from north to south. During the summer, the typical minimum and maximum temperatures are 50°C and 38°C, respectively. During the winter, the average maximum and minimum temperatures are 22°C and 12°C, respectively. The average annual precipitation is 115 mm, with mugginess ranging from 40% to 60%.

4.5. Physical Features

The city of Larkana is divided into three pieces by two physical barriers: a railroad line and the Rice Canal. The ancient town is located east of the railroad line, which is densely inhabited and has recently been developed as a business and retail centre. This part includes Qafila Sirai, All Goharabad, Galib Nagar, Surahia Padhar, Kadri Muhalla, Ghareeb Mukaam, Dari Muhalla, Leelaabad, Karma Bagh, Murad Wahan, Gajanpure, Allahabad Zulfiqar Bagh and Jinnah Bagh.

The other part of the city is located west of the ancient city, between the railroad line and the Rice trench. Circuit House, Sir Shahnawaz Library, Chandka Medical Hospital, Chandka Medical College, DCO office, SP office, High Court, Pilot Secondary School, Boys Degree College, Lahori Muhalla, Latif state, Peoples Colony, and Doctors Colony are the primary structures and provinces in this section.

The third section is located north of the town, between the Rice canal and the two sides of Ghar Wah. This includes the newly established Municipal Housing Colony, Sheik Zayed Women's Hospital, District Jail, Children's Hospital, Director Education, FM Radio Station Larkana, Sheik Zayed Colony, and an emphasis on police training.

4.6. 1 Rivers and Lakes

The district, along with the talukas of Ratodero, Larkana, and Dhokri, is bordered by the Indus River, which flows north east to south west. The rains in the highlands cause hills torrents, locally known as Nais, to develop, which generally dry out after the wet season. There are 31 natural depressions known as Dhandoo (lakes) that hold water for an extended length of time.

4.7. Flora and Fauna

A few years ago, this region was abundant with wild life. The Himalayan mountain bear (urusloqualus) was discovered on the kirthar range's statures, and one was shot at kute-ji-kabar in 1902 by Mr. H. Lucas, a Larkana gatherer. The smallest of the Indian world sheep, the Oorial (ovisvegnei), better known in Sindhi as stray, was discovered on Khirthar, separate from other wild people, which gradually diminished with the colonisation of the wild people. Currently, the flying creatures include the hyena, jackal, and fox eolg.

Babur (acacia Arabica), bahan (crowded euphratica), kandl (prosopisspecigera), slras (mimosa sirissa), ecclesiastical (Ficusreligiosa), and Lao are the key regular backwoods tree areas. Aside from the trees mentioned above, exocatlc species such as amaltas, gulmohar kuchnar, toot, eucalyptus, poplar, and simal have been planted recently in the Irrigated land of the neighbourhood backwoods office.

4.8. Tribes

In the area, there are a few clans. With the exception of the pilgrims from Arabia, the majority of them are of Aryan descent. A fraction of the population of the metal Arab era who converted to Islam or continue to practise their own religion. Bhiiis, for example, have a Pre Aryan Dharavian ancestor. LarkanaTaiuka is dominated by the Bhuttos, a non-Baiochi tribe. The Khuhros are a small group of people that live mostly in the Larkana Taluka. Hakros are non-Balochi clans who live mostly in Kamber, Ratodero, and Larkana.

Abros, ChhajrasKaihoras, and Bughias are non-Balochi clans. Israns, Phuls, Wagans, Junejos, and Naichs are all Israns. Some sheikh families live in LarkanaShahdadkot and the surrounding area of Kamber town. Rinds, Lisharis, Gopangs, Magsis, and Mugheris are the other Balochi clans besides the Chandias. Thousands of Indian migrants settled in Larkana,

Dokrri, Baslrabad, Naudero, and other places. Some agriculturist vagrant families were also located in rural areas, where they developed land. The bulk of them have gone into business, while others continue to work in horticulture.

Thousands of Indian migrants settled in Larkana, Dokrri, Baslrabad, Naudero, and other places. Some agriculturist vagrant families were also located in rural areas, where they developed land. The bulk of them have gone into business, while others continue to work in horticulture.

There are also a large number of Hindus that dwell in this area. These Hindus refused to return to India following the partition in 1947, preferring to stay in Pakistan. In terms of composition, appearance, and physical features, they resemble Muslims. Bagrles, Bazigars, and Bhangis are Hindu clans.

The appearance of the individuals of unique Sindhi stock is for the most part tanned dark colored and that of Balochis is wheatish. The Sindhis are respectably gorgeous with durable and expansive appearances. They ordinarily have huge mustaches and long facial hair. They are typically more grounded than different clans of Sindh. By and large the tallness of the individuals ranges from 5' to 5'8".

4.8.1 Major Castes and Tribes

Main casts and tribes in this area are Chandio, Memon, Samo, Magsi, Siyal, Abro, Brohl, Jatol, Sandilo, Kalhoro, Sheikh, Soomro, Unnar, Mirbahar, Bughlo, Mashori, Machi, Jlskani, Junljo, Khuhawar, Khuhro, SahltaPlrzada, Jamali, Harljan, Hindu and Bagri etc.

4.9 Educational Facilities

Larkana has the second highest literacy rate in rural Sindh, which is 35%. This high rate concentrated more in the city, compared to other areas of district. Although the city holds many government and private educational institutions, there are three universities in the district; Shaheed Mohtarma Benazir Bhutto Medical University and Quaid e Awam University of engineering science technology and campus of Sindh University jamshoro at Larkana.

4.10 Administrative Setup

The locale is under the charge of a representative chief who joins the elements of the area justice just as authority. He is additionally answerable for co-appointment of elements of all country building divisions in the locale. On the legal side, he is helped by an extra area justice and a couple sub~ divisional officers. The agent chief goes under the general control of the magistrate of the division. Larkana sub-division comprises of three Talukas to be specific; Larkana, Ratodero and Dokri. Each Taluka is under the authoritative control of a Mukhtiarkar.

The director of police is responsible for the police organization of the locale. He is helped by the appointee director of police (D.S.P). The region charge is separated under fourteen police headquarters, each run by a station house official (S.H.O). The legal organization of the area is under the charge of a region and sessions judge, who is helped by some of extra session judges and common sub-judges. There is additionally an occupant justice's court at Larkana which manages the instances of Larkana town as it were.

4.11 Irrigation System

The entire area of the district is surrounded by protective bunds. The bund on the Western side prevents hill torrents in rainy season and the other on the eastern side Drotects the canal irrigated areas from river flooding. The cultivated land is irrigated bya network of canals viz the Rice Canal, Dadu Canal, Warah Canal, Kirthaar Canal and SaifuliahMagsi Canal. The area irrigated by these canals is 870,127 acres.

4.12 Communication

There is a network of metal and rough roads all over the district. All the taluka headquarters are connected with the district headquarter either by metal road or by rail. Pakistan railway also runs through the district from north to south. Larkana itself is a railway junction. 34

4.13 Forests

The total area under forests is about 25,532 hectares. Some of the important forests are Salihani, Agani, Nauabad, Amrote, KetlChandka, Khuhra, Madeji, Khokhar, Tajudero, Visar. Ademji, Sharifpur, Dasu, Behman, Hassan Wahan, Gajidero, Abrepota, BoliGaji. Bagi ,Shahbeg, Gangherko and Tatrl.

4.14 Industry

Industrial development could not keep pace with time due to insufficiency of raw materials, skilled labor and suitable climate. Textile is an important industry in the district. A Sugar Mill is also under construction at Naudero Taluka. There are 84 Rice Mills in the district. other small scale industries Include Silk Weaving and Handlooms, soap, perfumery, engineering and foundry works are also established.

The main cottage industry is the making of embroidered caps by women particularly in Larkana Taluka. This handicraft has a good market in the towns. It is a source of income to the poor people. There are other cottage industries namely, angoshas, lungi, and sosi.

4.15 Economy of the Area

The main source of income of the people in city is business of various natures and small industry, while in rural areas agriculture is the mainstay of economy. Both in rural and urban areas, people keep livestock in their homes to meet the needs of milk, butter and yogurt.

4.16 Occupational Specializations

Lion's share of individuals of Larkana are locked in legitimately or in a roundabout way to farming and exchanges. Others are gifted work viz. artisans, woodworkers, goldsmith, smithy, taxpayer supported organizations. There are likewise instructors, legal advisors, and promoters. The ladies of cultivators in provincial zone work with their male individuals in the fields. They likewise take care of their family unit issues. There is no regular movement of laborers starting with one spot then onto the next in this region. A couple of groups of meandering clan of Brahui, nonetheless, descend from the slopes 35.

during winter season to protect from the extraordinary virus. These live in the inside of the locale for gaining their business and return when the season is finished.

4.17 Festivals

Two main festivals are held annually in Larkana district

1. In the honor of Pir sher at taluka Larkana
2. In the memory of Peer Taki Shah a fair organized at Baded Town Taluka Dokr'i.

4.18 Settlement Patterns

The places of a wealthy individual in towns is worked with blocks and secured with limestone mortar. Network individuals with a normal practical position constructed their homes with katchi blocks and mud. There are adequate plans for seepage, ventilation and lighting. The houses for the most part comprise of three to six rooms, one corridor, verandah, washroom and kitchen. One room is additionally given for the most part to each house as a baithak or visitor room. The houses are furnished with essential limiter.

The houses in towns are worked of katcha blocks and secured with timber, wood reeds, and grass. The yards are encompassed by fence of prickly hedges. These are worked in a random way and not in smaller squares. The poor workers and ranchers lives in hovels made of reeds and secured with sur grass. There are little courses of action of sanitation and seepage in country zones.

4.19 Food and Dietry Patterns

The staple food of the people is wheat and rice. Some people also take juwar. Fish, pulses, pickles, yogurt and vegetables are used by people as food items. In cities, water is obtained from hand pumps and wells, while in the rural area it is obtained from katcha wells and canal water courses and ponds.

4.20 Dressing and Ornamentation

The dress of Muslims living in urban region is undergarment (goudd) or pant, turban of ap, while the people in the country zone put shirt, flank and turbans. Dress of Hindus in 36 country region just as in urban regions is shirts, loln fabric and turban or a top of an uncommon kind. The dress of Muslim females is shirt, shalwar and dopatta. The Muslim

Females watch parda and use cover (burqa). In any case, there is o custom of parda, recognition in baloch clains in the provincial territory.The female normally wear accessories, hoop, rings, noselet (Natha) Bangles and jhumir of gold or silver as per their standard and budgetary position.

The dress of a Muslim male living in the urban regions is a shirt, undergarment (dhotl) or pant, turban or top, while the people in rustic zones put on shirt, loin doth and mrbans.

The dress of Hindus in rustic just as urban regions is a shirt, flank doth and turban or an asp of uncommon sort. The dress of a Muslim female is shirt, shalwar and dopatta. The Muslim families watch parda and use cloak (burqa). There is, be that as it may, no custom of watching parda in Baloch clans in provincial territories. The females of Bloch clans wear Shalwar and huge shirt up to their lower legs which is called ghagho in Sindhi. It is free and not tight like shirts. There is weaving take a shot at it in front and on the sleeves. It is for the most part of red thick unpleasant material.

The females of wealthy Muslim families wear pieces of jewelry, ear rings, rings, noserlngs (nath), bangles and jhumars of gold or silver agreeing their standard and monetary position. The decorations utilized by the females of Baloch clans are for the most part the equivalent.

4.21 Customs and Traditions

The majority of the number of inhabitants in the Larkana's is Muslim. The social existence of Muslims is significantly impacted by the Islamic lifestyle. The pits and murshids are held in high regard and certainty among the Muslims especially by the ignorant masses of the country regions. Urs functions of pirsare consistently held at their holy places. The Hindus likewise hold extraordinary trust in Thakurs and Brahmans, for the most part, perform profound ceremonies of Hindus on exceptional events.

The dialects for the most part spoken in this Larkana are Sindhi, Brohi and Urdu. Anyway, Urdu is comprehended by an incredible larger part of the populace.

Ladies don’t move in broad daylight among the male group of spectators Tablas, dholaks, sarangis and quiets are the fundamental melodic instruments and are played on the events of relationships, pre-wedding assurance, Eids and melas. Melodies of various types are sung by men just as ladies on such events.

Ghanas (pitcher) are likewise used to make melodic cadence. The two people move jhumar on these events and particularly on wedding services. Jhumar is a prevalent move around there.

In the vast majority of the relationships, assurance to be wedded goes before the real marriage. Now and again it disregarded altogeter. The guardians and different relations of the lady give money, decorations and preo'ous garments to the lady of the hour and groom. There is likewise a custom of giving dairy cattle in share to the lady. Gold adornments, watches, Television-sets, bikes, and even autos are given by the wealthy people to their little girls.

4.22 Music and Entertainment

On the occasions of marriages, Eids, and fairs, tablas, sanrangia, and musical instruments are played. On speaaloccasrons, both male and female ladies sing songs of various kinds. On certain occasions, both male and female dances (Jhumer) are performed, notably during weddings, however women do not dance in front of male audiences. People have managed to preserve their socio-cultural identities in some way. They participate in ceremonies wholeheartedly.

4.23 Social Organization

Human beings are organised into sub-groups in a society. Every civilization is built on a set of fundamental norms and connections. This necessitates that everyone in a society follow a predetermined path. Because they are dependant on one other for shared goals, they must conduct specific rituals in order to live in peace and harmony. They must also share culture and pass it on to future generations. The impression was gathered from residents of lahori Muhalla larkana and the surrounding area, as well as hotels and ottak/guest houses, and those who lived near Marhi.

4.24 Outskrit of *Marhi*

Marhi is the place/house where transgender living together as a family, the research was conducted in Rahmatpur Mohalla, there were three *Marhi*, the first marhi was beside the road which was *Paki,* the second was personal house of female transgenders there was not

allowed male transgedner, it was well furnished, and the third was a building, ground flour was the bike‟s garrage and first flour was the Marhi in the Lahori Mohalla.

4.25.Language

Sindhi is the local language and the mother tongue of the most of the people living in the Larkana. Beside Sindhi, Siraiki and urdu language is also spoken. People of the city can communicate very easily in urdu language. They have generally Sindhi is the medium of the conversation among the people belonging to the all hierarchy groups in the city. People feel much difficult to communicate in english language. The children belonging to upper hierarchy group in the city generally speak Sindhi and urdu with the mixing of the words from English language which is the reflection of their education and the style and broad u. English is the considered as the status symbol as the language of learned person.

4.26. Economic conditions

The city is also stratified along the lines of occupation and division of labour. Some of the people living near the villages of Larkan city are involved in agricultural activities. Some people are doing government jobs as they were educated and avail employment opportunities. There were also few members who were working abroad and send handsome amount to their families living in the village. Most of the people of different castes do manual work like laborer, trailor , cobbler, barber, artisan and driver. For manual works people used to move towards other cities likes Sukkur, Hyderabad and Karachi.

4.27. Religion

The religion of the people living in “Lahori Muhalla Larkana" is Islam. There was not a single household whose inhabitants belonged to the religion other than Islam. According to the data came from the socio-economic and census survey forms, the city is stratified along the lines of sects. A predominant number of people belong to the Shia and sunni sect. This is following by the Brailvi sect. after this comes the Ahl-e-Hadith and the last in sect in number is Deobandi sect.

4.28. Mosques

Every sect in the Muhalla has the mosque and people generally prefer to perform the religious obligations like offering prayers five times a day and the weekly gathering for special prayer of Jummat-ul-Mubarik in the mosque of their respective sect. There are two mosques in the Lahori Muhalla Larkana: One belong to (sunni) sect. and one mosque belong to shia. Beside this there are two Imam Bargah belonging to the Shia sect in which they perform the religious obligations especially in the month of Moharam.

4.29. Religious seminaries

The people in the village are much inclined towards the religious education. This is evident from the number of Madrassas inthe village. There are two Madrassas of all the sects which are functioning in the area. These two Madrassas also contain hostel facility as well for the out- sectioned students. One Madrassas is of (sunni) sect. It is foe boys only. There is one Madrassas for the sect of shia and they send their children for religious education and recitation of Quran to the Madrassas of the sect.

4.30. Household Physical Structure

Generally the type of housing reflect the economic positions of the inhabitants. All the houses in the village could be reduced to three types as far the kind of physical appearances and construction style is concerned. Other category of houses which contains similar number of houses the village is called as "Semi Packa" These kinds of houses Most of the households in the village are made up of cement and concert stuff and called as "Packa" houses. These kinds of houses depict the higher economic level of the inhabitants. The features of these kinds of houses are that there is separate bathroom, kitchen, drawing room and generally two rooms with a big courtyard. These kinds of houses generally have iron gage in front of the houses. Some sort of lawn in part of the houses is also maintained by growing grass, planting trees and putting flowered plants in "gamlas". The comprise of almost the same kind structure as those of packa houses but with the difference that it has some part of the houses. Mostly the people belonging to the middle-class in terms of economic level own these kinds of houses In few of the houses belonging to this category, some Katcha portion is dedicated to the animals. There are also some of the houses that the "Katcha" in nature. The poor people with lower economic status own this kind of houses. These houses are made up of mud and wood and contain space for accommodating the

animals as well. There are some houses in this category that comprise of only one or two rooms and they also lack the toilet facility as well.

Figure 3 **Field visit**

4.31. Family Structure

In the past, Larana life was chracterized by the extended and joint family systems, but this kind of structure has undergone tremendous changes and has been replaced mostly by the nuclear family structure. People though praise nuclear and extended type of family structures but say nuclear family system as pragmatic and according to the needs of the present world. In the village there are almost 80% of the households in which nuclear family system is operating. In nuclear type, the family comprises of husband, wife and their unmarried children. There are some households where the type of family was extended in which parents live with their married and unmarried children. While very few families, where joint family system was prevalent. In this type of family structure, married brothers live with their unmarried brothers and sisters.

4.32. Facilities

The Muhalla has got certain facilities therefore it lacks in different life facilities.

4.33..Electricity

The citizens take the benefits of electricity. Owing to the availability of electricity in the houses, there are many accessories that people benifit from. Their includes fans, tube light,

electric bulbs, TV, fridge, iron, computers etc. The use of electricity facility also indicates the pattern of life and the economic status of the people in the city. The people of upper hierarchy group with strong economic background use expensive items like Air conditioner, Geezer etc. in their houses which are not use these things as they could not afford to bear their expenses. The usually use electricity for routine purposes.

4.34. Health

There is proper health facility for the people of Larkana in the City while according to research on thalassemia patients they have not proper health facilities. There were 3 Government and one private foundations was there in the city. There are many private clinics in the Lahori Muhalla Larkana city but there were one private center of thalassemia patients named as Irfan hussain medical center Larkana. The people of upper class who can afford their expenses they went their while others went to Shaheed Mohtarma Benazir Bhutto foundation, Fatimid foundation , Al Murtaza foundation and blood bank, Pak Voluntary blood bank, The checkup form the private doctors and hospitals is highly the matter of affordability rather than choice. People of upper hierarchy and strong economic background go in private hospitals for checkup. People of middle class go in government hospitals while the lower class people go in free dispensaries in the city for checkup.

Source: Field Visit

Figure 4 **Thalassemia centre**

Figure 5 **Fatmid Foundation**

4.35. Education

In the Muhalla, people are not very well educated formally. At present people are very much conscious about the education of their children though. They send their children in schools, In the city and outside the city, and to madrassas according to the esteem, affordability and ideology. As for the educational facilities in the village are concerned, there are 4 government schools, 6 private schools. Two Madrassa's one for shia sect second for Hafiz-e-Quran of sunni sect. People prefer that the females stay in the home to get religious education while there were separate bargah of females for dars hafiz-e-Quran . The majority of females go for higher education outside the city after the completion of their elementary education. People also send their children to private school. It depends upon their economic level of the parents and the conscious about the quality of education in minds of parents. Generally the enrolment ratio of the children in some sort of educational institute is quite high.

4.36. Communication

The people of the village have not to face any difficulty as far as transportation to the other areas is concerned. people can very easily go by foot at this point. Most of the people have

line telephones as well as mobile phones. there is frequently used mode of communication for the people of the village.

4.37. Shops

At the very entrance of the Muhalla, there is small market in that area. In the Muhalla as well there are few shops which people have open in part of their houses. People take the day to day things from these shops. The things which are not very commonly used in the Lahori Muhalla are not available at the shops. For This people use to purchase things from the mart of the city. If people have to take things in large quantity then also they purchase things from the mart.

Figure 6 **Field Visit**

4.38. Streets

The streets in the village are vast generally. Most of the streets are paved with bricks. They are also interconnected with each other which help people to easily move from one place to other. During the rainy season passing through the street is not easy due to the mud.

4. 39.Graveyard

In Lahori Muhalla there are two graveyards which is the government land. To offer the funeral prayer, there is land dedicated for this purpose. This land is called as "Janazgah" (place of funeral prayer). People from all the sects offer funeral prayer. People from all the sects offer funeral prayer in Janazgah and bury their dead ones in the graveyard.

4.40. Religious Ceremonies

Religious rituals are celebrated as religious obligationswith interest and passion. People participation in the religious rituals is also very significant. Due to the dominance of Shia sect is in the city, month of 'Moharram' is celebrated with religious passion. They rituals performed by the Shia during this month are very apparent. Majlises (religious gathering) are very common in this month in which the event of 'Karbala' and martyrdom of Hazrat Imam HussainR.A and their companions R.A has been remembered. Besides this, the Eid-ul-Fitar and Eid-ul-Azha are also celebrated with religious strength by believers of all the sects. EidMilad-ul-Nabi (the birth of people Muhammad (P.B.U.H) is also celebrated especially designed to celebrate this occasion.

4.41. Marriage Celebrations

Marriage in the village are predominantly along the lines of caste system. The proposal is initiated by the parents or close relatives of the boy or girl. The women of both sides take the leading role in finalizing the proposal. The usual age bracket of marriage for males and females is 20 to 27 and 18 to 23 years respectively. As for the marriage city is stratified with respect to caste and the religious sect is also considered to varying degree. Out of the caste marriages are non-existent. The preferred marriage is with close relative, in the same caste group and in the same religious sect. The members of Shia and (sunni) sect can intermarry but here the caste is not to be compromised. The members of Ahlk-e-Hadith, Deobandi (sunni) sect do not marry with the people from Shia sect, but here too the caste is the defining parameter.

Guests are invited from far off places and money is spent very lavishly. Females start singing emoluments(*Lada or sehra*) at night in the houses of bride and groom almost one week before the marriage. The custom of 'Mehndi' is perform in the houses of bride and groom at the last night before marriage. One the weeding day, relatives and friends of the boy assemble and proceed in the form of procession towards bride's house. This peocession is generally headed by the musical bandor the local drum beaters are called for this. The marriage procession is received by the relatives and friends of the girl's family. This marriage party is then entertained with old or hot drinks depending upon the weather.

Afterwards 'Nikah' ceremony is performed which is followed by 'Dua' (prayer) for the long-lasting and happy relationship of the couple. Then the feast is given to all the guests. The famous ritual of (*lanwa*) ,is performed by bride and groom's family members and other famous ritual of *'DodhPelai'* is performed by the sisters, cousins and friends of the bride in which milk is presented to groom in a well decorated glass. When the groom drinks the milk, they demand for money in return which is generally negotiated. After this the weeding party from groom's side takes with them the bride and returns to the house of groom. Parents and relatives of bride also give dowry depending upon their economic status.

4.42. Birth rituals

Birth of the child is the occasion of happiness for the people in the city. Because of the patriarchal nature of the society, Birth of male child is considered as the occasion of great rejoicing and sweets are distributed to friends and relatives. Soon after the birth 'Imam Masjid' or some elder male of the family recites 'Azaan' (call for prayer) in the ears of the child which signifies the birth of the child in Muslim family. On the seventh day *Chathi* (celebration of birth) ceremony is performed both for males and female child. And other religious celebration called "Aqiqa" is also performed for child generally, one goat in case of girl and two goats in case for boy are sacrificed on this occasion. This is also dependent upon the economic level of the people. Circumcision of boy is performed by the entire local barber who is either done soon after birth or after couple of years.

4.43. Death Occasion

Death is the occasion of great tragedy for the family and considered as the will of God. The neigh borers, relatives and friends assemble in the house of the deceased in order to console the family and also as their religious and social obligation. After the death, dead body is given 'Ghusal' (bath) and kept in the white cotton sheets called as 'Kafan'. Roses and rose water is sprinkled over the body. afterwards, the 'Namaz-e-janaza' (funeral prayer) is performed. For this mourners take the dead body to 'JanazaGah' in the form of procession. They recite 'kalmaShahdat' all the way through. Funeral prayer is offered which is followed by 'fatiha' for the dead. After the prayerone of the close relative of the deceased especially the son stands before the gathering and asks about the financial deals of the deceased and presents himself as the authorized person in case of any recovery or debt. People then have

the last look of the face of the deceased, in case the deceased is male. Then people take the dead body in the graveyard where the grave has been dug. The dead body is placed in the grave while reciting religious sologans. At the end 'Fatiha' is again offered and people pray to God for the forgiveness of deceased and his mercy.

Chapter 5

5. SOCIO-ECONOMIC ISSUES CHALLENGED BY THE FAMILIES OF THALASSEMIA PATIENTS

Thalassemia is very serious health issue for the public of world. Particularly in Pakistan it is a very serious factor for people who faced many problems along with their children who are victims of this chronic disease. According to my research in this chapter I will discuss some major socio economic issues faced by thalassemia children and their families. In traditional society especially in rural areas of Sindh the attitude of the families were mainly determined by socio-economic factors. These factors were shaped by inhabitants of the community to faced challenges of thalassemia. Some problems are mention below:

5.1 Financial burden

The families of thalassemia children said in their statement that they took challenges the many difficulties in the treatment of children. According to this study the people were inconveniences, when they did travelled to other big cities to get medications and blood at their personal expenses, that is mandatory in large quantity of time period and their highly income to face the difficulties of families meanwhile they had challenged their other issues and managed their activities along with other sources to co-operate with themselves.

In Larkana district there is only two blood transfusion centers available one is private center which is very costly for treatment and the other is government. However, as the center is run on donations, it lacks resources and does not provide all the medicine and blood required for transfusion. As the life of a thalassemia major child is dependent on the transfusion of blood. It was very difficult to arrange blood twice a month and the transfusion of blood, arranging blood donors for transfusion is hectic and difficult process for the parents.

Case Study 1

Sabiha is the mother of two thalassemia children. Her husband worked as labor. She can't afford treatment of their children. She said that the blood transfusion center does not provide blood for transfusion which makes things very difficult for us. My Participants said that all time we had worried about that how can we manage to arrange blood for children after month, we arranged blood by announcing in the loudspeakers of mosques, and put them request to give blood to their children than we arrange a campaign and get in touch with people through social media who are interested in it. She became very frustrated about their children future. She stated that I am fed up from my life I could not bear any more.

As my respondent expressed that:

اهڙيپنڻ واريڙندگيڪانبهترهيوتهمنهنجبار جمر قتوئي مري وڃن آ۔

''I wish my kids have died at the time of birth then living in this abject poverty''.

It is quite difficult to arrange blood for the patients who are diagnosed with thalassemia major and minor disease, the children who have not common type of blood group they are facing very painful and challenging situation for their families. When their families are not able to find donors, it is unbearable for them to see their children in pain that sometimes lead to their death. According to the participants of my research the respondents stated that we get a lot trouble to arrange blood for transfusion as I have two children and their blood group is O - negative that is very uncommon and hard to manage every month. The participant stated that: sometimes we are not able to arrange blood transfusion because of that we missed the transfusion, and our children get face to hard situation while we are arranging blood donors ourselves.

As mentioned before, arranging blood and blood transfusion involves huge amount of time and resources. The families and their thalassemia major child

ren have to travel frequently for blood transfusion and even arranging blood from different places.

One of the respondents expressed:

We get difficulties in blood transfusion and travelling we arranged the blood through personal contacts, and sometimes through campaigns in colleges, and universities for blood donation. Due to very limited availability of money for public transport that too with pathetic service, it is difficult to frequently travel on public transport.

Especially in backward areas, we must walk miles to find any transport. Women have more difficulties in travelling especially because of remote areas. The travelling cost is also very high.

Case Study 2

Muhammad Jamil was the father of one thalassemia child (Saqlain). He worked as salesman. He stated that the high treatment expenditure for thalassemia major children is non-bearable for many poor families. The medicines for thalassemia are very expensive and are not even available in the city Larkana. From other sources the parents of thalassemia children request to their relatives for taken loan to get treatment of their children and to manage blood.

Cost of treatment per month is fifteen thousand rupees. The cost of one tablet is five hundred which is also available only in main cities of Pakistan like Karachi, Islamabad or Lahore. Sometimes we have to travel ourselves for purchasing the medicine. I am working as a salesman on a grocery shop. My salary is twelve thousand only. We have to take the loan for the treatment. Sometimes we have to skip the transfusion if there is no availability of donor or money for purchasing the medicine.

As one of my respondents expressed:

پيسو آهي ته زندگي آهي نه ته بيماري ۾ ڪوئي سنڄڻي ڪونٿو

''*When you have money, you have everything. Otherwise, no one helps in this disease''.*

Case Study 3

Jawaid Ahmed was working as a laborer in England when my wife informed me that my son has been diagnosed as a thalassemia major. It was not possible for my wife living in a rural area to travel to far away hospitals for the treatment. So, I decided to quit my job in England and came back to my home is in Larkana. Using my savings, I started a small business of my own in Larkana but soon I had to sell out my business to meet the high treatment expenditure of my son.

Now I am working as a salesman in a pharmacy on a salary of fifteen thousand rupees monthly. My son had to undergo blood transfusion twice a month. I have to take advance salary and loan for the treatment due which my other household expenditures and the needs and education of other children are negatively affected. He said that: being a laborer it was hard to manage after 15 days to get blood transfusion and medicines for my thalassemia children. Because of blood transfusion my son had faced Iron issues and he had not being able to do any activity he also effected with a lot of diseases like, headache, stomach pain, skin problem and laziness.

As my respondent said that:

هڪ اُميد آهي. هڪ ڏينهن منهنجو پٽ ٿيلاسيميا جي هن بيماري کان صحتياب ٿيندو ۽ پنهنجي ڪيريئر تي ڌيان ڏيندو

''There is a hope. One day my son will recover from this disease of thalassemia and will work on his career''.

As highlighted by the above respondent, managing the treatment of a thalassemia major child that bother their members of the family and because of the high expenses they lead to their family in critical situation, everyday travelling, and constantly doing struggle to arrange the blood. This condition might be bad for their parents that are controlled by the females because of the breakdown of married relationships which are connected. The

following excerpts indicate the challenges faced by two mothers for managing the treatment of their thalassemia major children.

Case Study 4

Nusrat bibi has three children two boys and one daughter, her daughter was diagnosed by thalassemia major in the age of twelve months. Now she is eleven years old. She stated that: My thalassemia major girl has to undergo blood transfusion twice a month. I have to arrange the donors at my own. I have to request people for blood donation many times through cell phone campaigns. A respondent expressed that I am a female, I get a lot trouble because I am not be able to contact everyone freely to help me while arranging blood. I took care of my family because I have not any source to get help that's why I had to manage all expenses and needs for my family. I have to look after my other children who are at the school. "I took my daughter who is thalassemia patient to the nearby thalassemia center which is converted into hospital for thalassemia treatment and blood transfusion" my other children who take off from their school they became hungry and they can 't be able to take meal because I was not at home

I get difficulty to buy medicines that was prescribed by doctor from Larkana which is unavailable, and I must go outside the city to request the bus drivers that were ran from Larkana to Karachi to buy me the prescribed medicine from karachi. Sometimes they do bring the medicine and other times they do not due to which the treatment of my daughter is affected.

Likewise, the one mother said:

ٿيلسيميا جي ڪري اسان جي ڌيءَ اسان جي محتاج رهندي جيستائين زندگي اٿس ڇو ته ڪوئي
انسان شادي نه ڪندو ۽ اڳتي اسرا ڪي ڪائي اميد نظر ڪون اچي.

''Due to this thalassemia disease, our daughter will be dependent on us till she lives. No one will marry her, and we can't see any hope in coming time either''

Case Study 5

Naseem khatoon has one child. She said that my son was born after the death of my husband. Later on, the doctors informed me that my son is a thalassemia major. But my in-laws are not willing to accept it because they think that I only go to city for my own purpose. My respondent told me that she is living in a rural area which is away from the main city where it is not considered appropriate for a woman to travel alone. So, I have to request a male from relatives to accompany me. This is a huge problem for me as my in-laws are not cooperative.

The thalassemia child requires full time care which is very hard to perform by the parents. Maximum number of thalassemia patient's family stated that their harsh and busy social life is effected on their profession though look after their child. Being a mother they had to face a lot of burden of responsibilities on them because they are care takers of their families.

Like other my respondent explains that:

ٿيليسيما جو ع.ج مهڱو آهي ۽ مانهاڻيتعويز دهڳي جي ڪوشش

هآيانتجيئرڪاءي اهدنظر اچي

''The treatment of thalassemia is so expensive. Now I am in search of ta'wiz dhaga, so I can get a way''

My participants stated that: Patient's mothers are mainly responsible for taking care of thalassemia child. They stated that they are not be able to carry out any additional household tasks. We seem unable to join social functions. We have to prepare healthy dishes for the children that increases their food bill.

Furthermore, like already said, those women who are house wives face additional challenges even though they may meet most of their family's requirements through their own. This is nearly hard for them to accomplish their financial and home obligations when they

taking caring of the thalassemia patients, if they do not have significant professional or casual public assistance.

5.2 Societal Response

The parents of thalassemia child who are already struggling to manage the treatment of their children often face severe response by the public. The parents were getting nervous while telling about the thalassemia disease with other people because people think worse about the disease that is transmissible i.e. it can spread from one person to another. Most people assume that birth of a thalassemia child is Allah's penalty of misdeeds. For such an unfavorable cultural beliefs, thalassemia families feel shamed and publicly excluded. Such negative attitudes also cause mental stress for the parents of thalassemia children. One of the respondent expressed it as “People are not aware about this disease. They believe that they are lying more about illness I'm afraid of telling folks that my child is suffering from thalassemia disease. Overall, the replies are negative and unhelpful, that so many times people may not inquire about our child's health.

In the remote areas of Larkana city, people are not aware about thalassemia disease and associate it with some kind of punishment by the God. The families of thalassemia children have to face such issues in their everyday lives. As shared by the

respondents, even in some cases, people restrain their children to play with thalassemia children. People think that thalassemia could be transmittable so they restrain to communicate with the family who has thalassemia children. Sometimes the close relatives, rather of helping the families, constantly exclude them, their condition also becomes more unpleasant and difficult for the parents.

As respondents told that:

اسان جي لاءِ ٿيليسيميا هڪ وچڙندڙ بيماري آهي ۽ اسان کي خوف آهي ته ٻين ٻارن ۾ به نه ڦهلجي وڃي.

''In my opinion thhalassemia is a contagious disease and I am worried it might spread in our other kids too''

As I have discussed before, the families who has thalassemia children are financially crippled because of very costly treatment. Other participants answered about the families that they do not assist since they were aware and there is really no any solution of the disorder but it also requires therapy for the rest of one's life. As a result, if they assist, people would be tied or compelled to assist over and over. Moreover, as the treatment expenditure is high, that is another reason though people do not help because their own budget will be disturbed.

Case Study 6

Sadia has four children. She has 2 twins' children which were fighting with thalassemia disease. She works as private teacher in nearby school. Her children were diagnosed with thalassemia in the age of 8 months now they are 8 years old. She were very frustrated mother. She stated that: People are empathetic to our children but do not help in managing the cost. I do not discuss my children's disease and try to be happy apparently so that my

children does not feel that he is any kind of burden on us. I am in constant tension as the disease is life-lasting and needs regular treatment. Relatives do not help and I also do not ask for their help.

Sometimes The Children which are diagnosed with thalassemia disease have an additional challenges in their academic life since other (healthy) children do not want to be sit beside them or become their friends. Such attitude is upsetting for me and other mothers and fathers of the thalassemia-affected children. I had faced difficulty to send their thalassemia children to the school since other children do not want to sit with them. Their families have also expressed dissatisfaction with the teacher.

One respondent stated that:

هڪ پٽ جو سهارو هيو هزار خواب ڏٺا هيا پر جڏهن ٿلسيميا بيماري جو شڪار ٿيو ته منهنجي
خاندان جي زندگي عذاب بڻائي ڇڏي. هڪ اڪيلي عورت ڇا ڪري, هڪ پٽ جو سهارو هو هزار
خواب ڏٺا هيا پر جڏهن ٿلسيميا بيماري جو شڪار ٿيو ته منهنجي خاندان جي زندگي عذاب بڻائي
ڇڏي. هڪ اڪيلي عورت ڇا ڪري هزار طعنا ڏيندا پيا آهن ته مان منحوس آهيان.

‘’My only son was my support, I had seen thousand dreams for him but when the thalassemia disease griped him, my family made my life a living hell. They call me cursed. I have totolerate all these taunts’’.

5.3. Worried about child Schooling and their career

My respondents were parents of the thalassemia children are in constant distress and concerned about their education and social life. The thalassemia disease has significant impact on education because it restrains the patient to perform like healthy children.
The thalassemia patient’s health is not in well condition that's why they are not be able to go to school for their studies.

Case Study 7

Rabia have 2 children. Her child was infected with thalassemia disease in the age of 15 months. She was house wife. She faced many difficulties due to the thalassemia in the academic record of her child. She said that: the thalassemia children is unable to study like other children. Moreover, as discussed before, in schools, children are sometimes mistreated and separated.

As a result, thalassemia sufferers have emotional consequences such as fatigue, loneliness, depression and helplessness. She expressed that: The parents of thalassemia children know that they have to take care of their special needs for the whole life and manage the expenses of treatment which have adverse impact on social and financial status of the whole family.

Most of the parents were not able to send their thalassemia children for the study in any institution due to their illness though it considerable long distance for travel. As there are no special schools available for thalassemia children in the remote areas so that is worst situation ever for the families of thalassemia patients when they think regarding the children's education.

Case Study 8

Moreover, as thalassemia is a hereditary disease so People are worried regarding the thalassemia major disease in their children they are also afraid for the thalassemia major children's marriage because no one would accept them. Families of thalassemia major girls are especially concerned about their marriage and future life. My respondents was a mothers of thalassemia major daughters shared the issues regarding their daughters:

Likewise, one mother told that:

مان اڪيلي ماءُ ٿي ڪري ڪجهه ٿي سگهان.صرف اونداهيرو ھي نظر پيو اچي.منهنجي

ڌيءُ جو ته ڪوئي مستقبل ھي نه آھي ان جي الاءِ ڇا زندگي، ان پنهنجا خواب ڪيئن پورا ڪري

سگهندس يا ڪجهه به سوڙهي ماريج لئي ڇا ٻيو برابر ٿيندو آھي

''Being a single mother, I can't handle it alone. Future is dark for us. My daughter doesn't have any future, I don't know how much she will live. How can I fulfil my dreams? No matter

whether it is daughter or son, mother suffers in pain for both'

They are the concerned regard the marriage of their daughters as due to the disease nobody would marry her. This thing makes me worried. This thalassemia disease is the long term disease and here is nobody to look after their daughters except them. My respondents expressed that: If something happened to me then who will take care of their daughters. This makes me more concerned about her future. I think for parents of thalassemia girls' This condition is to be extra challenging and concerning about the female patients when they said to be adolescents in their teen age.

In addition, due to lack of and very expensive treatment facilities and health risks, parents are even uncertain that whether their thalassemia children will be able to live long-life or not. As one of the respondents expressed "We are concerned about our son's life because we have not seen many children surviving long with this disease. We are not hopeful about his health so it makes us concerned about his life."

5.4 Parental education

Parental education have significant part to analyze the thalassemia disease in children since birth. Lack of knowledge about thalassemia disease is major factor that indicates the parents and patients of thalassemia disease to face the socio-economic and psychological issues. After analyzing the interviews from respondents, the main themes extracted include the less information regarding the treatment options and about the thalassemia disease, issues regarding blood transfusion, treatment expenditure and travelling, concerns about child education and future. Alertness and attitudes about the transmission practice of treatment of the thalassemia disease depends on the parental education which is on higher level. However the Parents of thalassemia children with lack of knowledge are failed to differentiate between the thalassemia major and thalassemia minor as well as the carrier of diseases.

5.5.Lack of Awareness about Thalassemia and its Treatment Options

It was surprising to note that almost all the respondents had very little or no awareness about thalassemia disease. The respondents told that they don't have any knowledge about the thalassemia disease when they disease was diagnose in their children than they learned about the major and minor thalassemia and they had to arrange the blood transfusion treatment. Likewise, no one want to take risk due to blood transfusion and treatment related to the complications in thalassemia disease, which may occur due to thalassemia.

Case Study 9

Tehmina was the mother of thalassemia child. She expressed that: before the consultation of doctors we don't have any idea about us that we both (father and mother) are carrier in this disease, we came to know after our child was diagnosed with thalassemia major. Particularly she explain that in my normal routine "I went to hospital for normal checkup then my doctor has told me that you have to require some medical tests and have to go to another big cities, after result I got shocked when I knew that my child was diagnosed with thalassemia major disease". When we decided to go to the hospital at Larkana, when we went at hospital the doctors gave us advised to take you child to another big city for treatment, than we decided to go to Karachi and there we came to know that the thalassemia is diagnosed in our child.
The lack of facilities for the diagnosing of thalassemia is one of major problem faced by the parents. Most respondents told that they had to visit Rawalpindi for tests.

My respondent said that:

ٿيليسيانپارڪي روز رونيمار ۽ ڪمزورڏسي ٺنگيڪينورملح ئيٽ جيڪوشش ڪيونٿا
پرسوچيڪريگهر جي ماحولتياسرپويٿوپر ان ڄ ئين رتلگيٿو ۳ڏينهنسهيٿي وري
ان هي حلتٿي وجيٿي.

''We are trying to spend a normal life by looking at my thalassemia child, but the thoughts are adversely affecting my family environment. After getting blood my kid leads a normal life for three days but afterwards the condition is same''

According to this study and my participant's answers, I observed that the major reason behind thalassemia disease is the cousin marriages. My other participants explain that: we were not lived there and they were doing job to another country.

We don't have idea regarding the thalassemia major and minor before it diagnosed in our child. It is a blood disorder in which patient has to rely on blood transfusion. Like many people, I thought that the cause of disease is marriage within blood relatives. But I married outside my family but still my child is a thalassemia major. So I think it is a genetic disorder. It is a life-threatening disease. We only know so far about blood transfusion as a treatment method.

Case Study 10

Asia Parveen got marriage one year ago. She was the mother of thalassemia child. She said that: Before marriage we did not know about the screening test in pregnancy which is necessary for children to diagnose thalassemia disease. She said that they are unaware about this genetic disorder. However, later on they felt that it was the lack of awareness about disease due to which their children became victim of it. If they would have known about pre-marital screening and test for genetic disorder, they would have been saved from raising thalassemia child. Now they are fighting with this disease, they said that it is unbearable for us to face this critical situation every day. We don't have any idea about this disease and treatment, we don't have hope that our second baby will born normal. As one of my other respondent told that: We did not know anything about thalassemia screening test during pregnancy when our first child was diagnosed as a thalassemia major. Nor were we aware of the causes of thalassemia.

When I became pregnant second time, the doctor informed us about the screening test during early pregnancy. However, such test facility was not available in our district and we had to go to Karachi and pay Rs.7000 for the test. After the test, we were informed that the baby was a thalassemia major so we went for abortion.

Participants had very little knowledge about the thalassemia disease because of lack of education and awareness about the condition. Despite the fact "that in my research more participants were buying medicines for their thalassemia children they were unaware for the medication purpose and for the various treatment choices for thalassemia disease". As one of the respondents said that "I do not know about thalassemia in detail. I am an illiterate person. I only follow what doctor says. The only thing I know is that my child needs blood transfusion because he is a thalassemia major."

My respondent expressed that:

اسان کي پهرين ڪا خبر نه هئي ته ڪهڙي بيماري آهي، ۽ هي بيماري ڪزن ميرج جي ڪري
ٿيندي آهي. هاڻي اسان خاندان ۾ شادي ڪرڻ بند ڪري ڇڏي

''We were not aware about this disease before and neither we knew that this disease spread from cousin marriages. Now we have ban cousin marriage in our family''.

5.6.Government Interventions

All the respondents were angry and hopeless with the government's negligence regarding thalassemia disease management. In the remote area of Larkana city, there is not even a single blood transfusion center established by the government. As one of the respondent expressed his concerns:

There are no governmental or non-governmental organizations working in our area for thalassemia patients. Sindh government should make the centers like those that exist in big cities of Pakistan where patients are assisted properly and have treatment facilities are available and even free medicines are provided.

There is dire need of medical facilities required for early diagnosis of thalassemia. Thalassemia Centre Provide Blood to the patients: There is only one blood transfusion center in near lahori Muhalla Larkana where study was conducted and the residents of the adjacent area have went for the treatment and wait hours in the center to provide blood to their children. The center is run purely voluntarily by the doctors and its functioning is dependent on donations, mainly by few philanthropists. The center lacks facilities because government is not willing to finance it. Due to the lack of resources, the center is unable to provide free medicine to all patients as the availability of medicines is dependent on donations. However, the blood transfusion is performed free of charge provided that thalassemia patients arrange their own blood donors.

According to the respondents, the local government has not shown commitment or any interest to address the issues of thalassemia patients and their families. One respondent shared that a Karachi-based NGO was willing to establish a thalassemia center in Larkana but the government did not allow the organization to work in the remote area of city for unknown reasons.

Moreover, as I have highlighted before, even the medicines of thalassemia are not available in the Larkana city, so the parents of thalassemia children have to travel to karachi or other big cities in Pakistan to buy the medicine or ask somebody to buy medicine for them which is an additional burden on them. The respondents were of the view that the government should immediately take steps to establish a big thalassemia center in Larkana with all the facilities and provision of free medicines.
The Fatmid foundation donate blood to their patients.

According to the blood groups some thalassemia major and minor patients got blood from the thalassemia Centre every month. Here I have mention blood groups and total number of patients which is diagnosed from the Lahori Muhalla Larkana where the research was conducted. There were 49 thalassemia cases detected in that area and they provided blood by Fatimid Foundation.
There were registered patients of Lahori Muhalla Larkana in Fatimid foundation. According to their blood type out of total patients 9 have A+ blood type, 13 have B+, While 15 have

O+ further 5 have AB+ type. Some Patients have rare blood type, 1 with A-, 2 have B- blood type, and 3 were O- and 1 with AB- (Negative).

Table 2 **Registered Patients in Fatimid Foundation**

Blood Groups	**Patients**
A+	**9**
B+	**13**
O+	**15**
AB+	**5**
A-	**1**
B-	**2**
O-	**3**
AB-	**1**
Thalassemia cases	**49**

Source: Field Visit

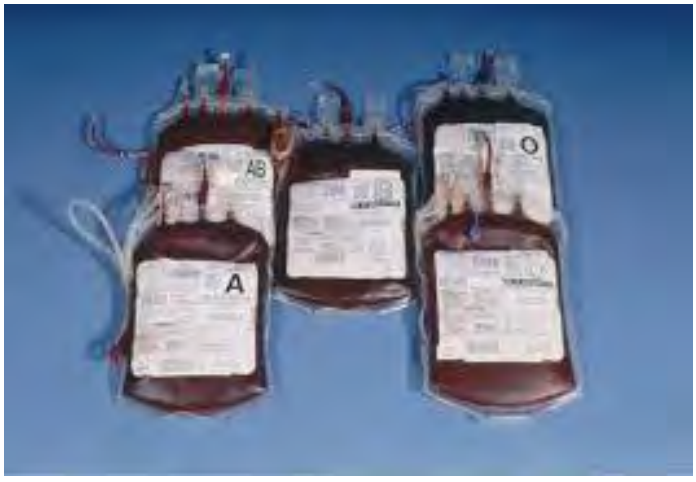


Figure 7 **Blood Packs**

Figure 8 Source: field work

Chapter 6

6. PSYCHOLOGICAL PROBLEMS FACED BY THE THALASSEMIA PATIENTS AND THEIR PARENTS

This objective describes briefly about the problems which thalassemia patients and their families are facing in the society and the problems which they have to face after diagnosed the disease. These problems have been identified during the research by in depth interviews of the victims. These lines also focuses on the reasons behind these problems which have an intense influence on the lives of the thalassemia patients and their families particularly after the victims of disease.

6.1 Psychological Effects after the diagnosed thalassemia.

Thalassemia is a chronic and long term due to this disease many people were faced psychological issues. According to my present study many people got mental illness. They cannot satisfy with their routine of thalassemia children. They lives differently as normal children lived. Their children also being frustrated when they felt deficiency of blood. They were unable to do their activities with their friends because of their weakness.

Case Study 11

Mrs: Fareed told that I got married 6 years ago. I have 2 children one is 2 years old and second is 4 years. My first baby were 1 year old and second were 2 years old when they became victim of thalassemia disease. After the diagnosed it her husband died, she said that: I felt there is no more life left behind for them. After the death of her husband I have spent three to five years in trauma. She felt like their presence has no meaning after their husband's death. She thoughts how she can manage their children, it was quite difficult for them to arrange blood every month. When I asked her what was your feelings after your husband's death she said that many times we have considered dying as we cannot live in such a cruel society. How can I live in this society alone and manage all things? The main or basic reason at that time was the lack of resources and no money to run our family or to look after our children who are victims of thalassemia desease. There were many other problems waiting for us. All these problems or tensions affected our minds and our children too badly.

For a long period of time after the death of their husbands they were unable to take care of their children as they were living in trauma. Before their husband's death they had no disease but after their husband's death they are suffering from different kinds of diseases. Due to tensions some have blood pressure problems, lungs disease and depression etc.

My participant said that:

يٿيلسيميا هڪ نہ ٺيڪ ٿيڻ واري آهي ۽ جنهن جو آسر وڪلس ي ڇڏيو آهي.اسانبارنجيپاري ن ہ
مرندي ڏسيسگهون ٿا ن ہجيئندي.

''Thalassemia is a hopeless disease, which doesn't have any cure. We can neither see our child living like this or dying like this''.

6.2 Treat badly to thalassemia patients and their family.

As my respondents told that are alleged as bad omen by their relatives and friends as they think that they are not normal as like other children. So people make them feel different from their normal children. The patients is considered as a bad omen for the whole society special their family members and these patients are even not allowed to go outside the city. As their parents told me that they have fear for them because of their disease. They can't bear the taunt of the people for their children because of their weakness. People think that these patients may transfer their disease to their other normal children. Even the unmarried young girls don't like to talk or interact with the girls of thalassemia disease for the fear of bad omen.

6.3 Feelings after the diagnosed of the disease

After the diagnosed of the disease they felt they have got nothing left to live for in this world. They were worried about how they would manage all the responsibilities and faced the society alone with their children. Even they had no finance for survival of life in the society. The treatment of thalassemia is more costly and more families of victims can't afford every month or after 15 days.

6.4 Value/Importance

Families and thalassemia patients felt like they were alien of some other planet or were treated almost like slaves, as in this case they don't hold any kind of importance or value in the society. They felt like that there membership from the life had been expired and it does not required anymore. But the life was quite opposite while their other children were normal and they enjoyed a much esteemed status in that house with lot of respect and dignity. Their opinion in every decision to be taken for the house was essential in the past but this incident had snatched every right they used to practice in that house. They were even refused of freedom of expression. Their in-laws used to answer in return that they had not their right in this house while their children were diagnosed, they felt that were only burden on their family members, such behavior were the painful and unbearable to the parents of thalassemia patients.

6.5 Impact on Social Life

The social life of the parents and children of thalassemia was affected badly because they were all alone to manage all the burden of their child every month. To arrange Blood transfusion after 15 days and every month is not so easy. Their interaction with the people around them was reduced due to the burden of duties for their weak children. They had to manage all the issues all alone along with managing their children's life who is suffering from thalassemia disease. These duties kept them busy day in and out to take care of their children. Second reason behind the reduction of interaction was that their family members and relatives started to avoid them by the fear that they will ask for some help from them which they didn't want to do.

6.6 Inferiority Complex

According to my respondents they stated that the thalassemia patients consider themselves inferior to others as they are treated like aliens. They are not respected as the others normal children respected while they were with their friends and in other gatherings. As my respondents told me that they feel inferior to others because of their skin colour. Some of thalassemia children's skin colour were black because of the efficiency of iron due to blood transfusion. There are a few children who were even expelled from their schools and

colleges due to their disease they did not concerned on their study regularly. They were left alone in their school activities. They were even kept away from every competition in their academy due to their weakness because they have not any capability to manage things properly as other normal children did. That's why they considered themselves inferior to other as they are not allowed any kind of pleasure of life.

6.7 Consequences of Discrimination

Before diagnosed thalassemia they were treated by other people with respect and honor but right after that incident that respect's target was diverted. There were still some members though who treated them with honor and dignity even after their disease. There were some rare people who conceived their request for help as they had some kind of soft corner for those people. When these patients and their family came to know about the intentions of these people they start to avoid any kind of interaction with them. But some families still had to face these issues as they had no way out of their problems. As some of my respondents said that behavior of some people with the patients were very humble because of their disease. The harsh behavior by some people disturbs their minds and they cannot recover from this disturbance for days. To keep away from these problems the only way they sorted out was to avoid every people whether they belonged to their family or are relatives or friends as it was affecting their minds with a massive depression which disturbed their daily routine as well.

6.8 Psychiatric Disorder

I took a sample of 37 patients and their families. There were 21 girls and 16 boys which were diagnosed by thalassemia disease. They also were suffering from different kinds of diseases along with thalassemia major and minor i.e. TB, typhoid, Hepatitis and a few had very severe mental disorder. They were introduced by these diseases after becoming victim of thalassemia. They couldn't bear the burden of managing all the things indoor and outdoor simultaneously. The massive depression with no one to support dragged them into suffering of diseases. The second reason of this massive depression was the mocking from the society. Moreover their stress about their disease related stress ad linked to mental health issues such as anxiety and depression.

- **Health Issues**

  The families of thalassemia patients faced health problems due to lack of facilities of foundations because they were worried to manage blood for their children they were worried about her children's health and their future.

Case Study 12

Amjad Ali was the father of thalassemia child. He stated that: After diagnosed of thalassemia disease in our child we got shocked. He said that our child effected with many health issues along with this disease though, the improper treatment made their physical condition declined very badly day to day. They didn't want to survive anymore and faced many problems of blood transfusion. He said that: after blood transfusion some patients were faced allergic problem on their skin because in emergency case they did not provide by fresh blood through blood banks and going outside the city it was so costly for them. That's why they were very dissatisfied and very sad. They were not be able to get help regarding this disease they could not managed all those things along with their children. Some of patients very sick after blood transfusion due to depression and stress. However they did not take care of others thought regarding to the thalassemia because people have always thought negative about thalassemia patients. They did not manage all issues. They also experienced Dizziness, shortness of breath, headache, leg cramps, Fast heartbeat and pale skin.

One respondent said:

رت ڦيڻتڻواب جوڪم آهياگرڪوئي ماڻهو رت ڏيتهاسان جيپار جيزنگيپچيسگهي ٿيپراحساسبه هرڪنهن ۾ڪونهي۔

''Donating blood is a rewarding act if one person donate blood, it can save our child's life, but feelings is not in everyone''

- **Suicide:**

  Some of my respondents said that: Due to frustration in disease they had tried to suicide due to the social burden of disgrace of chronic disease. Most of time they felt they were alone

and there were no one around who can understand them and they share everything with them. They felt separated. At while, they thought they must be killed herself. They were so unhappy and they felt lonesome. They have to look after her families but they could not be able to take care of herself too. Always they felt tired and weak.

- **Trauma:**

  As my respondents said: In that chronic disease some thalassemia patients receive a lot of blood transfusion are at risk for iron loaded. In sometimes it results in serious consequences that the thalassemia patients and their parents reaches to stage of trauma. According to my respondents view it is a major reason of mental illness, they got shock due to disease in their life that they did not get involved in doings, They were facing depression and the most difficult thing in that situation of disease and treatment was lack of money, the doctors asked for money every 15 days or every month and then it takes long time for them to get treatment and manage it.

- **Feeling lonely and alone**

  The problem of loneliness was the other type of psychological consequence that was studied through interview. Few individuals mentioned feelings of loneliness and isolation as they dealt with the problem of chronic illness.

  Case Study 13

  Farzana was the mother of thalassemia child. She said that: after diagnosed thalassemia in my two children I challenged various issues. It's a fact that every normal child gets first priority in their family and they are the superiors for their parents in contrast of weak child who is victim of thalassemia. My respondents stated that: At that time I felt I could not be able to be friend of any one, no one want to be with me that I can share my everything with them, no one can understand my situation and I have no any future in my life due to that chronic disease (Thalassemia) I can't live more and enjoy my life. I am tired of this situation. She said that: When I felt lonely I used to crying in loneliness and praying to God that my child is your responsibility make me strong but when I was tired to faced my responsibility I used to wished about the death of my child and me because I cannot bear

myself anymore. Being a mother how can I left my child which is already fought with this curious disease?

As My Participants told that:

هن وڏيي ماري جي ڪرياسان جي ٻار ۽اسان خودڪشي جوسوچي آهيون اسان جي ٻارسان
اسڪول، ڪاليج ۽خاندان ۾ الڳ سان رويو رکيو ويو، ڪوئي احساس جي نظرسان ٿو ڏسي
ته ڪوئي نفرت جي

''Because of this deadly disease my kids and I have been thinking of suicide. My kid has been treated differently everywhere, in school, colleges and even in family. Some sympathize him and some hate him''

6.9 Depression in Thalassemia children

As my respondents view that argument that since childhood depression has been the major problem in thalassemia patients. Meanwhile it is usually known as phase with joyful moment along with hopelessness which disease is diagnosed without symptoms. Thus children suffer from mental illness due to thalassemia disease, they became the victim of untreated and undiagnosed illness which is known as depression. It is different type of illness that child and adults whether faced. It is a vital problem that depressive illnesses remain constant since childhood and it contains the threat of psychiatric diagnoses in majority of children.

- **Hospitalized children**

  According to my respondents when they admitted in hospital is a traumatic experience fot the thalassemia children and their families such as the threatening reason for lifetime. Those who are admit in hospital whether it adults or adolescences children were not be able to understand the requirement of hospital management and treatment. Several issues may cause psychiatric illnesses when they admitted in hospital. Moreover the main traumatic reason for children is to separate from their family which is unbearable for them. It was very difficult time for children especially preschool children who have more need for their mother's care and bond. It associated with worse consequences for the further mental growth. As I observed that those victims of thalassemia patients had greater needs because they depend

upon their parents and they were experienced fear for the regular blood transfusions and hospital management. Other hospitalizes patients also experienced lack of their personal space or lack of friends and anxiety for the success of beneficial attention. Such experienced was traumatic and stressful for their families and it is quite difficult to face their children in that disorder.

Figure 9 **Field Source**

- **Depressive adolescents**

  Adolescence is a transitional period between childhood and maturity, during which irreversible changes in the body occur. Thalassemia patients, on the other hand, develop slowly, thus their bodies do not undergo as many changes as normal adolescents. Adolescents face a variety of problems, according to some of my responses, including social, personal, and vocational challenges. Teenagers, for example, desire to go through new circles in their life experience in order to relive the delights of childhood, but they confront emotional problems as a result of their separation from their parents and the uncertainty of finding alternative sources of support. Adolescents were impacted by chronic sickness as a result of Thalassemia, and now that they are aware of the disease's chronicity, they are more aware of their condition and possible health risks. They were all dealing with major depressive issues. It was more difficult for them to deal with the weight of illnesses (blood transfusion, iron efficiency).

- **Depressive Adults**

  As more young individuals reach adulthood, thalassemia has evolved into a chronic illness with major long-term healthcare demands that must be met in adults rather than children. Patients' life expectancy has been significantly enhanced by including blood transfusion and iron efficiency. It was once a less frequent disease in adults, but it is currently becoming more prevalent in the younger population. Organ failure requires therapy, according to my replies, because adults are at risk for various consequences, such as heart illness. Adults were being transferred from thalassemia clinics to adult healthcare centres due to a lack of attention to patients. Despite the fact that doctors were not focused on patients unique problems.

Chapter 7

7. Summary and Conclusion

The study has been conducted on the Socio-economic and psychological issues challenged by thalassemia patients and their families. Here I summarized the study with above chapters. The chapter one is introduction of the topic. In which I explained about the thalassemia disease. Thalassemia is a prominent hereditary disease that is classified as a genetic blood disorder. Thalassemia is a blood disorder in which the body is unable to produce enough hemoglobin, resulting in severe anemia. Hemoglobin is a protein that carries oxygen throughout the body and is present in red blood cells. When red blood cells don't have enough hemoglobin, oxygen can't get to all parts of the body. In this chapter is classify in five parts: Globally disorder of thalassemia, Thalassemia in Pakistan, Thalassemia disease in District Larkana and the Anthropology of disease.

The chapter two comprehend the review of literature. I which I quoted different authors articles which is related to thalassemia topic. This chapter contains the over view of a main concepts of each source and combine them to articulate. In this chapter I analyzed and interpret with paraphrasing of others researchers. The chapter is based on the secondary source of data. The relevant literature regarding thalassemia disease and its types, management or treatment is mainly taken from previous research studies, online websites, journals, and reports. The material is available on Google scholars, Cooley's foundation, and Pakistan thalassemia federation. The source of different seminars papers, research papers, reports, articles on newspaper related with thalassemia was consulted to review the research material.

The chapter three contain Research Methodology. The methodology is to uncover truthful and helpful knowledge about a certain domain of phenomena in the universe and to find solutions to problems. In this chapter I used some strategies and methods to gather data during field work. To obtain data, I utilized qualitative approaches. I used data collection, Raport building, Participant observation, key informants, In-depth interviews, Focus group discussion, in sampling method. I used purposive sampling, daily diary, photography, secondary source, field notes, audio recording, case study and research ethics for research.

The chapter four cover the information about Area profile, in which research has been conducted. In this chapter I explain about the history of locale, population and their cultural patterns. In this chapter I also explained about the deductive cases of thalassemia and demographic profile of respondents in which respondents' occupation, age, income, family structure and total number of thalassemia cases according to research locale.

Chapter five and six is comprising the objectives of the present study in which socio-economic and psychological issues of thalassemia patients and their families were mention. In These chapters I also explained the level of awareness regarding thalassemia disease and existing the facilities for thalassemia patients. According to the study thalassemia is long-term disease and the treatment of this disease is very costly that's why most of families had faced difficulties to manage it.

Chapter seven is the last chapter of my thesis. In this chapter I concluded the results of present study. The study's main goal was to look at the issues of socio-economic and psychological that thalassemia major patients were facing. The qualitative interview method has been used to collect the data from the parents of thalassemia children from area Lahori Muhalla Larkana city district Larkana city.

It is concluded from the study that the parents of thalassemia children have to face numerous socio-economic and Psychological issues while taking care of the children. Some of the major issues include lack of awareness about the disease and insufficient facilities available for the diagnosis and treatment of thalassemia disease, managing regular blood donors for blood transfusion, arranging economic resources for expensive treatment, worries about the future of the children, facing health issues of psychiatric disorders and dealing with negative societal attitudes about the disease.

In today's culture, there is a dearth of knowledge regarding thalassemia illness. The families that were questioned stated that they were unaware of the condition until their children were affected. Neither did the parents of thalassemia major children understand the disease's treatment choices or the problems that come with it. From the time their children were

diagnosed with thalassemia major to the time they were treated, their families had to deal with a slew of issues.

For thalassemia major patients, regular blood transfusion is required. There is one blood transfusion center in Larkana district running on voluntary basis and sometimes medicines were also not available in the market. One of the most pressing issues for families with thalassemia children, according to the study, was arranging for blood transfusions on a regular basis at home.

The families were worried that sometimes due to unavailability of blood donor the due date of transfusion was missed. Taking care of thalassemia major children requires enormous resources and time. The families of thalassemia children have to compromise their social and professional life.

Due to high expenditure involved in the treatment of thalassemia major children. Many families found it difficult to gather money, and they were forced to take out loans and sacrifice other household requirements. Furthermore, because there was no additional help available to care for thalassemia children, parents were unable to attend social occasions such as weddings or funerals. Similarly, professional life has been disrupted since parents had to take time off work to accompany their thalassemia children to the hospital for treatment.

Some parents said that they were unable to avail better economic opportunities in other cities because their thalassemia children required full-time attention. Thinking about the future life and education of thalassemia major children causes nonstop pressure of anxiety and depression for their families. Particularly “many parents were worried about their future and marriage of their thalassemia children and who will take care of the children after their parents. As through the statement of my respondents the “Education was also a major issue as in schools the thalassemia children were many times social isolated and could not perform like normal children. In addition, negative attitudes prevailing in the society, e.g., thalassemia could be transmitted through normal physical contacts or it is a result of sins, make the lives of parents miserable”.

All of my respondents in this study were not satisfied with the government performance regarding thalassemia management strategy. They were faced certain situation against the less number of conveniences in the thalassemia centers, though there were not properly arrangement for the medication and treatment and also they were faced difficult to get blood for their children every month.

The government has not yet taken any significant interventions to provide services to thalassemia patients in Larkana Sindh.

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Interview guide

1. Since how long have you been caring for a thalassemia child?
2. What do you know about thalassemia disease?
3. What are the causes, risks, and treatment options?
4. How and when did you come to know that your child was thalassemia major?
5. Who in the family is mainly responsible to take care of the child?
6. Do efforts required for the care affect your other activities?
7. How have you been treating your child?
8. What are the problems you face in the treatment process?
9. How frequently your child requires blood transfusion?
10. How do you manage blood transfusion?
11. Does thalassemia centre provide the blood for transfusion or you arrange the blood donor?
12. Do you travel to other cities for the treatment of your children? Are there any issues in travelling?
13. What is the cost of medicine/treatment per month?
14. Are the medicine facilities provided by the centre?
15. How do you manage expenditure on the treatment?
16. How does thalassemia affect the education of your child?
17. How does thalassemia affect the social life of your child?
18. How do people react when they know about your child's disease?
19. Do you feel hesitation about talking child disease?
20. How has been the reaction of your relatives/friends?
21. What makes you concerned about the child future?
22. Are there any government or nongovernment organizations working on thalassemia issue in your area?
23. What steps should be taken by the government to address the problems faced by families of thalassemia children?
24. Do you feel that psychiatric disorder is due to the thalassemia disease or due to the age factor?

25. What are the impacts on your social life after diagnosed thalassemia in your child ?
26. For how much period you suffered from the agonies of your child's disease?
27. What kind of behavioral differences you faced while interacting with with your relatives and friends due to thalassemia disease in your child?
28. How this reaction effected on your mind while combating with these problems?
29. How do you feel when it comes to your mind that you are a father/Mother of thalassemia child?
30. Are you considered as a bad omen for your family or society?
31. What did you feel after the immediate diagnosed thalassemia disease in your child?
32. Do you feel that your child's presence has no meaning or has no importance due to thalassemia disease?
33. Do you feel inferior for your child to others after this incident? If yes then why?
34. How did these feelings affect your routine life?
35. How you arranged money for the blood transfusion and treatment of your child?
36. If you faced financial difficulties then was it hard for you to arrange blood for your child?
37. How do you earn your livelihood?
38. How do you arranged money for the blood transfusion and treatment of your child?
39. If you faced financial difficulties then was it hard for you to arrange blood for your child?
40. Did you face any problem while managing your social life?
41. Which kind of problems you face when you interact your relatives and friends with your child who is victim of thalassemia disease?

S. No.	Name	Sex	Age in years	Cast/ Zaat	Religion		Place of birth		Mar
					Main	Sect			

S. No.	No.	Marital status						Total No of thalassemia children			
								Major		Minor	
		S	M	Div	RM	SP	Wid	Male	Female	Male	Female

S. No.	No.	Place of work					Income			
		Local	Nearby town	City	Abroad	Other	Daily	Per month	Per annum	Per season